SCOTTISH HOSPITALS INQUIRY

Hearing Commencing
20 September 2021

Bundle 3 – Programme and Witness Statements for Week Commencing 20 September 2021

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SCOTTISH
HOSPITALS
INQUIRY

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Scottish Hospitals Inquiry

Witness Statement of

Cameron Gough

WITNESS DETAILS

1. My name is Cameron Gough. I was born on [redacted]. I am [redacted] years old.

2. I am the father of [redacted]. [redacted] date of birth is [redacted]. He is 10 years old.

3. I live with my wife, Colette, and our [redacted] children, [redacted], in [redacted].

4. I am a [redacted].

OVERVIEW

5. My son is [redacted]. [redacted] was diagnosed with a Wilms tumour in his kidney on 30 July 2018 when he was 7 years old. [redacted] was treated in the Royal Hospital for Children ("RHC") and Queen Elizabeth University Hospital ("QEUH") in Glasgow between July 2018 and May 2019 when he finished his treatment. He attended both hospitals as an inpatient and as an outpatient regularly over that year. Following the completion of his treatment, [redacted] attends at the hospital for check-ups. First of all it was three monthly, now it is six monthly follow ups where he has a scan just to check that he's okay and that there's nothing come back.

6. [redacted] spent time in wards 2A and 2B of the RHC which is also known as the Schiehallion Unit. He also spent time on 3B, 2E, 1A, 3C, PICU and CDU in the

RHC and also in ward 6A in the QEUH. Colette and I shared and managed the care of [redacted] between us, during all of his admissions as an inpatient and as an outpatient. I can speak to the experience [redacted] and I had on these wards.

7. There are some specific events I would like to mention. [redacted] contracted a serratia marcesens infection, which was a Healthcare Associated Infection most probably contracted in the RHC. Throughout his treatment there were issues with the water supply, ongoing construction works and issues with fungus which impacted on his experience with the hospital. I will come on to talk about these events on more detail.

8. I have provided the Inquiry with a timeline which I prepared along with my wife, Colette Gough. This timeline shows the dates on which [redacted] attended hospital and the wards where he was treated. The timeline is attached to this statement at appendix 1 (**CAG/01**) and I confirm that it is accurate to the best of my recollection. The timeline came about because Colette is phenomenally fastidious. During [redacted]'s treatment process there was a lot that we needed to be on top of, when you're medicating you need to be organised. The only way we could manage it was to keep a record, particularly when me and Colette were doing handovers at the hospital. Colette instigated the record. So this was what she did. She had a diary and kept all the records: [redacted]'s observations, his blood counts which became quite an important thing because if counts were at a specific level, and he's having a temperature spike, this enabled him to get certain meds that he wouldn't have been able to get otherwise. We became quite good at transferring information and Colette kept a repository for all the information, that's the way the timeline was created.

FAMILY BACKGROUND

9. Colette and I live in [redacted] with our three children, [redacted], [redacted] and [redacted]. is our eldest child and he is cracking; a fun wee boy. He is quite academic and

cerebral. His sisters are more sporty, [redacted] is more bookish which was handy when he was in hospital because he spent a lot of time reading during his treatment. He is quite practical and he has an engineer's brain. He is "on it" and he is aware of what happened to him. Now he's healthy and he's happy.

10. Colette and I worked really hard throughout the treatment process to make it as fun for him as possible. I know that it sounds weird to say getting chemo is fun, but you can make it fun. We, like all parents, shielded him as much as we could from it, so he's doing well. You know, fundamentally he's doing well. He is everything and more that we would hope from a boy that has been through what he has been through. He's great.

11. [redacted]is our youngest child. She is the third child, feral, lovely and wild. But great fun with it. [redacted] is our middle child, she's lovely. She's very physical and active and skis and skates. Throughout this process we were most concerned for [redacted] and that is not to underplay [redacted]'s emotions; [redacted] was quite good at rationalising things. [redacted] is binary, [redacted] 's analogue that is the only way I can describe the difference between the two. That is our family and they're all doing fine; they're good fun.

SEQUENCE OF EVENTS: EXPERIENCE AT RHC AND QEUH

Diagnosis: July - August 2018

12. It was the 4 July 2018 and we were on holiday in Alnwick. I remember it being a sunny day. [redacted] was in the toilet and he shouted us through and said, the toilet's a funny colour. I came through and the urine was bright red. He'd been eating beetroot, so the immediate thought was maybe it was that. The following day, Colette took [redacted] to the out of hours service and they gave him antibiotics. The next day blood cultures were taken at the out of hours service to see if doctors could work out what it was. A few days later the out of hours GP

phoned us back and the culture was clear. The doctor advised us to go and see our own GP when we got home from holiday.

13. On the 13 July [redacted] saw our own GP who took a urine sample, prescribed a second set of antibiotics and booked more blood tests for the following Monday. On 16 July bloods were taken, the urine cultures were clear and the following day the blood tests showed anaemia. The GP referred [redacted] to the Royal Alexandria Hospital ("RAH") in Paisley for a scan and renal referral. We spent that whole period trying to work out what it was.

14. It was a fairly slow process. A scan was booked for the 30 July 2018 The day before his scan, [redacted] bumped his abdomen and he went green; he wasn't well. He was vomiting so it was obvious that he was deteriorating. The run up to the initial scan was really fact finding and general investigations involving blood tests, urine tests, getting the scan and trying to work out what was going on.

15. When we were on holiday, he was tired. He wasn't sufficiently different that we noticed anything at the time initially. If it had been a girl, we would probably have assumed it was a UTI. That was what we were thinking. Whilst UTIs are not a fun thing for anyone and can be quite debilitating, we weren't looking for anything more than that at this time. There were no obvious swellings, he didn't feel anything or lumps or bumps.

16. In the days leading up to [redacted]'s admission I had ripped out the bathroom at home. Colette and the kids had gone to stay at my mother and father-in-laws, because I had ripped out the bathroom. On the day that [redacted] had his scan, the girls were at a dance class. Colette and I met at the RAH for [redacted]'s scan.

17. On 30 July 2018 we took [redacted] to the RAH for his ultrasound scan and all hell broke loose for want of a better phrase. Everything flipped at that point. There was a wee bit of toing and froing of whether it was a high priority or not. I

spoke to post event who said that he really had to push it to get the scan through because it wasn’t presenting itself as a major concern.

18. The scan at the RAH revealed that there was a mass on [redacted]’s kidney and he was referred to oncology at the RHC in Glasgow. Colette and I travelled with to the RHC and attended at the A&E department. The doctor in the A&E department was up front about [redacted]’s diagnosis. He told us that he was not beating round the bush, and that it was looking like cancer we were dealing with. We went through the Clinical Decisions Unit (“CDU”) and [redacted] was admitted to Ward 2A in the RHC.

Admission to ward 2A RHC – the Schiehallion Unit: August 2018

[redacted]’s treatment plan

19. When we arrived in ward 2A [redacted] was admitted as an in-patient to room 10. We met Dr Ronghe who was [redacted]’s consultant. An MRI was carried out and Doctor Ronghe confirmed that [redacted] had a Kidney tumour; a Wilms tumour measuring around 12cm x 8cm x 8cm.

20. Colette stayed with [redacted] that first night. I went home that night to install the bathroom, just to make it work. It was a low priority now. The following day I came back in to the hospital for the next three or four weeks. The girls stayed with their grandparents. Colette and I stayed with [redacted], tag-teaming. Generally, there was only ever one of us staying overnight, apart from one of the nights near to the beginning of his admission where we both stayed over. Generally the staff didn't want multiple parents staying in, they were still small bedrooms and it’s not a huge hotel room. The bedrooms were well set up though.

21. On the 31 July 2018 [redacted] had a CT scan and an x-ray which confirmed the tumour was contained in the kidney. The plan was to start chemotherapy.

22. On the 1 August 2018, [redacted] underwent surgery to fit the Hickman line. Once they knew what the treatment plan was, the staff didn't hang around.

23. [redacted]'s Hickman line was fitted via surgery under a general anaesthetic. It was fitted to his left side and [redacted] called it his "wiggly". The Hickman line was used to administer medication and draw blood. Given the nature of the medications [redacted] required, they had to be administered into a vein. The Hickman offered quick access to the vein. The nice thing about the Hickman was because the piping of the line was outside the body, it was a much easier piece of kit for staff to use and it worked well. I think [redacted] had a wee green cap on the end of his Hickman line which was to prevent nasties getting in to the line. If I remember rightly, the green caps were sterile and they might have been a barrier as well, but I could be wrong.

24. Underneath the skin there's a wee bend in the line just so it can't be pulled out too easily. I could be wrong but I'm sure that there was a wee tuck in the line and it was stitched in. The dangly bit of the line was taped up out the way. My concern was that [redacted], our youngest, would just come and pull it. The line was kept taped up and it was kept clean.

25. Generally the staff didn't use cannulas in Schiehallion. They avoid those like the plague with these kids. With a central line you've got a direct line in to the body so it makes sense to use it. Cannulas are not fun and they restrict movement and they bruise, particularly with these kids. All the staff were fully qualified, there were no first year doctors. With these patients being so vulnerable it was protocol that these patients shouldn't be practised on, for example it's difficult to find a vein on them when they are going through treatment. Schiehallion day care staff were great. They could find a vein in a rock.

26. The difference between a Hickman line and a port, is that a port is fitted into the chest, under the skin. To use the port a needle has to be pushed through the

opening and then the medical staff have to find the entrance to the line under your skin. It was great because it was sealed and it was clean. Sometimes with ports, if staff are not used to using them they can miss the opening and hit parts of the body, for example muscles, with the needle. [redacted] had a port later on in his treatment and I speak about that later on.

27. Throughout the process Dr Ronghe was the first and major point of call. He was the captain of the ship for lack of a better analogy. We had other doctors involved too: James who was one of the junior doctors and there were a few others Catherine, Kate, Anne-Marie. They were all super. All qualified, very capable and competent; they were fantastic.

28. I am not sure what Dr Ronghe's speciality is, however I do know that he has carried out a lot of work on Wilms. His work was getting published and at one point in [redacted]'s treatment he referred us to some publications when we were trying to work out what treatment might follow [redacted]'s surgery and he was named in these publications. It was clear that he was the expert in the field and we liked that. At the beginning of [redacted]'s treatment, he told us not to Google, because Google sucks and we'd just get worried.

29. [redacted]'s plan was the European treatment plan, which is to hammer it with chemotherapy for a period of time. In [redacted]'s case this was for four weeks in order to shrink the tumour to a state that it becomes removable. The plan was that there would be surgery to take it out, and the tumour would be cut open and examined to see what nasties were inside it. That examination of the tumour would inform the process that followed surgery.

30. On the 2 August 2018, [redacted] started his chemotherapy protocol which included Vincristine and Actinomycin. I think it started off with Vincristine every week, and the Actinomycin and vincristine was every second week. Then the protocol reduced post-surgery to Vincristine in every two weeks in three and

Actinomycin every third week. As I recall his regime was vinc week one, vinc and actin week two, week three off: but I would have to check that though.

31. At the start of treatment we were given a specific protocol which set out the treatment plan and medication that would be prescribed over a number of weeks. The protocol actually changed throughout the period. In [redacted]'s case the periods between the chemotherapy stretched as we went along because he would continually have chemo holds when his neutrophils dropped or he developed an infection.

Description of Ward 2A – the Schiehallion Unit

32. Ward 2A in the RHC is part of the Schiehallion Ward. It is an oncology ward for children and I think they care for some transplant patients too. The ward treated kids with a very specific set of medical needs, they were not quite ICU, but they need very particular care. The important fact is that the children on that ward are immunosuppressed. The infrastructure, staffing and protocols on the ward were set up to look after these kids and to address all the issues that are created by having immunosuppressed children.

Infrastructure

33. From an infrastructure point of view Ward 2A was set up to accommodate children who were going to have long stays within hospital. Our family only stayed in the ward for a month and we weren't that long. If your child had leukaemia, you might have spent a much longer period in the ward. To take account of that, Ward 2A had specific areas for the children to go. The younger children had a playroom. There was a room for the teenagers and they also had a specific part of the ward. The ward treated patients up to 18 years old; an 18 year old is somewhat different from a two year old and the teenagers need their own space. These specific areas were set up for immunocompromised kids, the children on chemo who were admitted to the ward.

34. There were rules and protocols for use of the playroom. Siblings were not allowed into the playroom. It was only the patient, the sick child, who was allowed to use the facility in the Schiehallion ward.

35. On one occasion there was a parent that brought a sibling in and I had to point it out, it was almost self-policing but these rules were established to protect the patients. Fundamentally you didn't want to jeopardise the children, and someone’s snotty brother or sister could be a major implication to a kid whose counts are so low.

36. Within the playroom, everything was fastidiously cleaned. Everything was locked away. Everything was issued to the child upon entering the room. There was one occasion where a family who had a less favourable outcome than we had, donated loads of toys. Some of the toys were porous and because that meant they were difficult to clean they could not be used on Ward 2A. Everything needs to be wiped clean and needs to be able to go in to the dishwasher. It was sparkling. You could actually eat your dinner off the floor.

37. The play leaders did the cleaning of the objects themselves. I assume that cleaners were involved cleaning the infrastructure. The play leaders were constantly cleaning up the room; if it was dirty, they cleaned it up. We all did actually. You cleaned and it became second nature within a day or two of being on the ward. It was to prevent infection as part of the infection prevention control protocols.

38. The play leaders used a lot of Baker Ross products in the playroom. Specifically they had wee school packs. Those packs contained three things: three dollies; three colouring ins; three sticky crafts; three activities and similar. The play leaders would take out the school pack, open it, drop it on the table for the kids and throw away the packaging. Once the kids was finished playing they would throw it all away. Everything was either sealed and disposable, or it was able to

be washed. The playroom didn't have books. I can't remember seeing any books or fabrics.

39. There were no school lessons as such. I do remember meeting a teacher at some stage during the process. I can't remember when. To be honest, it was so reactive. The kids weren't well. What [redacted] needed was what the play leaders could offer, and they were very much responsive to his needs at the time. We didn't need to do maths and English. It was low priority. The kids don't need to know how pyramids are built; they just need to get better really.

40. For us and for [redacted], the fact that the playroom was a dedicated space where he could just go along was great. It wasn't 24 hours but it was still great. The play leaders had these wee boxes and if the kids were having a bad day, things would appear, activities from them for us to do with [redacted]. There was very much a family theme to the activities they gave us.

41. It was good that the teenagers had their own area. I felt so sorry for those kids because, the thought of doing chemo and puberty and all that next to a two year old, you don't want that. It was good the teenagers had their own facility in Ward 2A, and it was a shame that they didn't have that facility in Ward 6A. I would hate to be a 12 year old having to put up with that. It was a really nice set up; there was a tea making machine in their room. We peeked in. We didn't go in because you're not allowed to go in. There was comfy couches and tellies. No adults. It was their space to go and be kids, teenagers. It was lovely actually.

42. In ward 2A we could get a cup of tea. There was a parents' kitchen where you could actually go and get a cup of tea. My goodness, that's a useful thing at three o'clock in the morning. It was also a place where we could go and speak to another parent that was going through a similar thing to us; that didn't really happen in any of the other wards that were outside of 2A.

43. The parents kitchen was good. You went in, there was a fridge and freezer. Everything that went in to that fridge was labelled, with your name and a date. The staff were really fastidious about cleaning out. There were two microwaves, a kettle and the freezer. Tea was made from bottled water and the dishes had to be washed in the dishwasher; not rinsed under the tap, everything had to be cleaned in the dishwasher. The dishes were not to be washed in the tap water because there had been an issue with the water. We were told this by the domestic staff. There was a big pile of bottled water in there for us to drink. There was a wee table and a comfy chair, which for us was great because during the day there were two of us in. Quite often, if one of us was with [redacted], the other one was through getting a cup of tea or chilling and chatting to other parents and that was good. It was good to have that space to go and de-stress, and get a cup of tea and food. The food wasn't provided for the parents or for the carers there, but there were facilities to allow you to cook, heat up and that was really useful. There were cupboards and everything had to be labelled so if you wanted to go and make yourself a bowl of cereal there was the space in cupboards to store stuff like that. Everything was dated and if it wasn't, it was thrown out.

Staff

44. From a staffing point of view Ward 2A was set up to deal with immunocompromised children. The ward had a greater number of nursing staff. They had, from what I understand, a greater number of doctors. There were no first year/second year student doctors amongst the doctors themselves. From our experience the doctors that treated [redacted] in Schiehallion had the time served experience and they weren't using our children to practice on. That was a major thing. The Schiehallion kids weren't getting practiced on for anything as they were too weak.

45. They did have an eye on dealing with children that were immunosuppressed, and who had the capability to deteriorate very quickly. Therefore the staff

reactions to specifics like high temperatures were very different within Schiehallion when compared to other wards in the RHC.

46. For example, when [redacted] had a temperature spike it was quite normal for him to rigor and start shaking. His temperature would be constantly monitored and managed with paracetamol. For these kids you can’t really do it with ibuprofen. It was incredible to see what the staff achieved and how they managed the situation. The Schiehallion staff were experts at managing temperatures with paracetamol, to the extent of determining whether to give IV rather than an oral because it would work quicker. I remember on one occasion when [redacted] had been given IV paracetamol already to manage the temperature the next step was to give him one oral paracetamol. One of the Schiehallion nurses stood and watched the clock counting down the seconds to be certain of the time that the paracetamol ran out so [redacted] could get the next dose.

47. The level of care was high. The staff were also very good at being aware of parents and they listened to us. For example, there was one occasion in Schiehallion when a piece of equipment that took a temperature returned a reading and I thought that [redacted] was hotter than the reading. I asked the staff to try the other ear, or change the machine. They did and it transpired, when they went in to the other ear with a different machine he was reading a degree hotter.

48. The attitude in Schiehallion is that you know your child better than us and we will work together. While Colette and I didn't have a clue, the staff were very willing to listen to us and listen to our concerns. I wouldn’t say it’s a team effort because they were doing the hard work but they listened to what we had to say.

49. There was a music person that came round the ward. Once we saw a music person playing a ukulele. There was a clown doctor who came round for the

kids. There was also the play team that came up to do work with kids particularly in explaining central lines, and they were great.

50. There was a high level of care from staff across the board. The ward also had something called the bad day box, I have maybe got that name wrong but it was something like that. It was a wee treat box where if a child was having a bad day, the staff would appear with something from the box. For example, one of the cleaners called Michelle would often go and get stuff out the box and give it to the child if they were having a bad day. In fact I think she sent her sons out to go buy presents for children, and actually - that's incredible. There was that level of care amongst all of the staff, and there was the understanding that keeping the kids healthy and making them happy made that process a lot easier. Everything was directed to keeping them healthier and all the staff worked together to do that.

51. The treat box had toys in it. Noreen who is on the reception desk in the ward controls the box. She is great. They're all fantastic. All the toys are sealed. When was admitted, he was handed a new box of Lego because they kids didn't get to share. He went to hand it back when he was finished, and they said no it's yours, we can't use it for any other child, so that's yours. If you're going to spend your money on anything, that's a great thing to do because it works. It was exactly what was needed. It demonstrates the protocols in the ward: the fact that everything's sealed, everything's non-transferrable.

Protocols

52. The protocols in Schiehallion were such that they were much more robust than any of the other wards. I have already mentioned the protocols in the playroom and with toys and treats for the kids on the ward. I have also mentioned the staff approach to managing temperatures with paracetamol.

53. When it came to monitoring and taking observations in Ward 2A, the approach was certainly more robust when compared to other practices on the wards where we stayed in the RHC.

54. The regularity of monitoring depends on the temperature. To be honest, Colette and I tended to monitor it more than anyone else because we were in the room. I can't remember whether temperature obs were two hourly or four hourly. Generally, [redacted] was monitored heavily and he always got monitored really heavily when he was spiking a temperature. When his spike subsided and he progressed out the spike, the level of monitoring tended to ease off slightly because he was getting better.

55. To be honest, they needed to put resources where they were necessary. But throughout the process we were also monitoring [redacted]. Not that we had any qualms or any issues but I'm just a paranoid father. It was pretty robust.

56. By comparison when [redacted] was in the orthopaedics ward in the RHC, there was only three or four obs a day which is nothing. On Ward 2A it was much more regular and that meant the staff were more likely to pick up stuff and see if there were signs of deterioration. Also in 2A, there was a bit of flexibility in how they did obs to limit the impact of it. For example, they worked obs round providing medicine, so they did everything at once. In some other wards staff tended to come in and do obs in the middle of the night then come in 20 minutes later once [redacted] had gone to sleep to give him medication. Then come in another half an hour to take another reading. And you just think, why don't you do it all together?

Description of patient bedrooms in Ward 2A RHC

57. There was maybe about 20 regular patient rooms on Ward 2A. There was an older area for teenagers, but we didn't explore that area. Room 10 was about halfway along the corridor.

58. As you enter the standard patient bedrooms there was a sink on the right. There was a patient bed with various pieces of storage furniture round about. From one of the walls, there was a proper fold down bed from the wall for parents and carers. It was comfy. It was a nice bed. We always had to get the bed up out the way during the day, but there was a space to have two twin beds or two single beds either side. Then there was the en- suite bathroom off there.

59. The en-suite bathroom had a shower, toilet and sink. It was a wet room, so it had a continuous floor from the bathroom out into the bedroom The flooring ran up the bottom of the walls for a little bit, and then there were wall panels running down on top of it - probably like you would see in the sports centre is the only way I can describe it. All the taps had filters fitted on them.

60. A lot of the rooms had TVs. On ward 2A there was access to electronic equipment as well, such as gaming consoles. These were cleaned and issued to you by staff on the ward. Once [redacted] had played with it we would clean it and hand it back to the staff. It was like a library really.

61. The bedrooms were a fairly reasonable size. The building is curved and the ward was situated on one of the curves. That meant that some of the rooms were slightly different depending whether they were on the inside curve or an outside curve.

62. Ward 2A also had a number of VAC room, which are negative pressure patient rooms. These were situated at the back of the ward. You enter the room through a door from the corridor, it took you straight in to a little hallway. There was another set of doors that you had to go into in order to enter the bedroom. At the double doors there was a holding space in between the two sets of doors.

63. Some of the VAC rooms had storage in the back room area. I couldn't tell you whether that was the VAC rooms in the Schiehallion or not. Generally when we

were in other wards out with 2A, we were in these VAC rooms because we were always in isolation because the other wards didn't have the level of stringent protocols that Schiehallion did. The only way they could keep us there, and keep safe, was just to put us in to isolation and not let us get involved in any of the rest of the ward.

64. I think that the negative pressure meant that the air was always blowing out of the room rather than blowing in to it, so that bugs couldn't swim in the air. Like the water's flowing downhill rather than uphill, for the lack of a better phrase. It is a double doored room because there was higher air pressure within the room and out with so that the air was moved out.

65. We ended up in a VAC room in Ward 2A at one stage, it was when had been discharged and he had a temperature spike. Quite often my impression was it was the sicker kids and the transplant kids who used these rooms in 2A, although I could be wrong about that.

Ward 2A RHC: The "Schiehallion umbrella"

66. For me the idea of the "Schiehallion umbrella" is something that existed in Ward 2A of the RHC. It is a level of care and appropriate awareness of cancer in children. It is knowing exactly what needs to be done and how it should be carried out. It is being aware of the subtle nuances that are created by the specific illness. It is being aware of the implications of being neutropenic and being immunosuppressed, and understanding how quickly things can go wrong for these patients. It is knowing that one minute things are very calm and then the next, it's not. It is understanding that there are specific protocols that need to be followed to maintain good infection prevention control and avoid infections.

67. The level of care that we got at Schiehallion was so much higher. I felt safe. At no point in Schiehallion did I have any concerns about [redacted]'s treatment.

68. When [redacted] was first admitted to Ward 2A in early August 2018, there was a bit of an induction. If I remember rightly, it was quite easy. That was a long day or two. We got shown around and it was a bit like first day of school: this is that, this is what you do, clean up after yourself. I'm sure in the playroom they talked about siblings at that point.

69. In terms of the medical processes we were talked through the process by the staff as they went. I don't really remember getting specifics. The medical staff were very good at communicating with us as they went along and involving us in the process.

70. Staff were very good at telling us that we might end up in another ward. They told us that the other wards were not as good as Schiehallion (my phrase, not theirs) and they told us that we had to be on it. The staff were quite good at making us aware. The nurses were great at involving us in it. Effectively, they were warning us that other wards weren't as hot as the Schiehallion ward, and they told us that the we had keep an eye on [redacted] when we were admitted to another ward. And we did.

71. I don't remember the Schiehallion staff ever saying "they won't do this and they won't do that" and "they will do this and they will do that". It was just the staff informing us what the Schiehallion standard was and telling us that not everyone was up to that. Maybe that sounds a bit braggy, but the Schiehallion staff were the best at their job; in hindsight that was absolutely true. They tailored care to the needs of the patient. You know, if you've got a broken leg, it's very different to having cancer.

72. Funnily enough, some of the better wards we were in dealt with high need patients. The cardio ward was great, they deal with kids that are about to have heart attacks. They were used to dealing with children that went from being very healthy to not very healthy in a short time period. Dealing with cancer and dealing with a bad heart, it's not far off the same thing; both deal with critical

children. If you've got a broken leg, it's not fun but you hope the patient wouldn't deteriorate significantly in half an hour.

73. In terms of administering medication, it was completely tailored to [redacted]'s needs. Therefore, if he needed paracetamol he got it when he needed it. Rather than say he should get paracetamol every four hours, the Schiehallion staff might say, "well he's okay, we could push it for an hour", or they stood outside the door counting down the seconds and he was given it bang on four hours.

74. The protocols for chemotherapy were established. Medication could only be administered by Schiehallion staff and in the Schiehallion Unit in wards 2A or 2B. There are very strict protocols and procedures as much from a health and safety point of view because these chemicals are nasty things. The staff wear plastic aprons and full gloves because if you get it on your skin it burns you, which is a bit scary.

75. In Schiehallion, doses are bang on. Everything they provided was with two people who check the doses. Quite often [redacted] got chemo in day care in Ward 2B and that was an art in itself. There's an awful lot of training to do before the staff can administer chemotherapy. There were Schiehallion nurses in ward 2A that were training to go to day care because it was a different set of skills. Although they could give chemo in ward 2A, generally it was in day care where they did chemo.

76. When it came to the practice of finding ports the day care staff were good at it because they did it on a regular basis. The staff in wards 2A and 2B understood each other's good points and tended to play to their strengths.

77. With regards to other medicines they might need, again it was dependent on the child. [redacted] had anti-sickness, ondansetron; that type of thing was prescribed by the doctor and given as needed, but there was flexibility. He was also given an additional metoclopramide to overlap with it. Generally ibuprofen

was just a no-no because of the low blood counts in these kids, but if it was needed to control a temperature there was a discussion whether it was okay depending if bloods had been taken. That is one of the reasons why we kept such fastidious notes. When we went in to another ward, the standard approach was "don't give them ibuprofen", but if your kid's spiking and you've only got four hits of paracetamol that you can give every four hours that's only 16 hours out of 24 hours, so you're looking for something to fill in the gap. Ibuprofen was a great overlap with paracetamol so you're stretching out the dosing because if was spiking for a day and a half, you don't what to have burned all the meds in the first 16 hours.

78. That is the level of conversation we had with staff at Schiehallion. Whereas there wasn't that level in the other wards. The staff on the other wards were quite good at listening to us and as long as we worked together, that was fine. I suppose that was the bit about me and Colette learning and taking that information on board, as we became very good at. We were not trying to tell the staff on other wards how to do their job because at the end of the day, they know what they're doing. But Colette and I became very versed at keeping to the general principles and then tweaking them for our child, and I think that's what Schiehallion were trying to instil in us as parents. Staff told us the important things over and over again.

79. In ward 2A we had been told to drink bottled water and we were told not to drink from the tap. We were told not to brush our teeth using tap water but to use bottled water. I can't remember the specific time when someone said at the start, but I'm sure we were told only use bottled water in the kettle and just drink bottled water.

80. When Schiehallion moved to ward 6A, while the staff continued to provide excellent care, the infrastructure impacted on the level of care that we received. The ward was smaller and did not have the facilities that Schiehallion had. That's just the way it was. After Ward 2A and 2B closed and the children were moved

to ward 6A QEUH, what had been two wards were then pushed in to one ward. It was a smaller ward anyway and they also added in day care, so it dramatically reduced the size of the ward itself.

81. The issue with the "Schiehallion umbrella" was not just with the new Schiehallion ward on 6A. [redacted] was often admitted to other wards in the RHC due to a shortage of bed space. As I will come onto, [redacted] was admitted with a temperature spike at the end of November/beginning of December 2018. Before we went in, the conversation between Colette and I was, "I really hope we don't end up in hospital for Christmas". After the experience in the ortho ward, it was, "you know what, being in hospital for Christmas is fine, as long as we end up in Schiehallion." That illustrated our level of concern and the differences in the care between the wards. The Schiehallion umbrella did not follow us when we were out with ward 2A.

82. We went from "we don't want to be in for Christmas", to "Schiehallion's great, we don't mind being in there, just not anywhere else". It's sad that it got to that stage.

Discharge and Chemotherapy continues: August 2018 – September 2018

83. [redacted] was discharged from ward 2A on the 8 August 2018. The plan was that he would continue to receive his chemotherapy in Ward 2B of the RHC which is the daycare ward in the Schiehallion Unit.

84. On 10 August [redacted] had a temperature spike and was readmitted to ward 2A and Room 10. When [redacted] had a temperature spike a certain procedure and protocol was followed. A temperature of 38 degrees and above is a sign of infection. This is a temperature spike. The huge thing that everyone was worried about was line infections. The procedure is that you call the ward. We then gave him a dose of paracetamol to get his temperature down and we had to get him to hospital. If we couldn't get him to hospital within half an hour/40 minutes, we had

to phone an ambulance. When we arrived at the hospital, if it was out of hours would be taken to A&E in the RHC. When we arrived, they put us in a wee side room because you can't have these kids mixing with any of the diseases and such like. From there he was admitted to whichever ward had a space for him. If this happened during the day, we would go straight to Schiehallion and he was admitted from there to wherever there was a room.

85. Once he was admitted as an in-patient, he was given a few tests, blood draws were taken from the line and then they started him on antibiotics.

86. The treatment was administered and he was treated as if he did have an infection. We had already given him his paracetamol to manage the temperature. The medical staff began taking observations.

87. When he was admitted, Colette and I got into the habit of running through all of ’s medication with the doctor on call in the ward. If he went through A&E, we told those doctors everything, right down to advising them that he was prescribed and could take Piriton, just so they knew that it had been approved if anything was required.

88. The blood cultures come back around 48 hours later therefore whatever happened, [redacted] was an in-patient for at least 48 hours when he spiked. If we went in on Friday night, he wasn’t getting out until at least Sunday morning. In order to be discharged, he had to have a temperature below 38 degrees for 48 hours. If he spiked again then it would reset the clock. Once we got the results of the blood cultures back, if they were clear too, then we could go home after 48 hours.

89. We tended to bounce in and out of Schiehallion during this period. It was a bit of a blur. [redacted] tended to spike a temperature quite a lot. In that initial period, when [redacted] required to be admitted with a spike, the admissions were all to

the Schiehallion. We didn't go to any other wards in that period. We bounced in and out, which was fine.

90. After chemo was administered, we would sit with [redacted] for an hour to ensure there were no issues or reactions and we took him home. We found that when got a double dose of chemo he was okay. If he got just Vinc, he spiked within about 48 hours and no one could work out why. I had a discussion with the doctors, they thought that the Actinomycin was more likely to cause a spike than Vinc. They thought that the spike was a delayed reaction; that he wasn't spiking 48 hours after Vinc but eight days after Actinomycin. We're not sure. What we did know was that every second week [redacted] was going to spike a temperature and we were able to predict it.

91. I always carried a thermometer with me. The in-ear ones could be problematic, so we had a strip called a TempaDOT that is put under the armpit or under the tongue and it's the most accurate of the lot. We carried a handful of those and the in-ear thermometer too. We would monitor the temperature with the in-ear and if in doubt we would throw TempaDOT in and also use it to confirm a spike.

92. In hindsight, I think the reason why he was so spikey was that the tumour itself was dying so it was sending nasty stuff all over his body. He was getting hammered. We definitely saw deterioration in him during that period.

Description of Ward 2B Daycare in the Schiehallion Unit (RHC)

93. Ward 2B in the RHC was part of the Schiehallion Unit. It was the day care facility.

94. Ward 2B was comprised primarily of rooms. As you entered, there was a wee central play area with a waiting area on the left hand side. The reception desk was on the right hand side. There was a long line of rooms in front of you where

patients got their medicine. It was like a waiting room, or a GP's office. It wasn't set up for long term staying. It was very much, go in, get your meds, get out. If something's serious, the child would be admitted as an in-patient to Ward 2A if there was space or somewhere else.

95. Day care was very much a place where [redacted] got an MOT and we found out how he was doing. We saw the doctor and would have a quick chat. Then we saw the nurses who gave [redacted] his chemotherapy.

96. In terms of the nursing staff, it is a very different set of nurses between wards 2A and 2B. It was fascinating watching the ward 2B nurses calculate the chemo doses. They used a calculator and worked through the math, it was checked and plotted out.

97. [redacted] was okay on chemo. He didn't lose his hair, just a little bit of it. He was nauseous and was given anti-sickness drugs. [redacted]'s great; you can give him medicine in his sleep, you can just put it in his mouth and he'll take it. We were giving an anti-sickness drug every four hours. Even when he was asleep so he didn't wake up in the morning drug free. He didn't need a feeding tube and kept his weight, which was good. Hats off to him, as it wasn't easy; primarily bribery with electronic equipment helped. He was told that if he put on weight, he got a Nintendo DS. And he did. So you know what, we bought him a DS. In these situations rewards are a wonderful thing. It kept him eating, by hook or by crook, he ate and kept his weight on.

98. Generally he was okay. Looking back at photos now, he looks like crap. He didn't look well. But there were an awful lot of children who suffered an awful lot more. The protocol that he was on was quite a compressed high level of drugs. didn't need many blood transfusions. He tended to get run down and get wee infections, for example got infections on [redacted] , he got a black tongue. They were infections from being just unwell.

99. Of course, he spiked every second week. Who can forget going in to hospital every second week with a temperature? Whilst it was scary, because there was always concern that it was something nasty, more often than not it could have been worse.

Admission to Ward 2A RHC – Room 2: 24 August 2018

100. When [redacted] was on chemo, he spiked every second weekend. On the 24 August 2018, [redacted] had a temperature spike when we were in daycare in ward 2B and he was admitted to Room 2 in Ward 2A. This was one of the VAC rooms and it was the first time we were in a room where we could actually control the heating and air conditioning.

101. The building was hot all the time. The heating just didn't work in ward 2A, or indeed in any of the wards. There was something wrong with the air handling system in there which would explain a lot of the bugs they were having. There was a lot of infrastructural issues in that place. It was very hot and when you're trying to get temperatures down with these kids, it's no good. We were using cold flannels just to try and cool him down. The only rooms where the heating did work were the VAC rooms in ward 2A.

102. During this admission [redacted] went in to rigor and that was the first time this happened when he was going through this treatment. Rigor is shaking and shivering. It's a fancy way of describing the state when you get a fever and you get all shivery. It's a shivery fever. One of the daycare nurses called Susan told us that it was not a good sign when chemo kids went into rigor. We were advised to tell the staff if [redacted] was rigoring, that we were not to suffer in silence or feel embarrassed about it. It was very affirming to have that support from the staff.

103. [redacted] was quite unwell when he was first admitted. It was during this admission that we saw nurse Kat waiting outside the room and counting down

the time between [redacted]'s paracetamol doses in order to get the best overlap in his medication. [redacted] could only have four doses of paracetamol in 24 hours. That only covers 16 hours so there could be long periods where you are without drugs. The staff had two ways of managing this. They could run a gap of six hours between paracetamol doses, but that means in the last two hours he was drug free. Or they packed the doses up at the front and hoped the paracetamol would take the temperature down. They could administer through IV which also helped.

104. That was the sort of stuff that we picked up from the staff. In addition we picked up cues from [redacted]. He worked well with hitting him hard at the start of a temperature spike with IV paracetamol. That admission really underlined for us the fact that it was a very precise level of care: nurse Kat was standing outside the door when [redacted] was in rigor, she was counting, looking at a clock to when it was time to give [redacted] his meds.

105. During that admission on 26 August there was an incident when [redacted] used the shower. [redacted]'s hair was getting long and he was losing his hair, so we decided to cut [redacted]'s hair and I would cut mine too. The bathroom itself was a wet room. I have drawn a picture on the timeline which is a representation of the bathroom itself.

106. To give you a bit of background, I come from maintenance and worked in water sports, so I have a wee bit of a clue. Generally you would find a wet room floor runs to the drain, and I would expect the floor in a room like that to taper to the drain.

107. I have drawn a diagram to show you the layout of the bathroom. This drawing was done two years afterwards and it is not to scale. The drain was below the shower head, the floor tapered to the drain but only 1 meter square. After this there was a slight ridge, almost like a levee then the floor flattened off. So if

water landed in the 1m it was ok, but out with this it flooded the room. The purpose of a wet room is it should all taper into the drain.

108. When I cut my hair, the hair didn't drop on the floor and the hair did not block the drains. That was the key thing. The drain wasn’t blocked, it was still draining. The easiest way for [redacted] and I to do this was to go in to the bathroom, get down to our pants and cut our hair. Once we collected the hair, we had a shower.

109. There was water fairly liberally round about the bathroom, but it was all in the bathroom and a wet room should be designed to cope with this. What we didn't expect was a tidal wave of water to continue on round the bathroom, through the door and into the bedroom. It then ran under the bedroom door and into the corridor in the ward. As soon as this happened, I got in about cleaning it, mopping it up. The cleaning staff were great but we were fairly proactive as well, I cannot remember exactly what was said but there was a comment made by one of the nurses in passing along the lines of, “that’s not the only room”, or ”that’s not unusual”, or “that is not the only room”.

110. What was clear from the comment was that this wasn’t an isolated incident. I was most apologetic because I was mortified that I had flooded the bathroom. In response the staff were confirming that it was not the only room that floods, or, that’s not the first time it happened.

111. Looking at the design of the bathroom floors, it doesn’t surprise me because the moment the water crossed over that slight taper in the floor, the nature of the run was that it run along the back wall, underneath the toilet pan and it ran around and down. Any nasties that were round about the toilet floor run into the bedroom. Following that incident we began to wipe the floor area with wipes and such like. The staff were great for helping us clean up afterwards but there is a structural concern. There is an infrastructural issue where you’ve got a wet room

where the water doesn’t drain downhill. We got to the stage of using old towels to create a dam between the bathroom and the bedroom.

112. The cleaners came in every day. But we made a dam with towels just to catch anything. [redacted] wasn’t well and we were trying to keep the Hickman line dry, the easiest thing to do to wash him was to get in there with him, take your clothes off and shower together. Two people in that small space, just doesn’t work.

113. I can't remember flooding happening to any great extent in any other room but we were on it. We were much more aware of it. That caught us by surprise on this occasion but it didn't catch us by surprise again as we were looking out for it. I can't remember water going out and flooding into the main bedrooms again, but in some of the bathrooms that we stayed in it was not unusual for them to be quite awash. But we just got extra towels that drank it up. We were aware that it could happen so we kept an eye out for it.

114. [redacted] was discharged on 27 August and then he attended at daycare on the 30 August for more chemotherapy.

Surgery – admission to ward 3B in the RHC: September 2018

115. On the 3 September 2018, [redacted] attended at ward 2B for some blood work and a pre-surgery meeting with the anaesthetist and surgeon, Ms Brindley. He was then admitted as an in-patient to the paediatric surgical ward which is ward 3B in the RHC. The procedure was explained along with potential implications and recovery. The surgeon told us about they were going to access the kidney. They said that they would need to go in through the front. Normally they would go through the back, which is an easier operation. For whatever reason they had to go through the front and it was going to be a long operation

116. There were a few doctors who looked after [redacted] during his time in Ward 3B. Miss Brindley performed the kidney removal surgery. Dr Hettle worked with her. Dr Hettle was her right hand person. They were both very good. There were a few trainee surgeons. Mel was another one, he liked Voltron and so did [redacted], so they talked about that.

117. Upon admission to ward 3B, the bedroom was not ready. Whilst we were waiting for the bedroom to become ready, Colette and I took [redacted] to the playroom. In the playroom there were other children who were not immunocompromised, they were healthy by comparison but some had runny noses and they were snotty. We waited in the playroom until the room was ready. The playroom did not have the same protocols as the one in Schiehallion; siblings were allowed to enter and the toys were not wiped down between uses.

118. Eventually the room was ready and when we went into the room we saw that the bed was covered in red/brown matter. I don't know what it was but it could have been IV contents, blood, poop. It wasn't very nice. We flagged it to the staff and to give them their due, they took it away and gave us a new bed. As soon as the staff went out the room, Colette and I proceeded to clean the room top to bottom. I am not sure if we actually had any cleaning products with us on this visit; we definitely cleaned the room from top to bottom. I think I might have blagged some from the playroom on the ward. Following the experience in ward 3B, that become our own protocol and we cleaned every room from top to bottom when [redacted] was admitted.

119. We observed that in ward 3B there were no filters on the taps whereas there were filters on the taps in Schiehallion. The bedroom has a patient bed, a sink and a horrible Z Bed plus an en-suite bathroom. Ward 3B wasn't quite as clean either. We didn't use the play equipment because it was easily accessible to everyone else. Ward 3B also used first year doctors, as good as they were, they were not time served so they didn't have the practical skills that were necessary to work with these kids.

120. On the 4 September 2018, [redacted] underwent surgery to have his kidney removed. Following surgery he was transferred straight to the Paediatric Intensive Care Unit ("PICU"). Parents are not able to stay in the PICU and we were sent home for some sleep. To be honest when your child is in the PICU, there's not much you can do. You just sit and watch and it's very bizarre. It's a very quiet, chilled place and it needs to be. I think that PICU is on the second floor in the RHC, next to ward 2E.

Line infection – Ward 3B RHC: 5 and 6 September 2018

121. During the night [redacted] spiked a temperature. The staff suspected a line infection and antibiotics were started. We were at home sleeping so I don't know what his symptoms were beyond that. I can't remember how it was communicated to us, but it was fairly low key. We were so caught up in the cancer treatment and the fact that he had just had major surgery. He was alive and the surgeons didn't have to remove any of his bowel, so for me the line infection was quite low priority at the time and I didn't appreciate the seriousness of it.

122. At some point on 5 September 2018 he was transferred back to ward 3B and as he was considered a high priority, he was put near the nurses desk. However he was not put in a VAC room, he was just placed into a standard patient room: so no vac seal doors, no water filters, year 1 doctors and a different cleaning protocol from oncology rooms. The only real nod to [redacted] being an immunosuppressed patient was the fact that he was put close to the front door near the nurse's station.

123. I think at the time that I spoke to one of the doctors on the ward, and he explained that the staff do have a specific skillset in post-surgery. Jenny was the nurse caring for [redacted] and she was absolutely fantastic.

124. In general, ward 3B was just a different type of care when compared to Schiehallion. [redacted] really wasn't well. He reacted to the dressing or the cleaning solution that was used round his scar, and he came out in a huge rash. Staff ended up treating it as a burn. Colette and I got to the stage where we were sleeping next to him and holding his arms as he was clawing at the rash. He was started on Piriton but it didn't work so they gave him something stronger which made him feel pretty groggy.

125. At this point [redacted] still had his epidural in place, morphine via Patient Controlled Analgesia ("PCA") and he was on antibiotics. I think that the antibiotics that he was on were just for the line infection. There might have been some post-surgical antibiotics as well. But certainly I wasn't aware of any other antibiotics.

126. On the 6 September 2018, [redacted] was still an in-patient in ward 3B. At 11:45am two first year doctors came in to get blood from his hands or his feet and blood was drawn from the line in order to do a compare and contrast with the blood in the line. This was to allow them to start antibiotics. Emla cream was put on his hands and feet. Emla numbs the area to allow the doctors to find a vein and draw blood. Generally the doctors hit two places, just in case they can't find a vein and so they've got a backup plan. In these doctors' defences, it wasn't going to be an easy task because [redacted] wasn't well but they just slapped on the Emla cream and didn't really pay much attention to his veins. They slapped it on to everywhere on his hands and feet then they went away. Forty minutes later [redacted] was very unwell.

127. When the line was accessed [redacted] started going in to toxic shock, his heart beat shot through the roof. He was tachycardic which means his heart beats were more than 200bpm. His temperature began to spike, he began to rigor and vomit. Vomiting for [redacted] is a sign that he is really not good.

128. Colette was pressing the buzzer in the room. No one responded. She had to go out to the front desk in the ward for help as there were no staff around.

129. When the first year doctors came back to the room, they began to attempt to draw bloods however they didn't manage to get any out of his hand. This was problematic because without the peripheral draw for comparison, this delayed them getting more antibiotics into him. They were just jagging him trying to get the blood draw. They continued to try to get the peripheral draw as he was going into toxic shock. They could not get the blood draw from his hands or feet.

130. [redacted] wasn't an easy draw but the proper procedures weren't followed and they were just learning. I did say to the nurses afterwards, you can stick needles in all over me, I don't care, do whatever you want, but get someone that has a clue to put these in to my son. Hats off to them, they did go and find someone who could take the draw.

131. [redacted] was getting flappy at this point and the doctors continued to try and draw blood without success. Post event [redacted] developed an aversion to needles and it was associated with this event. He was great with needles up until this point, but it took a lot of work for him and us to deal with it in the aftermath.

132. [redacted] went from being a reasonably happy boy to being very unwell in the space of 40/45 minutes. At this point Dr Hettle came in and he just calmed the room. He was great. He came in, got the draw and basically said, just get antibiotics in. He calmed [redacted] down by talking to him about dinosaurs. So the staff banged in antibiotics rather than waiting around for blood test results. Colette had left the room at this point.

133. Jenny the nurse was also in the room. I'm sure she was encouraging the doctors to start a bolus. She was fantastic and also was very much calming the room. As soon as the bolus and antibiotics were started, things began to settle. A bolus is a flush of liquid. Whatever it did, it seemed to do the job.

134. The big issue there was that we had two junior doctors who didn't have the experience to deal with this escalating situation. It happened over lunchtime and there were no staff on the ward to help. It took a bit of time for people to get on site. It wasn't until Doctor Hettle attended the room that things started moving forward, and it took a bit of time for [redacted] to settle down. It was scary. was panicking as he had a huge toxic shock reaction and his heart rate went through the roof. Colette broke the alarm on the heart rate machine. That experience was a bit of a shift for us. It wasn't great.

135. On the 7 September Doctor Ronghe visited [redacted]. The microbiologists had advised that medical staff should place an antibiotic block in the line which cleans it out. This required accessing the line. In discussion with Dr Hettle, I said in a passive way, let's not do this at 4:30pm Friday afternoon when staff are going home. I asked if it could take place earlier in the day and he agreed.

136. At some point, we were told that the infection was serratia marcescens. I can't remember who first told us that the infection was this specific bug. I remember Dr Ronghe told us at some point and we had a meeting with him. Colette and I kept on asking people to tell us the name again, because it's not an easy word to remember. Dr Ronghe definitely told me. Whether he was the first or not, I cannot recall.

137. The problem with this bug, to quote Dr Ronghe, is it's really sticky. It sticks to plastic and it doesn't scrub off easily. From what I understand, the plan was to fill up the line with antibiotic so it's like pouring bleach down the toilet. My concern was when they put in the block that could release a flush of nasties.

Line block – Ward 3B RHC: 7 September 2018

138. It was 4:10pm on the afternoon of Friday 7 September when the antibiotic block was placed in the line and 40 minutes later it all kicked off again. [redacted] had

the same symptoms as before: temperature spike; rigors; vomiting. He received a toxic shower from the line block.

139. Dr Kamal, who was one of the other doctors, attended and started the bolus. He gave ibuprofen to manage the temperature. There was a wee question about whether he should be getting it. Children who are in receipt of chemotherapy would not ordinarily be prescribed ibuprofen. It is related to their blood count, they need to have a certain number before it can be given. I think if he had a blood count of hundred and ten, ibuprofen can be prescribed.

140. [redacted] threw up the ibuprofen. Dr Kamal did what was necessary to save 's life and I thank him for that. I suspect the risk of ibuprofen was less than the risk of toxic shock.

141. One of the consultant doctors from A&E arrived who was the head of infection control, because it was now 4:50pm they had issues getting people on site so doctors were called from all over the hospital. Eventually two Schiehallion nurses arrived and I felt sorry for them, because they could hardly breathe as they'd ran from the second floor. The room was full of very intelligent people. Wendy, one of the Schiehallion nurses said that [redacted] should not be getting ibuprofen and that he was not to have anymore.

142. I wasn't paying attention to the doctors. I was watching [redacted], holding his hand. Every time I looked up there was more doctors. It was five o'clock and they couldn't get people. The staff were just picking up the phone and got anyone they could. The bed was busy when I looked up and there were lots of people coming in and out. But at one point I did look up and go, man, this room is full

143. When she was in the room, the A&E consultant doctor said that the infection that had was a "poo bug", I don't know the doctors name, she had brown curly hair. Colette might know. It was a bit of a surprise and this was the beginning of us

finding out what the infection was. We didn't know the name of the infection at this point, we did know that it was a line infection though. Dr Ronghe had described it as quite a nasty one to deal with because it was sticky, and it gets in to plastic and hangs on. It wasn't an easy one to deal with and this block was to try and save the line. It didn't work and it took 90 minutes to stabilise [redacted]. I looked around the room and saw a sea of scared faces, I clocked Doctor Kamal's face and he wasn't a happy man.

144. It was a bit touch and go and staff considered admitting him to PICU. Dr Hettle had been in the middle of surgery and eventually he arrived in the room. He made a plan then and there to pull the line. He ordered the line as out of bounds and told staff not to touch it.

145. The following day on the 8 September, Doctor Hettle took [redacted] into surgery and removed his Hickman line. It was crisis management to be honest, management of two severe crises in two days.

146. It took everyone by surprise how quickly he deteriorated but it was very much an eye opener of how far and fast things could go downhill. That was the thing, I didn't really get to grips with how serious it was until we had a discussion with Doctor Ronghe on the 17 September. I made a glib comment that "it was only a line infection". Doctor Ronghe corrected me and said that the most concerning thing was the line infection, not the kidney, not the cancer, not the chemo.

147. [redacted] had two severe reactions but he came through it. He dodged the bullet and that was all that really mattered. On both occasions the inexperience of the room was shown. We were in ward 3B without the full umbrella of Schiehallion care. If we had been on Ward 2A the staff would have been on it and managing that situation within minutes. Now they might not have treated the wound as well as the post-surgical staff, but certainly they would have been all over the line infection.

148. When it happened the second time around, again the staff dealt with it as well as they could but the timing really wasn't great. They began the procedures on a Friday afternoon and within 40 minutes it had all gone Pete Tong.

149. It was concerning to say the least. I don't know whether the second time was worse or better than the first, because I knew what was happening the second time. During both events, we were at the height of the crisis fear. We were always very aware of [redacted]'s mortality throughout this process; one in ten of people with [redacted]'s tumour don't make it. We were always working for a positive outcome. I don't want to sound melodramatic but that was the bit where I looked at Colette and thought, we're now in the ten per cent land. This is the crunch point. It was scary. But we got through it and that's all that matters.

150. I would say that in some ways it was easier for me. I think it hit Colette because I was sitting at the head of [redacted]'s bed, holding his hand. To give you an indication of how busy the room was there wasn't space for Colette to come and hold her son's hand and that impacted her. Hats off to Colette for taking that bullet, because that's a huge thing for a mother to be able to do, is to stand back. That was shit. That's the only way you can really describe it. It wasn't fun for anyone. We were very aware of [redacted]'s mortality, and at point he stared it in the face.

151. I commend the doctors for saving him. I try and rationalise everything, that's been my way of dealing with it all. When [redacted] went walked into that hospital with cancer, he had zero per cent survivorship. He was dying. That's it. He was dead. Dead boy walking. The moment the doctors started to intervene, they started to change those percentages. We went from being a hundred per cent in the red to ten per cent in the red. We wanted to keep [redacted] in the good figures, not the bad figures. What the doctors did was to keep in that. Colette and I had very little control over that 90 per cent. The 90 per cent is what the medical staff controlled. The ten per cent is bad luck, genetics, all these other influences, and stuff like line infections. This is what concerned me, the other

stuff. If we as parents can affect the odds by even one percent is a difference between one in ten children dying and one in 11 children dying. This is what you think of late at night.

152. That thought process influenced me more when we ran in to issues with rooms and set ups not being good. When [redacted] had the line infection, that was a point at which I felt we were in the red rather than the black. We were that ten per cent and there was a risk to his survivorship to say the least. Thankfully, I have been able to compartmentalise it afterwards, because it was a crisis and it was averted. We went back in to the black. Colette had a lot of help, particularly for that event. It was traumatic.

153. Following the line infection and the two incidents, physically [redacted] wasn't great. He's quite a robust boy but he was ill. There's no polite way to put it but this time was the only part of the process where I thought, "mm this is touch and go here". When you look up from a bed and see a sea of faces and they're all looking as concerned as you are, that's a bit harrowing. I have a laugh and a giggle about these people being gods and fantastic people, but they are just people. They're doing their job. Until Dr Hettle came in the room, there was a lot of people looking very scared and it was my gauge of how unwell [redacted] was. It took him time to get better from this. He did get better and, we got a good result.

154. The other physical impacts is that [redacted] had to undergo surgery to have the line removed. I can't say for sure whether the whole episode slowed his recovery down but it must have. I can't compare it with anything because it has never happened to us before. Not only was [redacted] dealing with losing a kidney and a reaction to the meds, he was also dealing with a monumental infection and toxic shock and all these other things. You don't just bounce back straight after this. As good as children are, they're not super people but he bounced back faster than I expected to be honest. The line infection really knocked it out of him.

155. The big difference is between the Schiehallion staff and other staff is being responsive to the particular situation. The fundamental thing here is that in 45 minutes [redacted] went from being okay to critical. The primary concern of that stay was this whole episode, it was the crisis point. In Schiehallion they would have been on it in five minutes. I know for a fact they would have been on it quicker. Could they have prevented it from going further? I feel we would have had a much, much faster response in Schiehallion, plus Schiehallion was full of doctors. We always knew that we had two senior nurse practitioners, and had loads of doctors available. The staffing levels are higher in Schiehallion. They wouldn't have been scooting around trying to find doctors or nurses because it was lunchtime or five o'clock. At the other end of the corridor of Ward 2A, you've got the outpatients ward which is full of doctors as well. Within the ward or the ward beside, you could have filled the room with people that knew about line infections and were experts on line infections: that's their concern. For the line infection, the Schiehallion staff would have been much faster at response, whether that would have led to a quicker recovery, I don't know. [redacted] was immunocompromised. He was the scary risk area.

156. Don't get me wrong though, Jenny and Dr Hettle were fantastic, and I thank them. But Schiehallion would have been faster because their area of expertise is oncology and line infections.

157. I don't know how long that [redacted] was on antibiotics to treat the line infection, but he didn't have them when he was discharged on the 13 September.

<u>Hospital Acquired Infection ("HAI"): 17 September 2018</u>

HAI: Communication

158. On the 17 September 2018, Colette and I attended a meeting in Ward 2B with Dr Ronghe and Dr Inkster. At that meeting the doctors spoke about the Serratia

Marcesens infection [redacted] had contracted. They told us it was hospital acquired. I do remember saying, “you know, it’s only an infection”. Dr Ronghe wasn’t forceful because he’s such a wonderfully gentle man, but he made it clear that no actually this infection was the most serious thing. This infection was the most concerning thing of this whole period, not the kidney, not the cancer. No, the infection was the major concern. That was a rocket up my backside and there is no other way to put it.

159. At one point there was a suggestion that it might have come from PICU and that it was possibly from the drains. But I don’t know whether it was that meeting or another discussion. Colette will be able to fill in on more of the specifics from that meeting as I can’t recall much more than that. For me to move forward, I had to compartmentalise this stuff. The crisis point was done: we’ve climbed over a hill, let’s not get another hill like that again.

160. When we were told that the infection had come from the hospital and it might have come from the drains or from the water, it was a double edged sword just to use another analogy. Some of me was slightly relieved. The moment they said “poo bug”, you immediately assume…is this my fault? Did we not clean the bathroom properly? Is this our fault that our son was so seriously ill? Hospitals are clean, we thought that you don’t get infections from hospitals. I assumed it must have come from us.

161. I had quite a lot of guilt and I questioned if it came from us. I thought that maybe we needed to up our game. It was a major concern that it was our fault. I know Colette felt the same way as well. We actually discussed it afterwards. In some ways we were quite happy. On the other hand it was a bit sucky, so while it eased our conscience it put an awful lot of pressure on us post-event. We had to be on point every single time we walked in to that hospital.

162. I suppose that’s where I would say that it put a bit more pressure on me as I was first line of going in with [redacted] when he was admitted with spikes. That was

where I felt it was on me, I felt I couldn't trust anyone and I couldn't relax at any point.

163. We didn't need the additional level of anxiety of wondering, is this ward going to be okay? Is this going to be clean enough? Are the filters on the taps? I had a mental checklist every time he got admitted which was every second weekend. I was thinking, have I got this? Have I got all the appropriate infrastructure to be able to cope with whatever ward I'm in? When I got into that ward, I needed to be able to make sure that it was clean. But I also need to do it in such a way that I didn't damage the relationship with the staff. Another key thing we found out quickly was that we had to try and establish rapports with the doctors and nursing staff with every ward where [redacted] was admitted.

164. This was primarily because if you had a good relationship with the doctors and nurses, it makes your life an awful lot easier to be honest. These people become your family, almost. You don't want to be seen as a pushy parent because having seen pushy parents on wards, the staff tend to perceive them as a difficulty. They become an inconvenience. Whereas if you're a nice parent, people are more likely to be there for you.

165. Every time I walked in to a hospital I had to be able to go in, clean the room, get everything we needed, but do it in such a way that it didn't get the backs up of the nursing staff because we needed to maintain a good working relationship with them.

166. It did create a lot of pressure for me. I suppose that was my kickback. It wasn't so much a crisis, but I found that it wore me down. For me, it was very much a marathon. To summarise, it put a lot of pressure on me to make sure that the hospital did their job properly because they didn't do it the last time when contracted his infection. It was on me.

167. At that point, in some ways the cancer became superfluous because this infection had been underlined by Doctor Ronghe as being the most concerning thing; not the cancer. For me this was the ten per cent, this was us in the red. The cancer was getting treated. It will either kill him or not. I can't control that. Where we might be able to control some of that ten percent, of course you're not going to sit back. It is not an individual responsibility but actually it created a lot of responsibility on me as a non-trained person.

168. At the meeting on the 17 September when we were told about [redacted]'s infection, we were not told a huge amount about the closure of ward 2A at the time. From what I remember, we were told it wasn't going to be for a protracted period of time. I think we expected to be going back to Ward 2A around about Christmas time. I do remember people saying it was not going to be long. Oh how wrong we were.

169. I think that Doctors Ronghe and Inkster told us that the reason for the ward closure was issues with the water system. I can't remember the specifics though. At that point I can't remember if we were told where the children were going to be moved to.

170. I can't remember specifics of any of the hospital staff sitting us down and saying: this is what's going on, and we've got a plan. I don't remember ever seeing a letter saying or an email saying: here's a summary of what's going on, this is where we're going, these are your new protocols, this is how we're going to do it. I don't have a copy of anything like that.

171. I don't remember being sat down specifically having a retraining on the new set up in Ward 6A. I don't remember a formal or specific time where we sat down and we were told, these are the new parameters. It felt like it was an evolving process, and understandably so because it was a make do and mend if we are brutally honest. Ward 2A was gubbed. The solution was a bit Heath Robinson. It felt like the hospital did make it up. They did their best with what they could, but

the fact that they had to move the kids in to the adult ward was reactive rather than proactive. That is okay, but it was ever evolving.

HAI: Needle aversion - Impact on

172. Following the line infection, [redacted] became very needle averse. We had to do a lot of work with him. He's a smart cookie and we can rationalise with him. Thank goodness that we were able to do that, because there was an awful lot of work with him. [redacted] and I developed a strategy. This is going to sound brutal but it was a restraint technique. I had a conversation with him about how we would do this. To stop him jumping about all over the place, [redacted] would sit across my thighs and I would lock my arms and restrain him. He was lying in a banana shape across my legs. We discussed it and found the position that he was comfortable with.

173. I was restraining him: physically restraining him to have a needle. Thankfully I could rationalise with him but we had to do a fair bit of work with the play team to deal with it. We did lots of stuff, and bribery, games, threw money at it, threw computer stuff at it and did everything we could: carrots. Thankfully it was more carrots than sticks.

174. We discussed it quite a lot and the thing that he goes back to there is the needles and being treated like a pin cushion. It didn't make it easy post event and it made the access to his port something else we had to deal with too. It was the nature of the subdermal where there was a needle going in to the skin and they needed to be bang on. I speak about that later on.

175. We did some work with the play team to help [redacted] with his needle aversion. We looked at infrastructure. There was a wee buzzy bee that desensitised him. It's like a holding a sander and it blocks neurons or something like that. We placed the wee buzzy bee upstream of the area where the needle was to be inserted and it desensitised him. [redacted] liked the sounds of that and he could

get with that. There was a lot of work that we had to do and it coincided with his treatment as it progressed.

Treatment plan following surgery: September 2018 to June 2019

176. In [redacted]'s case, the chemo that he had in the lead up to the surgery killed the cancer completely. Normally what happened is the doctors would remove some live flesh and they could do tests to completely identify what type of cancer it was, and work out whether it was a nasty or not so nasty one. In [redacted]'s case they couldn't do that because it was dead. At this point Doctor Ronghe told us that [redacted] was so unusual. Treatment protocols are developed by creating data, but there's no data existing for [redacted]'s case as there was no live tumour left. So the question was what do we do next? At this point he told us that there was the opportunity for Colette and I to go and have a read and see what we wanted to do about the final protocol once the kidney was removed. There was a discussion as to whether we should give [redacted] chemo if the tumour was dead. If he was a younger child, the recommendation was not to give him chemo because his cancer was stage one. But because [redacted] was older, it was a more complicated. Doctor Ronghe kept us completely involved in the process as we looked at options. He referred us to some articles he published.

177. It was a bit up in the air because of [redacted]'s age. There was not enough background evidence to suggest what the correct course was. There was a fair bit of head scratching, every year around 60/70 kids get this tumour and maybe only one of them is [redacted]'s age. That could be anything from a stage one to a stage four. If you start doing the math, there's not that many children that are in [redacted]'s position where the chemo hammers the tumour so effectively.

178. Eventually it was decided that [redacted] should undergo chemotherapy post-surgery. As tough as chemo is, it was very much seen as a disinfectant cleaning up of the area rather than treating specific stuff that's still there.

179. As a result of the infection, I am not sure if there was any delay to [redacted]'s post-surgery treatment commencing. He was discharged on the 13 September and within a week he was back getting chemo treatment. The line infection might have delayed the next stage because he didn't have a line in following the infection. He began post-surgical chemo on the 20 September, and Colette and I had to pin him down so that two nurses could get a cannula in. That was hellish but it was necessary to get on with it.

180. Similarly when [redacted] had a chemo spike on the 21 September and he was admitted to Ward 2A. Staff worked through the protocol and antibiotics were given via cannula. When [redacted] spiked, generally his chemo continued as the spike was considered to be a reaction to the chemo

Port fitted – Ward 1A RHC: 26 September 2018

181. On the 26 September [redacted] underwent surgery in ward 1A in the RHC in order to have a port fitted. Colette took [redacted] in for that surgery.

182. A port is a valve that sits under the skin. There's a wiggly line attached and that's all below the skin. To access the port, staff stick the needle through the badge. The needle sticks in through the port and it has a cable on it, they strap that to him. There's a way of docking the needle in using a gripper, so it is in your body. The advantage is the port can be sealed up between uses, so you're less likely to get an infection. However to use it staff need to hit the needle in the right place, therefore it's a bit more of a faff to access the line, and it needs to be accessed the correct way. If you don't get the gripper needle in at the correct angle you hit muscle and not the line.

183. [redacted]'s port was up on his chest on his left side. The port moves around a bit, because it sits underneath the skin. When Schiehallion staff accessed his port they had him lie in a particular way. There was a very specific angle to go in

at, and the great thing about the Schiehallion day care nurses is that they knew exactly how to get him in to that position and get it right. They instructed us when accessing his port.

184. Whereas we found that if [redacted] was being cared for by people who were trained but not an expert, they quite often missed the access with the needle. This meant the needle was going in to the muscle. With [redacted] you always knew whether they hit it first time: if he yelled, they missed. If he didn't make a sound, they were fine.

Transfer to Ward 6A QEUH: 26 September 2018

185. Following his surgery to have a port fitted, [redacted] was transferred to Ward 6A in the QEUH as the Schiehallion Unit in the RHC was closed and the ward had been decanted to the adult hospital. Colette was with [redacted] for that admission and she will be in a better position to provide details about that particular experience. [redacted] was discharged on the 27 September 2018.

186. Throughout October 2018 and into the start of November 2018 [redacted] was in and out of Ward 6A for day care appointments, to receive chemotherapy and also for a few in-patient admissions when he spiked a temperature following his chemotherapy treatment. We rode with it, but the facilities in Ward 6A were not great.

DESCRIPTION OF WARD 6A QEUH

Infrastructure

187. Ward 6A was an adult ward. I think it was geriatrics. I could be wrong but geriatrics were next door. The ward was set up for adults so you had a standard sized room with a standard sized bed which was great because we ended up having to sleep with [redacted] a lot of the time. The bathrooms were smaller

rooms but they were square in shape. That was one advantage rather than some of the wedge shaped rooms that existed in ward 2A. However, in terms of the infrastructure in ward 6A, they didn't have as much storage space as ward 2A. There were wee plastic storage tubs in the toilet as there was less storage for the parents in Ward 6A.

188. When we went into ward 2A, we had space in the bedrooms to spread out because we were doing long term. The rooms in ward 6A were weird rooms. They had a fold down Z-bed rather than the wall bed for parents and carers. I don't think they were any VAC rooms in 6A. The kids were pretty much always in isolation in their bedrooms, this was infrastructural isolation as there was nowhere to go. There were no facilities for parents. There was no play facility. There were no VAC rooms in ward 6A and anyone who needed a VAC room was down on floor 4.

189. The ward itself was split in half so the top end became the old 2A for in-patients. The other end of the ward became day care which was the old Ward 2B. A small waiting area for day care patients was created. The patient rooms were adapted at that end by removing some furniture to give space and allow chemo to be administered.

190. The infrastructure was set up for geriatrics, not for kids. Certainly not for kids who are staying long term and who are immunocompromised. There was no play room. Staff ended up putting a couple of tables in the corridor but that gave rise to issues related to infection control which wasn't great.

191. We didn't encourage our kids to go and play in the corridors. Patients and families were much more isolated because there was no focal point for you to actually go and chat with anyone. There was no area for a parent kitchen.

192. In ward 2A, Schiehallion was very much based around the nursing station. The playroom was straight across from the nurses' station so everything was there

and the nurses were on hand to make sure you're safe. While there was a small station in ward 6A, it did not act as a focal point.

193. There was a dramatic reduction in bed spaces in ward 6A. This wasn't great either. Which is why there was no playroom for kids and common room for the teenagers, because at the end of the day the attitude is it's more important to fill the beds rather than to have space for play. There were no areas for the play staff.

194. It was just a hospital ward. The staff did as well as they could. The key thing was it led to a more isolating experience. The fact that there were fewer rooms and the fact that the day care was integrated into the same ward opened up issues about people traipsing through the in-patient ward. There was some control but the parameters for day care access is different from the parameters of Ward 2A. It is like walking through ICU to get to A&E.

Staff

195. The ward itself was full of Schiehallion nurses and doctors so in that respect, it was absolutely fantastic. The cleaning staff and the cleaning regime was as it had been previously in Ward 2A, so we still had the same people round about us. We still had the umbrella of the Schiehallion people which was a great thing.

Protocols

196. The treatment was the same, from what I understood. The protocols were established, for example if you have a temperature, you will be treated in same ways. The procedures for observation and medication remained the same as in ward 2A and we had the umbrella of the Schiehallion protocols. The level of care was fantastic.

Impact of the move from ward 2A RHC to ward 6A QEUH

197. Following the move from Ward 2A, we had the partial umbrella of the Schiehallion staff and protocols but Ward 6A did not have the infrastructure and that made everything harder.

On the staff

198. I don't know how the nurses and doctors did it because they must have felt the strain. In some ways it was a shared battle that we all went through. Colette and I really felt for them, but the level of care didn't diminish. The staff worked their socks off to be able to be as professional as they could be under their new surroundings. But it was a different environment, so it must have been difficult.

199. The move to ward 6A must have been very difficult for the nursing staff. It is a credit to the staff that the impact of this didn't come across with their working practices because their morale must have been shot to heck, particularly coping with all this additional stress. They didn't say much, but you got the odd wee comment and nothing specific, but it must have been hard. They did so well to cope with such difficult surroundings. The staff didn't have the infrastructure on Ward 6A and that must have made their life hard. I am complaining about not having a kettle. The staff didn't have adequate storage facilities in the ward and the infrastructure around about them to allow them to do their jobs. It must have been really, really difficult for them.

200. I am surprised it didn't impact more on them. It's a credit to them that it didn't impact on them more. In particular the nursing staff would try and keep us as up to date as they could but it was such a moving thing. There was never a, formalised thing where we were told "this is what's going on". I don't remember a formalised approach. Again as this was so changeable, it was not an easy task for them and I do not envy them.

201. The staff were having to cope with other stuff on top of that. There wasn't a parents' room, so we had to press the buzzer in the room to get a drink of water. This is stuff that they shouldn't be bothered by, but they were being bothered with it because the infrastructure was not there. There was much more focus on patient management rather than patient treatment, because the infrastructure wasn't there.

202. As there wasn't a parents' room, anytime you wanted anything like water or a cup of tea, the medical staff would go and do it. But that meant that they had to leave treatment to go and make you a cup of tea. It increased their workload. I was reluctant to do it, but I did occasionally. Although I did work out where pretty much every hot tap was in the whole hospital and we became pretty good at it. It was like Raiders of the Lost Ark to get a cup of tea. The staff had to deal with additional workload that wasn't there in Ward 2A.

203. We were quite unusual because when [redacted] spiked he tended to spike over the weekend and we didn't really see any of the play team when he was admitted to Ward 6A. Whether they were available midweek, I couldn't really tell you, but we certainly didn't have access to them. The staff might have been there mid-week but I don't know how they could have done their job as there was nowhere for them to do it. They must have either gone and done it on a room by room basis which is a nightmare, or they were just not being able to do their job at all. I did see them once and one of the play leaders mentioned that their storage was over the other end of the hospital. If they needed anything, they had to get the lifts out which is a nightmare because they took so long or they took the stairs, six flights of stairs. They then had to walk over to the RHC, get the stuff and walk back to the QEUH. One of them had a pedometer, I forget the numbers they were talking about, but it was thousands and thousands of steps to be able to do their job because they didn't have a storage area in ward 6A.

204. While we didn't have access to them, I think they will have been trying to provide the service but it would have been dramatically impacted.

Impact on witness

205. We stopped meeting other parents when we were on ward 6A. I was so glad that [redacted] received his diagnosis when he did, while we were on ward 2A, because at least we had the chance to meet some parents before the move and we had some support. I remember going in to ward 6A to pick up meds one night and I met guy in the lift. We started chatting we spent two hours just gassing. The ward environments tend to be quite female heavy, it tends to be filled with mums rather than dads. That's just the way it is. I think I was the first guy that he'd had an opportunity to shoot the breeze with since his child was diagnosed. It is good to speak to people who are going through the same as you as they get it. Afterwards I thought, my goodness, I am glad I'm not in that situation where you don't have the people for the support. At least we had support at the start.

206. I really felt sorry for the parents who began their journey in ward 6A. They would likely have all the scared emotions, they'd be dealing with all the issues of chemo. In ward 6A it felt like there was no one to speak to who had gone through it and walked in your shoes because everyone is trapped in their rooms. That is tough and it can't have been easy for them; not easy for them at all.

207. The nature of the infrastructure in Ward 6A was though that even if you weren't in isolation, you kind of were because there was nowhere to go that was safe for the children. It was infrastructural isolation rather than a prescribed isolation in a properly fitted out room. There was nowhere for us to go. There was nowhere for us meet up, and you can't go in to other people's rooms. It's not as if you could even go and chap on the door go in to their bedroom.

208. In ward 6A we got meals with the children. Although the food wasn't great, I'm not going to complain as they gave us free food. We were very limited to those meals and the nature of having a chemo kid is their appetite reduces so the key

thing is to get food in to them I found we never actually ate our dinner at the time we would normally eat dinner. It could take a while to get food into [redacted] if he was feeling unwell. By that point the hospital food had turned a bit rubbery. In ward 2A, we would just go and make something in the kitchen. There was no facility in 6A, so the options were you could go over to one of the other wards in the children's hospital which meant leaving your sick child, or you survived on chocolate and crisps. As a result we carried a lot of food with us and ate an awful lot of sweets and chocolate. It was necessary. Whereas in ward 2A, we brought stuff, microwaved it and it worked really well. You could at least try and eat healthily. More importantly you had the ability to heat food for your child if the hospital food wasn't working.

Impact on

209. [redacted] became very isolated in Ward 6A. He wasn't socialising with people of his own age, and he wasn't socialising with people who were going through the same experience as him. One of the good things about Ward 2A was that while the kids didn't really talk about treatment, he was in the same space as the other patients so there was a shared experience, a shared bond: there's a normalisation. If you're in a room full of five kids and they've all got shaven heads and feeding tubes in, it makes them normal. Actually [redacted] not having a bald head was unusual.

210. If the children don't have that experience, then it removes that area of normalisation and removes the opportunity to just play. There was no opportunity for that in ward 6A. When you're with other cancer kids you become just a normal child. [redacted] was always a cancer kid with everyone else and he didn't have the opportunity to be just a normal kid, because he didn't have his peers round about him. He did cope with it very well but he ended up socialising very much with adults. I wouldn't say he lost his childhood, because Colette and I worked hard to mitigate that, but in ward 6A there wasn't an opportunity for him to play as much as he could when in Ward 2A.

211. We worked at it but we're very lucky that [redacted] was so cerebral because we did lots of books and reading. His Grandad brought in wee Warhammer soldiers and he enjoyed painting them. It was all very geeky, for lack of a better phrase. There was no socialising. He became a grown up geek rather than a wee boy. At seven, he shouldn't have been doing activities for a 13 year old. I did expect that he would get into these things eventually, but not at the ages of 7/8 years old.

Communication: Move from Ward 2A RHC to Ward 6A QEUH

212. I feel that the hospital management did not really have a clear plan and they didn't really communicate anything about the move to ward 6A. Hindsight's a wonderful thing. I understand that the move to ward 6A was a reactive rather than proactive response. No one planned for this to happen. No one wanted this to happen. To a certain extent, I would suspect the hospital management were having to roll with it. Therefore, they couldn't have given us say, a six-month strategy, because no one knew what the strategy was. I think a lot of parents were rolling with the punches. For us, as long as [redacted] was getting better, we'd get around it.

213. In that respect there's only so much you can expect to happen. I think in any one of these situations you always wish there was more information and maybe more formalised communication with us as parents. With hindsight the hospital should have been clear at the start what the issues were and how it was going to impact the patients. If they knew the decant to 6A was going to be long term, then they should have told us what their strategy was. They should have highlighted any problems and told us how they were going to deal with the problems.

214. To develop a strategy like that would have taken a fair bit of resource that maybe they didn't feel were necessary at the start, because they hoped it was only

going to be a fairly short period. However as time progressed, it would have been useful to have had a more concise and robust strategy for how they were going to deal with it. I can accept the sticking plaster at the start in September 2018, but after Christmas 2018 which was the first deadline then the hospital management really needed to have a plan B.

215. I'm a planner. I would have had a plan B at the start, if it were me. Maybe I wouldn't have had time in that situation because I was dealing with implementing plan A, and it's more important that they dealt with plan A than producing plan B. However, having more information would have been much easier for everyone involved and they should have been transparent and highlighted any issues with their strategy issues and delivering the strategy.

Temperature spike Ward 2E RHC – Cardiology ward: 13 November 2018

216. On the 13 November 2018, [redacted] spiked a temperature and he was admitted as an in-patient to Ward 2E in the RHC which is cardiology. There was no bed space in Ward 6A, and this meant that [redacted] had to be accommodated out with the Schiehallion. There were fewer beds in the ward when Ward 2A closed and moved to Ward 6A.

217. We found that because the number of beds in ward 6A had reduced, the kids with A.L.L. (Acute Lymphoblastic Leukaemia) tended to go in and stay in for longer periods. Beds would very quickly get tied up with A.L.L kids. There was very little capacity to cope with the [redacted]s of the world.

218. [redacted]'s temperature spike in the cardio ward was an easy spike. Some are more difficult than others. The cardiology medical staff were absolutely fantastic. The ward was nice and it had a parents room as well. It was a lottery as to where you would end up though.

219. When [redacted] was admitted to other wards, the full Schiehallion umbrella didn’t travel with him. He didn’t have the Schiehallion staff, he was cared for by the staff that worked on the ward where he was admitted.

220. The established protocols for treatment travelled with him. When he was admitted for a temperature spike, he was given his antibiotics as usual. Blood cultures were taken.

221. The key thing was there wasn’t a Schiehallion nurse on the ward with us and there wasn’t an expert available who dealt with his things. I would say that some wards had a greater level of expertise and we felt more comfortable in those wards. In the cardio ward, we felt like these were the top dollar. And whilst they weren’t experts on chemo, I had confidence in them.

222. With regards to the actual travelling, we were just put into isolation in these other wards. This was because the other wards did not follow the same general protocols as 6A, the common spaces would not be safe for [redacted]. That was us, we were in our own wee world on other wards. We were treated like a separate entity. [redacted] still got the meds. But the level of care was different in other wards.

The crash bag

223. We kept a crash bag in the car at all times in the event that [redacted] required to go to hospital. The crash bag was a wheelie bag which had thermometer, and a spare thermometer as one time we ran out of batteries, so we needed to carry a spare. We also carried paracetamol. Generally we kept all the drugs together as a centralised thing that we’d grab and take with us and we’d just hand them over when we got to hospital so they could start treating him straight away.

224. We also carried changes of clothes, toys to keep [redacted] amused, cleaning products, food and water. We always carried bottled water because we didn't

know how easily we would get it on other wards. Food because we didn't know whether we would get food or not. Lots of chocolate and sweets just to get you through the night. Wallet and phone. The crash bag stayed in the car the whole time.

225. We also carried a travel kettle and flasks at three o'clock in the morning and you hadn't eaten or drank all day, there was maybe no hot water facility nearby and was unwell it was good to have some way to get a cup of tea. We learned where the hot water points were, for example beside PICU there was a really good parents' room. So you could come down, fill up your flasks and you had your flasks for through the night.

226. This sounds really sad but Colette and I got to the stage where we published a guide on Facebook for all the parents saying, if you end up in this ward, this is what you need to take. If you end up in that ward, this is what you need to take. You never knew which ward you would end up in.

227. I also had a separate rucksack. My rucksack had a change of clothes, a thermometer and a bottle of water and paracetamol. If we got caught out anywhere, I could go straight to the hospital. I always carried that rucksack with me.

228. Given the amount of stuff we had, that was why I tended to be the first one in, just to physically manhandle all the stuff that was needed. Most of what was in the bag was toys and cleaning stuff. The reason we carried so many cleaning products was a protocol we implemented ourselves which was born of experience on other wards. Having seen the dirty room in Ward 3B, and having [redacted] getting a line infection in that ward: it was not acceptable. Generally cleanliness was okay but the level of cleaning in Schiehallion was so much higher and we couldn't take the risk, especially when we didn't know where we would end up.

229. When [redacted] was admitted, the first thing I would do is get [redacted] to sit on the bed and I would go round and clean the room top to bottom and clean the bathroom. Normally it didn't look like it needed it, but we didn't want [redacted] to contract another hospital acquired line infection, and we would tell people we were doing it. Even if the surfaces were clean, I cleaned under the tables inside the drawers, all the handles and toilets.

230. I didn't have concerns about the level of cleaning in Schiehallion: we had confidence in Schiehallion. Certainly visually, Schiehallion always looked considerably cleaner than every other ward because they had two or three cleaners doing one ward as opposed to one cleaner doing two wards. By the law of averages it's going to be getting done better. We also didn't find stuff lying around in Schiehallion. In other wards you would open up drawers and find things left in them. I found a pair of women's underwear in a drawer in one of the wards we were in, it wasn't Schiehallion but I don't recall what ward it was.

Admission – Orthopaedic Ward 3C RHC: 7 December 2018

231. On the 7 December 2018 [redacted] was admitted to Ward 3C of the RHC with a temperature spike. Ward 3C is the paediatric orthopaedic ward. There was no bed space in Ward 6A. He was admitted via A&E.

232. The A&E staff struggled to get the line in his port and immediately this flagged up concerns for me. While it was never explained, if you can't get the line you begin to question if is there a problem with the line, is this a line infection we're dealing with here? After 5 failed attempts, staff couldn't access the port and that was concerning. [redacted] was spiralling and becoming more distressed.

233. Eventually one of the doctors said, stick in a cannula. I questioned them and asked, can you get this? Are you actually going to manage that? The doctor in charge assured me that he would get the cannula in and he did. They were able to start antibiotics. This event occurred in A & E.

234. In Ortho I tried to keep the mood chatty and light. Colette and I did not want to be perceived as pushy parents, we really made an effort. We always make an effort to be as accommodating to the nurses as possible. We tried to remember that they might be having a crap day as well. Generally we erred on the side of cutting them some slack.

235. The key thing was they couldn’t get the line in, so I was already at a heightened state of concern. We received very poor care in the ortho ward. The staff were not regularly monitoring [redacted]. I counted three observations in one day. If a child has a line infection, they should be getting monitored more than three or four times a day. As we know, last time he spiked he went from okay to not in 45 minutes. That was another key concern for me.

236. We also had issues about actually getting medication at the appropriate times. It is important that medication arrives at the right time. Medication when you're spiking has to be reactive so the timing has to be flexible. If [redacted] needs paracetamol, he needs paracetamol at that point. The staff weren’t on ball reacting to this. I had to go out to the nurses station two or three times to say, “he’s spiking, you need to come and see him, he needs some meds”.
was spiking, he was going into rigor and he needed a doctor and some medication.

237. It was the attitude of the nurse that was so disdainful and this is why I wrote a complaint: it’s the only time we really encountered it. I was just like, I'm sorry I'm inconveniencing you here, but my son’s taking a spike.

238. I remember the nurses sitting chatting round the nursing staff station. I hasten to say staff need to be able to decompress. They need to be able to chat. They need to be able to stand round the watercooler and complain about each other because we all get to do it. But really when it got to a stage where I had asked for help on a couple of occasions and they’re more interested in chatting about

the Christmas night out, who was going and who wasn't going. It was clear that I was an inconvenience to them. It was just complete disregard.

239. It was an imposition for them to come along. Or it felt like we were an imposition. Fair enough, they're having a bad day or they might not like me, but their personal thoughts about the situation shouldn't have influenced their level of treatment and I really felt that in ortho.

240. The nurse in question was called [redacted], and sticking up for [redacted] maybe she just didn't have a clue about temperature spikes in chemo children. If had had a broken leg, they might have been all over it but this was obviously out with her realm of knowledge. Maybe it felt as if I was being a pushy parent. I think fundamentally she didn't have the expertise and knowledge to deal with the situation and that put [redacted] in the red. I felt we moved from the black to the red there. That was very dangerous territory and that wasn't good.

241. On reflection that was what the Schiehallion staff warned us about. That's why we were warned to keep an eye out. It was the joke afterwards. Did you get ortho? No. Oh then you're lucky. Where did you get? What have we got with other parents? Do you go to 2E cardio? 2E's great. Don't go to ortho. Avoid ortho. That was the chat between the parents.

242. Afterwards we were told by the Schiehallion nurses, next time this happens, come and speak to us. They told is to throw a flare up and they would come and deal with this. They told us that we shouldn't have to go through that. They were disgusted about the level of care.

243. I wrote a formal complaint following this experience and the Health Board responded. Despite what they say in their response, they were not monitoring adequately. I was reeling, to be honest. The concerning thing was I wrote a complaint immediately after the admission and 6 weeks later I have not received a response. I chased it on the 15 and 22 January 2019. It wasn't until the end of

January 2019 that we received a response, eight weeks later. I speak about the complaint in more detail later on.

244. In the orthopaedics ward, the nursing staff in general didn't have the expertise to deal with [redacted]. If they had knowledge and expertise to deal with [redacted], they wouldn't have treated him as such an inconvenience. Now the staff in every other ward, even if they didn't have the experience, professionalism kicked in and they upped their game to meet [redacted]'s needs. In ortho, they didn't and that is why we complained. If it was a line infection rather than a reaction to the chemotherapy that cause the temperature spike, we would have not been in a good place. In surgery, the staff made an effort to find doctors. In ortho they didn't bother. I shudder to think what the outcome might have been if it were something more serious, as we were not in a good place with the staff on that ward. They didn't have a clue.

245. We ended back at ortho and [redacted]'s last treatment was in ortho. To give [redacted] her due, it was frosty but she was diligent. She couldn't help but not be diligent. We ended up in Ward 3C again because Ward 6A had moved and was closed due to fungal issues. It must have been the start of 2019.

246. In wards such as ward 3C, there was infrastructure for [redacted] to play. He could go and play in the playroom but I wouldn't trust them as far as I could throw them because the protocols in their playrooms were very different to Schiehallion protocols. They weren't cleaned anywhere near as much. So although the infrastructure was there, the protocols weren't and that was limiting. If [redacted] wanted to use a PlayStation in Schiehallion these were issued. In most other wards you could just go, take one, and again we just cleaned it top to bottom. I trusted nothing.

Fungal issues - Closure of Ward 6A QEUH: January 2019

247. In January 2019, when Ward 6A QEUH was closed due to fungal issues on the ward. The ward was moved to the Clinical Decisions Unit ("CDU") in the RHC. It was the only time I actually broke down throughout this whole period. When news broke about this move, I felt like I couldn't cope with it. I said to Professor Gibson, I can cope with my son's cancer, we can deal with that. I told her that I couldn't cope with not knowing where we're going to be admitted in the hospital. I felt safer with Professor Gibson and the staff in Schiehallion. I didn't feel safe anywhere else.

248. That put a lot of strain on me. The infection showed what could happen if he had an infection, what could happen if his body went wrong. Ortho showed us what happens if the care went wrong. The two combined meant that every time we walked in we just wanted to go to Schiehallion – wherever they were.

249. You can put up with not having a playroom, you can put up with not having a cup of tea because at least you know the care was so much better than anywhere else. This move just turned up the level of anxiety and stress.

250. I was very aware speaking to the professor that it wasn't her fault. This was out with her control. She would rather this wasn't happening. All I wanted to flag was we are dealing with all these concerns and every time we are admitted it is just so much stress. I flagged with her we went from being, "please don't end up in hospital over Christmas", to, "as long as we end up in Schiehallion over Christmas, we don't care."

251. I was also aware that this must be impacting them, so how does that impact their work? I was at the end of my tether at that point. Professor Gibson was great. I would have hated to be standing in her shoes, going round telling people, "we're going to move again." Imagine having to do that. I really felt for her because

we're in it but we're only dealing with our own children. She's dealing with a ward full of children and she knows what happens when it goes wrong.

252. We didn't get much notice of the move. It was days not weeks. I'm sure there was a letter from the hospital, but the letter might have come out after we were told. Colette might be better placed to speak to this detail.

253. Prior to the move, Ward 6A was busy. There was lots of stuff going on. It was like moving house, and again the auxiliaries and the nurses bore the brunt of it. Hats off to their professionalism because it was an upheaval. The staff made it fun. For us it was the fact you're having to pack up your room and put it all away; it was just like moving a hotel room. It sucks. We made it as fun as we could and we all worked together.

254. We transferred to CDU which was a different ward. There were some good points about that. There was a central area the kids could go and play at; so that was great. We were also close to the PICU which was just up the stairs, and it had a parents' kitchen so you could get to there really easily.

255. CDU was also on the ground floor level so when [redacted] and [redacted] came in to see we could go out and play in the atrium, because there was nowhere to play. Again, that was a bit of a risk if there was potential disease issues, but we could go out and play.

256. At the time the thought of the move felt like quite a lot for me. We made it fun though and the staff did really well. Ru was the auxiliary there and we scooted down on the bed and [redacted] sat on the bed and Ru pushed it. [redacted] skooshed water out of a syringe at people going past, like a pirate ship.

257. It was a move; another upheaval: it was another set of variables. It was another nail in the coffin of the realisation that this environment isn't working. It was another flag up that it was going to be a while before we were back in ward 2A.

Communication about the move from ward 6A QEUH to CDU RHC: January 2019

258. I think there were some letters from the hospital. Colette very much was much more aware of what went on in the background. She was on the Facebook page and she's better at that. I did the heavy lift going in to the hospital. She did the intelligent stuff.

259. From what I understood, there was a fungal issue in Ward 6A and I assume it was airborne because they were using HEPA filters in the ward. Kids were being treated with antifungals as a preventative medication. Doctor Ronghe said that shouldn't get the anti-fungals because it would work against some of his medication, and in particular Vinc. In addition [redacted] was in an okay place at that point; his counts were okay and the hope was that he would be at low risk of picking up a fungal infection.

260. There were filters in the rooms in 6A, which were better than getting the fungus but not very good and they are a bit noisy.

261. It didn't impact us really. It raised the anxiety levels though. Could there have been more information? Probably. There was probably more information about that than there was regarding line infections that the kids were getting on the wards; so the hospital were learning. In these situations, you can never have enough information.

262. I did wonder if the fungal issue was affecting Ward 6A, and whether it was in every other ward. I don't remember ever seeing a HEPA filter in one of the outlying wards. It was same with the water filters, there were filter water filters in Schiehallion but they didn't have any in post-surgical. Should there have been? I

don’t know. It took time for it to filter out to other wards because they didn't have the crisis kids. Was that another thing that didn't filter out very quickly? Possibly.

End of [redacted]’s treatment: April 2019

263. [redacted]’s treatment ended on 4 April 2019 and he had his port removed not long after that. Following the completion of his treatment, [redacted] attends at the hospital for check-ups. First of all it was three monthly, now it is six monthly follow ups where he has a scan just to check that he’s okay and that there’s nothing come back.

WATER EVENTS: OBSERVATIONS ABOUT WATER SYSTEMS

264. When in ward 2A we had been told to drink bottled water and we were told not to drink from the tap. We were told not to brush our teeth using tap water but to use bottled water. I can't remember the specific time when someone said at the start, but I'm sure we were told only use bottled water in the kettle and just drink bottled water. We were told that there had been an issue with the water before we arrived (by multiple people including nurses and domestic staff), and to use bottled water for drinking and brushing teeth. There were signs at the sinks that told us not to put anything down the drains.

265. If we were given bottled water on the other wards, it was different from the one give in Schiehallion. The one in Schiehallion was nicer, the bottled water in the other wards was really powdery and salty. In the other kitchens and hot water points throughout the hospital, I do not remember seeing any signs which told people not to drink the tap water. It was just in Schiehallion. The bottled water was brought into 2A first of all and then it was rolled out over the whole hospital over a period of approximately 2-3 weeks.

PHYSICAL EFFECTS ON

266. [redacted] got a line infection and that hit him when he was most vulnerable. It was hospital acquired. Right now I can't say what the entire physical impact of the line infection was because we don't know. But it must have had an impact on him, because his immune system was the lowest that it could ever be and then he got an infection on top of that. It would have been a lot easier if we didn't have it. And let's not beat around the bush, he was put in a situation that was life threatening.

EMOTIONAL EFFECT

On

267. In terms of the emotional effect on [redacted], Colette and I tried to offset it as much as we could. We have to tell ourselves that as parents that we did as much as we could to offset any potential emotional effects. [redacted] was very, very good at making the best of a bad situation. It will have had impacts. has probably picked up the anxiety from us. We tried to shield him as much as we could but it wasn't normal. There was no continuity, he needed to have continuity. He needed to have normality and he needed to be able to be a wee boy. He needed to be able to interact with people who are going through the same things. And he didn't have that opportunity when ward 2A closed.

268. It's a testament to him that he has bounced back as well as he has, or we feel that he has. We've had to do an awful lot of work with him. We still regularly go out for wee walks where I ask how he is doing. I ask him how he feels and he's still quite positive about it. But there was an awful lot of impact. Whether that would have been there or not, I don't know. But the impact of the issues related to the building put an awful lot of additional stress that wasn't necessary on him and all of us.

269. It also meant that he had to undergo physical things which really weren't fun. Because when he wasn't getting treated in Schiehallion, his actual level of care was not as good therefore he had to endure stuff that wasn't fun like getting people sticking needles five times in to his muscles; like having to be pinned down to get a needle into his port or to insert a cannula. All the stuff that he shouldn't have to go through.

270. I think there will a bit of this that only time will tell. I'm more than aware that this could come and bite us on the backsides in his teens. This was a traumatic thing, and we're aware of it. We see these clouds on the horizon; it must have had an impact. I couldn't have come out of it as positively as he did. He's done really well but it is going to have an impact.

On the witness

271. It was tough. I'll be honest. Whether that was cancer or whether that was the issues in the hospital, I will always look at this as being a marathon. When was diagnosed, my wife and I said, whatever happens with us, it doesn't matter as long as [redacted] comes out of this healthy. Everything else isn't important. We had to shelve everything else and just get with it. We, kind of, knew it was going to be a bit of a marathon.

272. But it went on and on and it felt like we were running uphill. We were always running uphill. I hope to God this is the most stressful thing in our lives. The additional worries of not knowing where you're going to end up in the hospital, of not knowing what ward, or not knowing whether the infrastructure was going to poison my son and if it was going to kill my son. Brutal, but cards on the table. Is the building going to kill my son? Is this the ten per cent? Is this where it goes wrong? And that's hard. That's hard.

273. I knew the cancer could kill my son. But I didn't expect the building to be doing it. The building and the infrastructure was as much of a concern as the cancer itself because the cancer was being treated and was a known variable. The chemo was either going to work or it wasn't, full stop. We can't do anything about it. The building was an additional bit we just didn't need.

274. My wife and I's bounce back from this was hard. I think it was a lot harder than maybe it would have been had it not been for the building issues. I think we were much lower down because of this.

275. It took us an awful lot longer to get back up. Colette's got a lot of help through some of the charities following what happened to her when [redacted] had the line infection. They are using phrases like post-traumatic impact. Seeing going through this and his line infections, it had a huge impact on her and therefore on us.

276. The general rundown of me meant that by the end of this, I was done. I am very lucky to have a supportive work environment because if I hadn't had that, I wouldn't have been able to carry on to be honest. I was just done. My work was great. I said to my work, I'm struggling. I had gone from a person that was dealing with my son's cancer and the issues related to that, to going back to work. There was not really much space to get my head back in to it. They told me to do what I had to do. They told me "we will support you, we will work with you." If my work was old school, I would be out of a job.

277. The stuff that I fixated on, the stuff that I struggled with wasn't [redacted]'s cancer. It was the constant state of stress, not knowing what was next which is directly related to the impact of the issues with the building. That's what really sent me off the rails.

278. It was the huge responsibility I felt that I had to get everything right going in to that room, getting everything set up. If I didn't get it right and I didn't manage the

situation properly, and [redacted] did spike, it was on me as the person that went in first. I couldn’t trust any of the nurses and doctors in the other wards, unless it was in Schiehallion. I could only ever relax in Schiehallion.

279. Schiehallion deals with immunocompromised children differently. We were made aware of that from the way the staff responded to [redacted], and that was right from the start of his treatment. There were a lot of procedures in place for these children, for example when you went in to A&E, we were kept separate from the others in the waiting area because the staff didn't want [redacted] in a place where he could pick up bugs.

280. We were very much made aware that Schiehallion kids are sailing close to the wind, and the level of care in Schiehallion was appropriate for that sailing close to the wind. Other people might not necessarily be as aware of how touch and go it can be, so therefore we as parents had to keep an eye on things as well. It’s on us as much as the nurses and doctors.

281. That was really useful because it meant that we were able to go into these situations when [redacted] was in other wards and we were aware. The incident with the line infection was a great learning curve for us.

282. Whilst we didn’t have a huge amount of control over that ten per cent we did have some influence there. The kid’s got cancer. I felt that we couldn’t trust anything unless we were in Schiehallion. That’s it. We cannot trust anything and anyone. We couldn’t trust anyone else’s care. A lot of the time those fears were unfounded, but because of those fears I couldn’t take my foot off the gas.

283. It is really important that we don’t go in to every hospital ward and go, oh this is terrible. There was an awful lot of really good doctors and nurses in that hospital. Particularly those in units which are used to dealing with critical children or children that can deteriorate very quickly, because just as oncology kids are sailing close to the wind, cardiac kids are sailing close to the wind in a very

different way. PICU are sailing close to the wind in a very different way. We've not got the bragging rights for being the only people that have very seriously ill children.

284. When we went in to wards where there were children that were very seriously ill, we definitely got treated better.

COMMUNICATION

General

285. I think communication from the hospital with parents could have been better. I'm sure the management group who are sitting at the other side of this will agree. The closure of ward 2A and the move to 6A was a knee jerk reaction. There should have been more strategising on their part about how to deal with this in the long term. There needed to be better communication about that, the plan A, plan B, plan C. And there wasn't. It wasn't there. After a period of time we knew we were not going back to Ward 2A anytime soon, it was utterly obvious that we were going to still be in other wards for a long period of time. We started working round it.

286. When we went to the meetings with the Health Secretary we, and other parents were flagging the issues that we had experienced. She told us that there was going to be an investigation and then they would response to our questions. They probably had a good idea what the problems are, for example poor design/construction/maintenance. I'm not the expert on it but there is probably going to be a problem with the pipe system. There must have been an expert at the health board end, at the hospital end, at the government end who could have shed some light on the issue and how to quickly deal with it. If there was this, it was not communicated to us i.e. drains have been badly installed we need to rip them out and start again.

287. The hospital didn't seem to have any strategies about how to deal with the problems that presented with the building, as in the strategy of how to deal with the symptoms. They did not have a strategy to deal with the root causes either, and I found that quite annoying. They did not have a strategy that addressed the capacity issues that arose when they closed Wards 2A and 2B. They did not deal with the fact that there was a loss of facilities for the children. It did have huge impacts and we flagged that on numerous occasions with staff on the ward and at the meeting with the Health Secretary.

288. In terms of whether communication has changed or improved at all, I don't know. I've pulled away from it. Colette deals with that now. [redacted] will always be a cancer kid and just because you ring the bell doesn't mean it stops, because in theory we can go tomorrow and it could be back. You've got to be aware of that. But on the other hand, I don't really want to live in this world anymore. I don't mind doing this, I think speaking to the inquiry is a good thing because this is a positive thing. But for me it is done. It is put to bed. I'm not running away from it, it's just that it's time to move on to the next stage of our lives.

Communication - Meeting with Jeane Freeman: 2019

289. Pre-lockdown in the autumn or winter of 2019, Colette and I attended a meeting with Jeane Freeman, the Health Secretary. I don't know the date. It took place at a hotel in Glasgow next to Central Station. There were a number of other families there. At this meeting there were a lot of people that have gone through a lot. These sorts of meetings are an opportunity for people to offload, particularly when you're dealing with a politician.

290. I had concerns going in to this, that it might just turning in to a bitching match. It wasn't. It was quite a good positive thing. It was nice to be listened to finally. For us, it was the first occasion that someone's actually gone, okay, let's pull our fingers out and look at this. There were other families at that meeting that were

more vocal than us, and everyone was quite rightly upset with the situation. People have been through a lot.

291. It was a useful meeting because we had an opportunity to raise our concerns. A lot of the concerns raised were specific to the line infections that a number of children had contracted. Towards the end Colette and I got opportunities to raise concerns about infrastructural stuff. So for example we asked why was there still no a playroom in ward 6A? Following that meeting the kids got a playroom. You think, why is it taking so long to get a blooming playroom? Why does it take us speaking the health minister to get a playroom? It was useful thing and hopefully kicked the process forward. It was good even just to be heard. That's the thing, even if nothing changed, it's nice for people to listen to you and respond to your concerns.

COMPLAINT

292. I made a complaint following the admission to Ward 3C in December 2018. I received a response from the Health Board 8 weeks later but I had to chase it twice. The Health Board were apologetic and they identified more training for staff. I don't actually know if there were any other repercussions for staff, but there should have been

293. The response to the complaint didn't really allay my concerns. I was up to ten already. You go in to hospital assuming that you're going to get treated with respect and to the appropriate manner. The water issue flagged that the infrastructure and the environment was not set up for our children to be treated properly: that immediately reduced your level of trust in the environment.

294. Going to a ward where the level of care of treatment wasn't appropriate resulted in low levels of trust in the care and staff. The low level of trust in the environment and the care meant that trust was gone completely. As a result I was more concerned and had higher levels of anxiety.

THE INDEPENDENT CASE NOTE REVIEW

295. [redacted] was included in the Independent Case Note Review conducted by Mike Stevens. Both Colette and I thought it was really good. We asked a lot of questions and they listened to us. It was nice to actually find some information out; that was the first and only time where we were given a lot of key information about [redacted]'s infection. Colette waded through the report, it was a big document. I didn't read the main document.

296. Following receipt of the report we were provided with more information than we've ever had. There were bits of information where we wanted to know more. Specifically there were questions about where [redacted] was on the spectrum of likelihood of his infection being hospital acquired. Dr Ronghe had told us it was hospital acquired, and I trust him more than the review. The review itself it had said there were people that were highly likely to have contacted a hospital acquired infection that was attributed to the environmental issues in the building, and people that were less highly likely to be. Colette asked where was on the spectrum. They let us ask questions. It was good that there was dialogue rather than, "we're just telling you this".

297. Colette and I met with the panel members to discuss [redacted]'s individual report. That meeting took place in Spring 2021. [redacted] was one of the only children who contracted Serratia Marcesens. They confirmed that it was likely to be hospital acquired. We were able to ask the doctors on the panel questions, such as after [redacted]'s surgery why he went to post-surgical ward rather than Schiehallion. The doctor who we spoke to had trained Dr Ronghe and he was very complimentary about him and that was good. We felt that we were dealing with someone that had surgical knowledge and oncology knowledge all of which is relevant to [redacted]'s case. He told us it was normal to go in to a post-surgical ward, rather than back to an oncology ward because post-surgical was

used to dealing with patients coming out of surgery. That was fine and it made sense. However we didn't expect him to get a line infection in surgery.

298. The case note review was a good process. Fundamentally it flags that it’s good to get information that we weren’t getting. I think that any information provided is positive. There were periods where we just didn't have that information and it really highlighted that the more information we can have, the better it is for us.

OVERSIGHT BOARD/REPRESENTATIVE GROUPS

299. I am not aware of the work of the Oversight Board and I have not had any interaction with them.

300. I am not a member of any groups. Colette does a lot of Facebook stuff and is a member of some groups.

CONCLUDING COMMENTS

301. I have mixed feelings about the hospital now. Colette and I are half full rather than half empty in our approach. When we go to hospital now, [redacted] still bounces in. He’s still quite positive about it. We worked really, really hard, both during treatment and after treatment to not turn it in to Castle Grayskull, or whatever scary place there is. Fundamentally the hospital staff saved our son’s life. That’s all that mattered. We have a son. When we first walked in through those hospital doors, [redacted] was a dead boy walking. We walked out of that building and hopefully cancer is not going to be an issue again.

302. To some extent whatever we went through, doesn’t matter. I have a son that’s alive. Fundamentally that is the most important thing. I bless the hospital doctors and nurses who do that job.

303. There are periods where we look back at the experience in the hospital which are fun. You know some people might think how can you be positive about sitting in an oncology ward? The nurses, the doctors, the cleaning staff were just great. They did such a wonderful job. It's just only a shame that life was made so difficult for them, and for us because some idiot construction worker or designer who can't build or design a bloody hospital. I feel pity for them having to deal with this scenario.

304. Whether the hospital dealt with the situation as well as they could have done is a matter of question, and that is what this inquiry is about. The hospital should have dealt with the issues in the building, they had to deal with them. They put our kids' lives at risk.

305. The people that designed and installed that hospital building should be getting their arses kicked. I have anger towards these people because the level of construction is appalling.

306. There needs to be a level of accountability and responsibility for those people that commissioned the work, that built the hospital and that signed off on the work. In addition the resulting situation wasn't dealt with as well as it should have been. This process could have been easier for us all. My major anger is directed towards the people that did the work, not the people that had to cope with it.

307. The people like, Dr Ronghe and all these other doctors and nurses have been dealt a really bad hand. They were dealing with and trying to treat really sick kids in an environment that's not fit for purpose. The building is not fit for purpose and it's toxic; it nearly killed my child. That's brutal. The building nearly killed my child. Dr Ronghe didn't install the building. The contractors did and that's who I have issue with.

308. Would it have made life easier if we were communicated with more regularly about what was going on? Yes. Fundamentally yes, it would have made my life easier. Would it have been easier if we had a playroom and access to facilities? Would [redacted] have less emotional shrapnel if we the environment was better set up? Would we have less emotional shrapnel? Probably yes. But my focus of anger is really directed at the people that carried out the work on that building. I don't know how Dr Ronghe's still working because if I was him, I would have shut down. I don't know how half the nurses haven't given up. Or the cleaners. It's a testament to them to be able to work under such conditions.

309. As regards the health board, there was very little information and action that came from them. They should have been pulling their fingers out. Fundamentally the buck stops with them; they needed to be on this. It felt like they were dodging bullets. It was the type of problem where it would have been better if they went, "let's look at who's to blame later, but more importantly let's deal with the symptoms, let's deal with it now. Let's sort it now and mop up the pieces later".

310. I think we're still in the position where we don't know what has happened. We're still at a point where whatever problems that there are, have not been solved. They're still working at it. What we're doing here with the public inquiry is very important. However what is more important is that the situation must be sorted, and I feel that the health board are still waiting to find out who's responsible before they actually go and deal with the issues with the building. The need to get it sorted; they need to get it put to bed. They know how the children died or how close some came to dying due to issues in the hospital.

311. My concern and annoyance is with the people who built the hospital and then with the health board. Everyone else is fine. The doctors, nurses, cleaners; I feel pity for them. Imagine having to work in the building. It hasn't stopped for them. They're still in it.

312. In terms of any ongoing concerns about patient safety and the hospital building, Colette and I discuss how we would deal with [redacted] and a return to the hospital if his cancer came back. If we are in that situation again, and Schiehallion is not reinstated, we have discussed moving to Edinburgh to access their facilities and that's really summing it up.

313. If [redacted]'s cancer comes back, the big concern for me would be that his numbers for fatality move from one in ten to a third. I'm majorly concerned about that. The thing is Dr Ronghe's in the RHC and he is great. We don't want to lose Dr Ronghe. But a huge concern is also be going back in to the hospital. Can I trust that building? In that situation the nature of the medication would require is robust and he's more likely to have reactions which would mean we would be in the hospital more often. No, I don't want that. I just don't want that.

314. In order to address my concerns about safety at that hospital, the health board has to get Schiehallion back in to ward 2A in the RHC. In order to make Ward 2A safe for these children, that probably means a ripping it out and starting again. The health board must implement proper procedures, whatever works that they're doing in the building. There should be a more robust sign off protocol for the works because they obviously don't have that given the problems with the building. There needs to be someone who has responsibility of checking up on the works, a clerk of works is the old school terminology. It is my view that the workman have obviously just skimmed things, that a view has been taken of "that'll do". Friday afternoon, that'll do. It appears that no one's checked up on the construction work and that's why we've got this situation with the issues with the building. They need a sign off procedure that's more robust, and that is carried out by someone that's independent and by someone who has knowledge of building and construction.

315. Let's hope that people learn and move on forward from all of this.

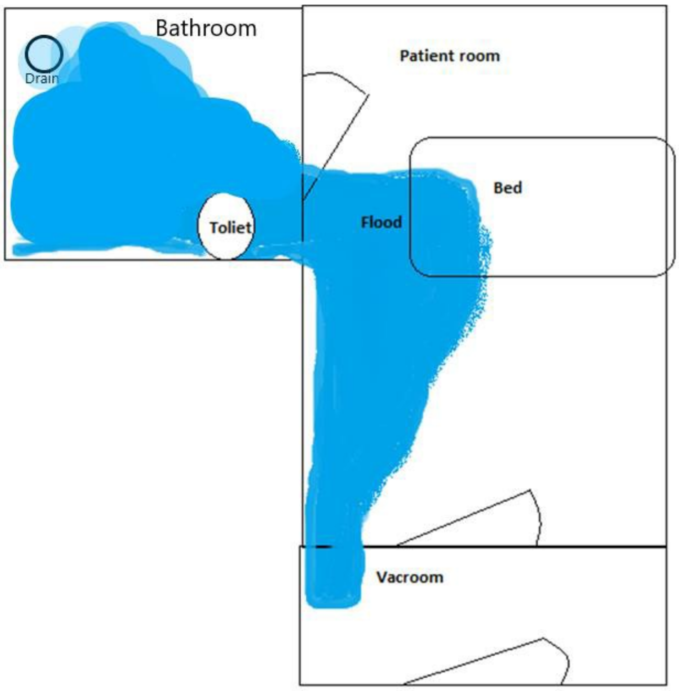
316. I believe that the facts stated in this witness statement are true. I understand that this statement may form part of the evidence before the Inquiry and be published on the Inquiry's website.

Appendix 1 – CAG/01 – Timeline

2018

- 04/07 Discoloured Urine – thought from eating beetroot
- 05/07 Blood in urine – Alnwick out of hours – Antibiotics given and urine culture taken 09/07 Phone Alnwick GP – Culture clear advised to follow up with own GP
- 13/07 Urine sample to our GP and 2nd antibiotics given with bloods booked for Monday 16/07 Bloods taken, Urine cultures clear.
- 17/07 Bloods showed anaemia – scan and renal referral made. 24/07 Blood in urine more prevalent (now scarlet)
- 25/07 GP call – Scan date is booked - nothing more can be done until scan appointment
- 29/07 Bumped abdomen while playing and went green, low appetite for the rest of the day then vomiting through night.
- 30/07 SCAN RAH : Scan revealed mass on kidney – referred straight to oncology. MRI confirms Kidney tumour, Wilms. Dr Ronghe now on board. Tumour 12cmx8cmx8cm. Admitted via CDU to Ward 2A room 10
- 31/07 CT and X ray confirms containment in the Kidney area. Plan to start Chemo asap. 01/08 Surgery to fit Hickman Line
- 02/08 Chemotherapy protocol started, Vincristine (Vinc) and Actinomycin
- 08/08 Discharged
- 09/08 Daycare 2B - Chemo, Vinc
- 10/08 Spike re-admitted to 2A room 10 via CDU
- 13/08 Discharged
- 16/03 Daycare 2B - Chemo, Vinc and Actinomycin
- 20/08 Day care presented with a black tongue – told to monitor.
- 23/08 Daycare 2B - Chemo, Vinc
- 24/08 Spike admitted through Daycare 2B to Ward 2A room 2? Our first Vac Room also first room where air con actually worked. Went into rigor for first time, and we were communicated how serious his was, Nurse Kat waited outside with meds to get best overlap.

- 26/08 Showered in room and flooded the room as drains did not function properly. Water pooled along wall, under toilet, into room, and out into vacroom. Reported to staff – response was eyes rolled “yes loads of the drains are dodgy.



- 27/08 Discharged
- 30/08 Daycare 2B – Chemo, Vinc
- 03/09 Daycare 2B - Blood work and pre- surgery meeting with anaesthetist and surgeon Ms Brinley. 3.30 at surgical ward 3B for admission. Room not ready so had to wait in playroom until room was ready. We cleaned the surfaces down and on lifting the bed guard found it to be covered in brown/red dried matter. Not sure if blood, faecal matter or chemicals from operation. Bed was replaced. Not in room appropriate for immunocompromised patient i.e. protocol/procedures is for vac room. No filters on taps. Also different general failing of protocols i.e. reduced cleaning regime/dirty; all play equipment/areas accessible to everyone and not just patients (also cleaning of play area and equipment not as stringent) therefore unable to access these spaces/facilities due to risk of infection. Patient care different to chemo wards. Chemo wards do not have yr1 (1st year doctors) as

these doctors do not have the experience and practical skill necessary for care of chemo kids. In both prep and post-surgical we had YR1 doctors.

- 04/09 Surgery. Kidney and tumour removed then into PICU
- 05/09 Temp spike through night – line infection suspected and antibiotics started.
- Transferred back to 3B – no vac seal doors, no water filters, yr1 doctors, different cleaning protocols for rooms as described above
- [redacted] had epidural still in place, morphine via PCA, and was on regular doses of antibiotics.
- 06/09 Line infection confirmed Serratia Marcesens Blood drawn via the line at 11.45. Emla cream applied to hands and feet to get peripheral bloods. (this is usually left for 30- 60mins to work). 40 mins later toxic shock. Taccacrdic (heart exceeding 200bpm); temp spike, rigor, vomiting. Had to go to front desk for help as no one around. Two YR1 docs arrived to help. – tried to get the peripheral draw. very distressed by this point.
- The nurses on the chemo ward would meticulously inspect the site and find the vein before applying the anaesthetic then come back later to take the blood – so they knew where to look. This YR1 doctor just put 4 patches on and came back later and started jagging. After multiple attempts to get the blood they stopped trying. This left [redacted] with a real aversion/fear of needles, which required extensive work with the play team to reduce the impacts to a point that they could use a needle without me having to physically restrain him. Additional nurses also in the room. Colette Panic – had to leave.
- Dr Hettle – surgeon on call arrived and the room calmed. Line was ordered out of bounds. He got the blood draw first time while calmly talking with [redacted] about dinosaurs. Antibiotics were pushed, bolus was started and after an hour things settled down.
- 07/09 Visit from Dr Ronghe. Microbiology advise to place an antibiotic block in line (which required accessing it). In conversation with Dr Hettle, I raised concern this should not happen late afternoon on a Friday due to people leaving the building if care required. Dr Hettle agreed – not on a Friday afternoon 16.10 block put in.
- 40 min later toxic shock again due to toxic shower from line. Same symptoms as before. Duty docs call in Dr Kamal – jnr surgeon starts a bolus and gives ibuprofen

to help manage temp. Consulting doctor from A and E (also on infection control) called in said “it’s a poo bug”. Wendy and Jane, Nurse Practitioners from Schiehallion, arrive and advise no more ibuprofen due to the dangers of ibuprofen for chemo-kids. Takes 90 min to stabilise, Kamal considers readmitting to PICU. Dr Hettle arrives (who had been in surgery) and makes plan to pull line.

- 08/09 Surgery Line out. Visit from Mr Davis Head surgeon on rounds.
- [redacted]’s skin has become inflamed and itchy around the entire surgical site. Dermatology referral made
- 13/09 Discharged
- 17/09 Daycare 2B Meeting with Dr Ronghe and Dr Inkster (infection control). Apologised for line infection and they confirmed it was hospital acquired and should not have happened, and it came from drains. I made light of the issue saying that compared to what he went through in surgery this was not our biggest concern. The response to which was that the infection was the most concerning thing that happened during [redacted]’s stay. Not the removal of a kidney, or removal of a cancerous growth, or stay in ICU. They confirmed one of six children ill at same time, part of ongoing issue with water system and they are planning to close ward
- 19/09 Daycare 2B antibiotics for [redacted]
- 20/09 Daycare 2B Chemo, Vinc via cannula. Had to be pinned down and restrained by mum, dad and two nurses.
- 21/09 Spike admitted via 2B into ward 2A room 10 – all treatment via cannula and had to be pinned down again.
- 24/09 Discharged
- 26/09 Admission ward 1A Surgery - port fitted
- Transfer to 6A – adult ward ‘New Schiehallion’ with no facilities, fold down adult bed, no play room, no play team, no facilities for adults to get food/drink bar bottled water (Schiehallion had parents room with fridge, freezer, kettle and microwave). It was like going into full isolation with no contact/support from other patients, carers or play team. Not having general facilities like proper bed, access to kitchen, etc made a difficult experience much worse for the carer, you can’t just leave a child to

go and get a hot drink if it takes you 40 minutes. We travelled with insulated picnic bags with ice blocks to keep snacks cool, thermos flasks, snack noodles etc.

- 27/09 Chemo Vinc and Actinomycin and discharge
- 01/10 Daycare 6A infection neck wound site – given cream
- 04/10 Daycare 6A chemo Vinc
- 05/10 Spike admitted to 6A via CDU room 4
- 07/10 Discharged
- 08/10 Spike admitted to 6A via day-care room 21
- 11/10 Chemo Vinc, transfusion and discharge 13/10 Spike admitted to 6A via CDU room 23
- 16/11 Discharged
- 18/10 Daycare 6A- Chemo Vinc and Actinomycin
- 25/10 Daycare 6A- Chemo Vinc
- 1/11 Daycare 6A- Chemo Vinc
- 8/11 Daycare 6A- Chemo Vinc and Actinomycin
- 13/11 Spike 2E (cardio) admitted via Daycare 6A
- 22/11 Daycare 6A – bloods and dressing check
- 06/12 Daycare 6A - Chemo Vinc. Schiehallion confirm decant for another year X-ray and ultrasound.
- 07/12 Spike admitted via CDU to 3C Orthopaedics. 5 failed attempts to get port access. Cannula fitted to allow antibiotics to start. It was not until one of oncology Daycare's excellent nurses saw [redacted] that they could get line in. While struggling to get line in this was raising concerns with us in case of line infection like previously rather than standard chemo temperature spike. Very poor care in orthopaedics (especially considering heightened concerns due to issues accessing line). Failure to do observations at correct times, failure to respond to temperature spikes in timely manner (let's not forget his last line infection in 40 minute he went from ok to a room full of consultants discussing if he should be going to PICU), failure to administer medicine at correct timings causing discomfort and distress to the patient, and general lack of interest by the nursing staff (too busy standing

round the nursing station chatting about the Christmas night out). I put in a complaint due to my concerns

- 09/12 Discharged
- 10/12 Dermatology – skin reaction to dressing a very difficult visit with being uncooperative due to the trauma of most recent stay. Wouldn't let Doc examine him, didn't want to be touched, poked or prodded.
- 11/12 Daycare 6A [redacted].
- 20/12 Daycare 6A - Chemo Vinc and Actinomycin
- 27/12 Daycare 6A – Chemo, Vinc
- 28/12 Spike- admitted 6A
- 31/12 Discharged

<u>2019</u>

- 10/01 Daycare 6A Chemo, Vinc and Actinomycin
- 17/01 Daycare 6A Chemo, Vinc
- Spike admitted 6A via Daycare
- Fungal issue on ward had been identified now HEPA filter installed in corridors and every room
- 19/01 Transferred with ward to CDU rm 19
- 20/01 Discharged
- 31/01 Daycare 1A Chemo, Vinc and Actinomycin
- 1/02 Spike admitted via Daycare 1A into CDU rm 19
- 4/02 Discharged
- 7/02 Daycare 1A Chemo, Vinc
- 9/02 Spike admitted via 2A (temp CDU) to CDU 12/02 Discharged
- 14/02 ENT follow up appointment
- 21/02 Daycare 6A Chemo, Vinc and Actinomycin
- 27/02 Spike admitted via Daycare 6A
- 3/03 Discharged
- 4/03 Daycare 6A Chemo, Vinc
- 15/03 Dermatology

- 18/03 Daycare 6A Chemo, Vinc and Actinomycin
- 24/03 Admitted 6A

[redacted]

- 25/03 Chemo Vinc – last dose
- 26/03 Spike admitted via Daycare to 3C 27/03 Ultrasound and x-ray
- 29/03 Discharged
- 4/04 Daycare Dr Ronghe meeting
- 8/04 Day Surgery 1A port removal surgery

Date not noted May/Jun – Daycare visit – chickenpox exposure – had to walk length of ward 6A to access Daycare. Raised potential infection risk at hospital board.

Scottish Hospitals Inquiry

Witness Statement of

Colette Gough

WITNESS DETAILS

1. My name is Colette Gough. I was born on [redacted] . I am [redacted] years old.

2. I am the mother of [redacted]. [redacted]'s date of birth is [redacted] . He is 10 years old.

3. I live with my husband, Cameron Gough, and our three children, [redacted], [redacted] and [redacted], in [redacted].

4. I am a [redacted].

OVERVIEW

5. My son is [redacted] [redacted]. [redacted] was diagnosed with a Wilms tumour in his kidney on 30 July 2018 when he was 7 years old. [redacted] was treated in the Royal Hospital for Children ("RHC") and Queen Elizabeth University Hospital ("QEUH") in Glasgow between July 2018 and May 2019 when he finished his treatment. He attended both hospitals as an inpatient and as an outpatient regularly over that year. He still attends at the RHC for six monthly check-ups. I have provided the Inquiry with a timeline which I prepared along with my husband, Cameron Gough. This timeline shows the dates on which [redacted] attended hospital and the wards where he was treated. The timeline is attached to this statement **(CG/01 – Appendix 1)** and I confirm that it is accurate to the best of my recollection.

6. [redacted] spent time in wards 2A and 2B of the RHC which is also known as the Schiehallion Unit. He also spent time on 3B, 2E, 1A, 3C, Paediatric Intensive Care Unit (PICU) and Clinical Decisions Unit (CDU) in the RHC and also in ward 6A in the QEUH. Myself and my husband shared the care of [redacted] during all of his

admissions as an inpatient and as an outpatient. I can speak to the experience and I had on these wards.

7. There are some specific events I would like to mention. [redacted] contracted a serratia marcesens infection, which was a Healthcare Acquired Infection most probably contracted in the RHC. Throughout his treatment there were issues with the water supply, ongoing construction works and issues with fungus which impacted on his experience with the hospital. I will come on to talk about these events on more detail.

FAMILY BACKGROUND

8. I live with my husband, Cameron and three children in[redacted]. [redacted] is ten and he is eldest. [redacted]is [redacted]and[redacted] is [redacted].

9. [redacted] is in[redacted]at school. He was in [redacted]when he was first diagnosed. [redacted]. He is a smart cookie and loves to read, particularly “knowledge” books as he used to call them. Even at a young age he was reading geology books and learning about rocks. Him and his dad love to read science and physics books together. This really helped us during treatment as we could read books with him then.

10. He’s an imaginative wee soul and loves to draw his own comic books and make up his own stories. In fact, one of the things that developed when we were in treatment was the storytelling games that we do as a family. We have these wee dice and we create characters and we roll the dice and that tells them whether or not their character was successful in whatever little trip they were doing in the story. All the kids love making up stories. And that was something that his dad did with him an awful lot. He also loves to build Lego and he is really competent at following the instructions, but also has a great imagination for free-building. At the end of his treatment his wish was to go and visit the Lego Headquarters in

Denmark, which we did, and he met some of the designers. He absolutely loved it.

11. As I am a stay-at-home mum, I am very hands on with all the kids, so is their dad. We spend a lot of time doing fun stuff together and all the kids get on well. We're an outdoor family and do things like walks in the forest, trips to the seaside and going to the park. They don't really go to any clubs, but they do go to Cubs and Beavers and they enjoy that.

SEQUENCE OF EVENTS: THE FAMILY'S EXPERIENCE AT RHC AND QEUH

Admission to hospital: July 2018

12. In July 2018 we were on holiday in England when [redacted] first had blood in his urine. We went to the GP there who thought it might be an infection and gave him some antibiotics. Once we were home he had blood in his urine again and we took him to our own GP who arranged for [redacted] to have some blood tests. They called us and said that the blood work was concerning and referred us for an emergency scan, which was two weeks later. The woman doing the scan told us that we should go home and pack an overnight bag as she was phoning our GP right away and we would be going to the hospital that afternoon. When I spoke to my GP later on that day I told him that [redacted] had actually been sick through the night as he had bumped his side. The GP told us to go straight to A&E as he didn't know which department we could be getting referred to. We still didn't know what was wrong at this point.

13. When we arrived at A&E at the RHC they lady behind the desk couldn't admit us because Dr Ronghe, who was the consultant oncologist in charge of [redacted]'s care was already in his file. He was the first doctor that we saw in the Clinical Decisions Unit ("CDU") which is where we were sent after A&E. When you go into A&E you cross the re-sus corridor into the CDU which is in the part of the

hospital that has curved walls. All the rooms in the CDU are individual rooms and that is where we waited until a bed was ready for us up in Schiehallion.

14. By this point we had read the referral letter from our GP and had seen the word "oncology" so we knew it wasn't good. Dr Ronghe came and told us that [redacted] would be going for an MRI scan and then up the stairs to the Schiehallion Unit, which was ward 2A.

Description of Ward 2A

15. Wards 2A and 2B are both in Schiehallion which is the oncology ward for kids. 2A is the inpatient ward and 2B is the day care ward. 2A is one of the horseshoe wards so it's on the end of the hospital in a big curve. When you go into it, you walk round a big semi-circle and the rooms are all off either side. There were twenty something bedrooms on the ward. As you walk in the door the first rooms are training rooms and then the parents' kitchen. As you walk further along you come to the 'VAC' rooms which are rooms that are set back from the corridor. Those rooms have a double entry system to get in and are for the kids that have had transplants. They are on a heightened level of cleanliness and infection control management. These 'VAC' rooms also had monitors on the walls outside which were pressure gauges, they were negative pressure rooms. I have no idea what this means, it was just something I was told by the staff on the ward. There were maybe four of these rooms.

16. After those rooms was the playroom on the right. It had lovely big windows and colourful pictures. That's you in the curved area now so the rooms are all a funny shape from the outside. They've all got an arched wall. Then there was the nurses' station and behind that there were two bedrooms that were set back. Round the corner was the utilities and the bedding room where you could go and get extra bedding, pillows and things like that, and extra sheets. Then then the

bedrooms carried on round the curve and as you were coming off the curve at the other end there was the Teenage Cancer Trust Area ("TCT") which was the area for older children. They had a playroom that was just for the teenagers, and was set up with PlayStations and gaming chairs and things like that. Then you got to the other end of the horseshoe and there was an exit door out to go back out towards the lifts there.

Infection Control on ward 2A

17. When [redacted] was an inpatient on the ward, we were not allowed in anyone else's room. That was very clear very quickly. We became like parents chatting over the back gate and would stand at the doors, chatting to each other. The children would go up and down the corridor talking to each other and playing with each other. This was all to do with infection control and there were several protocols in place.

18. We had to use hand sanitiser as soon as we walked in. We called it magic hands. There was a restriction on the number of visitors allowed, you were only allowed two visitors in a room, except if it was siblings. The staff said to try and keep visiting to a minimum just for traffic going in and out of the ward.

19. In the parents' kitchen everything had to be cleaned before it was put into the fridge. We had to make sure that everything was single use and you weren't allowed to leave opened food sitting. Edie who was the domestic, they are the staff who wear green shirts, managed the parents' kitchen. When I met her that first morning, she gave me the lowdown on how the parents' kitchen worked and keeping everything clean and the things that weren't allowed in the fridge. You weren't allowed eggs; you weren't allowed seafood. Everything had to be in date. Anything that was out of date was binned. Anything that came in that wasn't sealed from a shop, you had to put the date on and it had to be binned the next day. If you had cooked something at home and brought it in, it had to be used that day. The children had to be given sealed food and if they opened a carton of juice and didn't drink it you had to bin it and give them a new one. We were told not to worry

about the waste. We had to clean everything down in the kitchen after we had used it. We had to use the dishwasher for dishes and if you were washing dishes in the sink you had to use the hot, hot water and the soap and then you had to rinse them with the bottled water. We had to use bottled water in the kettles and bottled water to drink for all of us, especially the children.

20. If we wanted anything we just had to ask because they kept a supply of sandwiches and things like that in the staff kitchen. We didn't want to put the kids at risk, so if you give them a ham sandwich and they don't eat it, it would be binned after an hour and we could go and get a fresh one. It shouldn't be left sitting there in the heat of their room. The rooms were warm, especially in the summer. It was about keeping everybody safe.

Description of bedrooms

21. In terms of the bedrooms themselves, they were all standard. You walked in and there was a sink on the right hand side, then a bedside cabinet, then a bed for [redacted]. There was another bedside cabinet and then a wall unit which had a fold down bed for the parents. It had to be put away during the day. There was a big purple reclining chair which you had to move out of the way to put the bed down. There was a wardrobe unit and a chair with two arms and the high back. There were also stacking chairs that you could bring in if needed. We had one of them in the room as well so there was a chair for us all to sit on, so we weren't sitting on the bed. We were told by staff that visitors shouldn't sit on the bed, for infection control. As his parents, we were allowed in his bed and we spent a lot of time in his bed with him sleeping and comforting him. Then there was a bathroom off the bedroom with a toilet, a sink, and the shower area.

Description of parents' kitchen

22. The Parents' kitchen had two big kind of American-style fridges, a sofa, a TV on the wall, which the remote was never there for, and a wee circular table and four chairs to sit at. There was a microwave and two instant hot water kettles. So you pushed the button and it spat out a cup of boiling water. There were a few cupboards, another, smaller larder fridge and a dishwasher. There were zip seal bags and labels and pens in the cupboards so that you could label everything. Edie looked after the room and she was the one who knew where everything was. She was like a granny to everyone and looked after us all.

23. We did use the parents' kitchen. It was the only place you could go for a break really. That first day I went along a bit tentatively and I collapsed in a heap on the couch. There were two other women in there and they immediately comforted me. It was the first place that I cried because I couldn't do that in the bedroom. You were often in there by yourself, but it was a place to speak with other parents and get to know them. You could also leave things on the table in the kitchen and other parents could help themselves to it, for example, if you had fruit that you weren't going to use, or the charities would leave gifts for the kids. I really feel for parents who didn't have that space once we moved to 6A.

Description of Playroom

24. We quite often used the playroom when [redacted] was an inpatient and we would often go there to find something for him to do. He wanted to colour in and play board games. It also meant that he could meet other children. There were simple toys like cars and dolls, building bricks and that sort of thing. There was a big cupboard full of arts and crafts that the play worker would bring out and there were always different craft activities every day. It was all easy stuff. There was also a cupboard full of board games and a whole selection of books and DVDs. One night, we had a cinema night in the playroom and all the kids watched a DVD. It was lovely to hear them all laughing.

25. I have mentioned the play workers. One of them, Anne, was funded by the hospital charity and was there nine to five during the week. There was also Linda who was a CLIC Sargent play therapist. She had a slightly different role and helped us with things like dealing with [redacted]'s aversion to needles and what tactics we could use to help him.

26. Anne was in the playroom on a day-to-day basis and she would also come into the bedroom if [redacted] was too ill to go to the playroom. She would bring some activities along for him to do, or would sit and play with him for a while to let me go and get a cup of tea. There were also volunteers from the Children's Hospital Charity who would come in and go round the rooms as well and be in the playroom. That was maybe two or three times a week.

27. Only patients and their parents were allowed in the playroom. Siblings weren't allowed. Everything was wiped down constantly; anything that you played with. We got into the protocol very quickly where you finished playing with something, wiped it down and put it back on the shelf.

28. There weren't officially any facilities for siblings, but if you gave the play workers a heads up that they were coming then they would bring along the activities that they were doing in the playroom. We were told just to keep it in the room and even to leave it sitting and they would wipe it all down before they would put it back in the playroom.

Facilities

29. There were big TVs in the bedrooms. They had these flat screens that were on a big arm that would come out from the wall and sit wherever you wanted it to sit and they were touch screen so the children could operate it themselves, the ones in the children's hospital were quite big. The ones in the adult hospital are probably the size of an iPad. The children's ward ones were much bigger, maybe so the child and the parent could both watch. We noticed that difference when we

were transferred to the adult hospital, that it was all the wee screens that you were using then.

30. Quite often on Schiehallion the TV wouldn't work and the staff would just say "ah, well, TV doesn't work". It would be reported, and quite often it just needed a hard restart and a tech support guy who worked in the hospital would come and unscrew everything off the wall and hit a button and then it would work again after that. If your TV didn't work, there was nothing the staff could do about it. They would just bring you a PlayStation in so you could watch DVDs instead.

31. There was patient Wi-Fi that you could log into, but you would get booted off it every hour so we'd use our phones to log into it. It wasn't great and at busy times during the day it was very poor. Probably due to the number of people trying to access it.

32. We were also gifted an iPad from one of the children's cancer charities. The CLIC Sargent social worker arranged it so that [redacted] could play games if he wanted.

Staffing

33. There were a lot of nurses on the ward. I don't know if we were on one-to-one with a nurse, it was maybe one nurse looking after two or three children, but the staff did tell us the ratios were much higher in Schiehallion because the children did need more care. There was a nurse near us whenever we needed them. When you pushed the buzzer, it was the same nurse that came in every time. There was a specific nurse keeping an eye on our buzzer in our room. There was always someone available to help us out if we needed it.

34. In those early stages, the nurses were teaching us a lot. They were also managing and noticing how he reacted to things and what his preferences were. They were very reassuring and very quick to help. That first night when he started being sick, I didn't even need to buzz the nurse because she was standing outside and she

could hear it so she came in straightaway and noted that the doctors had reduced one of his anti-sickness medications so she arranged for that to be increased. They would come in and check him over and they learned his little routines such as he liked to have his temperature taken on a particular side. He was the driving force. They didn't force anything on him and they would always look to us for reassurance before they did anything. [redacted] was the leader of his own care which was lovely to witness. They were very reassuring all the time and kept calm all the time and the ward was a fun place to go. [redacted] was always happy to go in and see them all. They were a wee family. It was a positive place and the staff made it as easy on the kids as they could.

35. The nurses were also very strict in their timing of [redacted]'s observations and the timing of his medications. They were almost ahead of the game in knowing when his next dose of medication was needed. In one particular instance [redacted] was spiking a temperature. When a child spikes a temperature, they rely on paracetamol as ibuprofen is not a great drug to use along with chemo. On this occasion the paracetamol had taken the edge off but he was still above 38 degrees and he was due paracetamol at, for example, seven o'clock. The nurse was standing ready with it at three minutes to seven. We didn't need to chase them for medication or anything.

36. There were also specific nurses that were chemo nurses and it had to be one of them that gave the chemotherapy. There were always some on a shift who could do it. There were also the advanced nurse practitioners who were trained to a higher level so they could prescribe medication.

37. The consultant would come and do a round every morning. They would also come in and out at other times too. I suppose with [redacted] at that early stage, they were more attentive because they'd be checking on him to see how he was doing. There was the consultant, Dr Ronghe; Senior Registrar, Caitlyn, Registrar, Anne-Marie; and then the junior doctor, James, who rotated onto the ward just as we started.

It was his first week on Schiehallion that we were there. James was there I think for three months. He then rotated out and someone else rotated in. When we asked for a doctor, he would be the first one that would come. He would then refer us up the line if we needed it. During out-of-hours there wasn't a doctor on the ward, it would be the A&E doctor that would have to come and prescribe any medication that was required. So there was one night, for example, [redacted] was really itchy and he was having an itchy reaction to something and they had to get a doctor to come and prescribe Piriton so that he could get it. He had to wait until the doctor came up from downstairs to do the prescription for it. So no doctor would only be there for overnight; it would be a downstairs doctor. For weekend cover, consultants took turns. If you needed a consultant over the weekend there were four of them that would do every four weeks. There were no first year doctors in Schiehallion and part of that is because they need to have a certain level of training to be there. Our first experience of first year doctors was when we went into the surgical unit and we realised then why they don't have first years in Schiehallion.

38. The nurses were supported by an auxiliary team who wore the kind of light blue shirts and quite often if you pushed your buzzer, it would be an auxiliary that would come to you first because more often than not an auxiliary could do what you needed them to do. If you were pushing your buzzer because we were finished with our food, they would take the tray away or if he'd been to the toilet, they would take the bedpans away. As they walked into the room they would always put on gloves and a disposable apron. It was a much higher level of infection control going on and we saw the difference when you went to other wards; there wasn't that same level of infection control protocol.

39. There were also the cleaners on the ward. The bedrooms would get done once a day unless there was extra which sometimes there was if there had been a spillage or something. We got to know the cleaners quite well because they would be in your room often. When we were in old Schiehallion they would stick their head in

and ask if it was okay to come in and we'd go along to the playroom and let them clean. When we were in other wards there was nowhere else for us to go, so we'd just have to sit there while they did the cleaning. The standards of cleanliness were high. We never noticed anything dirty. We were asked to keep surfaces clear and we were given a book when we first came into ward 2A which told us all about infection control and the importance of cleanliness and keeping the bedrooms free of clutter.

Diagnosis of Wilms Tumour: 30 July 2018

40. On the evening of 30 July 2018, the doctors confirmed that [redacted] had a tumour on his kidney and he was to get a CT scan the following day to see if it had spread. At that stage no one was saying the "C" word, just that there was definitely a mass on his kidney. I asked Dr Anne-Marie, one of the Registrars if it was "that", meaning cancer, and she nodded. They were very careful about the language they used in front of the children.

41. The next day [redacted] went for his CT scan, to see if the cancer had spread and to help the doctors stage it. Later that day, Cameron and I went to one of the consulting rooms with Dr Ronghe and he showed us the scans. He said they could assume it was a Wilms tumour given its presentation so they didn't need to do a biopsy to confirm. The CT confirmed it hadn't spread into his liver or lungs. Once they knew what it was, they started treatment straight away.

42. The next day [redacted] had surgery under general anaesthetic to have a Hickman line, inserted into his chest. They made an incision in his neck and put the line in. There were then two access points going into his central vein and that became the access point for all the medications. This was better than working with cannulas which can fail quickly and mean the kids have to get jags which is traumatic for them. Getting the Hickman Line is a good thing because it immediately means treatment is easier on the kids and it's not as traumatic.

43. The day after that, which was a Thursday, [redacted]'s chemo started. The plan was that he would get four weeks of chemo to try and shrink the tumour and then there would be surgery scheduled to have his kidney removed. He was in room 10 on ward 2A and that was where he stayed during this admission. The plan was that they would start the chemo as an inpatient so that they could manage his reactions and symptoms and then hopefully let him go home and attend for treatment as a day care patient. It was also an opportunity for us to be educated about his condition and get as much insight as possible.

44. [redacted] was given vincristine (vinc) and actinomycin, which are the two standard chemo drugs for treating a Wilms tumour. The vincristine was more regular than the actinomycin. The actinomycin was fortnightly. To begin with it was a double (vinc and actinomycin), then a single (vinc), then a double, then a single. We kept that rhythm going for a good two months and then it became a single, a double, a week off, a single, a double, a week off. The kids are only allowed a certain amount of all of the drugs within the course of treatment. Dr Ronghe explained that they try and give them the smallest amount of chemo that they can because of the side-effects and the long-term effects of it and also keep some "in the bag" for if there is a relapse. If [redacted] were to have a relapse but has had the maximum amount of a particular chemo, he couldn't have any more of that drug and a different treatment protocol would need to be used which comes with its own long-term side effects and risks.

45. Dr Ronghe was very good at giving us background information on Wilms tumours and how it manifests and develops. We were also given information sheets about the chemo and the related possible side effects and risks. The problem with [redacted] is that he was older than most children who present with a Wilms tumour; typically, they are about three years old. As he was the top of the age bracket, there wasn't a lot of data to help the doctors project what his treatment plan would be. No one knew how [redacted] was going to react to the treatment and all the doctors could do was treat him based on what they knew and had worked previously in other children.

46. [redacted] did suffer from some side effects once he started getting chemo. He had no appetite and stopped eating. He “took to his bed” and just wanted to sleep. On the first night after the chemo he was sick, so they upped his antiemetic (anti-sickness medication) to stop that, he had a temperature, and he just felt rubbish. This lasted two or three days before we then managed to coax him to eat a bit, coax him to drink a bit. If a child has a reaction to the chemo, the medical staff are carefully monitoring the ins and outs of their fluids. We had to report everything that [redacted] was eating and drinking and they were measuring everything that was coming out. He was on IV fluids all the way through because he just wasn’t keeping anything down. Or wasn’t putting anything in to begin with and anything that did go in, he was being sick again.

47. After that first round of chemo [redacted] was discharged on 8 August 2018 which was a Wednesday and we were to come into ward 2B the following day as a day care patient so that he could get his chemo. His day for chemo was going to be every Thursday. We were given a tour of 2B and told where to go to report in and then where we would wait and where the chemo would be given. The staff were very good at prepping the kids so that none of it was scary.

48. In the run up to [redacted]’s discharge we were also being prepped by the medical staff in relation to how we would manage [redacted] and his symptoms at home. The plan was that he would get his chemo as a day care patient and then we would manage him at home unless he spiked a temperature. That’s the magic word that they kept on using, a “spike”. A spike means a temperature spike. So if [redacted] had a temperature over 38 degrees, it’s classed as a fever and we had to get to the hospital as quickly as we could. If we couldn’t get there under our own steam within half an hour we had to ’phone an ambulance’.

49. The “spike” protocol was that we had to ’phone the ward and tell them that [redacted] was spiking. If it was during day hours, then we would go straight to day care and they

would then start antibiotics. We had to be there and have antibiotics started within an hour if possible. If it was out of hours, then the ward would ’phone down to A&E to let them know we were coming and we would be taken straight into CDU and they would start the antibiotics. It was a very slick process and the system meant that all the worry of getting to hospital and being seen was gone.

50. The reason that it was treated with such urgency is because the medical staff were treating any spike as a potential line infection and that was serious. By that I mean the Hickman line. If [redacted] had a temperature of 38 degrees at the house, then we were to give him paracetamol before we left and get to the hospital as soon as we could. Even if his temperature was 36 by the time we got to hospital that didn’t matter. The staff always erred on the side of caution and wanted to see him.

51. Unfortunately, [redacted]’s pattern was that he would spike a temperature in reaction to the chemo and so we were in and out of hospital all the time during his treatment. This doesn’t seem to be something that happened with other children. I think he is just a child who gets a temperature when he is not well. Some other children might vomit, or get a headache, but [redacted] gets a temperature, which meant that we had to treat it like a line infection every time.

52. At the time of his first discharge we were also given information by the nurses. I didn’t keep it. This was an A4 sheet of paper with a table that was pre-filled. A nurse went through the list with us and signed a box to confirm that everything had been explained to us. It was things like infection control, line management, what to do if [redacted] spiked a temperature. It was a standard form, but if there were things specific to [redacted] they were handwritten in. They went through it with us and made sure we understood everything that we needed to before we took [redacted] home. This included the medication that we were to give him and the hygiene protocol. We were told that we were not to touch the line. The line came out of [redacted]’s body and had two white lines, very similar to an iPad charger, and on the end of it there were two access ports with green caps on them. We weren’t allowed to touch the green

caps. Each time [redacted] had his line accessed, the medical staff put a new sterile green cap on once it had all been cleaned with sterile wipes. We hadn't to touch that or go anywhere near it, and if it came off, we were to go straight in to the hospital because the staff had to deal with it. It was okay to shower with it on, but then when he was dressed you could actually get a wee bag to keep the ends of the line in. [redacted] . This stopped them from dangling around or getting caught on clothes.

53. When I knew [redacted] was coming home, I'd gone around the house so it was spotless. Although the nurses did say to us, don't keep the house too clean. Don't be bleaching everything because the bugs that he's used to will help his immune system. They told us to keep surfaces clear and that washing hands was really the biggest thing. We were to make sure that anything that goes in his mouth, like the syringes that they used for giving medicine, were new every time we gave him anything.

[redacted]'s ongoing treatment: 8 August 2018- 3 September 2018

54. [redacted] was discharged on the 8th of August and we were back in on the 9th in day care in 2B. 2B is a straight ward rather than on the curve of the building. When you walk in the door, there is a reception desk and then a waiting area/ playroom. There was a play worker there, Alison, who gave the children some activities to do and there was a PlayStation for the ones that wanted to do that. Then you would be taken round to where the bell was. This is the bell that the children ring when they are finished their treatment. There was also a set of chair scales so each time the children came into day care, their height and weight would be measured. The staff were monitoring weight loss because of loss of appetite due to the chemo. There was a magic ten per cent that we had to watch for and if fell below a certain weight, that would mean he would have to get a NG feeding tube placed to then up his feeding and you would be giving him feeds through the night and things like that. [redacted] managed to avoid having to get an NG tube. He managed to avoid this because we heavily encouraged him to keep eating. We

would motivate him with rewards, things he wanted and it worked. It was hard for him, but he managed.

55. There were maybe four treatment rooms with consulting rooms down on the right-hand side of the ward and on the left-hand side, a larger bay that had maybe four beds in it. We were never in there because that would be where the kids that needed to get chemo through an infusion would go. [redacted]'s chemo was called a push where they would just push it in through [redacted]'s Hickman line and that would be it. His only took two or three minutes, but some of the other kids could be in there all day getting chemo infusions and other things like blood transfusions.

56. There was a door at the end of the ward which we learned later was a door that you walked out straight across the corridor into 2A if you were being admitted there.

57. The plan for [redacted]'s treatment was that he would go to ward 2B every Thursday and he would get his chemo. He would get one every week (vinc) and two every two weeks (vinc and actinomycin). He was due to get four treatments, although it actually ended up being five due to surgery scheduling. So this equated to five weeks of treatment. His first week he got vinc and actinomycin, the next week he got vinc, the third week he got vinc and actinomycin, the fourth week he got vinc and then he got an extra round of vinc on the fifth week, then he got his surgery to remove his kidney.

58. Every time that [redacted] attended day care he would have to go into clinic three, which was not in ward 2B, but which is one of the outpatient clinics on the bottom floor of the RHC in the big atrium, and get a thumb prick. The nurse puts a wee bit of Vaseline on [redacted]'s thumb and they puncture it and do little drops of blood into a tiny little vial that then gives them a quick blood count and white cell count. It would give them four magic numbers: white count, haemoglobin, platelets and neutrophils. These were the four numbers that they would then report for him

and if the numbers weren't right, he wouldn't get chemo. Or if the numbers weren't right, he might also need a blood or platelet transfusion with his chemo. It would dictate the treatment for the day.

59. On that first day on the 9 August, 2B told us just to go straight there and they would do the first thumb prick as [redacted] was a bit scared about it. We said, no, as we wanted to get [redacted] used to what we needed to do each week. We bribed him with the promise that, every jag he got, he would get a Lego mini figure and that worked.

60. After the thumb prick had been done, we sat in the waiting room in 2B and waited for that result to come back. It only took about 20 minutes. Then [redacted] was taken in and weighed in one of the consulting rooms. As soon as we got the okay that his blood work was okay, the call went to the pharmacy that his chemo could be prepared and someone would go from the ward to collect the chemo. Because he was getting vincristine, which is one of the really nasty ones, it had to be collected from the pharmacy by a nurse. Once the nurse had the chemo she would glove up and put on cuffs to protect her arms and she would flush the line. When they first connect the line, they make sure that it's flowing properly because you can get blood clots in the line so they'll draw from it to make sure that they can draw off and then they'll flush it with saline to make sure that it's flowing well. Then they would give [redacted] the vinc. After the chemo has been administered, they flush it again and then put a lock in it so that it's not sitting empty. Then they'll put a new clean green cap on. There was an awful lot of double and triple checking that the chemo was right and then they would watch the chemo go in. Later on in his treatment, there was one instance they had to give the vinc through a cannula post op after [redacted] had his Hickman line removed, and they had to watch it so carefully because it can burn the arm as it's going in which is why they prefer to give it into the central line. It does less damage. I learned that day that people have lost arms because it's done so much damage. If it doesn't go deep enough and get flushed away quickly, it can cause there to

be burns to the limb, bone. Awful, absolutely awful but it does the job. So they're watching it go in and they're watching all of the skin around about the site to make sure that it's going in and getting flushed away into the body straightaway. Then you have to wait 20 minutes or so to make sure that there's no reaction or anything and then that's you free to go. When you were leaving they would reinforce what to do if he spiked a temperature.

61. That was the process for every round of chemo and, after his first round as an outpatient, on 9 August he did spike a temperature. It was early in the morning of 10 August. We didn't sleep and had been monitoring his temperature. It was creeping up and up and once it hit 38 degrees we phoned ward 2B and they told us to make sure we gave him paracetamol and bring him in. Because it was out of hours, we had to go in through A&E and then to CDU to then be transferred up to Schiehallion. When we got into CDU we were put in a room and a nurse came along and took cultures from the line. This meant blood was taken from the line and then antibiotics were administered through the line. It had to be done by a nurse who had had some training in working with the lines. They started giving antibiotics, I think it was tazocin on this occasion, just in case it was a line infection as they have to wait 48 hours for the culture results to come back.

62. On 10 August, [redacted] was admitted back onto ward 2A, back into room 10 and we had to wait for the results of the cultures. He was given paracetamol to manage his temperature and I think his culture results were clear. He had to be 48 hours without a temperature before being discharged, so we were discharged on the 13 August.

63. As time went on with [redacted] the staff got a bit more lenient with letting [redacted] go home after a spike as this was just his pattern. If his culture had come back clear but he was still spiking a temperature they wouldn't make him stay for another 48 hours. His pattern seemed to be that he would get chemo on a Thursday then

he would be back into the hospital on the Friday or Saturday with a temperature spike. It only seemed to happen when he had the vinc chemo on its own. When he got the two doses of chemo together he was more sickly and nauseous but temp would be generally okay.

64. After he was discharged on 13 August he was back in day care on 16 August. He didn't spike on that occasion although he did get a black tongue. It was very strange. No one knew why it happened and It never happened again.

65. On 23 August [redacted] was back in day care in 2B to have the vinc chemo. He spiked a temperature on 24 August. This time it was during the day so we went in through 2B. We didn't give him paracetamol before we took him into hospital and that was a mistake we never made again. When we went in to 2B, we waited for a long time to be transferred into 2A, so we were left in a room in day care while he was fading. He was getting warmer and warmer because we hadn't given him paracetamol yet. The ward was really busy and eventually a nurse came in to say we could go through to 2A. By that time, he was in rigor which is when you start to get shivery. At that point, the nurses jumped into action and realised that he hadn't had any paracetamol. They gave it to him immediately and then watched him closely to see if his temperature came down. There were five or six people in the room at that point because they were worried about him as rigor is a sign of sepsis. He had been given the antibiotics when he got into day care, and we did tell a nurse that he hadn't had paracetamol yet, but that didn't seem to register. The nurse came along later and apologised.

66. On this admission, [redacted] was in one of the VAC rooms. This was one of the rooms with the double doors that are used for kids getting transplants. We were only in there because it was the only room available. It had a double door entry so you go through the first door which is from the corridor and there is a sink and there's a place to hang your coat and you've to wash your hands there before you can then open the second door to go into the room. That didn't need to happen for

us because we weren't there because we needed that extra level of infection control. Although, when we were on other wards that did not have the Schiehallion levels of infection control, we were put into a VAC room because that was an extra level of infection control.

67. This VAC room was number 20 something and it was in on the left just before the nurses' station. This was one of the rooms that I had been told by the nurses had negative pressure, where there is no air being brought in from outside. We didn't need it, so I didn't find out any more about what that meant, but it did mean that the air conditioning worked in that room.

68. [redacted] was being monitored closely by the nurses on this occasion to make sure his temperature came down, but also because he had a reaction to the antibiotics they gave him, Tazocin. They gave him another kind of antibiotic (meropenam) and then they had to monitor him to make sure he didn't have a reaction to that. They were in taking his blood pressure and temperature constantly. He had also had cultures taken and they came back negative after 48 hours and his temperature stabilised and he was discharged on the 27 August.

69. This room was the only room in the hospital that we stayed in where the air conditioning worked. In any other room we were in, it was rubbish. There was a little bracket on the wall where you could control the heat in the room. The first thing we would do when we would go in would be hit the negative number because it would be sitting at 25 degrees and the wee light would come on to let you know that we had interacted with it. The light came on and it would click down to 19 degrees, but the temperature would never actually change. The general temperature was 25 degrees all the time. In this VAC room we could lower the temperature to 21 degrees, so it was positively cool. We hadn't been told by any of the staff that the air conditioning worked in that room, we just discovered it for ourselves. We had mentioned to the nurses that, in other rooms we were in that it was very hot, but they never said much about it, they just told

us that the air conditioning doesn't work. It was just accepted that the air con didn't work. The wee bottles of water that you would get would be in the freezer to become ice blocks so that you could have them in your room at night and they would gradually melt overnight so that you could get a cold drink. That was the standard. Everybody had frozen bottles of water in their room to try and get a cold drink because it was always so warm. Once the condensation from the frozen bottle frazzled my phone.

70. We had issues with water drainage whilst we were in this room. [redacted] was nervous about cutting his hair, which it had been suggested that we do as his hair was going to start falling out with the chemo, so Cameron said he would shave his first. We let [redacted] have a go of the clippers and Cameron was sitting on a chair in the shower cubicle so we could clean it up easily. [redacted] had a great time. Afterwards we cleaned up the hair and I left Cameron to have a shower. I was sitting in the bedroom and I saw water came out from under the bathroom door and all the way through the room and out into the corridor. I had to dash and grab towels and clean up and buzz the nurse to ask for a mop because the water was everywhere. The nurses just rolled their eyes and said that sometimes the water goes everywhere and they would report it. From what they were saying, it wasn't the first time it had happened. I don't know how it had flooded. It wasn't clogged with hair as I had picked all that up. It looked like the water wasn't running into the drain. It seemed like the angle of the floor meant the water didn't run the right way. No one came to look at it or tried to fix it while we were there. Cameron wondered how it had passed inspection. This was the only time this happened and it didn't happen in any other rooms we were in. There is a diagram of this in the appended timeline **(CG/01- Appendix 1)**.

[redacted]'s admission for surgery: 3 September

71. On 3 September 2018 we went to 2B and [redacted] got some blood taken to check everything was okay and then we had a consultation with Dr Ronghe, and then the surgeon, and then the anaesthetist. We were told to come back later in the

afternoon and go straight to the surgical ward to get admitted. The plan was that would get admitted that day and the next day he was going to have the kidney removed and then he would go to the PICU that night. The surgery was scheduled when there was a PICU space available. He would be in the PICU overnight and then back to the surgical ward and then recovery and home. We were told he would be in hospital for about a week.

72. The surgical ward was in ward 3B of the RHC. We had chatted about this ward with some of the nurses from Schiehallion and they had warned it was quite different. They said Schiehallion is first class and 3B was definitely not first class. I'm sure there's a bit of competition between the wards and between the nurses but they said that there were not the same facilities for the families. We had been warned that we needed to be "on it" and pay attention to [redacted]'s medication and his fluid balances, which was monitoring how much fluid he was ingesting and what was coming out, to ensure he didn't get dehydrated, as the nurses in 3B would not pay as close attention as the Schiehallion nurses. We were also told that they didn't have the same number of nurses. We had heard stories from other parents whose kids had had temperature spikes and been put into other wards about how they really had to pay attention to the fact that the kids were needing their medicine. They were phoning down to Schiehallion asking why nobody was coming. So we were a wee bit anxious about going into the other wards.

73. When we arrived on ward 3B, [redacted]'s room wasn't ready so we were told to wait in the playroom. 3B is a big long straight ward and when you walk in, you're in the middle so the nurses' station and the clerk desk are there and the playroom is straight ahead of you. Then there are rooms along each side and a bay with four beds in it. There is also a kind of kitchen area. It was a staff kitchen so the door was open all the time, and that's where you would go and help yourself to breakfast for [redacted]. We were given a bit of a tour and then sat in the playroom. I was immediately aware of all of the other children in the playroom who were

snotty nosed. At this stage we were very conscious of [redacted] getting infections and we wiped everything before he touched it. Eventually we gave him his iPad and told him not to touch anything. It definitely wasn't the same level of cleanliness as the Schiehallion playroom. All the cupboards were open and the kids could go in and touch anything and put anything back. There was no member of staff in there. So I was a wee bit apprehensive and I just sat there and wiped everything. There were some kids in there who were cystic fibrosis patients and they were being looked after by the nurses, their families weren't there with them. So there were little kids playing in the playroom by themselves and it was a bit of an eye-opener. I couldn't imagine leaving [redacted] on his own in hospital, but it was totally normal for these little kids and they were used to it.

74. Once [redacted]'s room was ready we were taken round and the nurse told us that they were really busy. I think that's because there were two cystic fibrosis children who were staying on the ward and needed the nurses to care for them, which I totally understand, but we immediately felt we weren't getting any care. By the time the nurses came to actually do [redacted]'s admission, where we sit down with the forms and actually admit him, it had been a good couple of hours. In Schiehallion you never had to wait that long to get admitted.

75. As we were putting [redacted] into bed we pulled the sides of the bed up and noticed that they weren't clean at all. They were covered in something brown. I don't know what it was. It could have been surgical wash. Cameron was annoyed and told the nurses that the bed wasn't clean. My initial reaction was to clean it but Cameron wouldn't let me. The nurse came along and was mortified. She organised for a new bed to be brought in straight away. Then we set to clean the room from top to bottom with wipes we had brought from Schiehallion because we didn't trust that anything was clean. We really didn't feel safe, and we were already thinking, that this really wasn't first class.

76. The room we were in was nearest to the nurses' station and I think the protocol was that the kids that were going into surgery that needed the most care were closest to them, but there was a VAC room on this ward and, with hindsight, I should have told them we should be in that room. That would have meant we had some added infection control protection and were away from the other children. At this stage [redacted] was neutropenic; neutropenic is the word that they use when you have no immune system. There was no acknowledgment that he was neutropenic, or a Schiehallion patient. After this stay on ward 3B, I spoke with Wendy and Jane, the advanced nurse practitioners from Schiehallion, who had come to help [redacted] in ward 3B and they were not happy with what they saw in ward 3B and seemed upset about it, but they couldn't criticise nurses on other wards. None of the nurses on Schiehallion explicitly said that [redacted] should have been in a VAC room in ward 3B, but we learned from later stays in other wards, when he was put in a VAC room, that this is what we should be asking for if we had to go to a ward other than Schiehallion. Nobody actually sat down and told us that is what we should be expecting and asking for. I made sure that I put this, along with other advice about what we'd learned, on the Facebook group for Schiehallion parents which was set up by Schiehallion parents. This was maybe November 2018. I said that we seemed to be jumping in and out and going to lots of different wards and we've learned that when you go to another ward you really should be in a VAC room. I also gave my experience of which playrooms were clean in which wards, where you had access to a kitchen and what the rules were on each different ward for things like hot drinks, as some of the wards didn't allow hot drinks.

77. The facilities on ward 3B were not as good as Schiehallion either. The playroom was there but wasn't clean. We were shown the staff kitchen and could go and get a cup of tea and that's where we got breakfast for the children. There was a fridge in the corner with sandwiches and wee yogurt pots and wee juice pots because they recognise that children don't want to always eat at lunchtime especially if they've been fasting for surgery. So we could help ourselves to

those things, which was good to have access to. Every time I went into the kitchen, I had to clean it. There were always mugs from the staff in the sink. We had been taught in Schiehallion that leaving stuff on the draining board is a breeding ground for bacteria and I thought that these nurses must surely have known that.

78. I don't want this to sound dramatic, but usually if you told people that [redacted] was a cancer kid then, from anybody in the outside world would give quite a strong reaction. That didn't go with us to other wards. What I mean is that the Schiehallion kids should have got different treatment, preferential treatment, if you like. As soon as the staff were aware that someone on their ward was immunocompromised, they should have upped their game. Even if normally they left their kitchen in a riot, there's somebody here that's immunocompromised, so they should have recognised they would need to bring it up to scratch. That's what I was fighting against when I said this umbrella of Schiehallion should have gone with us wherever we went. I shouldn't have to be washing nurse's cups.

79. After this experience, it became our standard that, whenever we were admitted to a room that wasn't in Schiehallion, the first thing we did was clean. This wasn't something that the Schiehallion nurses told us to do, it was something we were doing off our own back, although when we told the Schiehallion nurses what we did, they said they would have done that too.

80. [redacted] had his surgery on 4 September under general anaesthetic. It all went well, his kidney was removed cleanly and the surgeon was happy. We happened to meet the surgeon as we were walking onto the surgical floor and she took us to the recovery room to see [redacted]. He didn't look great. He was pretty pale, very small and desperate for water, he was asking for sips of water, which he threw back up immediately. His bed had to be stripped and he had to be changed, which was very painful and quite traumatic for him. He was then transferred round to the PICU so we had to wait in the PICU waiting area while they got him

established. Because it had been such a big operation he went into PICU for constant monitoring as there's one nurse per patient.

81. PICU has very restricted entry, there are only two of you allowed in to visit. As you go in, there's a whole area which is the family area where you have to leave everything. You're not allowed to take anything with you into the ward. We didn't have to gown up or anything but you weren't allowed even to take a cup of tea in and sit beside him. There was a little family room with lockers with stuff in it so that you could leave your jackets and your bags and things. When we went into the PICU, [redacted] was in a bay with four beds and each of them had a complete space around about them and a nursing station at each space. It was a very dark room, no natural light, no windows. There were individual rooms along the corridor but I wasn't really aware of them because I just went in and turned right, into [redacted]'s bay. We had to wash our hands on arrival. There was a sink right beside him to wash our hands and we weren't allowed to stay overnight. We had been warned that we wouldn't be allowed to stay overnight because there is no facility to put a parent bed but you can stay as long as you like. We could have gone to the family suite, but he seemed comfortable and we stayed until about eight o'clock that night and then he had settled into a sleep so we were encouraged to go home and get a rest ourselves.

82. He was attached to loads of IVs and cannulas and he was heavily medicated. We weren't in control of anything, we could only sit and watch him. This was only overnight and he was discharged back to ward 3B the next day.

83. Whilst he was in PICU he spiked a temperature in the middle of the night, but they didn't panic about that because a high temperature is quite a common reaction to general anaesthetic. They started an antibiotic protocol anyway and they did cultures and we were told when we arrived the next morning that he had a bit of a temperature. He seemed okay and he was managing to build some

Lego which is a measure of how well he was. Nobody seemed too concerned about him, but then the cultures came back that there was a line infection.

Serratia Marcesens infection

84. [redacted] returned to ward 3B on 5 September 2018. Once [redacted] was back in ward 3B, Dr Ronghe told us that there was a line infection so [redacted] was going to get some more antibiotics. This was quicker than 48 hours after the cultures were taken. They wait 48 hours to see if anything grows, but it in this case, something had already started growing. Dr Ronghe didn't know what the infection was at that point. had antibiotics administered in his Hickman line. Although [redacted] was not in Schiehallion at this point, Dr Ronghe still came to see him, along with the surgeon, Ms Brimley.

85. On 6 September I think the doctors knew what the infection was as they were going to give him antibiotics for it, but we were never told the name of it. We were just told he had an infection that needed to be treated. Once they knew that there was an infection, they checked to see if the infection was anywhere else in his body or just in the line. This is called a peripheral culture. These are the blood draws that the first year doctors attempted to take from [redacted] and made a real mess of. They also check the levels of where else it is in the body so they can give him an additional antibiotic. I remember that the A&E doctor who came to see [redacted] after he had gone into septic shock on the 7 September looked at [redacted]'s chart and told us that he had a "poo bug" so the name of the infection must have been noted on the chart for her to know that.

86. So on 6 September, before they could give [redacted] the antibiotic, they had to get a peripheral draw from the line and elsewhere on his body. The first year doctors were sent to do this and because [redacted] was so dehydrated after his operation, it was like getting blood from a stone. Blood was drawn via the line and it took a bit of time to do. They were going to have to come back and take blood from elsewhere on his body, so the doctors put EMLA cream on his hands to numb it.

[redacted] realised he was going to have to give blood through a needle which he did not like doing.

87. Minutes after the doctors had taken blood from the line, [redacted] went into septic shock. At the time we didn't know it was septic shock. His temperature spiked, he had rigor and he started vomiting and grunting. That's something that we'd seen in as a wee baby, when his temperature was really high, his breathing would become different. So that told us he had a really high temperature. At first we thought he was just anxious and panicking because he was in so much pain from the operation. He had a wound right across his torso. Cameron said to get someone so I pushed the buzzer. An auxiliary came and said she would get someone but nobody came. The fact that it was lunchtime meant that there was nobody floating around the corridor to deal with it at that moment. I pushed the button again and no one came. By this time, I was starting to panic a bit and I went out to the desk. I was finding it difficult to speak at that point because I was getting quite panicked and so I just said to the clerk at the desk, that [redacted] was "going down fast, somebody needs to come". I was starting to imagine the worst and it was suddenly getting a bit scary. The first year doctor came running. It was a first year doctor that we'd only seen once, hadn't even been on our service. He said he was there to help and said he would do some obs and check [redacted]. He agreed that [redacted] was definitely not good, but that they needed to get the peripheral draw of blood before they could do anything. The whole time I was just concentrating on [redacted] and trying to keep him calm, thinking this was just a panic attack. He was vomiting and his temperature was through the roof but he'd already had paracetamol so they couldn't give him anything else for the temperatures, so we just had to manage it. The first year doctor tried three or four times to get a needle into [redacted]'s hands to get the blood draw. They had injured him. It was all a bit chaotic and they then moved on to his feet and were trying to get a blood draw from there. After a while the surgeon arrived, Dr Hettle, or "Hettle" as we knew him. He totally calmed the room down. He sat down, took

[redacted]s' foot and started talking to him about dinosaurs. He was American so had an accent which was exotic for [redacted]. [redacted] was being sick but was trying to talk to him and as he was interacting with him, Dr Hettle managed to get the blood draw. He totally took control and gave instructions for [redacted] to be started on antibiotics. Within about 20 minutes or half an hour, [redacted]'s heart rate started to come down and everything calmed down.

88. That was the day I had to leave the room. I was upset because I stepped out of the way to let the nurses and the doctors get in at [redacted]. I recognise now, that I lost my grip on him. I lost my anchor that was keeping me calm. I was just kind of standing at the edge of the room watching the chaos around about and thinking, "oh, this is not good", but it was quite traumatic for us, that whole episode. I was the only one who left the room that day. I don't know how much of it [redacted] remembers because I've never asked him about it. I don't want to ask him about it. He's never really talked about it. I don't think he remembers a lot of that first couple of days because he was so heavily drugged. He had an awful lot of morphine kicking round his system. The hindsight and the aftereffect of that particular episode, that's the one that I keep dealing with and had to go to a bit of therapy for afterwards. I keep remembering the panic and I get panicked and emotional talking about it because I really feel that I failed [redacted] in that scenario because I left the room. I really did feel in that moment that they were about to turn round and say that there was nothing more that they could do. He didn't lose consciousness at any point. They didn't have to do CPR on him at any point, but I was already at that stage.

89. The septic shock itself was caused by the infection. They used the term "septic shower" because they had accessed the line to take blood out of it and part of any access to the line is they flush it. This means, they connect the syringe to the line with a wee screw and they draw from it first to make sure that blood comes out. It's a syringe with saline in it, and they'll pull back and you see a wee bit of blood going into the syringe and they push the saline through to flush the

line. So in doing that they flushed more infection into his blood. So anytime that line is accessed, it's flushing infection into his blood and so his body went into shock because of all of the bad stuff going into his blood.

90. The way that the situation was handled definitely made us aware of why there are no first year doctors in Schiehallion because when kids get sick there, they get sick very quickly. We definitely felt that the doctors didn't have a grip on the situation and that it was out of control. As soon as the more qualified surgeon arrived everything calmed but it took half an hour or so. When we compared this incident with the episode that we had witnessed in Schiehallion when [redacted] had rigor, that they had caught quicker, we felt that there wasn't the same panic. It definitely wasn't the same panic for me. I had seen [redacted] with rigor before but at that moment in 3B it wasn't the rigor that I was worried about, it was the operation. It was the fact that he had just had major surgery. It was the fact that he couldn't move. It was the fact that sitting up to vomit was painful for him and witnessing that hurt. He was just so small and so delicate, so fragile. Even when he wasn't well before he was never fragile.

91. Having discussed this incident with Professor Michael Stevens as part of the Case Note Review, I think there were an awful lot of things that could have been better and had been ill timed. Ward 3B is a surgical ward and [redacted] was there so his wound from his surgery could be managed. They were maybe less experienced in that ward in dealing with line infections and that inexperience is perhaps why things happened the way they did. If they had experience of dealing with line infections, the doctors and nurses may not have worked on the line and then left the room and gone for their lunch. They would perhaps have stuck around and monitored [redacted] for a while. This may not have happened in Schiehallion as they were more experienced in dealing with line infections and this is a situation where the Schiehallion umbrella was not over us. I didn't know this at the time, this is all with the benefit of hindsight.

92. The following day (7 September) word came from microbiology that they knew what the bug was and that they wanted to put what's called a block in the line. A block is where this little tube area in the line is filled with solid antibiotic. Dr Ronghe came round and talked about microbiology asking for the block to be put in and he explained it to us that it would be a very specifically measured amount of antibiotic that would be put in to fill the length of the tube so it was very accurately measured. That would then hopefully kill the bug in the tube and he described the infection as a very sticky bug. It likes plastic so it's a difficult one to clear and that's why microbiology had recommended that the block be put in to try and save the line. We weren't told what the bug was at that time.

93. Putting the block in had been discussed in the morning and it didn't happen until four o'clock in the afternoon. Dr Hettle and Dr Ronghe were in the room telling us this in the morning and we laughed and said, don't leave it until five o'clock. Do it early so there are plenty people here to deal with it if something goes wrong. Of course, it happened at four o'clock and the septic shock happened at 4:40pm and there was nobody in the building. Dr Ronghe had finished for the day and Dr Hettle was in surgery. By this time on a Friday afternoon, the staff had changed to the weekend shift and there were less staff on duty. I don't know why it was left until the last minute.

94. The delay in the instruction from microbiology and the block actually being put in the line is something we raised with Professor Stevens when dealing with the Case Note Review. He said there was a long gap between microbiology's instruction and it actually happening and that's something that was getting highlighted as it took too long. If microbiology ordered it at ten o'clock that morning, it should have happened at 10:10am. It just took time, I suppose, for the antibiotic to be drawn up or to be sent up from the pharmacy but I'm not sure, we weren't part of any of that discussion. There's also a question of at what point it was noted in the medical notes, because when we were asking questions about this, the Case Note Review came back to us confirming the exact times that

things had been written down in the medical notes. The medical notes say that the antibiotic was given before lunchtime, but we know that is not true as we were carefully noting when it was given and when [redacted] took a reaction. It was given at 4pm and he had a reaction exactly 40 minutes later. Professor Stevens commented that the notes could have been written in hindsight because going by our timeline of events, it doesn't quite marry up. They're more inclined to think that it was noted retrospectively. The medical staff were busy dealing with a patient, they weren't standing writing notes so that's fair enough, we've no issue with that, but the exact time that microbiology sent their instruction, I don't know.

95. [redacted] went into septic shock exactly 40 minutes after the block went in. Our first recognition that something wasn't right was that [redacted]'s heartrate went through the roof. Cameron told me he saw it was above 200bpm at one point. He was vomiting and he was in rigor and at that point we knew that this was because the line had been accessed to put the antibiotic block in. We knew he wasn't well and we were much quicker to get help in the room. The nurse, Jenny, who put the block in, was brilliant. She reacted very quickly and started monitoring him and doing obs constantly. She had a student stand and just constantly taking his obs. A junior surgeon came into the room, Dr Kamal. I think he was called in by one of the nurses. Dr Kamal was Hettle's junior; Hettle was in surgery at that point. Hettle and Kamal weren't our surgeons, it just so happened that they were the surgeons that were on that weekend. Our surgical team were on their days off as they had just done a big surgery.

96. Dr Kamal started a bolus, which was a rapid fluid infusion to flush his system and to help with this kind of scenario, and he gave [redacted] ibuprofen to try and manage his temperature. He'd already had paracetamol and had already maxed out his morphine clicker so the decision was made to give ibuprofen. That was given orally and within two or three minutes [redacted] had vomited it back up again. Officially, he'd had ibuprofen so they couldn't give him any more and they were desperately trying to manage this temperature and stop it spiking. I'm sure he was up above

40 degrees by that point. I did not feel that Dr Kamal was fully in control of the situation.

97. Around this time, Wendy and Jane, nurse practitioners from Schiehallion arrived. I think one of the junior doctors had gone to them for some advice. They came running in out of breath and started examining [redacted] and talking to him and trying to calm him. They told Dr Kamal not to give him anymore ibuprofen. We didn’t know at that point that you don’t give ibuprofen to chemo kids because the chemotherapy itself stops the blood from making red blood cells and ibuprofen kills red blood cells and it can stop recovery from chemo. After that it was just a waiting game to see if the bolus would work and his temperature would come down and he would stop being sick. There weren’t really any other interventions they could do at that point and all the medical staff were standing back while the nurses kept taking obs.

98. At some point another doctor came in. She was a female A&E doctor; I don’t think I got her name. She must have been the on-call A&E doctor and had been responding to a call to come and assist. She didn’t stay long. When she first came into the room she didn’t speak to us. She spoke to the other medics in the room, looked at a chart and they stepped outside the room and had a conversation and then came back in and asked us some questions about the antibiotic block. She asked who had said it should go in. When we told her ‘microbiology’ she said she could understand that. She then told us that she was an A&E doctor but also a consultant with infection control and that is when she told us that he had a “poo bug” in his line. She told us that it wasn’t a good one and so she could understand why microbiology had put the block in. Then she and the other doctors disappeared out the room again. I think Dr Hettle had arrived by that point. Whoever she was talking to, I think it was Dr Hettle, came back in and told us that [redacted] was getting surgery the next morning to take the line out. So the conversation they had outside must have been that it was better to

pull the line rather than continue trying to save it. We weren't given any more information about the "poo bug" or how [redacted] might have contracted it.

99. When Dr Hettle came into the room, he definitely calmed the room. I was right beside [redacted] and had moved as far up as I could so I could keep a hold of him and so I was right beside Dr Hettle and Dr Kamal at the bedside. I noticed that when Dr Hettle came in, the first person he looked at was Dr Kamal and the look was "are you alright?". It was interesting to see the interaction between them as there was definitely seemed that things weren't going the way they wanted as quickly as they wanted. After that, it seems that the bolus started to work and I think the physical impact of the septic shower started to wear off. The decision was made that the line would get removed the following morning. This meant that the easy access point for treatment would be lost and all the treatment would have to be given through cannulas, which are reliable but don't last as long and mean more needle sticks for [redacted].

100. During this incident, the doctors were in the room quicker; it was the junior surgeon, Dr Kamal that was in the room managing the situation. I didn't let go of [redacted] that day. I held his hand but moved back to let people get in and access him if they needed to but I didn't leave him because I knew that I needed to keep hold of him to keep me calm. I can definitely say that there was a fear in Dr Kamal's eyes that he wasn't in control of the situation because I was looking at him and he was biting his nails and surgeons don't bite their nails. So there was definitely a feeling of things weren't good. Whether we would have felt like that in Schiehallion, I don't know and we'll never know. [redacted] was part of the Case Note Review and one of the questions was why he was in a surgical ward after the surgery and not Schiehallion. The answer was: that is the protocol for that surgery because the surgical ward has the skillset to deal with the wound and the treatment of the wound. Schiehallion may have the skillset to better deal with the line infection but the fact that he got a line infection was a fluke. If he hadn't had the line infection, he would have been in the best ward for the care being a

post-operative patient. It was noted as part of the Case Note Review that perhaps the neutropenic aspect of it wasn't given a high enough priority. That is what left him open to a line infection and if he had gone to Schiehallion we'll never know if it would have been dealt with better. We don't know whether the Schiehallion staff would have been as good at dealing with the pain management and the wound management; probably not, because that's not what they do every day.

101. [redacted]'s line was removed on the 8 August 2018 under general anaesthetic. The lead surgeon, Mr Davies came round to see [redacted] afterwards and see how he was doing after both the line surgery and his big surgery. I was concerned that the line infection might have damaged his heart as the central line is a fast-track to the heart. Mr Davis said that we didn't need to worry about that. He told me that the antibiotics that [redacted] was on were very strong and would kill everything. He told me that the antibiotics he was on were Meropenem and gentamicin. They were the go-to antibiotics that were used in Schiehallion whenever there was a suspected line infection. During this admission, [redacted] had been given prophylactic antibiotics when he was in surgery and then, when he spiked a temperature afterwards he was started on intravenous antibiotics in line with the protocol. When it was confirmed that he had an infection, he remained on those antibiotics intravenously for the remainder of his admission and when he was discharged home he continued to take the antibiotics orally for a further 4 or 5 days. I don't know if the infection was gone before [redacted] was discharged, although he was constantly getting his blood drawn. He was discharged on the 13 September and we were asked by Dr Ronghe to come in to day care on the Monday which was the 17 September.

102. The other side effect of surgery for [redacted], was that it became evident that he was allergic to something and we still don't know what that something was. When he'd had his first line placement, we noticed that he had a rash where the ChloraPrep, the antibiotic wash that they put over the skin, had been. After he

had his kidney surgery, the area where they superglued the outside shut, a big strip an inch wide all across his torso, became red and inflamed and it was an allergic reaction to the glue or to the ChloraPrep under the glue. We're not entirely sure but the whole area, the whole surgical field became intolerably itchy, where we had to lie and hold his hands at night to stop him scratching it because if he was scratching at the wound he was going to make it infected. He then had to be sedated so that we could pick the glue off. We still don't know what it was he was allergic to. That, plus the infection on top of the big surgery meant that it was a really difficult hospital stay for a few days because he was so uncomfortable, he was so itchy, he was so sore.

Meeting with Dr Ronghe and Dr Inkster: 17 September 2018

103. When Dr Ronghe asked for us to go in and see him on 17 September, we thought it was just for a check-up, to talk about how [redacted] was doing. Dr Ronghe came in and sat down asked how [redacted] was doing. He was being very cagey and wasn't chatting the way that he normally would. We now know that that's because he didn't know what he was allowed to say without Dr Inkster being there, he told us that after the meeting. We formed the view that he was angry and upset about what had happened and that the building was not up to scratch, although he didn't say that to us. Dr Inkster was an infection control doctor. When Dr Inkster came in, I got her name after the fact, she told us about the infection and she said that they now had to apologise to us because it came from the drains. We weren't given any more information about the drains, or which drains they thought the infection had come from. We were just told that it was a hospital acquired infection and they were very sorry. She said it was an ongoing situation and they were addressing it. She said it shouldn't have happened and they were now working to try and make sure it didn't happen again. She told us that [redacted] was one of six children who got ill that same weekend and they were looking into it and trying to solve it and they were going to close the whole Schiehallion unit and move it somewhere else. It was only the Schiehallion unit

that was being moved. Angela, the staff nurse in the Schiehallion day care unit, later told me that they were closing Schiehallion as a precaution as there were immunocompromised kids there who were at risk if there were bugs. The rest of the children's hospital didn't need to be shut as kids elsewhere in the hospital weren't immunocompromised and could fight these bugs. The doctors didn't know where the unit would be moving to at that point, they were working with estates management to try and work something out. They thought potentially somewhere in the adult hospital. We were told what the bug was, serratia marcescens, and they described it as a biofilm. They said it's a build-up that happens in drains and it's in your drain at home and it's soap that causes it. They described the pink stuff you might find in your bathroom on the side of the bath. The bacteria grow and eats the soap. They said they had been having problems with it in the ward and had been trying things to get rid of it but [redacted] was infected with it. We sat in stunned silence and really just said "oh okay". We made light of the issue and said that, compared to the surgery he had just gone through, the infection was not our biggest concern. The doctors' response to this was that this infection was the most concerning thing about [redacted]'s stay in hospital, not the removal of the kidney, the removal of the cancerous growth or the stay in PICU. We weren't expecting that and we didn't ask any questions about it. To be honest it went right over my head as I was just thinking about what was coming next. We now know he had this infection, but he was okay and I was focused on what the outcome of the surgery was and finding out the staging of the tumour so we could deal with the next stage of treatment.

104. When the Case Note Review was being carried out, we asked whether it was possible to pinpoint when [redacted] had contracted this infection. We were told he could have contracted it up to two weeks before it manifested itself. He could have caught it in 2A, but he could also have caught it in surgery or 3B, we just don't know. It is possible that he could have caught it when the bathroom flooded in the VAC room in 2A as it is within that timeline. We just don't know.

[redacted]'s ongoing treatment and announcement of decant to Ward 6A: September 2018

105. After this meeting, [redacted]'s treatment continued. As a result of his infection [redacted]'s treatment wasn't delayed, but the doctors did have to change the way his chemo was administered. When [redacted] had his surgery, they removed the tumour from his kidney which went to pathology for analysis. The results of that analysis were discussed at a "tumour meeting" between radiography, pathology and the Schiehallion team. The feedback from that would then dictate the next course of treatment depending on what the staging the tumour was. If it was stage one which is completely contained in the kidney, no spread at all, then he would get four more weeks of chemo and that would be the end of his treatment. If it was stage two, then it would be six months more of chemo and that would be the end of his treatment. When the pathology report came back, the entire tumour was necrotic which meant everything was dead and there was nothing left to test, so they were unable to stage it. Because of [redacted]'s age, it was unusual that he would have this type of tumour and because they couldn't give a decisive staging, the decision was to err on the side of caution and go with six months' treatment. It took them two weeks to come to that decision and in the intervening week, [redacted] was to come in and get either the first chemo of either a four week or six-month plan. Dr Ronghe said that, if he was only getting four weeks of chemo, it could all be done through a cannula. If it was going to be six months, then they would insert a port-a-cath. As the decision on the six-month treatment hadn't been decided by the time of his first chemo session, he had to get it through a cannula. When went in that Thursday, which was the 20 September, he had to get his entire chemo treatment through cannula. So his chemo wasn't delayed as a result of the infection and the line coming out, it was just given differently. It also meant he had to undergo another surgery under general anaesthetic to get the port-a-cath inserted.

106. That appointment where they had to give the chemo through a cannula was one of the most traumatic day care appointments that we had because

Cameron and I both were pinning [redacted] down while two nurses were pinning his arm down to keep it completely still. That was hard going. That was a really difficult one. [redacted]'s fear of needles had built up through the course of the surgery and the infection, because it wasn't really that big an issue before. He had just had so many needle sticks, and so many failed needle sticks, during that time. He is usually a very logic-minded boy, he doesn't let emotions override him, but I think that this had all been too much for him and it took him a long time to get over it.

107. When the decision was made that [redacted] was going to get six months of treatment, he was booked in on 26 September to get his port-a-cath fitted. This is a subdermal access so the line is put into the vein the same as a Hickman line but there's a little device, with three lumps, shaped like a triangle, that is inserted under the skin. To access it, the nurses come and they feel the three bumps and then they insert a needle through the skin into the port and that's the access point. So it's a jag every time but when you're not using it, the skin is closed which means there's less risk of infection so that was the preferred option because of the issue that they'd been having with the Hickman lines.

108. [redacted] had chemo on the 20 September and he had to have his chemo through a cannula. He then spiked, which was a reaction to his chemo, and he had to be admitted to ward 2A on 21 September. He had to have all his treatment through a cannula on that occasion too. It was during this stay that we were told that ward 2A was definitely moving to an adult ward and when we found out that was going to have his surgery for his port-a-cath on 26 September, we were told that was the day Schiehallion was moving. We were being told all of this information by Angela, the day care manager staff nurse. All we were told was that the whole ward would be moving and taking up a unit in the adult ward and it would be for us only. There wasn't any reassurance given that the Schiehallion protocol would be moving with us but we didn't really ask for it; we were just assuming that everything would be fine. Angela told us that it would be for a few

weeks because they needed to do work on the drains and pipes so everyone needed to be out of the way. Dr Ronghe told us the same as Angela when we saw him, just that we were moving upstairs and it will just be the same except in a different bit of the building.

109. There had been informal chat about the move and bits of paper handed out. We got a letter dated 18 September 2018, a copy of which is attached to this statement **(CG/02 – Appendix 2)** telling us about that there was a new cleaning process being introduced on ward 2A and that we would be moving to one of the adult wards to allow some work to be carried out on 2A which was linked to the infections.

110. On this same date we also got a letter dated 7 September 2018, a copy of which is attached to this statement **(CG/03 – Appendix 3)** telling us that we should access the hospital via the discharge lounge of the adult hospital. At this time a window had fallen out of the adult hospital and smashed on the pavement so there was scaffolding at the main entrance to the adult hospital and there was no entry whilst they carried out the work. At the same time, there was work on the cladding being carried out at the main entrance to the children's hospital. I don't know if this was anything to do with what had happened at Grenfell. This letter told us that the work that was being done on the cladding could cause dust which could affect the air quality so, as a precaution for all the immunocompromised kids, we should not use the main entrance to the children's hospital and should instead come in through the adult discharge lounge. This meant quite a walk as when you came in that entrance you had to walk into the adult atrium then through the link corridor into the children's hospital then upstairs to ward 2B for day care. That entrance was always crowded with smokers as well so it wasn't great. We used that entrance until the decant to 6A at which time I queried why we had to use it and I didn't like it because of all the smokers and we were told that we could use the main entrance to the adult hospital.

111. The move to 6A happened on 26 September 2018 and we were initially told, informally, that it would be for 4-6 weeks. At some point, I can't remember when, Angela told us that the decant would be more like 3 months and we would probably be in 6A until after Christmas. Then, on 6 December 2018 we were told that the decant would be for another year. We were told that when they were looking at 2A, it wasn't just the pipework that was an issue but actually the air conditioning units weren't up to scratch when the building was first built so they were going to retrofit something whilst the ward was shut. This was all informal through Angela and we weren't given any formal explanation about the ward closure, or an explanation about what work was being carried out in 2A, or given any updates on progress.

Admission to ward 1A in the RHC for surgery and decant to ward 6A in the QEUH: 26 September 2018

112. [redacted] went into ward 1A in the RHC on 26 September which was a surgical ward to have his port-a-cath inserted. We hadn't been in this ward before. It was a day ward, so the children would go in and go into bays and then would go round to surgery and come back to a bay. We were immediately given gold standard treatment. They knew we were Schiehallion and we got a wee VAC room in behind the nurses' station. The standard procedure was that when your child went to surgery, you then had to go and wander about and wait in the waiting room outside, but because [redacted] was in a VAC room, I could sit in his room and wait for him. That room was very clean. In fact, when we got there we were told they were just finishing cleaning the room, so I did feel confident that the room was clean. Then the doctor that came to do his pre-op admission was one of the juniors from the surgical ward that we had just been discharged from so she knew us and she was very pleased to see [redacted] looking well. He went away for his surgery and I stayed in his room until he came back so I was with him as soon as he came back. That unit only stays open until seven o'clock at night because usually the children that have been in for their tonsils out, or whatever,

are either sent up to the surgical ward to be admitted or sent home. We were then transferred up to ward 6A, which was the “new” Schiehallion unit in the adult ward, in order to stay overnight for [redacted] to be monitored as he had a general anaesthetic. We had a good experience in 1A.

113. When we got to 6A everyone was rushing about trying to find a place for everything. They didn’t stop. The auxiliaries were in and out of each room asking if we had what we needed. No bed had been put into our room yet, so they had to go and find one for [redacted] and one for me. They were full of apologies because there was no kitchen for the parents. There were no facilities and they were just so apologetic that it wasn’t up to their usual standard. They looked after us as [redacted] hadn’t had dinner yet and there wasn’t much left so they got him a sandwich from the staff kitchen. They really were very kind even though not one of them stopped the whole time we were in.

114. Despite how busy they were, there was absolutely nothing we could complain about. [redacted]’s obs were done on time, his medication was given on time. The next day he had to wait all day for his chemo, as the day patients get priority, but he got his chemo about 5pm and we were discharged.

Description of 6A

115. The adult hospital looks like a square in the middle, this is where the big atrium is, and then there are 4 legs that come off the square at each corner so it looks like a X. Ward 6A looks a bit like a Y shape. There are two corridors on the square part of the hospital that meet at a right angle at the corner of the square and then the main part of the ward is on one of the legs of the X that comes of the square centre. The entrance to the ward is on one of the corridors on the square part of the building and there are rooms to the left hand side of that corridor as you come into the ward. The right hand side looks out onto the atrium. You then go right round the corner and onto the other corridor which is on the square part of the building. There are rooms on that corridor too which

look out onto the car park. There is an exit door on this corridor, but this was only accessed by staff. The main part of ward 6A is on the leg of the X that projects out from the square centre and there were rooms on both sides of this corridor with toilets, facilities and storage rooms down the centre. At the end of the ward is day care. At the very end of the ward there was a big window which gave great views over Glasgow. All the day care patients had to walk right through the ward to get to day care and it meant the ward was always busy and had loads of through traffic. On [redacted]'s first admission in 6A we were in a room right up at the entrance to the ward and right next door to us was a store room and there was somebody in there the entire night shift putting stuff in, tidying, finding homes for things.

116. The rooms in 6A were still single rooms with en-suite bathrooms, but they did not have the fold away parent beds which had memory foam mattresses. We just got a "z-bed" which had mattresses that folded in half. They were rubbish and didn't have the proper support. They were okay for one or two nights but if you're in for anything long-term then it's an absolute waste of time. Then, of course, when it's folded up, there's nowhere to put it because the rooms in the adult ward are not designed to have a space for a parent or for a fold-down bed so there wasn't even a bit of wall long enough or square enough to sit it against.

Facilities

117. There were no kitchen facilities for parents in 6A. We would bring our own kettle and flask so we could get a hot cup of tea. It was only post-event when I went to Jak's Den and got some counselling to help deal with some of the traumas of it the counsellor was aghast when I explained that we took our own kettle in and we took our flask to have a hot cup of tea in the middle of the night. She said we were effectively camping in the hospital and that was not okay. But we did what we had to at the time. We just found a way to get through it.

118. There were no play facilities for the kids. They improvised a wee plastic table and two chairs, like an Ikea-style wee plastic chairs in the corridor. This had colouring in stuff, but there were no toys. The play team, at that point, didn't even have a cupboard up in ward 6A, so if somebody wanted something, they had to go all the way back to the children's ward to get it. Part of the remit of the play workers was to manage a scheme called the Beads of Courage. The children are given a string when they start treatment and for every single thing that happens to them in the hospital; so every needle prick, every x-ray, every meeting with a specialist is a specific little bead. These beads then get threaded on and its part of a counselling thing for the children to be able to represent their treatment. At the end of it, they have these big long strings with all these beads on it that show their journey. We would get a sheet and fill in what beads we were to get and the play team would get them for us. When you handed the sheets in up in 6A, they would run all the way to the children's ward to get them and bring them back to you, but loads of kids didn't get their beads for months and months and months because that was the lowest priority. For some children that really was a reward and really important they were able to put the beads on their strings.

119. The TVs were smaller generally in 6A. and the Wi-Fi was as sporadic as it was in the children's hospital. The auxiliaries would come into the room asking if we had all that we needed and if the TV was working. At that point they were still getting to know the ward and at that point there were a lot of breakages and a lot of things not working. They were on it. They got an awful lot of things fixed as quickly as they could but obviously the PlayStations and Xboxes were in high demand at that stage.

120. In terms of the staffing and the protocols, that was all the same as ward 2A, it was the same staff team. There were some rooms in 6A where you felt quite isolated, like you were on island because no one walked past your door,

but you always had your buzzer and your assigned nurse would come and see you if you buzzed them.

[redacted]'s ongoing treatment: October –December 2018

121. [redacted]'s chemo continued as a day care patient and he would attend day care in ward 6A. He had several times throughout this period when he spiked a temperature in reaction to his chemo. If this happened, then we would be admitted through the CDU unit in the RHC to ward 6A if it was out of hours, or through day care in ward 6A if it was during the day.

Stay in ward 2E in the RHC: 13 November 2018

122. There we some occasions when we had to be admitted to other wards in the RHC when [redacted] spiked a temperature, because there was no room in 6A. The first time this happened was on 13 November 2018.

123. We were admitted from day care to ward 2E in the RHC which was a cardio ward. We hadn't been told by anyone at the hospital that it was a possibility that we would have to go to other wards, but we had been told by other parents that it might happen.

124. When we got to ward 2E were given a VAC room as [redacted] was a Schiehallion patient. The cardio ward was heavily staffed and they were on top of all [redacted]'s observations and there were actually monitors showing the obs on the wall outside the room because it was for cardio kids, so he was well monitored. We really rated that ward. Because it was a VAC room, the staff had to adhere to the VAC room protocols. This meant that the staff should wash their hands in the room outside the bedroom before and after they came in to the room and they should wear gloves and an apron. All of the VAC rooms we were in had double doors with the room in between where the sink was for washing hands We were actually in isolation; we didn't come out of the room. That was to protect [redacted]. We were advised by the nurses not to take him to the playroom as

there were lots of “snotty” kids there and we were advised it was safer to just keep him in his room. So he could have used the playroom if it had been safe for him. There was also a staff kitchen that I had access to and because we were back in the children’s hospital, there was a parent’s bed for me in the room, not a “z-bed”. We were in for two or three days just for him to be monitored and then we were discharged.

Stay in ward 3C: 7 December 2018

125. The next time that [redacted] spiked was on 7 December. This time it was out of hours and he was admitted through CDU to ward 3C in RHC because there were no beds in 6A. Cameron had major issues with the nurses in CDU accessing [redacted]’s port during this stay. The port is harder to access and fewer people are trained in that than the Hickman line. On this occasion, they were trying to access the port but would miss, so when they were sticking the needle in it wasn’t going into the port, but it was sticking into [redacted]’s skin. After five failed attempts, Cameron said, “enough already” so they started a cannula to get the antibiotics going.

126. [redacted] was then admitted to ward 3C is an orthopaedics ward. This was a hard stay, although it was mainly Cameron who dealt with it as he dealt with the admission. [redacted] got a VAC room, but it was not a good experience in terms of the care that [redacted] got. Cameron was phoning me at home and telling me that he was having to shout to get attention. He felt the nurses weren’t attentive at all and they weren’t properly monitoring [redacted], whose temperature was continuing to spike. He found it really concerning as we’d witnessed how bad a line infection could be and we didn’t know that it wasn’t that at this stage. The experience was so bad that Cameron put in a formal complaint to the hospital using their complaints procedure.

127. In ward 3C they worked with the cannula for a while. The nurses there did not make any attempts to access the port and said they would try and get

someone from Schiehallion day care to come and access the port. Dr Ronghe came and said that he wanted to make sure that the port was okay as he was worried that there might be a reason that the CDU nurses had had difficulty accessing it. When he said this, Cameron was worried that [redacted] had a line infection and that was why he was spiking. As no one had accessed the port yet, no one knew if it was compromised or not. So Cameron put [redacted] on his back and ran him along the corridor and up to 6A. Rather than someone from day care coming to us, he took [redacted] to them and they accessed the port first time as they do it all the time. They took the cultures and it came back that it wasn't a line infection so it had just been another reaction to the chemo. I wasn't there for any of this. By the time I got to ward 3C it was the night shift. Everything was timely and the staff were great. The spike had ended and the fever had broken. I took over to do the night shift and Cameron was pretty broken. That's the worst I've seen him because he didn't sleep at all. He couldn't relax at all because he didn't feel that he could. He just didn't feel [redacted] was being cared for

128. The next day, [redacted]'s skin had started to react under the dressing. If you can imagine they've put the access point through the port and then they've put a big sticky dressing over the top of it to stop the line that's in from falling out, to give it a bit more purchase. His skin started reacting underneath that dressing. I told the day shift staff about the inflammation, but because they weren't trained in dealing with a port, they didn't want to touch it. I kept asking for someone to come and nobody came. Their answer was to just put another plaster over the top so that didn't help treat the allergic reaction that was happening. Finally, someone from Schiehallion came down at nine o'clock that night to change the dressing and give him Piriton. I had been saying from about one o'clock that afternoon that there was something going with the dressing. The nurses in 3C had phoned someone in Schiehallion but they hadn't told me that they had done that. I only knew once they arrived. So when we were discharged from that stay, he was on steroids for four days to try and treat the skin reaction.

129. We then had a referral to dermatology that following Monday on the 10 December 2018, which was a referral that had been put in post-surgery because of the reaction he had to the dressing. That's one of the worst appointments I have ever had with [redacted] because he just wouldn't let that doctor touch him or look at him. He wouldn't even lift his t-shirt. He was just so uncooperative. I was getting irritated with him, but then the calmer person in me was saying that he doesn't want anybody to touch him because he's just fed up of being poked and prodded. The Holy Spirit was with me that day because I didn't shout at him. I just gave him a big hug and when we were finished we went for doughnuts. He had had a rubbish weekend because it was a particularly bad spike as well. He didn't sleep well and he was just feeling terrible. The knock on effect of all these little things that didn't need to happen meant that he became difficult to engage and work with; this was all knowing that we still had another five months of treatment to go.

Complaint about stay in ward 3C

130. On our next visit to day care on ward 6A on 11 December we told the staff there about our experience in ward 3C. We were saying that, although we didn't want [redacted] to be in hospital over Christmas, after the stay on ward 3C we had gone from saying, "I really hope we're not in over Christmas" to just, "I really hope we're not in orthopaedics". I don't care if we're in Schiehallion over Christmas, just don't put us back in ortho again because it was just grim". The staff in Schiehallion told us that we should put in a complaint because otherwise nothing will change. They knew about what had happened because they were getting the phone calls about accessing [redacted]'s port. They wanted to come down and help but their seniors wouldn't release them to go and help. They were pleased when Cameron showed up with [redacted] on his back and were relieved that they could help. So it was after that conversation that we decided put in a complaint. We took a few days to do it as we took a bit of time to write it without trying to be vindictive and without trying to be just angry, to take the emotion out of it.

131. We went through the official hospital procedure for complaints**.** We didn’t hear anything for weeks and weeks and weeks and then Cameron prompted them to say nothing had come back. We got a reply saying they were very sorry and that they would respond in “x” number of days. Those days came and went and we didn’t hear anything, so we sent another email prompt. Someone from the official complaints department, I don’t know who they were, had a meeting with the nursing team and it was all discussed with the nurses in question. We then got a response dated 7 February 2019, and they were full of apologies and said extra training will be put in place for any gaps and they recognised that the failings that we pointed out should not have happened. We were satisfied with the way the complaint was dealt with as long as the changes would be made. When we did return to 3C a few months later it was a better stay.

132. After this stay in ward 3C on 7 December 2018 [redacted]’s chemo continued as a day care patient. He had another spike on 28 December and was admitted to ward 6A. Again this was just a reaction to the chemo, not an infection.

133. During this whole period when we were moving around between wards, there were filters on all the taps and as Schiehallion patients we were drinking bottled water.

Fungal Issue on ward 6A and decant to CDU: 17 January 2019

134. Once we got into January 2019, [redacted]’s chemo continued and he spiked on 17 January and was admitted to 6A via day care. At this time there was a fungal issue on the ward which was being blamed on pigeon poo. We had only heard about it on the news and saw it on the chat among the parents on the Schiehallion parents’ page. We thought “what now?” and that this was ridiculous. There was a lot of anger on the Facebook page that we hadn’t been given any information about this from the hospital. When we went into the

hospital on that occasion, there were HEPA filters in the corridors and in every room. We were given very little information from the nurses on the ward about what was going on. We were not told anything official by the hospital at this point, we were only being told by Angela, the day care staff nurse that there was a fungal issue in the hospital and the filters were there as a precaution because the kids were immunocompromised and were too precious to risk. She was the person who was giving us all the information at this point and the poor woman was in the firing line every time. It was about a week later that we got a letter from the hospital telling us about the pigeon poo. This letter is dated 23 January 2019 and I have a copy which is attached to this statement **(CG/04 – Appendix 4)**. I think we only got this as the parents were so angry about the lack of information and what we were hearing in the press. That was the first instance of the hospital deliberately making sure everyone got a copy of a letter. January 2019 was the point that they started giving us formal headed notepaper letters. We got a copy at day care and it was also posted to us so it had obviously been posted out to every patient on the unit. This letter said that people had been infected. This is what it said: "*I write to you to personally offer reassurances that we are taking these issues very seriously and we apologise for any anxiety it may have caused. We're focussed on ensuring a safe environment for all our patients and are actively managing this instance. As you will have seen from the news reports, we're investigating two isolated cases of an unusual fungal infection, Cryptococcus which is linked to soil or pigeon droppings. These were identified in December and the likely source detected and dealt with immediately*." It is basically saying that there's nothing left to worry about so stop worrying about it.

135. Around about this time, we were starting to see orange seals around some of the bedroom doors, and they were closed for repair work to be carried out in specific rooms. We saw that happen on a couple of rooms up on ward 6A, but never when any of us were in them, obviously. They did it while the rooms were empty. During [redacted]'s admission for a spike on 17 January, I think he was moved

rooms because there was work being done in the room next door. Cameron was with him at this time so will know the details better. They had just moved and got settled into their new room when they were told they were getting moved to the CDU.

136. On 19 January, the whole ward was decanted down to CDU for a week and a half or two weeks while they were repairing flaws in the bathroom seals. We noticed that some of the bathrooms in ward 6A weren't up to scratch. Some of the flooring was peeling off the walls and some of the seals weren't properly sealed so there was bacteria and fungus growing and it needed to be fixed. We took over that ward. It was no longer CDU. It was now Schiehallion in CDU and CDU were moved up to ward 2A to allow the work to happen in 6A. The day care unit moved to ward 1A in the RHC.

137. There had been an awful lot of chat on the parent's page about how the Professor, that is Professor Gibson, had been having meetings and information sessions with families about the issues on ward 6A at that time. There was an awful lot of panic among a lot of the families at that point. We weren't at these meetings as she wasn't our consultant, she was the consultant dealing with the kids with leukaemia. From what I heard on the Facebook group, these meetings consisted of a lot of discussion around the anti-fungal medication that the kids were being given. Professor Gibson was on the ward on 19 January and I don't know whether it was her that came and told Cameron that they were moving but he got very upset and very angry that they were having to move rooms again. He had arrived in with [redacted] spiking, he got no sleep for the first 24 hours while the temperature was being managed and he'd unpacked the basics of the suitcase, in which he'd had to bring his own kettle and flask, and he now needed to pack it all up again to move room again. He had had enough, he was knackered. So that was difficult. I wasn't in the hospital at that time, but he was on the phone telling me what was going on so that I knew where to go to when I came in to do my shift change.

138. When [redacted] was in hospital on this occasion, Dr Ronghe came to visit, doing his usual daily rounds with us when we were in and he told us what was going on and what would be happening next. He told us that there were repairs being done to the bathrooms up in ward 6A and that when we went back to 6A the filters would still be there. He also mentioned that there was an antifungal medication that they were prescribing for a lot of boys and girls that were on the ward but [redacted] wouldn't be getting it because it can react with the vinc. He reassured us that, because [redacted] was in and out of the hospital, because he wasn't staying for any length of time, then he wasn't at such a high risk of contracting a fungal infection, so he was satisfied that, we were better off not giving him it because if he did, he would need to change the vinc protocol and, they were better off continuing with that. All he said about it was that it was a fungal thing and that they were giving prophylactic treatment to all the children to protect them, but as he had explained why [redacted] was getting it, it didn't impact us. I had also heard through the Facebook group that the anti-fungal medication might have had some side effects so I was quite happy that [redacted] wasn't getting it and I didn't ask Dr Ronghe anymore about it.

139. When we were decanted to the CDU all the staff came with us and it was back in the children's hospital so there were parent beds and there was a playroom for the kids so they got to mix again. It was actually great for us because it was on the ground floor. My mother-in-law is disabled and on a wee scooter but was claustrophobic so couldn't go in the lift. She hadn't actually been to visit [redacted] in the hospital because she couldn't get up to his room. So when he was in CDU, she could come and visit.

140. [redacted] continued to have his chemo during the decant to CDU. He had a couple spikes where he was admitted there, on 1 February and 9 February and then the next time we went in on 21 February, we were back in 6A for day care.

Return to ward 6A: 21 February 2019

141. As I say, [redacted] had chemo in day care on 21 February and then was admitted with a spike on 27 February to ward 6A. I didn't notice any improvement in the bathrooms in ward 6A when we returned after the decant to the CDU. At this time, it was kicking off with the parents about why the kids were on these prophylactic drugs. It was building up in February and March and finally the hospital started having meetings with the parents in April/May time.

142. The HEPA filters were still on the ward and we weren't told anything about what was happening. We were just told to come to 6A if you have a spike.

143. After this admission, [redacted] had a couple more chemo sessions in day care and then had his last spike on 26 March 2019 and that is when we went back to ward 3C as there was no room in 6A.

144. We had a much better stay this time. The nurses who we had complained about stayed away from us and we were given a different nursing team, but it was definitely an easier stay. Everything was timely and he wasn't as unwell.

145. The Cleaners were also amazing. I had met the cleaner coming in, she was also the cleaner in Schiehallion. She asked me what I was doing there and told me that the room we were in had been gutted from top to bottom, so we knew it was clean.

146. There was one thing that happened with water during this stay in ward 3C. I went into the kitchen to get [redacted] a drink because I had left the suitcase in the car until I knew where I was taking him. We didn't have any supplies and he was thirsty and wanted a drink so I went into the kitchen, to get some water. The chief nurse of the renal unit was there, half of 3C is ortho, the other is renal. She told me to take a jug and get some water, but I told her that we were Schiehallion and would need bottled of water. We ended up using the tiny, wee

sterile bottles that are used for babies just so that he could get a drink until I brought in our supply from the car. Apparently by that point the water was fine to drink, although I was never officially told that by anyone. Across the board in the hospital the water issue had been solved but Schiehallion still weren't taking any chances.

147. That was [redacted]'s chemo finished. He had an ultrasound and an x-ray on 27 March 2019 which was us getting started on a three-month regime of ultrasound and x-ray. We went every three months from then for an ultrasound to check that his other kidney is functioning properly and that everything's still as it should be. The x-ray is to check for any spread in the lungs. We had a day care meeting with Dr Ronghe on the 4th April 2019 and that was to tie up treatment, to discuss the three monthly consultation which was just for keeping a check on [redacted] and to reassure us. He said that hopefully [redacted] will be okay and when he turns 18 he would be transferred to adult care and be monitored every five years. He'll be monitored his whole life because he's had chemo and this puts him at greater risk of various different things.

148. On the 8th April he had day surgery under general anaesthetic to get his port removed and they sent us home. We were allowed to then care for him because if he had a spike at that point, we didn't need to worry about a line infection so we were given back control.

149. He has been having his three monthly checks ever since, and since two years have passed, we have just moved on to six monthly checks.

WATER: EVENTS INVOLVING WATER SYSTEMS

150. There were some specific incidents that happened involving water when we were in the RHC. When we were admitted to ward 2A in July 2018, we were told that there had been issues with the water.

151. We were told to use the bottled water for drinking. When we first went on to the ward there weren’t any filters on the taps, but they appeared at some point in the first month. We were told by the staff that there had been issues with the water at the start of the summer. It was on the news apparently, but we didn’t pay attention to it and weren’t aware of it. When we did mention it other parents they told that there had been an issue and that’s why the filters were on the taps and why we’re using bottled water. It was very much played down by the staff. Whenever you asked about it they said to use the bottled water and the filters are on the taps and not to touch them, or interfere with them. And that was it.

152. We were allowed to use the water for washing, although there was a sign in the bathroom telling you to run the water for three minutes before you use it in the shower every day. We were also told by staff to run the water before we used it. I assumed that was for Legionnaires. There was also a sign saying “for handwashing only” at the sink in the bed area so we did tooth brushing and stuff in the bathroom. We used the water in the bathroom to brush our teeth and nobody told us we shouldn’t.

153. In August 2018 there was the incident in one of the VAC rooms in ward 2A. The water flooded out of the shower and ran right through the bedroom and into the corridor. The nurses did not seem surprised by this and said it had happened before.

154. We weren’t aware of any rooms ever being sealed off, or work being done whilst we were in ward 2A. We were in and out though so it is possible it was happening but we just never saw it.

155. When [redacted] was in ward 3B in the RHC in September 2018, before he got his kidney operation there was no filter on the tap in that room. When we were in

the second room, after the operation, Dr Ronghe came in and noted that there were filters on the taps this time. It was only after the fact, in discussion with him, that he said, yes, those filters should have been on the taps in the first room you were in. The filters on the taps and stuff wasn't really on our radar at that point. We were just eyes on [redacted] the whole time

156. Once we were decanted to ward 6A, the issues were not so much with the water, but with the conditions of the bathrooms and that is the reason we were decanted to CDU for a few weeks in January 2019.

Water: Communication

157. We were not told very much about why bottled water was being used and why the filters were on the taps. We just assumed it was for infection control. All we had been told was that there had been an issue with the water at the start of the summer in 2018. We were not aware of what that issue was, or whether it was still ongoing.

158. When [redacted] had his line infection in September 2018 we were told what the infection was, that it was a Hospital Acquired Infection and that it had come from the drains. At that point the hospital were aware that there had been other instances of infections so we knew that they were planning to close ward 2A to allow the issue to be sorted.

OTHER ISSUES RELATING TO HOSPITAL CONSTRUCTION

Air conditioning

159. The air conditioning did not work in many of the rooms in ward 2A. There were control panels on the walls, but they didn't do anything and more often than not, the rooms were incredibly hot, which wasn't great if [redacted] was spiking a temperature. The only place the air conditioning worked was in the VAC room that we were in that one time in August 2018. The staff just seemed to accept

that it didn't work in most of the rooms and that was it, nothing was ever done to fix the problem that we were aware of.

Issues on ward 6A

160. There were issues on ward 6A once we were decanted there. The bathrooms were not in a good state. In quite a few of them at the corners where the materials met, there was seal and that seal was broken in a lot of places and there was also a black rubbery seal between the floor and the wall and that would be degrading at points as well I was quite surprised at the state of disrepair that it was in, given that it was a brand-new building. It shouldn't be that degraded already because this stuff's built to last and it's built to be used regularly. It's built to be washed and disinfected regularly so I did wonder why it was already falling apart. There were quite often bedrooms closed off in ward 6A for remedial work to be carried out, although we didn't know exactly what was being done.

161. There was the issue with fungal infection related to the pigeon droppings that led to all the HEPA filters appearing on the ward. All the parents were very worried about this, but it was very much played down by the hospital and were told not to worry and that they were dealing with it.

162. As far as we were aware, the decant from 6A to the CDU was for the bathrooms to be fixed. I don't know if the clinical staff or the hospital board were being up front about this. We were told as little as possible. I'm assuming it's for self-preservation. I feel that the board only told us what they had to tell us in case we would sue them. You really did feel that they were being very protective of their position, and the clinical staff didn't know what information they were allowed to tell us so they just told us nothing.

HOSPITAL ACQUIRED INFECTION

HAIs: events and impact

163. [redacted] had one healthcare associated infection. That was the Serratia Marcesens infection he contracted in his line in September 2018 when he was in getting his kidney operation. I have described the circumstances of the infection in more detail above. The infection and the additional surgery where the line was removed, slowed his recovery from his kidney surgery. However, he was very unwell after the kidney surgery. We have photos from that time and he was so skinny, so drawn looking and weak, very, very weak but you would expect that after a major surgery. We'll never know the physical impact the line infection caused on top of that. The physical recovery was perhaps a bit slower because of the infection but we're not sure. I can definitely say there was an emotional impact for him with regards to needles and that was an ongoing impact. That was very apparent. Bribery with Lego mini figures wasn't going to cut it anymore.

HAIs: Communication

164. We felt that the communication surrounding the infection was adequate in terms of telling us what had happened to [redacted], but we weren't given any wider context. Dr Ronghe and Dr Inkster didn't explain that there was more than one issue with the hospital and when they said there were six children who got sick they didn't say that all of those children were sick with different bugs. We didn't know until we did the Case Note Review that, actually, [redacted] was the only one who had that particular bug. These six children all got sick from different things that came back to a water issue or a drain issue which, to me, means there's more of a problem. It wasn't just one bottle of Coke that everybody drank from and got sick. It was multiple points of contact. They also didn't explain to us the wider concern about the ventilation systems in 2A either. The first we knew

that there was an issue with the ventilation was when we were told, informally, by Angela that there was to be a retrofit of the ventilation system in 2A whilst it was closed. This was when we had already been decanted to 6A. We weren't told anything about what the issue was or why there needed to be a retrofit. They weren't upfront about any of it.

165. We were very, very surprised reading the case note review about the number of line infections that there were. It wasn't made clear to us how common it was. It wasn't made clear to us that for most children who get chemo, they will get a line infection at some point or most children who get chemo will get more than one-line infection. In fact, we're very lucky we only had one. That was quite scary that that was the norm, that it was normal for children to be in that state of ill health.

166. It's hard to quantify whether the issues with the water or the issues with the ventilation had a physical impact on [redacted]. Whenever we were spiking he was in a room that was 25 degrees but we'll never know if it would have been different if the building had worked. The water issue was there and we dealt with it. The ventilation issue, where the air conditioning wasn't working and the rooms were all really hot, was there and we dealt with it because ultimately the chemo was harder for us.

167. I think the issues with the hospital which led to the decant to ward 6A compromised [redacted]'s safety and care because the nurses were constantly having that extra level of anxiety, that extra level of hard work. They're already doing a very complicated job and then the ward as moved and they don't know where anything is. Their system that they had set up so brilliantly in 2A has suddenly disappeared because they don't know where the stuff was. The extra levels of cleaning that was going on always astounded us from the nurses. The nurses cleaned absolutely everything that they touched and used and then when they'd finished using it, they cleaned absolutely everything again. To have the extra

strain of all the building issues on top of them is something you can't quantify but it must have been something that wore them down. I would love to know the turnover of staff before the decant and after the decant because I'm sure there were a lot more leaving. It must be hard to retain staff through that. I'd say there was an extra level of anxiety for them all. They were the frontline for all the abuse from parents and also especially after the line infection stuff, their professionalism was getting questioned because if there's a line infection then it's the nurse that did it who is at fault. The nurses were getting questioned and their ability was getting questioned. To work with that level of anxiety on top of your job, that's unfair. It's unfair that they took the brunt of it when in actual fact it was the drains and it was the taps. Their protocols were robust.

OVERALL EMOTIONAL IMPACT ON [redacted] AND HIS FAMILY

Overall emotional impact on [redacted].

168. [redacted] became institutionalised. We all became institutionalised. He became isolated because he was in isolation all the time and after he'd finished treatment we really had to work hard to remind him how to play with other children because he spent time only with adults. That probably would have happened anyway, but not to the same extent because he wasn't even interacting with his peers on the ward once we moved to ward 6A. Had he been playing with other children on the ward then that would have made a big difference to him. The fact was, he had one-to-one attention from adults all the time and when treatment stopped we had to reverse all that, remind him that he's not the centre of the universe. I think this was a direct consequence of the decant to ward 6A where there were no facilities. We were just in isolation all the time and it wasn't just him; it was us as well. We were in isolation all the time because once we were moved to ward 6A there was no facilities for us to use or anywhere for us to socialise with any other parents. We weren't allowed

to go into other people's rooms so we were stuck in our room the whole time. We forgot how to interact with normal people.

169. There was also the issue of [redacted]'s fear of needles and that was really exacerbated by the experience he had when he had the line infection when several different doctors were trying to take blood from him unsuccessfully. We had to work really hard with him to get over that fear.

170. I think that the decant, the frequent moves, having to be in different wards and never really knowing where you were going to be if you came in for a spike had an effect on [redacted]. If nothing else, the impact on the family had an impact on him. That element of it was the bit that drained us. It wasn't the fact that [redacted] was getting chemo. It was the fact that we never knew where we were going and having to pack the bag ready for whatever eventuality, that was wearing on all of us. For him, he very much felt as though he was part of the Schiehallion family and the fact that he got to know the nurses so well and they knew him so well was a massive bonus to his treatment. So when he wasn't in that ward and it was people that didn't know him, that made it harder. It made it harder for him to be relaxed and comfortable.

Overall emotional impact on witness

171. The drip, drip, drip of not knowing where we were going to end up when we were admitted, especially after the ortho stay on ward 3C, and the anxiety about whether or not the nurses would be on it meant we didn't relax. We were like a cat on a hot tin roof whenever we were admitted. We had to clean the rooms and we didn't feel safe in the building when you're supposed to feel safe.

172. The rooms themselves in 6A weren't user-friendly at all. The furniture didn't fit. It was just harder at a time when you don't need anything to be harder. At the end of it, when [redacted] rang the bell at the end of his treatment I went to the GP and said, I'm supposed to be joyous but I'm just broken. I just don't want

to do it anymore. I'm still on medication. I'm still on anti-anxiety medication and still have issues. Any time we take him back to the hospital for scans, I find it really hard. "Scanxiety" is definitely real in our house and I don't know if it would have been as bad as this but I definitely know that the PTSD was because of the line infection scenario. That's what I kept reliving. That was the bit that I needed counselling for and it really was a stumbling block. So I'm still not back at work. Although I'm a full-time mum, I'm supposed to be job hunting right now and I'm doing anything to avoid it.

173. The charity, Jak's Den also helped me with counselling. I felt that I needed it as I kept reliving the incident with the line infection. It was readily available and they were advertising it, so I went in and asked and was in within 3 or 4 days. They were amazing.

Overall emotional impact on other members of the family

174. The girls, [redacted]s' sisters, were definitely impacted by the isolation. I loved watching and seeing photographs that people were sharing within the ward and within the unit of when their siblings would come to stay and come to visit. We just stopped taking the girls in because it was too hard because there wasn't a space that they could play easily because we were stuck in a hospital room in ward 6A and when we were in the other wards when there wasn't room in 6A.

175. Another issue was that we never knew what ward we were going into and it was easier to leave them at home. One of us took [redacted] and one of us stayed at home with the girls. Then, ultimately, rather than taking them into the building, because you never knew where in the building you were going to be, we would do car park swap overs. If Cameron took [redacted] in, then the next day he would come down, meet me in the car park, I'd give him the car keys with the two girls in the back and he would take them home and I would go in and be with [redacted]. This meant we were separated as a family for most of that treatment

time. We lived as two separate units and didn't do things as a family because there was always one of us with [redacted] and one of us with the girls. They missed him and missed playing with him and the wee one in particular barely knew him because she never saw him as he was always in the hospital. We didn't take them in to be in hospital because it was easier just to keep them at home.

176. I think it would have been different if all the treatment had taken place in ward 2A. We would have known the unit and the staff would have got to know them the same way that they did other families. When we first went in, there were families there and you got to know the siblings because they'd be playing but we couldn't do that when we were jumping about wards and 6A just was not set up for bringing the family in at all. There was nowhere for them to go. The play staff kit was at the bottom of a flight of stairs two buildings over so even to have the play staff come in and give them something to play with in the room, that wasn't feasible. Our emergency bag had stuff in it to entertain the girls. We took colouring pens and that kind of stuff for them and anything that would keep them contained in the space in the room. That was just so hard, so we just didn't bring them in. It was easier just to keep [redacted] isolated which meant he was on his own getting one-to-one adult attention and it ended up he got more and more plugged in to his games consoles. From having to Google how to switch on the PlayStation when we first went in, by the end of it we were asking for a PlayStation so he could sit and play it.

Support from Charities

177. There were several charities that supported us while [redacted] was getting treatment. CLIC Sargent was one of them. Cancer and Leukaemia in Children is what it stands for. Cancer and Leukaemia in Children merged with Sargent and that was named after the man that set it up. We'd never heard of them. But they fund the social workers, there's a social work team. So on our second day after [redacted] was first admitted, we were introduced to our CLIC Sargent social worker. They were then the person that did things like applying for disability for

[redacted], getting us a disabled car pass, getting us grants and things to support us while we were off work, care for [redacted], things like that. [redacted] was registered as disabled after three months of care, because you had to be in treatment for three months before that happens. He was registered as disabled and I was registered as a carer for him.

178. They also got things like grants from other children's cancer charities to do things. We would get passes to go to Blair Drummond for the day or things like that. And other charities were donating so they managed the distribution of a lot of that stuff. The social worker was the go-to for help that way, to support the family. She would come and visit us in the hospital, she'd come and visit us at home as well. Just to see how we were doing and see if we needed any help or support with anything. She would also do counselling for the children if we needed it. And she liaised with the school as well to support [redacted] when he was going back to school. Or to support the girls when they were going back to school.

179. We also had some support from charities like Team Hamish, Jak's Den, Love Oliver, Logan's Fund, Abbie's Sparkle Fund. But once the decant happened, a lot of that support disappeared. Jak's Den, for example, fund a music therapist to be in the ward. They're in the ward one day a week. When the decant happened, they weren't given access anymore so the music therapy stopped. [redacted] had been part of the music therapy programme. Jak's Den would do activities with the children. They weren't allowed in once the decant happened, so they couldn't go in and do activities with the children and things like that. Some of the support charities would send in stuff, like treats and sweets and toys and they were told to stop. The Christmas that we were in 6A, one of the other mothers started a bit of a campaign to get wee Christmas presents put together for the children that they knew already were going to be on the ward; that's the other thing, if you're in the ward, you can't go Christmas shopping. There was a bit of a pushback from the hospital charity because they

said they provided presents to the children, but they couldn’t as they weren’t allowed to come up to ward 6A. Even the clown doctors, who entertain the kids weren’t allowed in. They just shut the door saying, infection control, nobody’s allowed in.

180. Usually there would be visitors. For example, the charities would arrange for some footballers to come at Christmas time. There’s three or four days in one week where Celtic come one day, Rangers come one day, the rugby team come the next day, and they do the rounds, saying hello to all the children. They weren’t allowed into 6A. The charities also arrange for actors dressed up as Disney princesses to come in and they weren’t allowed in because the princesses wore gloves. They said they would take their gloves off and use hand sanitiser but it was just a “no”. The hospital wasn’t even willing to find ways around it, just we’ve been told access is off, that’s it. So things that would have meant a lot to the children on the ward, like getting a visit from Cinderella would have lifted their spirits, for Spiderman to come into the room would have lifted their spirits. They could go anywhere else in the hospital but they couldn’t go into Schiehallion in 6A.

181. There were other things that happened in the RHC that Schiehallion didn’t get to go to once the decant happened. In our first week in 6A there was a magic week run by the play team in the atrium in the children’s hospital and children that were able would go down and people would go up into the wards where children couldn’t go down. There was also the medi-cinema, that happens two nights a week where children are taken from their ward into the wee cinema that’s in the children’s hospital. Well, Schiehallion couldn’t go to those things because they were in another building and it meant that the children were excluded from lots of things. The reason given was Infection control, although I was never part of those conversations.

COMMUNICATION

The decants

182. We had no issues with the communication surrounding [redacted]'s treatment and we never felt that it was being compromised. There was maybe a bit less communication about where we were to go if we went in with a spike, but you really did feel that everybody was trying their best, especially when we were in the Schiehallion unit.

183. After the decant, we would phone in when [redacted] had a spike and they would tell us where we had to go. If it was out of hours we knew we were going to A&E. If it was within hours, we knew we were going to day care. And we would be told what ward day care was in. Then if Schiehallion was full then you'd be sitting in day care waiting or you'd be sitting in CDU waiting to then be transferred to wherever there was a bed. You were never told why there wasn't a bed, you were just told which ward you were going to instead. So the communication about the decants and why they were happening and what the background to all of that was wasn't really shared with us. We just took everything at face value.

Schiehallion Umbrella

184. If we had a negative experience in another ward, I would tell the nurses in Schiehallion about the complete contrast in care that [redacted] was receiving and they would roll their eyes and say "oh for goodness sake". They would encourage us to complain as they were telling us that it takes a parent to put in a complaint for something to be done.

185. We were never told that the Schiehallion protocols should be following us and, other than the nurses saying that it wasn't right, we didn't get anything official about it. It was only once we had had negative experiences that we started asking for particular things, like being in a VAC room and only drinking bottled water.

Remedial work

186. We weren't told anything about any of the remedial work that was going on in the hospital at the time it was happening. It was all just going on round about us and you almost felt as though you shouldn't ask. I didn't think it was my place to ask, why the big orange thing was on a bedroom door, or what was going on in the next room. It wasn't our place to question them and there was no information being volunteered.

187. The first time we got an in-depth explanation about what was happening was at the meeting at with the board in 2019 and the first time we got anything in writing concerning the impact of the issues with the building was when we got the Case Note Review.

Safety of the hospital

188. Throughout we were being told that everything was okay. When the issue with the fungus arose, the hospital was saying that the HEPA filters were there just as a precaution and saying, "it's fine, don't worry about it, it's only for the most vulnerable patients". But we were the most vulnerable patients. The hospital was downplaying the issues to us, so we were immediately downplaying it to my extended family. I was getting text messages from my sister who lives up north asking what was going on as she had seen stuff on the news about the pigeon droppings and we were telling her everything was fine as that is what we were being told. It was poor Angela in day care who was on the frontline of all of this communication because she was the one that was sent in to take the flak from all of us. It did get to the point where the parents were saying that it wasn't fair to send her. Where are the management? Where's the PR team? I think that was when the grumblings of all the parents got to the point where they couldn't ignore it anymore and that was at the point where there was the meeting with the Health Secretary and

then the meeting with the Board and then the Facebook group with Professor White was set up.

189. But that was only after parents really kicked up a fuss. Because we were hearing stories in the press about people dying unnecessarily and we didn't want our children to become one of those statistics.

190. Another issue that I never thought about at the time [redacted] was getting treatment was the proximity of the water treatment centre to the hospital. I was aware of the smell, but I didn't really think anything of it. Having spoken with some of the other parents I do now have concerns. At the meeting with the health board, the facilities manager spoke and told us that a new water filtration system was being put in. Why was this only being done? Does that mean the water wasn't safe when [redacted] was an inpatient? He also said that they didn't know how safe the water was as they hadn't been testing it. I think that was highlighted in the Case Note Review; why the water wasn't being tested. I am concerned that the issues with the water were caused by the water treatment facility being so close. If it is flooded, for example, does that then impact the supply of the water that goes to the hospital? I would still not drink the water if I was in the hospital now, in fact I think I would be even less likely to having heard all the stories from all the other parents.

Meetings

191. It was all kicking off on ward 6A among all the parents about the fungus and the fact that we weren't getting information from the hospital but were finding out from the BBC that something's going on. Parents were getting phone calls from reporters asking us to comment which we weren't happy about. One of the other parents, became a flagbearer and started calling for a public inquiry and saying that it was ridiculous the level of care that the kids are receiving at the time they should be getting the best care in the best hospital and it really wasn't.

192. In response to this, there was a meeting which the health secretary held in a hotel in Glasgow. I am not sure when this took place but it was after [redacted]'s treatment had finished so it was after April 2019. Speaking with the health secretary, you really did feel that she was shocked at the stories that everyone was sharing. The fact that then led onto there being a public inquiry validated our emotions and validated the fact that we were all feeling something ought to be done. So those meetings were very helpful.

193. After this meeting Professor Craig White was appointed to spearhead the Oversight Committee and he became our point of contact for communication. He would send us regular emails with updates. He also arranged for the meeting with the health board and we were all invited along to that. Again, I am not sure when that took place, I only know it was after [redacted] had finished his treatment in April 2019. There were maybe about 20 or 25 parents at this meeting. That was the first time we had met the Board and some of the things that were talked about were pretty surprising. I can only relay my own story and our own treatment story but some of the parents were very, very angry at the lack of communication and the lack of forewarning about what was happening and then finding out about it on the news. I think Craig White actually facilitated that meeting, he was there and it was after this the Facebook group was set up.

194. At this meeting we were given a break-down of what work was being done on ward 2A, and when it was expected to re-open. I did feel as though we all got a chance to speak and we were suggesting what needed to be changed and fixed. Members of the board which included the Nursing Director, the Chief Executive, the Clinical Director, and Professor Craig White, were frantically scribbling and reacting to what we were raising. I know that a couple of the things that I mentioned then, have been changed so it was worthwhile, having this meeting. One of the things I raised was, for three months after treatment,

you're still considered immunocompromised so there's certain protocols you have to follow, so if you're exposed to the chicken pox, you have to go and get an antiviral. So [redacted] had chicken pox exposure at school and I had to take him into day care and we had to walk the length of ward 6A to get to day care. It was the first time I had realised that he might be infectious and he was in a ward where there are people that could be infected. I raised that saying, that wasn't such a clever idea. I also raised the fact that there wasn't a playroom and there wasn't a parents' kitchen and these things were all then rectified which is great.

195. At both these meetings I raised the issue of the Schiehallion "umbrella" and how it wasn't fair that the care wasn't following us, and that extra level of anxiety that was put on the families could have easily been removed had that Schiehallion "umbrella" gone with us. There were then subsequent, regular meetings with the health board, but John Cuddihy attended those meetings as a representative for the parents. We could ask questions that he would ask at the meetings and then he would report back. I did ask questions through him and we did get answers, but I can't recall what those questions were.

CASE NOTE REVIEW

196. We were not involved in the Oversight Board that was set up, but [redacted] was one of the children who was involved in the Case Note Review. We received a copy of the report and it was quite substantial. I went at it with my wee yellow stickies and saw there was only one case of serratia marcescens, so I was guessing that it was [redacted], but I didn't know, so I sent the Review team an email asking them to confirm this and they sent us a specific report on [redacted], which then answered my questions and I did feel that it answered my questions fully. I was very surprised because one of the questions that I asked was, is it possible to be told if our son's case falls into the "highly likely caused by hospital environment" category? They said, we have answered this question above that, yes, [redacted] is in the group described as most likely to have been associated

with the environment. Really, that was me just looking for clarification for the purposes of the Public Inquiry so that we could say that [redacted]'s infection was caused by, or it is most likely to have been caused by the environment.

197. In the report they gave us there were a few errors in the information. It said that he went from surgery back to 2A and he didn't, he went to 3B. So we requested a meeting with the Review Team and that meeting was very informative because we were speaking to a consultant, Professor Michael Stevens, whose background was tumours and he actually worked with Dr Ronghe. He was able to answer questions about why [redacted] had gone back to a surgical ward and not Schiehallion. He said he was in surgery for the surgical management of the wound, rather than for line infection management and that is the protocol for that procedure. That's what happens in every hospital so it wasn't just Glasgow specific. So that was really helpful to have that background. They then followed up with another email, dated 10 May 2021 answering and commenting on the questions that we talked about in that one-to-one with them. Really, the upshot, again, was the umbrella of Schiehallion and how we felt that it didn't follow us into surgery. I don't know if there have been any changes made as a result of the issues we raised, but Professor Stevens said they would feed it back.

198. We were satisfied with the Case Note Review and felt it answered all of our questions. I'm not aware that there have been any changes as a result of [redacted]'s review, but in our conversation the team alluded to the fact that they would be making recommendations based on [redacted]'s case where antibiotics weren't given in a timely fashion and they should be, so that has to be part of the protocol. They have to make sure that there's enough staff trained in Hickman lines and port-a-caths because that was a failing for [redacted] that he had to wait for somebody that knew how to do it. They also said there has to be better training for the staff to deal with the children that are presented to them and that the umbrella should travel with the children.

FACEBOOK GROUP

199. By this I mean a Facebook page which was freely advertised on the ward as a means of parents communicating with each other and supporting each other. This was a parent-only group. You quite often get questions like, “what’s the number for day care again?”, and “my child’s got this symptom, is something I should be phoning about?”. It was a way of getting a bit of reassurance. This was a closed group and no doctors or anyone from the hospital had access. It was different to the Facebook Group that was set up by Professor White and run by the NHS. I did use that when it was established. All the parents were invited to be part of it. It was used to disperse information about the Case Note Review and the fact that the public inquiry was on the horizon. This Facebook Group started once we had finished [redacted]’s treatment.

200. I was aware of the Oversight Board and I know that Professor Cuddihy was representing us at that and he would put feedback through the NHS Facebook page of meetings he’d been attending and minutes of the meetings and recommendations that he was making on our behalf. He seems to be a very good spokesman and we could send him questions to ask, which we did do. I can’t remember what our questions were, but I do know that they were answered and Professor Cuddihy provided very eloquent reports of what happened at these meetings.

CONCLUDING COMMENTS

201. I think, now, if [redacted] were to relapse and we went back into the hospital, I think I would have a bit more confidence than I had two years ago because of this process. I feel that we have been listened to and that there have been changes made. I feel that we are better educated to be able to go in and say, “no, that’s not acceptable”. I would be more of a “gobby” parent if I was back in again which is not my personality.

202. The anxiety that we have of [redacted] relapsing is always going to be there, I think. When we finished treatment there was very much an element of, “oh, God, I really don’t want him to end up back in here” and if he ended up relapsing, would we want to go to Edinburgh because we really didn’t have confidence in Glasgow anymore, especially having heard all of the other horror stories. I thought ours was an isolated case. I still had faith in the system but when I read the Case Note Review and spoke to a lot of the other parents in the meetings it was horrific that these families were having to suffer because the building was broken. Meanwhile, the hospital is being held up as a wonderful flagship, yet it’s rubbish. The fact that whenever there’s any fundraising happening for any of the hospital charities, there’s a wee bald-headed child that draws the money but that money’s not getting spent on the wee bald-headed children, that is a kick to the teeth. Once the decant happened, the Schiehallion kids were not getting the benefit of any of the money raised by the charities as they were not allowed to come on to ward 6A. They are the ones who should be getting the diamond service because the treatment that they’re going through is horrific, but it felt like they were the poor relations who were not getting the same input from these charities as the children who were still in the RHC were getting.

203. I got a bit of a shock when I was talking to my dad about the hospital because my dad is the meekest man you’ve ever met. He is a retired carpenter who has built and worked on many a building site, many a house build. He got so angry about what was allowed to happen in the hospital. He said it was ridiculous that the shower was allowed to leak all over the floor and why had the clerk of works not come in and said it wasn’t up to standard at the time before the hospital opened? That would never have been acceptable, but now it is acceptable and the company that built the hospital will be into receivership and nobody will have to foot the bill? His view was that, even if a finding by the Public Inquiry says that the hospital was at fault or the builders were at fault, nobody’ll pay for it because it’s the way that it works now. Substandard is

acceptable now. It shocked me to hear my dad being so cynical because he's not like that at all. It does worry me that the board of directors went home and slept fine in their beds, not worried about what was happening. One of the questions one of the parents asked of the chair of the board was, "if your grandchildren were sick, would you bring them here?". They said that, of course they would, but really, them knowing all that they know, that we have not been party to, I'm not sure they would. The hospital is not a safe space to be in and that's the worrying bit, that the kids were safer at home and yet when they were spiking, we had to take them in.

204. I do have ongoing concerns about the safety of the hospital. [redacted] had to go in about seven months after [redacted] finished his treatment [redacted] and it was hard work. It was hard being in with her and taking her in and also taking her in and not being a Schiehallion patient because she didn't get a room to herself. She didn't get the same level of diamond care, and that was really hard because I was sitting with a critical eye on everything. I was cleaning everything around her and being the manic, cleaning mother because at that point I really didn't feel that the hospital was up to standard. I was really concerned taking her in for something as simple as that and she's a very healthy child, not immunocompromised at all but we just wanted to get her out of there as quickly as possible. I became a bit OCD. I didn't let her drink the water, I didn't let her got to the playroom. I didn't trust infection control and I just kept her isolated as best I could.

205. I don't know if is there anything that the hospital could do to address my concerns because when we were in it we just accepted and trusted them because we had to trust them and I think it's a good thing that the parents weren't able to talk to each other on the ward because we riled each other up a bit. There were some more vocal parents than others and I was very grounded in the fact that [redacted] got through it and he is well. He got through the line infection. We got a good outcome and it was only in all the meetings we

had that we then realised he could so easily have not had a good outcome we met the parents that have lost children and saw their anger. Having those meetings feeds that anxiety.

206. But I do think that the families forcing the board to have meetings, which then led to the Facebook group, has had made the board communicate better with the families. It is forcing them to be more transparent. Although I think COVID has been a catch-all for any failings that have happened in the last year. It’s a nice wee peg they can hang everything on just now. But when it comes to questions about whether the water is safe, that’s frightening. Will it ever be safe because of where it is sitting, because of the position of the hospital compared to the water treatment? Have they put a better cleansing unit in? Have they put better facilities in to keep it safe? We have to trust that they have but ultimately until something goes wrong we won’t know about it because they haven’t been transparent. It is only because of everything which has come out that they are being forced to be more transparent.

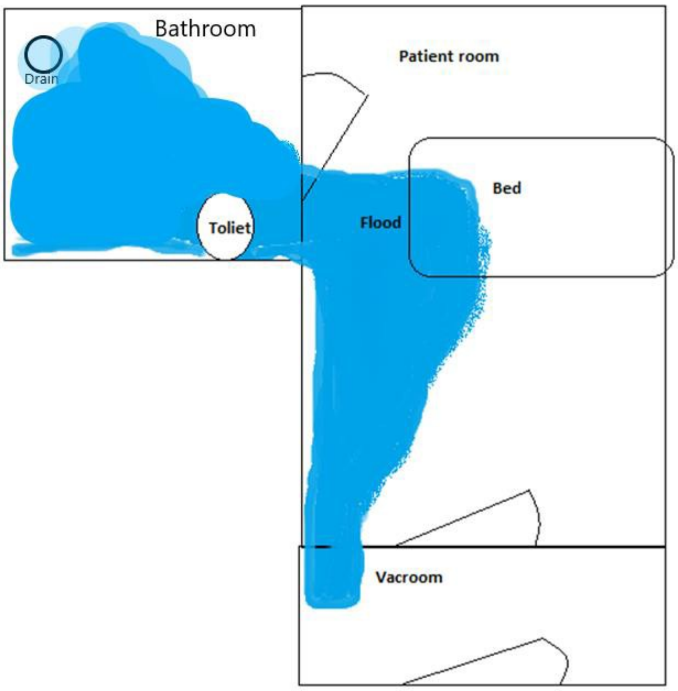
207. I believe that the facts stated in this witness statement are true. I understand that this statement may form part of the evidence before the Inquiry and be published on the Inquiry's website.

CG/01 – Appendix 1

[redacted]’s Illness TimeLine

2018

- 04/07 Discoloured Urine – thought from eating beetroot
- 05/07 Blood in urine – Alnwick out of hours – Antibiotics given and urine culture taken
- 09/07 Phone Alnwick GP – Culture clear advised to follow up with own GP
- 13/07 Urine sample to our GP and 2nd antibiotics given with bloods booked for Monday
- 16/07 Bloods taken, Urine cultures clear.
- 17/07 Bloods showed anaemia – scan and renal referral made.
- 24/07 Blood in urine more prevalent (now scarlet)
- 25/07 GP call – Scan date is booked - nothing more can be done until scan appointment
- 29/07 Bumped abdomen while playing and went green, low appetite for the rest of the day then vomiting through night.
- 30/07 SCAN RAH : Scan revealed mass on kidney – referred straight to oncology. MRI confirms Kidney tumour, Wilms. Dr Ronghe now on board. Tumour 12cmx8cmx8cm. Admitted via CDU to Ward 2A room 10
- 31/07 CT and X ray confirms containment in the Kidney area. Plan to start Chemo asap.
- 01/08 Surgery to fit Hickman Line
- 02/08 Chemotherapy protocol started, Vincristine (Vinc) and Actinomycin
- 08/08 Discharged
- 09/08 Day care 2B - Chemo, Vinc
- 10/08 Spike re-admitted to 2A room 10 via CDU
- 13/08 Discharged
- 16/08 Day care 2B - Chemo, Vinc and Actinomycin
- 20/08 Day care presented with a black tongue – told to monitor.
- 23/08 Day care 2B - Chemo, Vinc
- 24/08 Spike admitted through Day care 2B to Ward 2A room 2? Our first Vac Room also first room where air con actually worked. Went into rigor for first time, and we were communicated how serious his was, Nurse Kat waited outside with meds to get best overlap.
- 26/08 Showered in room and flooded the room as drains did not function properly. Water pooled along wall, under toilet, into room, and out into vacroom. Reported to staff – response was eyes rolled “yes loads of the drains are dodgy”



- 27/08 Discharged
- 30/08 Day care 2B – Chemo, Vinc
- 03/09 Day care 2B - Blood work and pre- surgery meeting with anaesthetist and surgeon Ms Brinley.
  3.30 at surgical ward 3B for admission. Room not ready so had to wait in playroom until room was ready.We cleaned the surfaces down and on lifting the bed guard found it to be covered in brown/red dried matter. Not sure if blood, faecal matter or chemicals from operation. Bed was replaced. Not in room appropriate for immunocompromised patient i.e. protocol/procedures is for vac room. No filters on taps. Also different general failing of protocols i.e. reduced cleaning regime/dirty; all play equipment/areas accessible to everyone and not just patients (also cleaning of play area and equipment not as stringent) therefore unable to access these spaces/facilities due to risk of infection. Patient care different to chemo wards. Chemo wards do not have yr1 (1st year doctors) as these doctors do not have the experience and practical skill necessary for care of chemo kids. In both prep and post-surgical we had YR1 doctors.
- 04/09 Surgery. Kidney and tumour removed then into PICU
- 05/09 Temp spike through night – line infection suspected and antibiotics started.Transferred back to 3B – no vac seal doors, no water filters, yr1 doctors, different cleaning protocols for rooms as described above
  [redacted] had epidural still in place, morphine via PCA, and was on regular doses of antibiotics.
- 06/09 Line infection confirmed Serratia Marcesens Blood drawn via the line at 11.45. Emla cream applied to hands and feet to get peripheral bloods. (this is usually left for 30- 60mins to work) 40 mins later toxic shock. Taccacrdic (heart exceeding 200bpm); temp spike, rigor, vomiting. Had to go to front desk

for help as no one around. Two YR1 docs arrived to help. – tried to get the peripheral draw. [redacted] very distressed by this point.
The nurses on the chemo ward would meticulously inspect the site and find the vein before applying the anaesthetic then come back later to take the blood – so they knew where to look. This YR1 doctor just put 4 patches on and came back later and started jagging. After multiple attempts to get the blood they stopped trying. This left [redacted] with a real aversion/fear of needles, which required extensive work with the play team to reduce the impacts to a point that they could use a needle without me having to physically restrain him. Additional nurses also in the room. Colette Panic – had to leave.
Dr Hettle – surgeon on call arrived and the room calmed. Line was ordered out of bounds. He got the blood draw first time while calmly talking with about dinosaurs. Antibiotics were pushed, bolus was started and after an hour things settled down.

- 07/09 Visit from Dr Ronghe. Microbiology advise to place an antibiotic block in line (which required accessing it). In conversation with Dr Hettle, I raised concern this should not happen late afternoon on a Friday due to people leaving the building if care required. Dr Hettle agreed – not on a Friday afternoon 16.10 block put in. 40 min later toxic shock again due to toxic shower from line. Same symptoms as before. Duty docs call in Dr Kamal – jnr surgeon starts a bolus and gives ibuprofen to help manage temp. Consulting doctor from A and E (also on infection control) called in said “it’s a poo bug”. Wendy and Jane,Nurse Practicioners from schiehallion, arrive and advise no more ibuprofen due to the dangers of ibuprofen for chemo-kids. Takes 90 min to stabilise, Kamal considers readmitting to PICU. Dr Hettle arrives (who had been in surgery) and makes plan to pull line.
- 08/09 Surgery Line out. Visit from Mr Davis Head surgeon on rounds. [redacted]’s skin has become inflamed and itchy around the entire surgical site. Dermatology referral made
- 13/09 Discharged
- 17/09 Day care 2B Meeting with Dr Ronghe and Dr Inkster (infection control). Apologised for line infection and they confirmed it was hospital acquired and should not have happened, and it came from drains. I made light of the issue saying that compared to what he went through in surgery this was not our biggest concern. The response to which was that the infection was the most concerning thing that happened during [redacted]’s stay. Not the removal of a kidney, or removal of a cancerous growth, or stay in ICU.
- They confirmed one of six children ill at same time, part of ongoing issue with water system and they are planning to close ward
- 19/09 Day care 2B antibiotics for sore on [redacted].
- 20/09 Day care 2B Chemo, Vinc via cannula. Had to be pinned down and restrained by mum, dad and two nurses.
- 21/09 Spike admitted via 2B into ward 2A room 10 – all treatment via cannula and had to be pinned down again.
- 24/09 Discharged
- 26/09 Admission ward 1A Surgery - port fitted

Transfer to 6A – adult ward 'New Schiehallion' with no facilities, fold down adult bed, no play room, no play team, no facilities for adults to get food/drink bar bottled water (Scheihallion had parents room with fridge, freezer, kettle and microwave). It was like going into full isolation with no contact/support from other patients, carers or play team.
Not having general facilities like proper bed, access to kitchen, etc made a difficult experience much worse for the carer, you can't just leave a child to go and get a hot drink if it takes you 40 minutes.
We travelled with insulated picnic bags with ice blocks to keep snacks cool, thermos flasks, snack noodles etc.

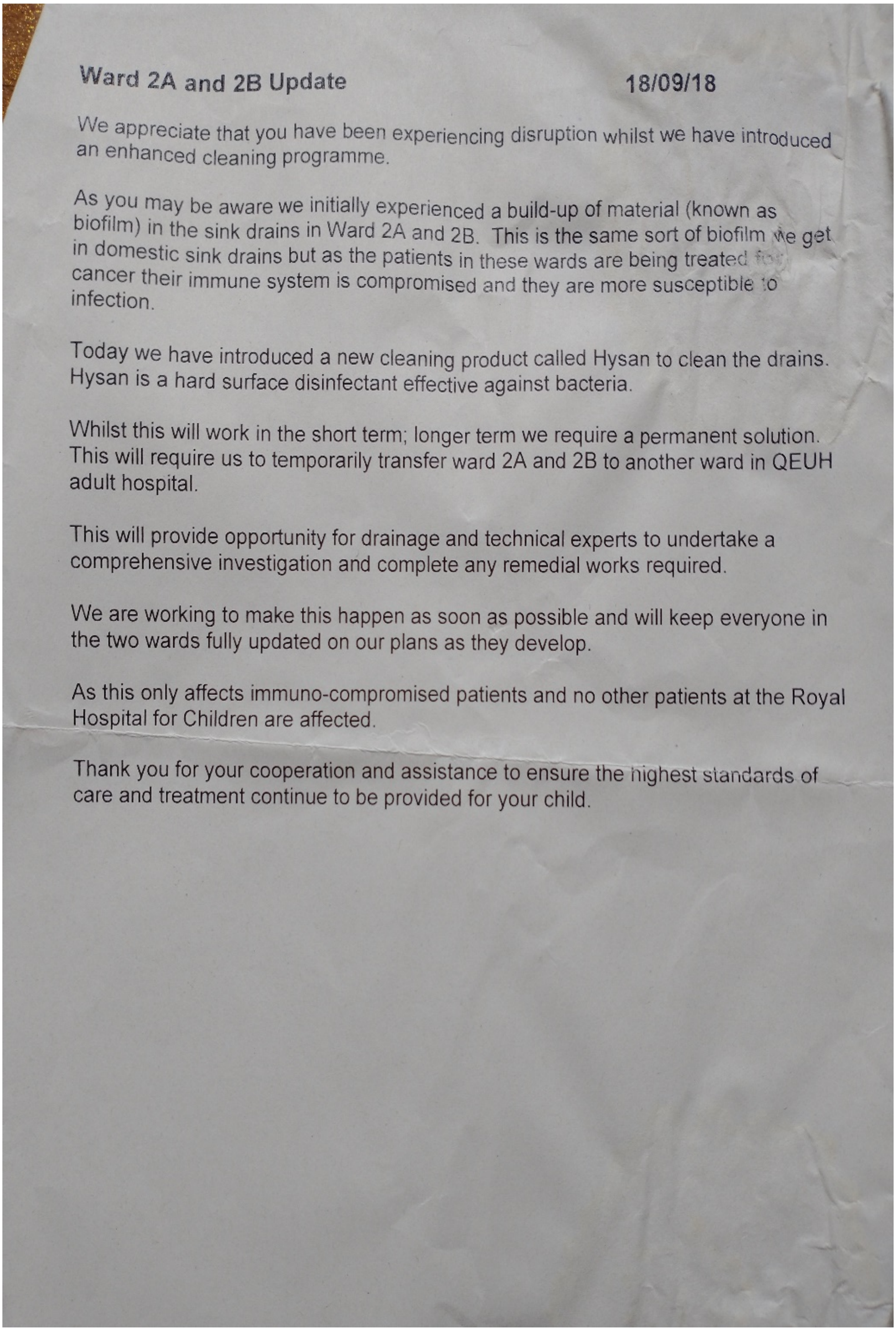
- 27/09 Chemo Vinc and Actinomycin and discharge
- 01/10 Day care 6A infection neck wound site – given cream
- 04/10 Day care 6A chemo Vinc
- 05/10 Spike admitted to 6A via CDU room 4
- 07/10 Discharged
- 08/10 Spike admitted to 6A via day care room 21
- 11/10 Chemo Vinc, transfusion and discharge
- 13/10 Spike admitted to 6A via CDU room 23
- 16/10 Discharged
- 18/10 Day care 6A- Chemo Vinc and Actinomycin
- 25/10 Day care 6A- Chemo Vinc
- 1/11 Day care 6A- Chemo Vinc
- 8/11 Day care 6A- Chemo Vinc and Actinomycin
- 13/11 Spike 2E (cardio) admitted via Day care 6A
- 22/11 Day care 6A – bloods and dressing check
- 06/12 Day care 6A - Chemo Vinc. Sciehallion confirm decant for another year X-ray and ultrasound.
- 07/12 Spike admitted via CDU to 3C Orthopaedics. 5 failed attempts to get port access. Cannula fitted to allow antibiotics to start. It was not until one of oncology Day care's excellent nurses saw [redacted] that they could get line in. While struggling to get line in this was raising concerns with us in case of line infection like previously rather than standard chemo temperature spike. Very poor care in orthopaedics (especially considering heightened concerns due to issues accessing line). Failure to do observations at correct times, failure to respond to temperature spikes in timely manner (let's not forget his last line infection in 40 minute he went from ok to a room full of consultants discussing if he should be going to PICU), failure to administer medicine at correct timings causing discomfort and distress to the patient, and general lack of interest by the nursing staff (too busy standing round the nursing station chatting about the Christmas night out). I put in a complaint due to my concerns
- 09/12 Discharged
- 10/12 Dermatology – skin reaction to dressing a very difficult visit with being uncooperative due to the trauma of most recent stay. Wouldn't let Doc examine him, didn't want to be touched, poked or prodded.

- 11/12 Day care 6A sore [redacted] again therefore antibiotics
- 20/12 Day care 6A - Chemo Vinc and Actinomycin
- 27/12 Day care 6A – Chemo, Vinc
- 28/12 spike- admitted 6A
- 31/12 Discharged

2019

- 10/01 Day care 6A Chemo, Vinc and Actinomycin
- 17/01 Day care 6A Chemo, Vinc
  Spike admitted 6A via Day care
  Fungal issue on ward had been identified now HEPA filter installed in corridors and every room
- 19/01 Transferred with ward to CDU rm 19
- 20/01 Discharged
- 31/01 Day care 1A Chemo, Vinc and Actinomycin
- 1/02 Spike admitted via Day care 1A into CDU rm 19
- 4/02 Discharged
- 7/02 Day care 1A Chemo, Vinc
- 9/02 Spike admitted via 2A (temp CDU) to CDU
- 12/02 Discharged
- 14/02 ENT follow up appointment
- 21/02 Day care 6A Chemo, Vinc and Actinomycin
- 27/02 Spike admitted via Day care 6A
- 3/03 Discharged
- 4/03 Day care 6A Chemo, Vinc
- 15/03 Dermatology
- 18/03 Day care 6A Chemo, Vinc and Actinomycin
- 24/03 Admitted 6A sore [redacted].
- 25/03 Chemo Vinc – last dose
- 26/03 Spike admitted via Day care to 3C
- 27/03 Ultrasound and x-ray
- 29/03 Discharged
- 4/04 Day care Dr Ronghe meeting
- 8/04 Day Surgery 1A port removal surgery
- Date not noted May/Jun – Day care visit – chickenpox exposure – had to walk length of ward 6A to access Day care. Raised potential infection risk at hospital board meeting.

CG/02 – Appendix 2



Ward 2A and 2B Update 18/09/18

We appreciate that you have been experiencing disruption whilst we have introduced an enhanced cleaning programme.

As you may be aware we initially experienced a build-up of material (known as biofilm) in the sink drains in Ward 2A and 2B. This is the same sort of biofilm we get in domestic sink drains but as the patients in these wards are being treated for cancer their immune system is compromised and they are more susceptible to infection.

Today we have introduced a new cleaning product called Hysan to clean the drains. Hysan is a hard surface disinfectant effective against bacteria.

Whilst this will work in the short term; longer term we require a permanent solution. This will require us to temporarily transfer ward 2A and 2B to another ward in QEUH adult hospital.

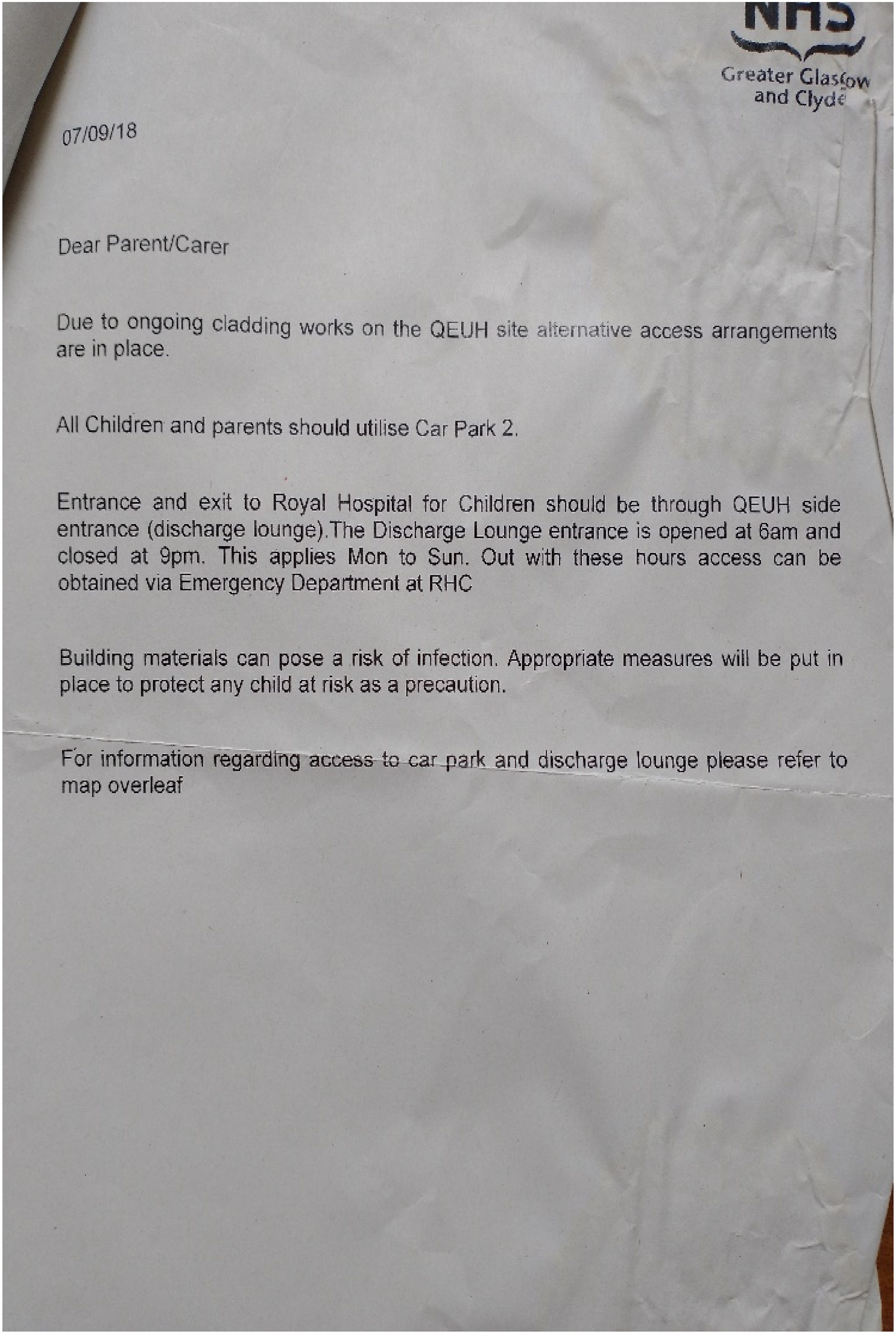
This will provide opportunity for drainage and technical experts to undertake a comprehensive investigation and complete any remedial works required.

We are working to make this happen as soon as possible and will keep everyone in the two wards fully updated on our plans as they develop.

As this only affects immuno-compromised patients and no other patients at the Royal Hospital for Children are affected.

Thank you for your cooperation and assistance to ensure the highest standards of care and treatment continue to be provided for your child.

CG/03 - Appendix 3
Part 1



NHS
Greater Glasgow
and Clyde

07/09/18

Dear Parent/Carer

Due to ongoing cladding works on the QEUH site alternative access arrangements are in place.

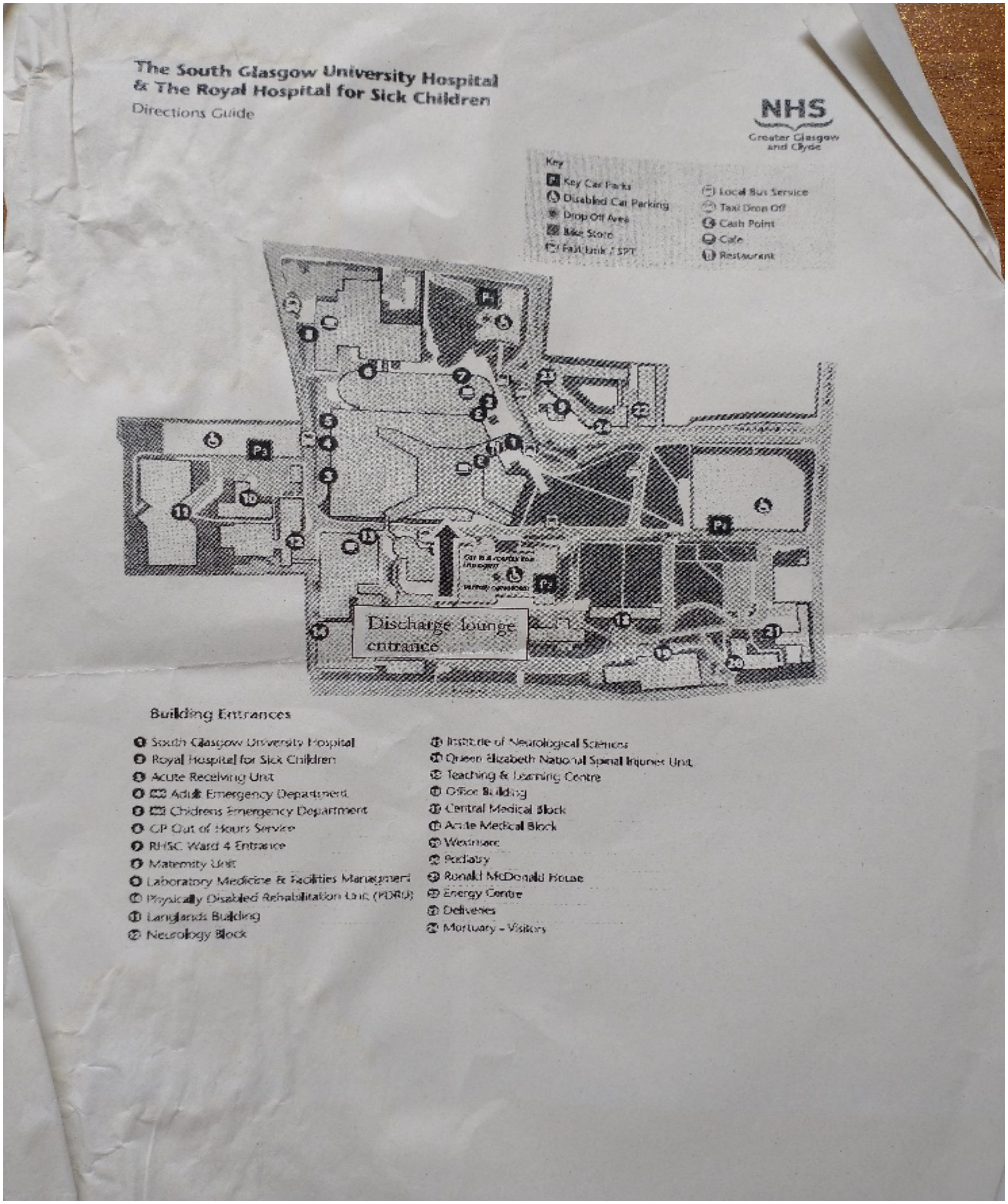
All Children and parents should utilise Car Park 2.

Entrance and exit to Royal Hospital for Children should be through QEUH side entrance (discharge lounge).The Discharge Lounge entrance is opened at 6am and closed at 9pm. This applies Mon to Sun. Out with these hours access can be obtained via Emergency Department at RHC

Building materials can pose a risk of infection. Appropriate measures will be put in place to protect any child at risk as a precaution.

For information regarding access to car park and discharge lounge please refer to map overleaf

CG/03 – Appendix 3
Part 2



The South Glasgow University Hospital
& The Royal Hospital for Sick Children
Directions Guide

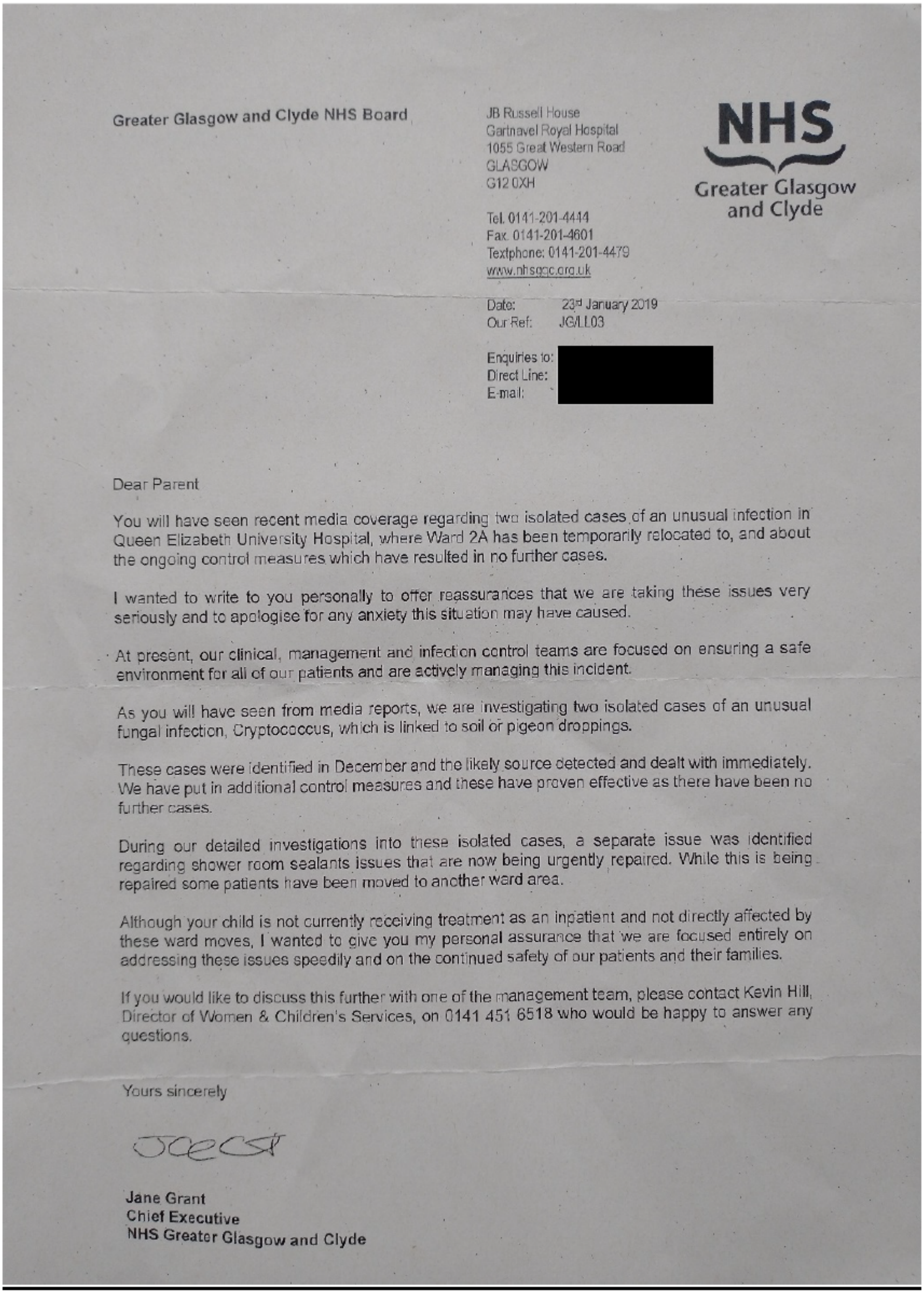
NHS
Greater Glasgow and Clyde

Key
- Key Car Parks
- Disabled Car Parking
- Drop Off Area
- Bike Store
- Fastlink / SPT
- Local Bus Service
- Taxi Drop Off
- Cash Point
- Cafe
- Restaurant

Building Entrances

① South Glasgow University Hospital
② Royal Hospital for Sick Children
③ Acute Receiving Unit
④ Adult Emergency Department
⑤ Childrens Emergency Department
⑥ GP Out of Hours Service
⑦ RHSC Ward 4 Entrance
⑧ Maternity Unit
⑨ Laboratory Medicine & Facilities Management
⑩ Physically Disabled Rehabilitation Unit (PDRU)
⑪ Langlands Building
⑫ Neurology Block
⑬ Institute of Neurological Sciences
⑭ Queen Elizabeth National Spinal Injuries Unit
⑮ Teaching & Learning Centre
⑯ Office Building
⑰ Central Medical Block
⑱ Acute Medical Block
⑲ Westmarc
⑳ Podiatry
㉑ Ronald McDonald House
㉒ Energy Centre
㉓ Deliveries
㉔ Mortuary – Visitors

CG/04 – Appendix 4



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NHS
Greater Glasgow and Clyde

Date: 23rd January 2019
Our Ref: JG/LL03

Enquiries to: [redacted]
Direct Line:
E-mail:

Dear Parent

You will have seen recent media coverage regarding two isolated cases of an unusual infection in Queen Elizabeth University Hospital, where Ward 2A has been temporarily relocated to, and about the ongoing control measures which have resulted in no further cases.

I wanted to write to you personally to offer reassurances that we are taking these issues very seriously and to apologise for any anxiety this situation may have caused.

At present, our clinical, management and infection control teams are focused on ensuring a safe environment for all of our patients and are actively managing this incident.

As you will have seen from media reports, we are investigating two isolated cases of an unusual fungal infection, Cryptococcus, which is linked to soil or pigeon droppings.

These cases were identified in December and the likely source detected and dealt with immediately. We have put in additional control measures and these have proven effective as there have been no further cases.

During our detailed investigations into these isolated cases, a separate issue was identified regarding shower room sealants issues that are now being urgently repaired. While this is being repaired some patients have been moved to another ward area.

Although your child is not currently receiving treatment as an inpatient and not directly affected by these ward moves, I wanted to give you my personal assurance that we are focused entirely on addressing these issues speedily and on the continued safety of our patients and their families.

If you would like to discuss this further with one of the management team, please contact Kevin Hill, Director of Women & Children's Services, on 0141 451 6518 who would be happy to answer any questions.

Yours sincerely

Jane Grant
Chief Executive
NHS Greater Glasgow and Clyde

Scottish Hospitals Inquiry

Witness Statement of

Lynn Kearns

WITNESS DETAILS

1. My name is Lynn Kearns. I was born on [redacted]. I am [redacted] years old. I work as an [redacted].

2. I am the mother of [redacted]. [redacted]'s date of birth is [redacted]. He is 15 years old.

3. I live with my husband, [redacted], and my two children, [redacted] and [redacted], in [redacted].

OVERVIEW

4. My son is [redacted]. In December 2017, when [redacted] was 11 years old, he had some blood tests which raised the suspicion that he had leukaemia and, after further tests, in January 2018 he was diagnosed with Aplastic Anaemia, a rare blood disorder. [redacted] was treated in the Royal Hospital for Children (RHC) between December 2017 and March 2018 when he finished his treatment. He attended the hospital as an inpatient and as an outpatient. He still attends the Haematology Clinic as an outpatient every 2 months and has his bloods checked monthly.

5. [redacted] spent time in wards 2A and 2B of the RHC which are known as the Schiehallion Unit. This is the oncology unit. My husband [redacted] and I were with [redacted] throughout his admissions and I can speak of or about the experience [redacted] and I had on these wards.

6. I will come on to talk about some specific events in the hospital which affected our experience. There were issues with the water throughout [redacted]'s

time in the Schiehallion Unit that significantly impacted [redacted]'s experience and there were also issues with other amenities like the air conditioning in the rooms and the facilities in the ward.

FAMILY BACKGROUND

7. I live with my husband [redacted] and our children, [redacted] and his sister [redacted], at our family home in [redacted]. [redacted] is [redacted] years younger than [redacted] and they are very close.

8. [redacted] is a very mature boy. He loves sports and was in [redacted] Running Club. He liked playing football and his passion in the summer of 2017 was scootering. He was always down at the skate park doing his flips and tricks on his scooter and he was very good at it. He actually made a scooter himself with a foam base that let him practice some of his stunts on a trampoline to save him getting hurt if he fell. [redacted] often had bumps and bruises because of all of his activities like his scootering and his football.

9. Other than when he was an in-patient in the hospital, [redacted] rarely missed school. He loves school, maybe apart from Primary 7, when he didn't like his teacher so much, but he was very sporty, was in the Scouts and loved doing different things like canoeing and climbing. He had been looking forward to the Primary 7 School Camp for many years, but sadly he had to miss it because of his treatment.

EVENTS LEADING TO [redacted]'S INITIAL VISITS TO HIS DOCTOR – NOVEMBER/DECEMBER 2017

10. One day in November 2017, [redacted] was at school, when he banged into a glass door and gave himself a very sore bump on his head. After this, he complained about headaches and alarm bells started to ring for me. He

was still going to school but with his other bruises that I'd just put down to his physical activities, I thought I'd get him checked out just in case and I took him to the doctor.

11. The doctor suggested it was probably just a virus and said we should give it a week or so and see how he was. But [redacted] still had the bruises after this time and I also noticed that he had some little rashes which I now know are called petechiae, to do with the blood and which can be a sign of leukaemia. I took [redacted] back to the doctor and they said they'd arrange blood tests. We had also noticed that [redacted]'s pallor was very yellowy, with black circles under his eyes.

12. [redacted] was continuing his running and scootering and was still very active, but he mentioned a few times that he was getting breathless, which was not like him. We didn't read too much into it but my husband took him to the doctor for the blood tests on Monday 4 December 2017. I remember the date as my[redacted]was the day before and we had all done a charity Santa Dash[redacted] [redacted] had been a bit reluctant to do the Santa Dash because he hadn't been feeling great, but he managed the run ok.

13. So the day after the Santa Dash, [redacted] took [redacted] back to the doctor for the blood test appointment. They struggled to get blood from [redacted] but put it down to how cold and frosty the weather was that day. I understand that it can be more difficult to take blood if the body is cold. They said that [redacted] should pop [redacted] over to the Sick Kids hospital where they'd be able to take the blood more easily.

INITIAL CONTACT WITH THE RHC– DECEMBER 2017

14. [redacted] took [redacted] to the RHC straight from the doctor on 4 December 2017. [redacted] phoned me at my work to say that they were giving [redacted] a

really good MOT but that [redacted] was quite happy and playing on his iPad. Then [redacted] phoned me when I was at the gym that lunchtime and said I should head to the hospital as they thought [redacted] might have leukaemia.

15. I shot over to the hospital and remember dumping my car outside A&E as I wasn't familiar with the hospital. [redacted] was in a room in A&E with [redacted]. They took me into another wee room with a Consultant, and she said "We're 90% certain it's leukaemia". We didn't want to worry [redacted] so I was trying to stay upbeat but he knew there was something wrong and we told him he had to be admitted as there was something wrong with his bloods. We didn't say what it was, just that he'd need to get some tests.

16. I have since found a letter that says [redacted]'s platelets on admission were at 5, which is virtually zero, his neutrophils, which fight infection, were at 0.2 and his haemoglobin was at 50 when it should be up at 200 or that kind of level.

17. We were moved to the Oncology Ward, 2A, which is part of the Schiehallion Unit. Ward 2A is a long corridor, in a kind of U shape, with individual rooms off the corridor at both sides. The nurses' station was at the far end as you entered the ward. There were some rooms behind the nurses' station as well. [redacted] was put into an individual room near the entrance. Of course [redacted], not being silly, saw some of the kids in the ward with no hair and said "Mum, is this the cancer ward?" I said it was and he said "Have I got cancer, am I going to die?" We reassured him as best we could and I know that the success rate for treating children's leukaemia these days is amazing.

18. [redacted] and I were taken into a room on our own and told that the next day [redacted] would go for a bone marrow biopsy. By this point [redacted] was getting blood and platelets transfusions and he had been fitted with a cannula.

19. That was an awful night. [redacted] was in tears thinking he was going to die, I was in tears and it was tough.

20. The next morning, 5 December 2017, the surgeons gave [redacted] the bone marrow biopsy. This was done under general anaesthetic. In the late afternoon, [redacted] and I were taken into another room again, where the staff told us that it wasn't leukaemia, that the bone marrow had no abnormal cells to indicate leukaemia and that basically it was empty, which was strange and not something they had seen before. [redacted] was not diagnosed with Aplastic Anaemia at that time. Apparently a diagnosis of Aplastic Anaemia (which was eventually diagnosed) is pretty rare and it was seven years previously that they had last treated it in Glasgow, so it wasn't mentioned at this time. This was another issue for us, as we were never quite sure how [redacted]'s treatment would go. The hospital had Professor Gibson as the big specialist for leukaemia, but they didn't have a specialist on [redacted]'s condition.

21. [redacted] got his transfusions but the staff couldn't do much more as they still didn't really know what they were treating at that stage. The transfusions were to increase [redacted]'s platelets. With his blood count back up, [redacted]'s consultant ,Dr Chalmers, decided there was no need to keep [redacted] in, so he was discharged on Wednesday 6 December 2017, two days after the admission.

22. After this, [redacted] was being monitored to check the level of his platelets, so we were back at the hospital every couple of days, in Ward 2B, day care, for bloods to be taken and twice weekly blood transfusions. I counted more than 100 visits to the hospital in total.

23. That continued until 23 December 2017 when [redacted] took [redacted] over to the hospital for a routine transfusion but [redacted] had a temperature spike, which the nurses always took very seriously because the spike could

indicate infection and [redacted]'s condition left him less able to fight infection. The hospital decided to keep him in because of this, which was a blow because we'd been hoping for as normal a Christmas as possible, as much for [redacted]'s sister [redacted], and it wasn't clear how long he'd be in. So they pumped [redacted] full of antibiotics, I can't recall which ones, and at 5pm on Christmas Eve he was released as his temperature had come down again. But the poor soul was pretty much zonked on Christmas Day with the effects of the antibiotics and because he wouldn't have slept properly in hospital.

DIAGNOSIS OF APLASTIC ANAEMIA – JANUARY 2018

24. Between Christmas and New Year, we were back and forward to ward 2B for the usual blood and platelet transfusions every couple of days, Dr Chalmers, the consultant, started other tests as they needed to know the cause of[redacted]'s condition and I remember Dr Chalmers mentioning Aplastic Anaemia. Of course I was straight on to the web when I got home to find out what this was and I saw that it's potentially life threatening, not directly from the condition but because the body can't fight any infections it picks up. I discovered there was an Aplastic Anaemia Trust that gave lots of information. After various other blood tests, and analyses carried out in a different part of the UK, they eventually confirmed the diagnosis of Aplastic Anaemia in mid-January 2018.

25. When we got the diagnosis, we were told by Dr Chalmers that the treatment is either a bone marrow transplant or ATG therapy. A bone marrow transplant should be a cure as you are completely replacing the cells in the bone marrow. ATG is anti-thymocyte globulin and it's just a treatment that suppresses the immunity to allow [redacted]'s own bone marrow cells to work for themselves again. There's two different types of ATG, one which is taken from rabbits and the preferred type now seems to be from horses. We joke with [redacted] now that he is part horse.

26. The nurses took blood samples from [redacted] but she was only [redacted] at the time and she howled when she was getting the blood taken. Unfortunately she wasn't a match and although [redacted] was on the bone marrow waiting list, there was no sign of a match there either so we decided to go down the ATG route. We were told that this was a very expensive treatment, around £20k. Dr Chalmers told us it would take a while to confirm the timing, both because of the cost and as it would take some time to source the treatment. That's why it took until 19 February 2018 to be told the hospital had the ATG and [redacted] could come in for treatment.

27. Ahead of the treatment, we took [redacted] to the hospital on 13 February 2018 for his usual transfusion and then again on 14 February 2018 to have his central line fitted. This was the Hickman line that remained in place until 5 December 2018. I was told the line would go into [redacted]'s chest during a general anaesthetic, and that it would be important to keep it clean to avoid infection going straight into [redacted]'s bloodstream. It looked like two long plastic tubes, maybe ten inches long, with different coloured caps. It went in just above [redacted]'s right nipple and it was kept in place with a dressing. We were told by Dr Chalmers that the Hickman line was the easiest way of getting the medication and transfusions into [redacted]. It would save him the pain of the injections each time, though we were conscious of the increased risk of infection around the entry point of the line into [redacted]'s chest. [redacted] was discharged after the line was fitted and we had to be taught how to clean the dressings around the line to save the nurses coming out to our house each time, though a nurse would come out each week to flush the line. The outreach nurses who came from the hospital were specifically from the Schiehallion Unit and they were great in coming out to help us with [redacted] after he had been discharged. They even visited him at school to try and avoid any disruption to his routine.

28. The ATG treatment was due to start on 19 February 2018, but after we turned up at the hospital that morning and after completing all the necessary paperwork for [redacted] to be admitted, it was discovered that the wrong ATG medication had been received in the hospital and treatment was unable to proceed.

29. We were sent home and advised that it may be a couple of weeks before treatment could begin as the medication was bespoke and had to be sourced from England. [redacted] was really upset about this as he had mentally prepared himself for treatment and it was now back to waiting for an admission date. I understand that it was the rabbit version of the ATG, rather than the horse type, that had arrived. I'm not sure if this was because the wrong item was ordered or the wrong one sent, it wasn't clear. I guess that the error wasn't discovered until they were taking the medication from the fridge in the pharmacy that morning but Dr Chalmers, the consultant, was clear that the horse variant had a better chance of success for [redacted] so we were better to wait and she said that the delay wouldn't cause a problem. However, this did mean that the Hickman line wouldn't have been fitted so early, so [redacted] had it in for a few more weeks than necessary and it meant some continued transfusions until the ATG treatment could start, which ended up being on 7 March 2018.

ADMISSION FOR ATG TREATMENT – 7-27 MARCH 2018

30. I can't recall how much notice we got that the ATG treatment could begin but it wasn't long before [redacted] was admitted on 7 March 2018. He went into Room 13, Ward 2A. Room 13 was a single room with TV, though the TV and blinds didn't work. There was also a pull down bed for parents to use if they stayed over, which was reasonably ok.

31. We immediately noticed that there were bottles of spring water at the sides of the sink in the bathroom and we were advised by the nursing staff that

these were to be used for everything including, washing and cleaning teeth, as bacteria had been detected in the water supply. I was not given any information about what this bacteria was. The water supply was still on as the taps in the sink in the room and the bathroom still worked. This obviously meant no hot water for washing was available. Showers were out of bounds. We weren't told how long the situation would last but we judged by the numbers of pallets of water in the corridor that it wouldn't just be a couple of days.

32. The room was clean but although fitted with a state of the art TV, it did not work. We had numerous attempts from various members of staff (play-staff, auxiliaries, porters) but despite them all trying, no-one could get it to work. So [redacted] couldn't use the TV. I'd have liked to use it too and other family members, like when [redacted] was sleeping, so it was frustrating it never worked and none of the staff seemed able to fix it.

33. The temperature was also an issue. It was often far too warm. There was a temperature controller in the room but it didn't change anything. We were told that the temperature was controlled centrally but it didn't seem to make sense to then put controllers in rooms that didn't actually do anything.

34. [redacted]'s treatment started on 8 March 2018. This immunotherapy was in the form of a solution infused to [redacted] through a drip connected to the Hickman line over a long period; around 12 hours. This was the horse version of the ATG which would trigger [redacted]'s own bone marrow to start producing cells again. He was in Room 13 at this time and was not in isolation, but he had to be monitored constantly during this period by nursing staff as there could have been side effects or an allergic reaction and obviously he was attached to the drip the whole time. This was all so difficult for a young boy.

35. We also discovered that the facilities on the ward for [redacted]'s age group were poor. The "playroom" was really for much younger children, up to age 10, I would estimate. We asked if he could access the Teenage Cancer Trust (TCT) Room but were told no. [redacted] was in that unfortunate age group, where he was too old for the play room but not old enough for the TCT room.

36. They did allow him to sneak into the TCT room briefly just before Christmas when it was very quiet on the ward. It was amazing but it did make it a bit worse because it gave [redacted] a taste of what he was missing out on. The TCT room had a huge TV with PlayStation and X-box, pool table, juke box and comfy chairs where parents and patients could socialise. [redacted] was only a few weeks away from his 12th birthday, which I think is the age they can use the TCT room, so this made it really hard for him. Three weeks without any entertainment just made the time drag out for [redacted]. So basically he was stuck in his room the whole time as the playroom was really for people younger than him, although he did go the atrium once or twice. Since then I know that fundraising has taken place by two previous patients to make a room for those who fall within this age group. This would have been a huge boost for [redacted], particularly since there was no working TV in his room. The charity work the two girls are doing is amazing.

37. I was really grateful when the Les Hoey Bellshill Charity got [redacted] a Nintendo Switch which helped him pass the time. He also watched the whole series of Stranger Things on his iPad. Public Wi-Fi in the wards was really bad and I heard lots of parents complaining about it. [redacted].

38. On 9 March 2018, [redacted] reacted to the treatment and presented with seizures, which are a known side-effect. He was sedated, intubated and transferred to the Paediatric Intensive Care Unit (PICU). He was given a

CT scan but it was thought after review by a neurological consultant that these were functional seizures brought on by the stress of hospital admission and treatment. These seizures can be controlled with reassurance and mindfulness and they don't necessarily require medical treatment. [redacted] still has the seizures to this day but we manage these ourselves, for example using the cognitive behavioural therapy techniques recommended to us by the psychology department.

39. It was agreed to stop the ATG treatment due to the seizures. Dr Chalmers and the Neurology staff didn't know what was causing the seizures but they didn't want to risk continuing in case it was the medication. The drawback of stopping was that the two days of ATG already given wouldn't have worked by this point so it would mean treatment having to restart at the beginning. The only other option was to wait again for a bone marrow donor but there was no guarantee how long this would take. This meant that the four days' worth of treatment that was planned needed to restart and the two days already given were effectively lost.

40. Dr Chalmers put [redacted] on a tiny dose of diazepam, a muscle relaxant, and they decided to keep him on this when they began the treatment again as it was more important to continue the ATG treatment even if this meant additional medication to calm the seizures.

41. On Saturday 10 March 2018 [redacted] was back in room 13, Ward 2A, after his brief transfer to PICU on the Friday. He had his endotracheal (I think that's what is called) tube removed, however, this was a harrowing event and also left him with vomit on his face. The first thing he wanted to do was have a proper wash or shower and freshen up. This was impossible due to the lack of hot water and showering facilities being out of bounds.

42. [redacted] spent the whole day in bed feeling dirty and sweaty, just wanting a good wash. This was a ridiculous situation, washing is one of the most basic of facilities that should be available, not least in a hospital.

43. We just had to use baby wipes to try to clean [redacted]. The nurses gave us wipes and I'd taken my own, but wipes just don't do the job. The staff were very nice about it and apologetic. I think they were actually embarrassed about the situation. The nurses didn't have any idea how long it would last and we asked Dr Chalmers about moving to another room or even a different ward that wasn't affected by the water issues. We were told the other areas were full. We even suggested moving back to the old Yorkhill but were told this wasn't possible. I asked on numerous occasions why patients had not been moved but was advised there was no room to move anyone to. Being in a single room, I never spoke with any other parents, so have no idea how other parents were managing to get their children washed.

44. [redacted] was fed up and upset – he felt really dirty and just wanted home. [redacted] and I were lucky as we could go home for a proper wash but poor [redacted]had no options but to remain unclean.

45. Sunday 11 March 2018 was Mother's Day. It was quite a nice day as they offered mothers a massage in the ward and gave us a wee bag of chocolates. I had an aromatherapy neck and shoulder massage from a girl who was giving free treatments. It was in a wee separate room she was working from and it was free of charge. They also gave [redacted] chocolate eggs at Easter time. These were really nice touches but I just wished they'd managed to get right the basics, such as hot running water, TVs that worked and decent food. [redacted] also had lots of family visitors that day, which helped break up the day.

46. On Monday 12 March 2018, we were pretty much in limbo with no treatment being provided although Dr Chalmers was in constant discussion with us and it was agreed that treatment would be restarted as soon as the ATG therapy could be obtained. They had to order it and I have mentioned the budgetary issues. I think Dr Chalmers had to make a case because they'd already paid for one lot of this expensive ATG and the treatment had to restart from the beginning again because of the pause when [redacted] had his seizures. I think Dr Chalmers mentioned the cost of the treatment and I probably googled it too.

47. During this time there was still no facility for a proper wash and there was no information about what was being done to resolve the situation. So finally, with [redacted] getting more and more upset about the situation, I asked if there was some way that he could have a wash.

48. I was provided with a basin of water, which I took a picture of and have provided it to the Inquiry [**Picture LK/01 – at Appendix 1**]. The water had been warmed, but I don't know if it was from the tap or bottled water. My 11 year old son, just hitting puberty, had to stand in the bathroom on a towel and I had to use a plastic cup to try and wash him. It was literally a case of me scooping up the water and pouring it over him. [redacted] was at the age where changes were happening and he was becoming more conscious about his body, so standing naked while his mum washed him was humiliating for him.

49. I asked for a gel of some sort to help with the washing and an auxiliary provided some baby wipes and an aerosol. I sprayed the contents on[redacted]'s back and discovered that it was actually "Emollient", a dry oil moisturiser and not a shower gel. I can't recall if I spoke to the auxiliary; I was probably so fed up I just got on with it

50. Portable sink units were installed in the ward at 4.30am on Tuesday 13 March 2018. Again, I have provided a picture of this to the Inquiry [**Picture LK/02 – at Appendix 2**]. I think these were put in all the rooms, certainly [redacted]'s. We were now advised by the nurses not to use the sinks in the bathrooms at all, only the portable sinks that had been provided, and a letter would be provided to all in-patients. We weren't given any particular information about the portable sinks. We also received a letter advising us to speak to an auxiliary if parents wished a shower and they could be provided with a taxi to go to Marion House, the CLIC Sargent place. I have provided a picture of the letter to the Inquiry [**Picture LK/03 – at Appendix 3**]. This is the accommodation for parents and families who did not live near the hospital. We never actually did this so I can't say where it is. It's fine if you had more than one parent on the ward but most parents take turns at staying with their children. Certainly I would not have wanted to leave [redacted] for a period of time to go and have a shower in another location. My husband and I had been taking turns at staying overnight so at least when we returned home, which was only a 20 minutes' drive from hospital, we were able to shower and clean our teeth properly.

51. On Friday 16 March 2018, we got a letter advising that the water would be shut off again. I can't recall when it had been turned off previously but I think it was only for a short period, maybe a couple of hours. I don't have a copy but I think it came from the Health Board. I can't remember when it had been shut off previously but I have an email where I told a friend that it was being shut off for the second time. At this point, parents were advised to go to another ward to use the toilet. With [redacted] experiencing seizures, even leaving him on his own to go to the parents' kitchen to make a coffee made me nervous so having to leave the ward to use the toilet was unacceptable. I think the easiest other toilets to get to were on the ground floor, so this is where I went and the round trip probably took about five minutes. [redacted] was advised to use a bed pan if he needed the toilet and he was shocked by this and understandably, as a young boy, refused to

do it. Of course he eventually had no choice and he just had to do it. I emptied the bed pan in the sluice area at the other side of the nurses' station as asking the staff to do it would just have added to [redacted]'s embarrassment. He got so agitated by all of this, I think it was one of the reasons that the staff agreed to allow us home the next day on the day pass. I believe that staff were also having to leave the ward to use the toilet.

52. Speaking to other parents there, I remember those with babies saying how ridiculous it was when they couldn't even bathe the babies. Given all the concerns about infections, not being able to wash properly was just not right. All the patients on that ward would have been particularly susceptible to infection, given the medical conditions that put them there.

53. All of this sent me over the edge and I actually contacted the Daily Record about the situation. I didn't see any point in an internal complaint. I wanted people to know what was happening as I just couldn't understand how it was being allowed, especially in a state of the art hospital. It wasn't until I read the newspaper article that I discovered that some children had actually contracted infections which could have been due to the contaminated water supply. I'd asked that my name wasn't included in the article but my story was covered.

54. Dr Chalmers advised me that [redacted] was to receive a course of antibiotics as a preventative measure to ensure he did not catch an infection due to the water situation. I can't recall precisely what the antibiotics were. By this time it seemed common knowledge that there was some kind of bacterial infection, people all seemed to know about it. I can't recall if this was from nursing staff talking about it. It has to be remembered that throughout this period [redacted]'s immune system was seriously compromised and his neutrophils which fight infection were often almost at zero.

55. On Saturday 17 March 2018, we were allowed home on a “day pass” which allowed [redacted] to get a shower and some proper food. During our stay the food in the hospital had been appalling, poor quality, little choice and only just edible. When [redacted] was an in-patient, everything seemed to come with chips and it was pizza, chicken nuggets, all processed and no salad options. I thought the food choices were really poor and hardly healthy options. I do think they have improved this since [redacted] was in, but I was really surprised at how poor it was at the time. My husband discussed this with a hospital manager on a later visit and I believe it is much improved now although offering something other than toast made from cheap white bread would be an improvement.

56. We spent the day as a family 10 pin bowling, eating at the World Buffet and walking in park. [redacted] got a proper wash and shower he was able to sleep in his own bed.

57. On Sunday 18 March 2018, we returned to Room 13, Ward 2A to have treatment restarted the next day. [redacted] wasn’t happy about going back in. Having had such a nice day, he didn’t like the idea of being stuck back in a hospital room, with the water problems, no TV, poor food, etc. We didn’t know how long it would take but knew it would be a while. We understood that we’d be in for at least another week after the treatment had completed.

58. [redacted]’s treatment restarted successfully Monday 19 March 2018. The length of treatment was determined by the rate of infusion, which they could adjust, increasing or decreasing the flow. Sometimes [redacted]’s blood transfusions would be up to five hours, sometimes much shorter. We understood that the ATG treatment would be for up to four days, though it ended up being three.

59. [redacted]'s treatment was completed on Wednesday 21 March 2018 and the after-treatment started, which involved steroids and anti-rejection drugs being prescribed. [redacted] had to stay on the steroids for two weeks and he was then put on to ciclosporin, an immune suppressant that he only finished taking in May 2021. He was still on this because I think it's his own immune system attacking the bone marrow cells. Side effects of ciclosporine are excessive hair growth, not so bad for a boy of his age. The steroids had also made his face bloated and increased his appetite so we had to be careful with his diet. [redacted] has a good sense of humour and his sister joked he had hamster cheeks after the steroids. Fortunately, these side effects were temporary and [redacted] soon returned to normal.

60. On Thursday 22 March 2018, [redacted] was finally able to have a shower. The nurses didn't explain why this was now possible but we just assumed that the water problems were sorted. I recall that the water was only good for washing, not drinking, but I can't recall the conversations. The design of the bathrooms we discovered was quite strange in that it was like a wet room, obviously for wheelchair access, but the water flooded into the bedroom so a cleaner had to be sought quickly to mop up this up. Water did not go down the plughole quickly and the floor wasn't angled away from room. I spoke to a nurse and they got a cleaner to come in with a mop. They were fairly quick. I can't recall asking if this was a common problem with using the bathrooms.

61. [redacted]'s treatment was successful and he was discharged on Tuesday 27 March 2018. He continued to get his transfusions until May 2018 while his system adjusted. We went back to ward 2B, as an out-patient, twice a week to begin with and then it was once a week. [redacted] is now in remission.

62. I understood that [redacted] should have seen a teacher while in the hospital but this didn't happen until just before his discharge. There is a teacher in

the Schiehallion ward and I think that the ward are supposed to send them details of new in-patients and what class they were in. But it didn't happen and I asked if [redacted] should have had a teacher. It seemed that it hadn't been put in place on [redacted]'s arrival but he did see the teacher two or three times before he left hospital. I remember the first time as [redacted] and I had both had a bad night, with little sleep because of everything going on and the noise from the machines. The teacher arrived at 8 o'clock in the morning, when neither of us were are our best. Having a teacher throughout his stay would have helped break up the time for [redacted]. They did have clowns that came round but they really weren't suitable for [redacted]'s age. [redacted] hated that and he just tended to ignore them.

IMPACT OF ISSUES WITH THE HOSPITAL ENVIRONMENT

63. The problems with the ward's water supply impacted [redacted] and me, both in relation to the difficulties created for [redacted] being able to wash and shower and also regarding the toilets, where [redacted] had to use bed pans and I had to go to the toilets on another floor.

64. We saw the external filters that were also fitted to the taps. They were white, soft plastic, bulbous things. Sometimes the workmen took the whole sink unit/faucet off though I'm not sure what they were doing.

65. In addition to the obvious concerns about keeping [redacted] clean and safe, and the talk about bacteria being present in the water, the humiliation for [redacted] and the overall inconvenience cannot be overstated. The situation was simply unacceptable.

66. Throughout our time in the ward, there was a constant procession of workmen coming into the bathroom, often when [redacted] was asleep or on treatment. I recall them checking the water in the bathroom sink with a dipstick and advising me "There's still bacteria" as they told me not to use

the sink. It was the workmen themselves who were confirming to me that there was still bacteria. I think this was also in letters from the hospital though I don't have copies. As well as the noise being disruptive, mentions of bacteria were really worrying given that [redacted] was immune-compromised. I was not happy to hear this and we just couldn't understand how this was happening and how the problems couldn't be fixed. My husband is an engineer and couldn't work out why it was so difficult.

67. The various works that were being done, mostly in connection with the water, could be noisy and disruptive, but I can understand why they were necessary if they knew there was bacteria.

68. Because of the water issues, there were challenges with personal cleanliness. Other than that, I think room 13, where [redacted] was, was clean enough. I have been less impressed with the cleanliness of the toilets, even during recent visits, including when I saw bins overflowing in a toilet in the adult's hospital.

69. [redacted]'s room was usually too hot. It wasn't helped by the fact that the blinds didn't work and although there was little sun when [redacted] was in, I can't imagine how bad it would have been had it been sunny. It just seemed strange that there seemed to be a temperature controller in the room, yet it seemed to have been disabled, I presume because it was all being controlled centrally. I wasn't sure of the point of the controller.

70. It was just really frustrating that the TV in [redacted]'s room didn't work and no-one was able to fix it. What made it worse was that he was at that in-between age where he was too old for the kids' play room but too young to use the TCT room so he was just in limbo. It all meant that his three weeks as an in-patient felt even longer than it was.

EMOTIONAL IMPACT ON [redacted].

71. Having the line fitted meant lots of limitations for [redacted]. He had to be careful not to bump it, dressings were changed twice a week, it was flushed once a week and of course it needed to be kept dry so swimming was not possible. He couldn’t do any contact sports at school or gym or running. The line would be obvious through his shirt and there was a period when some girls at school were making really cruel comments, like calling him “Cancer boy”. Happily, his pals were very supportive.

72. [redacted] had never had any seizures before 9 March 2018 and they did do a CT scan and tested him with the thing that had all the electrodes on his head. Nothing untoward was shown, which is why they put it all down to the stress of everything, the combination of being in hospital for a serious condition while having to endure the issues in the ward, like the water, lack of TV, poor food etc.

73. In November 2018, the CLIC Sargent social worker referred us to the Paediatric Clinical Psychology Service (PCPS) as they thought that [redacted] would benefit from their service. CLIC Sargent are a charity that allocates you a social worker who supports families and helps with applying for allowances, etc. Lesley Anne Gillan was the social worker who helped [redacted]. She was great, really first class. [redacted] had some issues that we were concerned about, for example where he would [redacted]. He used the PCPS service about 8 times, going every couple of weeks, so two or three months in total. The girl gave him coping techniques as they thought his seizures were stress related and kind of panic attacks. Dr Jo Skeldon dealt with [redacted] and she was really helpful. He was discharged when they were happy he was ok. Discussions centred on what he had been through and his worries about the future. He can sometimes [redacted] when he winds down and things tick over in his mind.

74. As I have said, [redacted] really struggled to deal with all of the problems that were over and above the serious medical challenges that he had to fight. Not being able to use the TCT facilities when he didn't even have a working TV in his room made the stay so much more difficult for him, but I know the lack of basic washing facilities and the need to use bedpans really caused distress. [redacted] didn't need this humiliation on top of what he was going through and I know this didn't help with his stress levels and the seizure type incidents which he was experiencing. In a way, I think that not even trying to wash [redacted] using the basin of water might have been better as it would have saved both him and me this really distressing experience.

OVERALL EMOTIONAL IMPACT ON WITNESS

75. I was off work with family-related stress from when [redacted] first went to A&E in December 2017. I was signed off work for around seven months. I couldn't cope with [redacted] being off, the uncertainly of his condition and it was all too much to be able to be at work at that time. My work were really good and understanding about it.

76. It still resurrects occasionally and I was myself diagnosed with [redacted] in 2019 when I was off work for three months, so my mental health hasn't been ideal over the last few years. I got the all clear [redacted] but still have to undergo regular check-ups.

77. The whole experience was horrendous, not only is being in hospital with your child who is seriously ill exceptionally stressful but to not have basic washing and cleaning facilities was a disgrace. However, what could we do, you want the best for your child and presume that the clinical and hospital management know what they are doing.

78. However the worry that people were going to catch something was always top of my mind too, especially after hearing about how other people had been affected and the Hickman line had been mentioned. The children were so vulnerable to serious infections, particularly when [redacted] and presumably all the children on the ward have little or no immune systems.

79. When I think back, the problems at the hospital just exacerbated what was already a horrible situation, having to deal with [redacted]'s condition. It made the whole experience so many times worse, when on top of the worries about [redacted], we had to endure the added stress of fears about the water supply and the risks of infection. Things like broken TVs and poor food we could just about tolerate but the potentially dangerous water situation really added to our stress as it was completely outside our control and it seemed to go on for so long.

80. Both [redacted] and I don't think we will ever stop thinking about it. It's not an experience we'd ever want to repeat and I think it will live with us for ever.

81. I joked with [redacted] that every time he took [redacted] to the hospital there's a problem so I tend to do most of that stuff. He was still working and was usually looking after [redacted] when I was at the hospital with [redacted].

OVERALL EMOTIONAL IMPACT ON FAMILY MEMBERS

82. [redacted] is very close to [redacted]. She missed him a lot and would come home from hospital and sleep in one of his T shirts. She was devastated when she wasn't a match for a bone marrow transplant and we joked about how she could have said she had saved his life.

83. We only took [redacted] to the hospital every couple of days. It wasn't a nice place for children and I was worried about the danger of infections and the issues with the toilets. We're wary even now of these things and even before Covid we felt that the toilets could do with a good clean and a couple of months ago I took a picture of an overflowing bin in one of the toilets in the adults' hospital outside the door to the Schiehallion.

HEALTHCARE ASSOCIATED INFECTIONS

84. Fortunately, [redacted] has not picked up any Healthcare Associated Infections during his time in the hospital. As I have previously mentioned, he did receive a course of antibiotics as a preventative measure to ensure he did not catch an infection due to the water situation. I can't recall precisely what they were.

COMMUNICATION

85. The communication around the water problems was really non-existent, other than a few letters about being told not to use the taps or the toilets. It was not acceptable but we just got on with it. In fairness, I think the staff were in the dark too and, as I mentioned, they were also affected by the likes of having to go to toilets that were further away so it didn't make their jobs any easier. The staff were great and it was clear that the problems were out their control.

COMPLAINTS

86. We never raised any formal complaints. To be honest, we had enough going on at the time. It was through exasperation that I contacted the Daily Record to highlight my experience. I wanted to remain anonymous but I

felt that the problems should be exposed to help others using the hospital in future.

87. [redacted] did speak to one of the hospital managers around December 2019 when [redacted] was in for a biopsy and basically sounded off about various issues, mainly about the quality of food, broken TVs and general poor facilities for [redacted]'s age. He didn't mention water as it was so long ago but it looks like it's still not sorted because ward 2A is still not open after all this time. [redacted] thinks that the manager took notes, he had a clipboard, but we didn't seek specific feedback. I think the food situation has certainly improved, judging from my recent visits. When [redacted] was in, everything seemed to come with chips and it was pizza, chicken nuggets, all processed and no salad options.

OVERSIGHT BOARD / CASE NOTE REVIEW / REPRESENTATIVE GROUPS

88. [redacted] was not part of the Case Note Review and we are not part of any representative groups.

89. I am not part of any representative groups, though I'm on the Schiehallion Facebook page and I've been keeping up to date through that. Sometimes it is helpful but I don't go in to it a great deal.

CONCLUDING COMMENTS

90. Throughout the stay, the nursing staff were always professional and I know that they were affected too particularly when the water was shut off and even they had to go elsewhere to use the toilet facilities. The staff didn't seem to know, particularly about water problems and I think they were kept in the dark until there were letters from hospital management. We got particularly friendly with a couple of staff who were inconvenienced

too by the water problems and having to use other toilets. I know they were unhappy about it all too but they just had to make the best of the situation.

91. I can’t understand why ward 2A is still closed. I suspect that the staff aren’t happy but it will be difficult to build up confidence in it when it opens again, after the problems of the past. I think there should be more publicity about the current situation, as no one seems to know what’s happening and when 2A will reopen, including the staff.

92. Even now, I am surprised at lack of security to get in wards in the hospital. There’s the buzzer but no one ever asks who is there and you are just let in. Even in the last couple of weeks, with the Covid restrictions, it’s easy to get in the wards without anyone checking who you are.

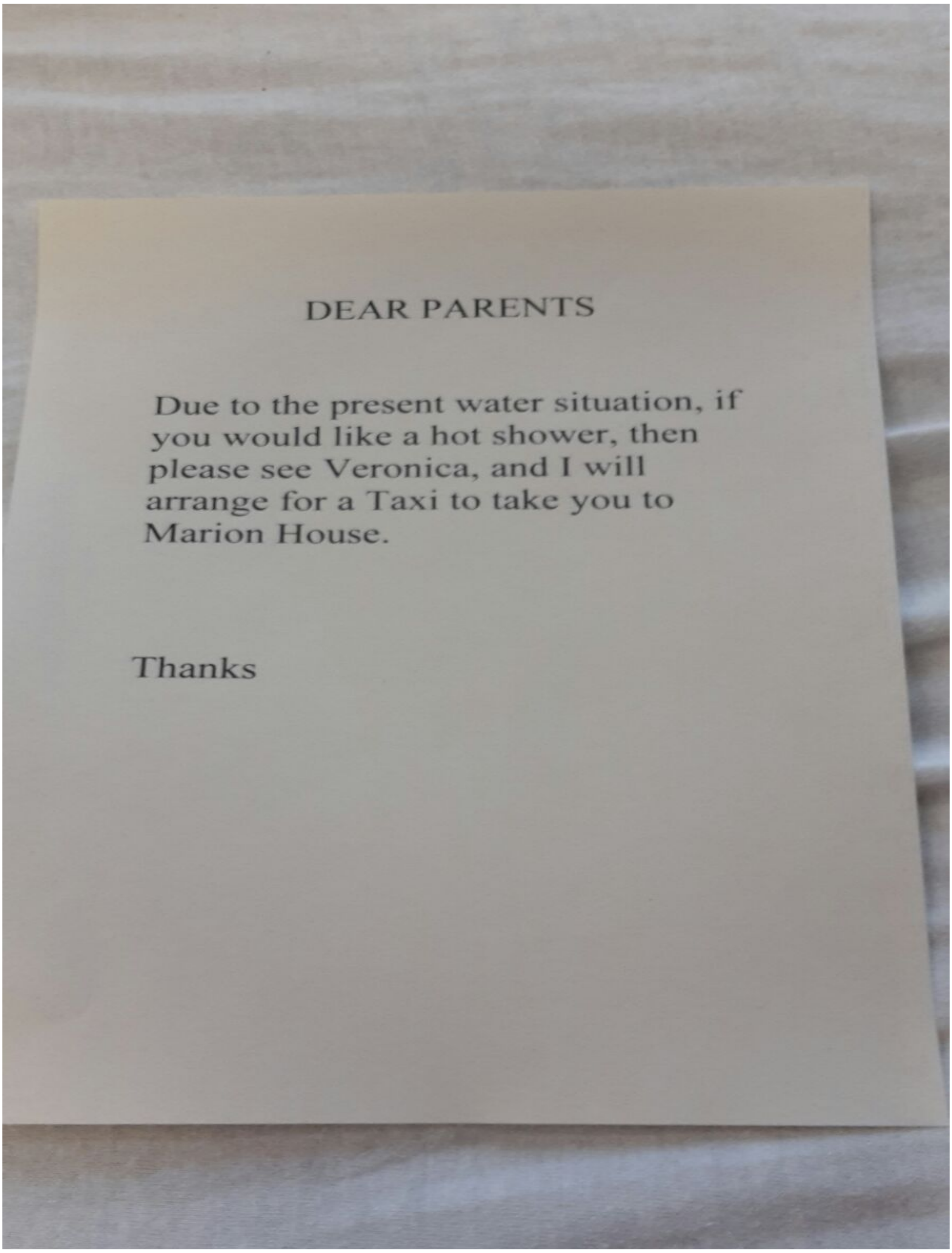
93. Though [redacted] has not been an inpatient there, we had to visit Ninewells in Dundee. It was the Easter just after [redacted]’s treatment and we were at our caravan near Crieff when [redacted] came out with terrible petechiae. We were told that Ninewells was the nearest hospital with a children’s Oncology Department. We were amazed at the facilities there, with rooms that were like suites, with bed and couch and kitchen for family, large TVs and it was hugely impressive. [redacted] said he’d like to be there if he ever needs treatment again.

94. I believe that the facts stated in this witness statement are true. I understand that this statement may form part of the evidence before the Inquiry and be published on the Inquiry's website.

LK/01 - Appendix 1

LK/02 - Appendix 2

LK/03 - Appendix 3



DEAR PARENTS

Due to the present water situation, if you would like a hot shower, then please see Veronica, and I will arrange for a Taxi to take you to Marion House.

Thanks

Scottish Hospitals Inquiry

Witness Statement of

Suzanne Brown

WITNESS DETAILS

1. My name is Suzanne Brown. I was born on [redacted]. I am [redacted] years old. I am a full-time carer.

2. I am the mother of [redacted]. [redacted]’s date of birth is [redacted]. He is 11 years old.

3. I live with my partner, Graeme McCandlish, and my three children, [redacted], [redacted] and [redacted], in [redacted], [redacted].

OVERVIEW

4. My son is [redacted] [redacted]. [redacted] was diagnosed with Acute Lymphoblastic Leukaemia (“ALL”) in December 2016 when he was 6 years old. [redacted] was treated in the Royal Hospital for Children (“RHC”) and Queen Elizabeth University Hospital (“QEUH”) between December 2016 and March 2020, when he finished his treatment. He attended both hospitals as an inpatient and as an outpatient regularly for over three years. [redacted] still attends the QEUH as a result of side effects of his treatment and for check-ups. I have prepared and provided the Inquiry with a timeline showing the dates on which [redacted] attended hospital and the wards where he was treated. The timeline is attached to this statement at appendix 1 **(SB/01)** and I confirm that it is accurate to the best of my recollection.

5. [redacted] spent time in wards 2A and 2B of the RHC which are known as the Schiehallion Unit. The Schiehallion Unit treats children with blood cancer.

[redacted] also spent time on other children's wards, being wards 1E, 1C, 2C, 3A, 3B and 3C of the RHC. Following the closure of the Schiehallion Unit in 2018, [redacted] was treated on ward 6A of the QEUH which was supposed to be the 'new' Schiehallion Unit. I stayed with [redacted] during most of his admissions to hospital as an inpatient and an outpatient. My partner Graeme looked after the other children. It was usually just me and [redacted] most of the time. I can speak to the experience which [redacted] and I had on these wards.

6. There are some specific events that I would like to mention. [redacted] contracted a staphylococcus infection in February 2017 very shortly after being discharged as an inpatient from ward 2A. He also contracted a parvovirus infection in March 2018. There were issues with the water supply throughout [redacted]'s time at both hospitals. I believe that [redacted] was prescribed preventative antibiotics in 2018 which may have been connected to issues with the water supply. There were ongoing construction works at the hospital throughout [redacted]'s time there which, in my view, impacted his experience. I will come on to talk about these events in more detail.

FAMILY BACKGROUND

7. I live with my partner Graeme and three children in [redacted]. [redacted] is the eldest. [redacted] is [redacted] years old and [redacted] is [redacted] years old.

8. [redacted] is in [redacted] of school, he starts in [redacted] after this summer. He was in [redacted] when he was first admitted to hospital. [redacted] is quiet boy, he is shy but he is funny and can be quite a character. He is a caring child. [redacted] like to play his PlayStation and talking to his friends when he is playing video games, he enjoys playing Fortnite and Roadblocks. On a nice day he likes to go outside and play football with his friends, or play outside with them. [redacted] is close to his younger brother, [redacted]. [redacted] and his sister, [redacted] can argue with one another and I

think that is because there is only [redacted] between them in age, they do get on when they need to.

9. As a family we like to go outside together. The kids love to go to the beach, it is one of their favourite places to play and they run about in the sand and in the sea. We can arrive first thing in the morning and be the first people there, then the last people to leave in the afternoon. We also like going for walks and to the local trampoline park.

10. Prior to [redacted]'s diagnosis, he was a healthy child and was very rarely unwell. The only time I can think of was when he had whooping cough at 14 weeks old and he was admitted to hospital then. Other than that he had kept well throughout his childhood.

SEQUENCE OF EVENTS: THE FAMILY'S EXPERIENCE AT RHC AND QEUH

Admission to hospital: December 2016

11. [redacted] was diagnosed with ALL in December 2016, when he was 6 years old. I first took him to the GP because he had been having trouble with his arms and legs. The GP told me to take him to Forth Valley Hospital. They did blood tests and suspected Leukaemia but we didn't have the diagnosis yet. We were told that [redacted] had to go to the RHC in Glasgow. I took [redacted] to the RHC on 30 December 2016 where he was diagnosed with ALL. He was admitted immediately as an inpatient to Ward 2A which is the inpatient ward of the Schiehallion Unit. Ward 2B is the out-patient unit.

[redacted]'s initial treatment: December 2016 to February 2017

12. The first week or so of [redacted]'s stay in the RHC was over the new year and was a blur. I remember that we were given a treatment plan which outlined all the protocols. There were different phases to [redacted]'s treatment. These included the Induction Phase, the Consolidation Phase, the Interim Maintenance Phase,

the Delayed Intensification Phase and the Maintenance Phase. Interim maintenance was around 4 weeks long, maintenance was the longest phase of treatment, being around 2 years long.

13. [redacted] was under the care of was Professor Gibson, his consultant. There were also nurses who administered the chemotherapy. There were other doctors too but he saw so many, I can't remember all the names. They changed every now and again and we got a load of new ones. They were maybe students or juniors. Professor Gibson is still [redacted]'s consultant even now he's in aftercare.

14. I remember some of the medications that [redacted] was on. Once a week he was to get Daunorubicin, a really strong chemotherapy drug with another one called Vincristine. There was also mercatopurine which is an oral drug. [redacted] was on Dexamethasone the whole time. Dexamethasone is a steroid. Unfortunately, had loads of side-effects from his treatment. His blood pressure was really high and he had to be medicated to bring it down, but it stayed high and he was on 2 different medicines just to reduce it.

15. The initial phase of [redacted]'s treatment should have lasted for four weeks according to the sheet we were given but it lasted much longer due to his side effects. [redacted] got very sick with the chemotherapy. He had really sore legs and he couldn't walk anymore. [redacted]'s kidneys were also affected due to the toxicity of the chemotherapy; his eyes were yellow. He was put on medicine to sort all those problems. [redacted] stopped eating and was put onto TPN (total patient nutrition); he had nothing orally then. The TPN provided him with all the vitamins and minerals that the body needs. All of that just set him back. In addition, he lost a lot of weight too when he got a sickness bug and he was only 6 years old at the time. The sickness bug made him very ill, he was sick a lot and lost his appetite. [redacted] was about 26kg when we he was first admitted

but he went down to 19kg. He was just really frail; really not well during those first few weeks of his treatment.

16. As a result of the side effects of his treatment, [redacted] was not discharged at the end of the Induction Phase. [redacted] was still an inpatient when the next phase of his treatment, the Consolidation Phase, started. The Consolidation Phase should last another four weeks. It is followed by the Interim Maintenance phase, Delayed Intensification Phase and the Maintenance Phase. We would be given a new sheet for each phase of treatment which explained what would happen.

17. [redacted] was discharged as an inpatient from ward 2A on 21 February 2017. He was part way through the Consolidation Phase of his treatment at that point. I think he was in ward 2A for about seven and a half weeks for the first inpatient admission from 30 December 2016 to 21 February 2017.

Experience on ward 2A: December 2016 to 21 February 2017

18. Ward 2A is specially set up for children with cancer and their parents to use. It has a playroom for the kids and we had a parent kitchen area with a wee couch. The parent kitchen was like a lifeline. I remember once when [redacted] had been admitted with a temperature and I met a lady when her wee boy had just been admitted and she was crying. It was her first time and I just helped her and consoled her a wee bit. I always remember my first night and I was panicking. There were all those other parents in there. When you spoke to other parents who can tell you their experiences it helps you greatly. I remember that when [redacted] was first admitted, it felt like a worse-case scenario, I was planning a funeral in my head. That’s the first thing you think about. When you speak to parents who are used to living that way it helps greatly. The parent kitchen is a lifeline. Its somewhere to go, to take a break, to speak to someone who has gone, is going through what you are, somewhere to

offload. The first night [redacted] was diagnosed I went to the parent kitchen in ward 2A, I was shell shocked to be told my child had cancer. Someone in there gave me a hug. People in that kitchen have been through it all before.

19. [redacted] was in a single room. They were all single rooms in Ward 2A. I think that there are about 26 rooms in total, around 3 of those rooms are Teenage Cancer Trust rooms and we could not use these due to [redacted]'s age at the time. Around 8 of those rooms were for transplant patients. That left approximately 15 rooms for the use of patients like [redacted].

20. Within those 15 rooms there was a bed for the patient, a small sink nearby the door of the room so that you could wash hands, there was an en-suite bathroom with toilet and shower. Within the bedroom area there was a bin, small chest of drawers and cupboard. There was a TV attached to the wall, most of the TVs did not work though. There was a pull-out bed for parents and that meant I could stay overnight in the room with [redacted].

21. Ward 2A also has a playroom which is set up for immunocompromised children. The playroom had board games, pencils and drawing materials. There were play specialists in the room and they would help the children play, set up activities, ask them what they would like to do and join in the play. The play room was for the use of the Ward 2A patients only, for example siblings were not able to access or use the playroom for infection prevention measures. [redacted] used the room, as he was often quite unwell when admitted to Ward 2A he was not really in the mood to use the facilities, he might go in for a short time then leave.

22. The playroom was for children up to 13 years old. Teenagers had their own facilities in the form of the Teenage Cancer Trust Room ("TCT"). [redacted] was in that in-between age in the 7-12 year old age group, and he didn't really want to draw with the young children and he was too young to use the TCT room.

The TCT room had facilities that [redacted]'s age group were interested in. They wanted to be in the room that had X-boxes and a pool table but they were too young to be allowed access. The staff on ward 2A were really great and they always came in to see [redacted] when he was in.

23. Ward 2A has special protocols. For example, there is the Protocol that applies when a cancer patient spikes a temperature. If [redacted] spiked a temperature during the day we'd go to Ward 2B which is the daycare ward. From there he was admitted. The nurses draw blood and send the samples away to the lab for blood cultures and to check for infection. It takes 48 hours for blood cultures to come back with results. Antibiotics are started immediately on admission as during those 48 hours the staff don't know what the cause of the temperature spikes are, whether it is an infection or not. Once the blood cultures come back then decisions on treatment can be made. Patients are discharged when the blood cultures come back negative and as long as they do not have a temperature spike. If the patient continues to spike and cultures are negative, then the protocol is to continue testing blood cultures every 48 hours to keep checking for infection. So patients can be in for a few days working through this cycle of antibiotics, drawing blood and checking blood cultures. Best case scenario patients can go home after 48 hours, but it can take a few days, sometimes up to a week, of working through this protocol before the temperature is manageable.

24. In Ward 2A I think that the nurses have specialist training in administering chemo, there were times when [redacted] was not admitted to Ward 2A and was not looked after Ward 2A nurses. On some of those other wards staff could not administer chemo as they were not trained, that is what the staff on those other wards told me. The doctors on Ward 2A are specialists in oncology and haematology. There appeared to be a lot of doctors coming and going, I think that they were junior doctors and were on training rotations so I'd see them for a while then they moved on.

25. Day to day, [redacted] enjoyed being a patient in Ward 2A especially when compared to his experience in other wards in the hospital. It felt like it was a home, apart from times when you were in isolation. That could be difficult.

26. For [redacted] being in-source meant being in isolation. The types of things that could lead to a patient being in-source was if the child had sickness or diarrhoea; cold or flu; or a virus that could spread. Sometimes [redacted] was in-source to protect him, to stop him from getting an infection. Usually if [redacted] was admitted to another ward (not 2A), he would end up in-source to protect him.

27. If [redacted] was in-source in Ward 2A there was a yellow laminated sheet that was placed on the door. I think it said "Please ask a member of staff before entering". I was allowed in to stay with [redacted] but I couldn't access the kitchen on the ward when in-source. For visitors permission had to be given by the nursing staff. If granted visitors had to put on an apron and wash their hands, as did the nursing staff and domestic staff who came into the room.

28. In-source isolation is a different type of isolation to "strict isolation", which is for patients who are waiting for or have received a STEM cell transplant. Those children stayed in the special isolation rooms that had the double doors, with a wash basin in between so hands could be washed before entering the room. [redacted] was never in strict isolation although he did use a special isolation room on one admission but I can't remember the date.

[redacted]'s admission for staphylococcus infection: 22 February 2017

29. Although [redacted] was discharged from inpatient care on 21 February 2017, he was readmitted to the RHC one day later on 22 February 2017. We had only stayed one night back at home. [redacted] had a check-up visit to the clinic as an outpatient at ward 2B on 22 February 2017. [redacted] had day care first at 2B and

we had gone home. When we were at home, he spiked a high temperature and we called the hospital. We were told to take him in. He was not even home for 24 hours. For [redacted], that was the first of a number of inpatient admissions when his temperature spiked.

30. We went to the ward 2A where they took blood cultures and put him on antibiotics. I'm sure he was neutropenic because he was in the aggressive part of treatment. The cultures came back showing an infection in his line. had a central line at that time. The central line was used to administer treatments and to take blood. They said they were going to change to a different type of antibiotics for that kind of infection.

31. When this type of admission happens, they stop all other treatment to get rid of the infection first. Chemotherapy would only be re-started when [redacted] had finished the antibiotics and even that was only if the swabs showed that the infection had gone. I think it was the ANP (Advanced nursing practice) nurse who told us about the infection; they come round in the morning. We weren't really told much so I didn't think it was too serious. They just put the antibiotic in and that was it really. But [redacted] wasn't very good. He had a high temperature, was shaky and feeling not very well at all. It made [redacted] quite sluggish. I'm not too sure how long he had the staph infection for. Admissions for infections would usually be for up to a week but I think we were in for longer that time from 22 February 2017 until 5 March 2017.

32. [redacted]'s blood cultures came back within 24 to 48 hours of his admission and it was confirmed that he had the staphylococcus infection. Once the staff knew that he had this infection then [redacted] was given an antibiotic to treat that infection. The specific antibiotics prescribed was a course lasting a week and that prolonged the admission. [redacted] was not required to be in-source during this admission. Following this infection, he was weak and not able to walk. I think this was due to both the infection and the treatment he had received. His

chemotherapy was stopped and treatment delayed, it started again once he finished his course of antibiotics and once his neutrophils in his blood had increased. I can't remember the exact date when he began chemotherapy again.

[redacted]'s treatment and other admissions during 2017

33. [redacted] moved on to the Interim Maintenance Phase of his treatment a few weeks after his second admission in February 2017. During 2017, [redacted] was going into hospital for his monthly chemotherapy as an out-patient, we attended clinic appointments in Ward 2B. Between clinic appointments, we'd be getting monthly supplies and treatment from the hospital pharmacy to take home. He'd get his Vincristine and so on to take home.

34. As an outpatient, [redacted] received his chemotherapy via a central line and then through a port-a-cath. He had a central line between January 2017 and July 2017. They were going to try and use cannulas but they just didn't work for him unfortunately. This meant that [redacted] had to have a port-a-cath inserted in October 2017. A port-a-cath is inserted via a surgical procedure under a general anaesthetic, [redacted] attended day care early on the morning of his surgery. Following the procedure he stayed overnight for observation and he was allowed home the following day. [redacted]'s port-a-cath was inserted into his chest on his right side, some children had them fitted under their arms. It still had to be flushed every month, the lady came out to the house and did that.

35. When [redacted] moved onto the Maintenance Phase of his treatment, he attended ward 2B for outpatient treatment as he had before for Interim Maintenance. I think that this phase started in around July or August 2017. The outpatient chemotherapy was accessed through [redacted]'s port and that got the chemotherapy into his line. We were in for outpatient treatment to the clinic in ward 2B every fortnight or four weeks.

36. Throughout 2017 [redacted] had numerous inpatient admissions. Only one of [redacted]'s inpatient admissions was for pain management, he was in such a lot of pain. All the rest were for temperature spikes. That involved him being started on antibiotics straight away.

37. Temperature spikes always worry the hospital staff and parents, because they think it could be an infection, so [redacted] was always treated. They're always worried about sepsis so it's a sepsis protocol they do straight away. They need to cover the line and check it's not a line infection. It could just be a cold with kids but they just want to get antibiotics into them straight away. It could just be something simple like rhinovirus, just a cold. The protocol in Ward 2A was that, if there was a high temperature it would mean Calpol to bring the temperature down, and then it would be checked an hour later. In other wards it was only every four hours. They take bloods from the line and send them to the labs for cultures. That takes 48 hours so they would always have to admit until the results come back. If they come back negative you can go home as long there isn't another high temperature. They take throat swabs too to check for viruses. Often both of [redacted]'s would come back negative and it's just unexplained, nobody knows.

38. If the bloods came back with a particular infection, like when [redacted] he got the staphylococcus line infection in February 2017, we were re-admitted. As I have already said, these protocols had to be gone through every time.

39. When there was a temperature spike, depending on his blood counts, they'd look at his last count, and if he wasn't neutropenic (too few white blood cells), for example, if they were not below one, they'd start him on one antibiotic. If they were below one he'd be put on two antibiotics, both by IV. One was an IV bag and that takes an hour and the other is in a syringe and they would just push it through the line. Sometimes he'd be put on fluids as well.

40. Temperature spikes can lead to delays in treatment. If [redacted] had an infection or low level of neutrophils, a hold would be put on his chemotherapy. Sometimes his neutrophil levels were close to zero and he would not be given more chemotherapy then. They would wait for the counts to go up. That causes a lot of delay, sometimes 2 or 3 weeks. Nothing is set in stone. In an ideal world it would be week by week treatment for the ALL. In reality, the chemo holds delayed things.

[redacted]'s inpatient admission for Parvorvirus: March 2018

41. There is another particular admission that I would like to mention. [redacted] was admitted to the RHC in March 2018 when he contracted parvovirus. Parvovirus is the virus linked to slap cheek in children. Normally it gives children red cheeks, but for children who are immunocompromised and on chemotherapy, it can really mess up their platelets and haemoglobin. This can result in a requirement for blood transfusions to replace red blood cells.

42. At that time, [redacted] was attending ward 2B for his monthly chemotherapy. He was getting monthly supplies and treatment to take home.

43. [redacted] had a high temperature, he spiked at home and we took him to ward 2B daycare, Ward 2A was full so he was admitted as an in-patient to one of the wards on the 3rd floor, either 3A, 3B or 3C – I can't remember which one. Blood cultures came back negative after 48 hours and his temperature came down so we were sent home. The next day he spiked a temperature again and we went back to the hospital to Ward 2B for assessment, he was admitted again and to ward 3C in the RHC as an in-patient. Ward 3C is renal, dialysis and orthopaedics. [redacted] was admitted to ward 3C instead of ward 2A because of capacity issues, the nursing staff in ward 2B told me there were no rooms in Ward 2A. A lot of the rooms in ward 2A as well as the transplant and

strict isolation rooms were getting boarded up. I will come on to say more about that.

44. During the admission, [redacted] developed a red rash all over his body. He was scarlet red. He had a very high temperature, over 39 degrees. His platelets were low and when the nursing staff placed a cuff round his arm to take his blood pressure he bruised really easily. He had blood spots on his chest that began to burst. He received 4 blood transfusions during this admission. There was no other treatment to give other than to manage the symptoms, his temperature was managed using Calpol and ibuprofen. The staff took swabs from his throat a few times but they kept coming back negative. Eventually staff told me it was parvovirus. His chemo was stopped during the admission and treatment for the virus.

45. I did my own research on parvovirus. I am a member of a few Facebook pages set up about kids leukaemia. They are pages with members in the UK, America and there are some parents of children being treated in Schiehallion who are members too. They are for parents of kids with ALL. Through those pages I learned about parvovirus, I wasn’t really told much by the staff.

46. When [redacted] was admitted to Ward 3C for treatment for parvovirus, it was for 4/5 days in ward 3C and then he was moved to ward 2A when a bed became free. For the 3 weeks as an inpatient he was in insolation. When we were in isolation [redacted] goes into himself. He wasn’t allowed to leave the room for 3 weeks. It’s horrible in itself, let alone for 3 weeks. It’s mentally hard when you’re only 6. Nobody is allowed in [redacted] could only stare at the clown doctors going past his window. The clown doctors are entertainment for the children, and I think they are provided by the charity Hearts and Minds. They wore yellow coats, had big shoes and red noses and came around the wards and made the children laugh. He used to love them. But that was only for 5 minutes a day, it was hard for him.

47. The experience is just not the same when you're not in ward 2A. On ward 3C, we did not feel as safe. The Schiehallion staff and protocols are not there with you. I felt like I was the nurse and had to make sure things were right. A lot of times when [redacted] was not being treated in the Schiehallion ward and when he was admitted to other wards in the hospital, there would be overdose amounts in the syringes. Sometimes there were under-dose amounts. It was crazy amounts. I sometimes had to take some medication out before giving him it. I said I would give him it. I wanted to check myself. If I was going to the shops for food for [redacted], I would ask them not to give him it because I wanted to check the amounts. I knew what he was getting because I was used to giving his oral medications at home. That happened during this admission.

48. The protocols on ward 3C were not the same as on ward 2A. When children are admitted in all the wards and do not have high temperatures, it is standard practice for the nurses to carry out observations every 4 hours. During obs [redacted]'s temperature is checked and his blood pressure taken. In Ward 2A the protocol changes when a child cancer patient has a temperature spike. The frequency of observations increases, calpol is given initially and then after an hour the nurses check the child's temperature again to ensure it is coming down. If temperature does not decrease then ibuprofen can be given, that is not normally given when kids are on chemotherapy but sometimes they have to give it, to get a bad temperature down. This did not happen during this admission. It was scary. I was carrying out the hourly observation on my own, using my own thermometer. His temperature was over 39 degrees and did not decrease when given calpol. During the parvovirus admission, [redacted]'s temperature was so high, he was drifting in and out of consciousness. He was so, so ill. I'd never seen him like that. In ward 3C, during the night-time, later at night, I was pressing the buzzer. The auxiliary came and said they'd get somebody to come and see him. But they didn't come. So, I was buzzing again. That was from about 5pm. Eventually, I went down to Ward 2A and

asked for help. A doctor came up from Ward 2A at 11 pm, I can’t remember his name. It was just Graeme and I there. I was trying to help. No one else was doing anything in ward 3C. [redacted] was given ibuprofen by the doctor from Ward 2A, he was also given IV paracetamol as it acts faster. His temperature began to decrease. There was a lack of understanding in the staff in Ward 3C, they had thought that they could not prescribe ibuprofen at all and so they didn’t.

49. Another thing I noticed was the staff had a different approach to taking blood out of the line in Ward 3C. In Ward 2A when drawing blood from the line, the nursing staff would take a discard sample and dispose of it. Then they draw the blood sample required, then put the antibiotic into the line, then flush the line and then cover the line. In Ward 3C the took a discard sample and kept it, then drew a very large amount of blood, larger than that taken in 2A. Then they administered antibiotics then put the discard blood back in the line and then covered the line. When I went down to Ward 2A from 3C to ask for help with [redacted], I asked the Ward 2A nursing staff about the blood draw. The Ward 2A staff told me that they shouldn’t take blood like this, that they shouldn’t be doing this. I was worried about [redacted] getting an infection in his line. It was a different way of doing things, maybe because it was a renal unit and that was their approach. It was different from Ward 2A. I asked the nurses in Ward 3C to stop drawing blood in this way, but it didn’t stop them.

50. There was a difference in the care provided, but I don’t think it was the staff’s fault. In Ward 2A there is a doctor available 24/7. If [redacted] was admitted to another ward then he only saw the Schiehallion doctor or an Advanced Nurse Practitioner during morning rounds. So I had 10 minutes each morning to ask all my questions. It was not the same as having the specialist doctors there all the time.

51. I was with [redacted] that whole time on ward 3C. At the time, I felt I just had to get on with it. But it’s horrible. During the first week it was horrible; we didn’t know

what it was, his whole body was shaking. He was going red. They didn't know what it was; he was spiking temperatures up at 40. I was crying, I didn't know what was happening. They were telling me he was fine but when it's your child you don't know if he is fine. His bloods were just tanking, he was getting blood transfusions every day. His platelets were really low so when they put the blood pressure cuff on him it was causing big red bruises on his arms. It's not easy, you just have to get on with at the time. It's later on when you think 'how did we get through that?'

52. The staff kept saying they'd move him to 2A to keep an eye on him but after I sought help from them, it was a full night during that stay until they moved him to 2A. We had to wait for a free bed.

53. During that admission in 3C, [redacted] was in-source and he was not allowed to use or access the Ward facilities.

Other admissions during 2018

54. [redacted] was admitted to the RHC as an inpatient on other occasions during 2018. These admissions usually related to temperature spikes. Often, [redacted] was admitted to other children's wards, not to ward 2A. Sometimes, we were put into TCT (Teenage Cancer Trust) wards, if that was the place a bed was available. They were supposed to just be for teenage patients though. They just had to give you any bed that became available. That started becoming more frequent in 2018; we just knew we weren't going to be in a ward where we felt a bit safer. Most of the time we knew this was going to happen. We knew that we wouldn't be admitted to 2A where we felt a bit safer.

55. We used to dread not going into our own ward. The admissions to other wards in 2018 were exactly the same, every single time. They didn't stick to the protocols we were used to on ward 2A. These wards aren't used to kids with

no immune system. I had to go down to 2A myself and beg the nurses there to get someone to come and look at him.

56. On the other children's wards, wards 3A, 3B and 3C, the only contact was when nurses came in to do [redacted]'s meds. We didn't have many visitors. We're from [redacted] and when you're two years down the line, visitors don't come so much. When [redacted] first went in he had visitors all the time but two years down the line it was different. They were allowed to come but they needed to wear an apron when we were in source. There was a lot that [redacted] lost.

57. In the other children's wards, such as ward 3C, there are playrooms and a parent kitchen but that is just for heating things up. The nurses use it as well. It's not the same as in Ward 2A. Also, even though there were playroom staff in children's ward, our immuno-compromised kids did not have access to them when we were put into source. When they were put into source in other wards, they lost that the access to playrooms and play staff. That was usually what happened with us, [redacted] wasn't allowed to use the playrooms. If [redacted] was in source to protect him, it was in case he caught something from somebody else.

58. There were a good few of those isolation periods, when he was in source. Most times when he came in, if he had diarrhoea or felt sick, you got put into source immediately. You had to tell them straight away to cut the risk to everyone else. They brought urine bottles, they had to check everything going in and out of him. People came in with aprons on. Everything would stay in the room, even the dishes, staff would take things away for you as you can't leave the room. You had to buzz and ask for things to be done. I would normally do that kind of thing but I wasn't allowed to or to go into the parent kitchen to get my dinner, I just had to get M&S microwaved meals which I had to ask the nurses to do.

59. We lost other things too when we were on other wards. You get friendly with the ward 2A nurses and they got to know [redacted], he knew them all. He could go and play with other kids on 2A too, like at home going out to play. In other wards it was just isolating. They didn't know us and we didn't know them.

60. Being on other wards, affected me too. It was hard, upsetting. I used to phone my mum and just cry because I just wanted to get out, it felt like prison and to see [redacted] like that. I just had to tell him that hopefully it wouldn't last. And you just hoped and hoped he wouldn't get another temperature and stay in much longer or have to be admitted. That was one of the worst things - where would he be put? The scariest thing about going back was he wondered where we'd be put. That was the first thing [redacted] thought about. If we were lucky, we'd be put on 2A but, even if we were, the chances we'd be moved so you never felt settled. It was unlikely we'd be put on 2A.

Closure of Ward 2A and the move to the adult hospital: late 2018

61. I remember that in 2018, wards 2A and 2B in the RHC closed. Wards 2A and 2B were moved to the adult hospital. [redacted] was in day-care as an outpatient at the time. I remember all the staff, auxiliaries and porters moving everything over. Big trollies were being moved.

62. I do not remember being told much about why the wards were closing. We were just told we were moving over to 6A in the adult hospital while work got done on 2A and 2B. I actually asked the receptionist lady what was happening. I think she called the registrar. I asked what was going on. She said 'we're moving for a few weeks 'til work gets done'. I think they're still there.

63. I was not given any detail about why the wards closed or what work was being carried out. I never actually questioned why it was getting done. Work

was always getting done so it seemed normal. As far as I know the parents were not told the reasons for the work. I do not know if the inpatient parents were told but outpatient parents were not told anything. I wondered how it would work in the adult ward. Would it be like a children's ward? We were led to believe it would just be a few weeks, we spoke to the member of staff that sits at the reception desk in ward 2B. We never really got communication other than it was to do with the water and that they were sorting the ventilation. The whole system was getting renewed. That's all I ever knew. The water issues were in the news at this point. I think the other parents spoke about that, it was what was thought. We were never told except when it would re-open. They initially said it would be 6 weeks and then more and more time was added on.

64. After the move to the adult hospital, things operated basically just the same but they split things into 2 parts. All of ward 6 in the adult hospital was used and half operated like in ward 2A, for inpatients, and the other half into day-care like in ward 2B in RHC. It was just in one big ward instead of two separate wards. It was all the same staff.

Experience in the QEUH (adult hospital): late 2018 – 2020

65. The experience on ward 6A was very different from ward 2A. In the adult ward there is nothing like the parent room. That's all taken away from you. You're in your room with the door shut and that's it.

66. In the adult ward, there was nothing at all for kids to do or even an adult kitchen for me. [redacted] is a fussy eater, I'd go to the hospital shop. Sometimes all he'd want was cereal or strawberries or tomato soup The food really wasn't nice, it wasn't nice looking. At one stage all he had to eat for 3 weeks was tomato soup. Also, there wasn't a fridge to keep stuff in or a playroom for the kids. There was nothing for kids to do. The TV was almost always

broken. The blinds were often broken and stuck shut. There was not even any daylight. the internet wasn't working and we were in isolation all the time. It was crazy. A couple of times he was in source in 6A. It was hard.

67. The loss of the facilities that he had in ward 2A and 2B had a big impact on [redacted]. It made him quiet. We would just play silly wee games. It makes me want to cry when I think of it. It was just me that he had. It's not the same as having the other kids. He lost a lot. There were no play support ladies to sing and dance. That was all gone. He was with me, in the room 24 hours a day playing whatever, snakes and ladders. He'd sometimes sleep just to pass the time. We'd watch TV if it was working; the picture was sometimes upside down or it wasn't working at all. You couldn't make it up in a new hospital.

Completion of [redacted]'s treatment: March 2020

68. [redacted] finished treatment in March 2020. He had his port-a-cath removed in September 2020. He had that until 30 September 2020; it was supposed to come out when he finished his treatment in March 2020. However, due to the pandemic it wasn't classed as emergency surgery and he had to wait. He still attends the adult hospital for check-ups.

WATER: EVENTS INVOLVING WATER SYSTEMS

69. I have been asked whether I have any recollection of specific incidents or concerns involving the water system at RHC or QEUH. I remember that there were issues with the water right from the start.

Water incidents in RHC: 2017 - 2018

70. During [redacted]'s first inpatient admission in early 2017 there was a time when I took a shower in room 9 in ward 2A. I don't know why I remember it. We'd just moved there from room 1 in ward 2A. Room 9 is en-suite. I was

washing my hair and heard Graeme, my partner, shouting ‘turn the water off!’. When I looked, the full room was covered in water. It ran under the door and was running into the ward. The drain was completely clogged and water was running right out of the room. It went into the patient bedroom where [redacted] was and into the ward. The nurses came in with loads of towels to soak up the water. We were told that maybe the drain had been blocked. Someone came and took it apart to try and fix it. I don’t know if that flooding happened anywhere else in the hospital.

71. I remember other issues with the water. At some point in 2017, there was a bathroom in ward 2A which was closed. There was a sign in the bathroom saying it was out of order and not to use it. It was away up at the other end of the ward. It was a wee room on its own. This was definitely in 2017, I’m not sure of the exact date; it was during one of [redacted]’s many admissions that year, I know that.

72. I cannot recall the exact dates but there were other things which happened relating to water. There was a water cooler that I always used to get a drink of water from but it was out of order so then we went up to day care and *that* water cooler was out of order as well. The next time we went up all the water coolers were gone too.

73. We started noticing that filters were getting put on all the taps. In 2018, during a clinic appointment in 2B, we were in one of the rooms with a nurse and all of a sudden a guy walked in and started fitting a filter to the tap so we asked what was going on. The person who was fitting the filter just said it was to try and get clean water or something.

74. At some point, when we were in ward 2A, we were told not to use any of the water for showers. There was an ‘out of order’ signs on the door of the room where the bath was. We were told not to use any of the water to wash our

hands, brush our teeth or shower. That's when we got the bottled water. When we were inpatients we were told not to use the showers and things like that. That is why we were given bottled water to wash [redacted]. They would drop off big two litre bottles of drinking water for us to wash him with and brush teeth and things like that.

75. I saw things in the building, like the water filters being added to taps. The workmen had to re-do the filters, I think about every 4 weeks.

76. Similar things also happened in wards 3A, 3B and 3C during all of the admissions in 2018. When we were inpatients in the other wards, 3A, 3B & 3C, the kids from our ward (ward 2A) weren't allowed to use the water but the kids who were the usual patients were still using the water then as normal. They have still got filters on their taps though.

77. [redacted] used the hydro-pool a good few times, in 2017 and 2018. I cannot remember all the times he used the pool but he definitely used it on 8 August 2017, 22 August 2017 and 27 February 2018. It is on the ground floor of the RHC, in the physiotherapy department. He used it due to his sore legs; he could barely stand, and couldn't walk for some of the time. He was in a wheelchair for a good while. The pool had heated water and [redacted] did his exercises. It was to get him moving again and build up his muscles. He had hardly any muscle in his legs as he just hadn't been weight-bearing or walking. When he used the pool the central line had just been removed. We stopped using the hydropool when all the issues with the water were coming to light in the news.

Water incidents in the QEUH (adult hospital)

78. The water in the adult part of the hospital was just the same. The only difference was that we could use the showers in ward 6A. Filters were on all

the taps and we were told not to use the water. It was the nurses that told us not to use any of the water but we were never told why. There were no signs up, it was just the nurses that told us.

Water: communication

79. I have been asked if I remember what we were told about the water issues.

80. At first, we were told nothing about the water. I was using the water, especially in ward 2A at start of [redacted]'s treatment. During the first inpatient admission at the start of 2017, we were using water as you would in any hospital. We never knew about any concerns at all with the water. We washed dishes, we washed our hands and we brushed our teeth. [redacted] was in a bath almost every night. We were told to try and give him a bath to ease his joints and the pain in his legs. This was when he had his central line in. We were never warned at all. At that point nothing indicated that we shouldn't use the water though. During those first months, there was nothing about us not using the water. It was after that we were told not to use it.

81. It was in 2018 when it all first started coming out on the news about the water. I'd say in maybe February/March 2018 it all started changing. Filters were being fitted on taps around the same time and that was also when the water coolers started to disappear in 2B and the foyer. When we were inpatients we were told not to use the showers and we were given bottled water.

82. I do not remember the hospital telling us anything about the water. We just were aware there was something in the water, a bug or germ, coming from the water, and the filters were there to stop it coming through the supply. This never came from them, it came from the news, not actually from *them*. They have never told us what it was; they've still never told us. They just

said ‘don’t use it…preventative…don’t use it’ but there’s never been a *why* we’ve not to use it. If you asked it was just said that it was preventative measure to do with what’s on the news, that’s what you’re told.

83. One day I was on daycare Ward 2B with [redacted] and I picked up a leaflet that was sitting out for people to take. It was from the hospital and it was about the water. It was along the lines of ‘you have probably heard on the news about the water’ and they reassured us not to worry. They told us, ‘well, you know what’s going on’ but we didn’t know *from* the hospital we were attending every week, it was crazy. I was mind-blown really. Still we weren’t being told anything, just what was already on the news. It was like they were scared to tell you. You get that feeling from the staff, they didn’t know and we were thinking, wow, really? It was scary, really scary.

84. I don’t think that the hospital staff always knew what was going on either. I was invited to a meeting with Professor Gibson in 2019, it was before [redacted] finished treatment and around about the time the water issues were in the news. I thought it was going to be a meeting to tell parents about the water issues, but it was actually about the proposal to lower the time that boys received treatment for ALL. Girls receive treatment for 2 years, boys receive treatment for 3 years and the meeting was about a study looking at reducing the time for boys. Professor Gibson began the meeting by stating that she was not going to tell us about the water as she didn’t know about it either.

85. We found out about concerns with the water from the news and other parents talking about it or saying their kids have got these infections. I thought the reason was because of the water and that was why these kids were getting sick and dying; I began to think that the water’s got something in it. I thought it was because it was built right next to a sewage works. Could it be something to do with that? When you got out in the carpark you

were just hit with this smell, it was horrible. In your mind it's all speculation because you don't know. You're just thinking you don't know what it is and nobody is really telling you. We were scared, absolutely terrified to go in the place. You felt angry that they weren't telling you about why were we getting put into a place where we were risking our child's life just by being there. You're dodging bullets the whole time.

86. The parents were using the water and washing with it as well. It was like a lottery, with the water, whether you caught something or not. Knowing what I know now, it was like a lottery with [redacted]'s life. We weren't told anything about the water.

87. In a way, I think [redacted] might be one of the lucky ones because he just had one infection; that we dodged that bullet. I've seen other kids who haven't been so lucky but we were all there at the same time. That will live with me forever. When I think of it like that it's scary. I was putting him in the bath every day, not knowing any of this was going on. So, I was putting him in danger just by putting him in the bath and by letting him brush his teeth. If I'd have known, he wouldn't have been anywhere near the water.

88. Overall, I would describe the communication about issues with the water system as extremely poor, really, really poor. It's made me feel that the hospital wasn't fit for purpose and that we should never had been there. We live in [redacted] and go to Forth Valley Royal Hospital normally, so we are pretty central between Glasgow and Edinburgh. I wished and wished and wished that we'd been put into Edinburgh. The distance between the two is hardly anything. Glasgow's supposed to be this *super-hospital* and at the time, we think, 'great', it's supposed to be fantastic. I've never seen any of that, *super-hospital*. I just wish we'd been put to the hospital Edinburgh.

89. The issues with the water and poor communication had an emotional impact on us. We were scared, absolutely terrified to go in the place. We felt angry that they weren't telling us about why we were getting put into a place where we were risking our child's life just being there. I say more about that below.

HEALTHCARE ASSOCIATED INFECTIONS

HAIs: events and physical impact

90. As far as I am aware, [redacted] had one healthcare associated infection. That was the staph infection he contracted in February 2017. I have described the circumstances of that infection in more detail above. The physical impact of the infection meant [redacted] was tired. He was in bed a lot and he had the shakes initially. He wasn't great. If there were other physical effects on [redacted] then I couldn't really say because we didn't really know much about it at that time.

HAIs: communication

91. I have been asked what we were told about the staphylococcus infection which [redacted] contracted in February 2017. I never knew much about the 'staph' infection. The hospital just told us one time that [redacted] had a 'staph' infection in his line. That is all we were told. I remember it was the nurse that told us about the infection but said the source had not been identified. The doctor does a round in the morning and you get swabs taken. The doctor didn't go into any detail about it. He said "we'll do this and that" and that was about it basically. [redacted] was put on antibiotics at that point but I don't know what kind.

92. We were never told of the likely source of the staph infection. I honestly don't know where it came from. It could have been anything. From what we've heard about all the things that went on in there, we're never going to be told. It's one of things we've accepted; that we'll never know.

93. When [redacted] caught the parvovirus in March 2018 it was the same, we were never told how he picked it up. [redacted] was ill, he got antibiotics. He was really ill then and that delayed his chemotherapy then too.

PREVENTATIVE MEDICATION

Preventative medication: events

94. I have been asked whether [redacted] was given any preventative medications. I think that [redacted] was given preventative antibiotics although we were not told much about it at the time.

95. All of the child cancer patients are usually started with Septrin. Septrin is to stop the growth of bacteria or fungus in the lungs and to prevent pneumonia. [redacted] got that the first day he started treatment. They said all the kids were the same. He got that on a Friday or Saturday, once a week. I think that was protocol that they were put on that but [redacted] took a reaction. The Septrin was keeping his blood count down. They had to stop his chemo when that happened. The Septrin stopped, I think in January/February 2018. They put him onto a new one, Dapsone. I think that's to stop pneumonia but [redacted] took a reaction to that too. It badly affects a very few cases, and [redacted] was one of them. It turned him blue, it affects blood/oxygen levels, they go really low. I think he was on that for 3 or 4 weeks. He got that when he had the parvovirus in March 2018. He was then put on Atovaquone right up until March 2020 when he finished treatment. I think Atovaquone was to prevent bad chest infections. I thought they were to stop pneumonia developing in the lungs. [redacted] was then put back on Septrin in March 2020. It didn't matter if his counts were lowered, because for the next 3 months he still had to take Septrin.

96. At some point [redacted] was put on another drug called Ciprofloxacin (Cipro). I was told that Cipro was to "cover his line". I am not sure when [redacted] was first given

Cipro. I know he was taking it in 2018. I'm sure it was at the time when they started putting filters on the taps in the wards. I never even thought to keep note of it because we were just told the new medicine was part of the treatment for ALL. We didn't think anything of it at the time. [redacted] was always getting different medicines so we didn't question it. We shouldn't have to question his treatment. One of the doctors, Professor Gibson, at the clinic told us that he was getting the Cipro. We'd go to the pharmacy to get his monthly supply and it was just added into that. We weren't told anything more about it. It was just a new medication, an antibiotic. I'm sure I remember it was 'to cover the line'. [redacted] had his port in then, so we were told it was only for children with a line who got it. We were told kids without a line didn't need it. We were not told exactly what it was for. Other parents were talking and were concerned about it, that it was linked to the water. They had researched it so I did too. I discovered that it had side effects, sickness, heartburn, stomach pains.

97. [redacted] was on and off the Cipro until he finished treatment in March 2020. I don't know why he would have been off it from time to time. I have no idea. We weren't told.

Preventative medication: physical effects

98. I think the Cipro affected [redacted] physically. All the side effects have really affected him in the long term. [redacted] stopped his cancer treatment in March 2020 but he still goes monthly to clinic as an outpatient and is waiting for a gastro referral. He still has problems with his tummy and his legs. He usually goes monthly for check-ups and bloods to be done. I think that usually, treatment goes down from once a month for 3 months, then every 3 months, then 6 and then yearly but [redacted] has continued to be seen monthly because of his tummy problems. It's not unusual for them to get side-effects. I didn't question it. He still goes to physio for his legs too. The

issues with his legs might be linked to a toe injury that he had but I don't know.

99. [redacted] experienced really bad side-effects from the Cipro. They include sickness, bad heartburn, indigestion, sore tummies. He still has these side effects and is waiting for a gastro referral. We've never been given a reason for the side-effects. There hasn't been any investigation into that yet, not for the gastro team or about his legs. We don't really know if it is related to the Cipro or if it is just side-effects of treatment. However [redacted] did not have any of these issues until he started taking Cipro, it all began after that.

Preventative medication: communication

100. I think that we were told about the Cipro by a doctor, I cannot remember their name, during one of [redacted]'s out-patient appointments It was just one of his check-ups. I think we were told that [redacted] was getting it to cover his line.

101. At the time, we didn't put two and two together. Nobody told us about possible side-effects. We heard some things from other parents. I started to Google it. It was crazy. I found it out it was a prophylactic which was to stop infection caused by contaminated water supplies. Alarm bells started ringing. We did what were told and we didn't ask questions. I was scared of him catching something so I didn't want him to come off it. I was probably quite naïve about it. The other parents were maybe more switched on and then I started to wonder about it all. I didn't raise concerns personally but I know others did.

102. There were news reports about the water at the hospital, about patients contracting infections, patients being admitted to ICU and some patients dying from these infections. Parents were up-in-arms about the news stories. We wondered, 'what is going on?' I think it's crazy we got all this from the

news. We had to rely on the news stories when it was the Hospital that should have been telling us.

103. I felt it was mind-blowing, we still weren't being told everything, they were changing medicines but didn't tell us why. We got the feeling from some staff that they didn't know what to say but they were being sent in to tell us. We didn't know what to feel, we just knew what we saw on the news and it was scary. It was like nobody really wanted to tell us what was going on. It was horrible, scary, really scary.

104. Eventually we found out the children were on the new antibiotics because of the problems with the water. I think one of the doctors, Professor Gibson, who told us why they were on the new antibiotic (Cipro). It was because of the problems and the things we'd seen on the news, not what *they* the hospital had told us about. I think it must have been Professor Gibson who told us what they did share. We saw her a lot at that time. Unfortunately, I can't remember exactly when we were told that.

OTHER ISSUES RELATING TO HOSPITAL CONSTRUCTION

Hospital build issues: impact of construction works

105. I have been asked if I remember anything about construction works going on at the hospital.

106. It felt as if there was always works going on in the hospital. It got to the point that you were told not to use certain entrances. They were cordoned off for work being done. Even now, there's work being done. There is always scaffolding up somewhere. We were never told about it except when we just got a sheet of paper saying come in using a different entrance. The kids' entrances were shut so we had to use the adult entrances. I remember after the Grenfell fire one of the other parents told me that the hospital had the

same sort of cladding. That had to be changed. He was in the buildings industry and we were stood looking out of the windows as the building was surrounded in scaffolding.

107. The biggest impact came from work on the wards. There was work always going on in the wards too. I think that impacted our experience at the hospital. I think that was the reason [redacted] was sometimes put on other wards, not on ward 2A. I think it was around the end of 2017 into 2018 when I saw works going on in ward 2A. They would cordon off rooms. There was a wooden box being built around the doors and the rooms were completely emptied. Windows were blanked off so you couldn't see what was going on. Guys with big white suits would be there in ward 2A. Sometimes we would be moved out of a room because there was work going on. There were big orange plastic sheets that get zipped up, going up around the room.

108. I also saw similar work happen in happen in ward 6A in the adult hospital but I didn't see it anywhere else in the RHC, apart from ward 2A. At the end of 2019, they were still cordoning off rooms.

109. I think that we were impacted by these works. Sometimes we had to change rooms within ward 2A. Sometimes we were moved out of ward 2A and other times we were not put on ward 2A in the first place.

110. Ward 2A is one of smallest wards There are only 26 beds. Some are for patients like [redacted] who are not in strict isolation rooms. Three are for teenagers so they can't be used for patients like [redacted]. About 8 are strict isolation rooms That means 11 out of 26 rooms that can't be used for patients like [redacted]. When some are blocked off there are even fewer rooms available. They were working with so many fewer beds which then meant you had more chance of being put into another ward. Some of the other wards had about 40 beds. It doesn't bear thinking about what it was like.

111. We were given hardly any notice if we had to move. We were just told there and then. We would maybe be told we had to move within the hour. The nurses would come in and tell us we were moving. When you're in a room for a while, you've got lots of stuff with you like toys and books. We would have to pile it all onto the bed beside [redacted] and push the bed out into another room.

112. When we were moved I didn't know what was actually going on. It was funny because you just grew to accept what was going on. You didn't even think this wouldn't be going on in other hospitals. It was just normal. Is this what goes on, is it normal? Probably not.

113. Moving wards impacted [redacted]. He knew what it would be like in other wards; he hated it there. He didn't know anybody, it was horrible for him having to go. He was getting older and knew he wasn't safe in another ward. He'd be crying. It was hard. But we just had to go, that was it. The nurses would come in and tell us we had to move. A lot of the time they knew the kids would be upset by the move, but they'd been told by someone further up than them that we were moving. It happened quite a lot, quite frequently. Sometimes to another room in 2A or to another ward. There was never a reason given, sometimes we thought someone else needed the room more than us, we just didn't know why.

Hospital build issues: physical effects

114. I do not think there was much direct impact on [redacted]'s physical health as a result of the build issues. That impact was mainly because of his treatment. His mental health has definitely been affected.

115. I should maybe say that there was an incident that might be relevant though. He injured his toe and it wasn't taken seriously. He had weak legs and his legs collapsed one day when he was in the bathroom, he fell and hit his head and his toe. On numerous occasions I asked staff to look at it but they wouldn't. I was worried about it but staff would say it was fine and shrug it off. After that, he never walked again for 9 months and ended up in a wheelchair. His muscles wasted and his bones got so brittle, his bone density reduced. He needed calcium drawn into his bones and that hurt. He ended up on different medication to tackle that. All because he fell and hurt his toe. I took pictures, I ask myself why nothing was ever done about that toe.

CLEANLINESS

116. I would like to make some observations about cleanliness in the hospital. As far as cleaning goes, personally, I would take my own cleaning stuff in clean things myself, especially the bathroom. We always kept cleaning wipes in the hospital bag and I used them wherever I needed to, that was in all wards in the hospital. I would clean the table that [redacted] ate off and all the handles. The cleaner's mop just looked like a dirty mop. It had a really thick bleach smell. They'd mop your room with it and put it in the bucket then move to the next room I assumed. They were cleaning the rooms but it wasn't clean, I would say. The cleaning was exactly the same after the move to the adult hospital. Things would not be cleaned up until the next time they were due in. So, for example, if [redacted] got a blood transfusion, there would be blood spilt all over the floor, next to the bed and it could be left until the next day. Some of the kids don't like to see the blood so they would cover it when the blood was being given by a transfusion, the bag was covered. I didn't want to touch it either because it's blood.

OVERALL EMOTIONAL IMPACT ON [redacted] AND HIS FAMILY

Overall emotional impact on [redacted].

117. I have been asked to comment on the impact which the issues I have described above had on [redacted]. When we were in wards 3A, 3B and 3C, the other children's wards, the loss of the facilities had a big impact on [redacted]. We'd watch TV if it was working but sometimes the picture was upside down or it wasn't working at all. Sometimes the blinds weren't working and you couldn't see any daylight. You couldn't make it up.

118. As [redacted] got older, he started noticing more about what was going on with the taps. The emotional impact got worse as he got older. He would ask why he couldn't have a bath and why he needed to be washed with bottled water or to brush his teeth and so on. At times he stopped interacting with the staff, he was inside himself. He wouldn't laugh or smile, he wasn't like himself. It was really hard on him. I don't know if he'd seen the news or maybe even someone at school had said, 'that's the hospital you go to'.

119. It was funny because he never once asked if he was going to die of the cancer but he started asking if he'd die if he drank the water. It was crazy. He just wasn't himself. He was always worrying about things. Even now, I'd say he's a worrier. If we are out and about, he won't even use a tap in [redacted] hospital. We never had a problem with their water but he's taken that with him to other places, maybe even to school.

Overall emotional impact on witness

120. The experience affected me too. I found it hard and upsetting. I used to phone my mum and just cry because I just wanted to get out. It felt like prison and to see [redacted] like that meant I had to try and make it seem like less of a problem than it was, for [redacted]'s sake

121. I suffered greatly from anxiety throughout the whole thing. I was afraid of taking [redacted] in there. When I saw things in the news and read online articles, I would worry that he'd have a temperature spike. It's absolutely shocking.

122. I also have a sense of guilt. I put him in that water not knowing it unsafe to do so. It's hard, even now. After all this time, I still have that guilt. It's something I don't think I'll ever get over. I feel like I unknowingly put his life in danger, giving him the bath, brushing his teeth. It makes me feel physically sick. I don't think it will ever go away.

123. I was affected by seeing these kids dying. I feel like we never should have been put in that hospital. You think having a child with cancer is the worst, well imagine having him in that hospital. You think that the cancer is going to kill him but to think that it could be the water, it's just crazy. It makes me really angry. I feel like these people should have been the good guys looking after him and they weren't telling us. There were kids not going home. My mind doesn't want to go there anymore, it was so dangerous without us even knowing, we never knew. Putting [redacted]'s life at risk every time he had a bath or brushed his teeth. It was like dodging bullets all the time.

Overall emotional impact on family members

124. My partner, Graeme, was diagnosed with depression, and is on medication still to this day. He saw me having anxiety about going in there and he was the one trying to stay strong for everyone. The man's got to be the strong person. It affected him as well. He tried to keep it together. It's men's mental health, it's not really spoken about. The mental health person at our GP practice diagnosed him with depression.

125. [redacted]'s brother and sister were not affected too much. They are younger than

[redacted] so not much impacted on them. They were with Graeme at the time. Obviously they saw us going through stress. They'd get passed around a lot, between my Mum and Graeme's Mum. I think they were young enough to be quite resilient to it all. My younger son, he wasn't even 1 year old then and my daughter was still able to go to school and keep her after school activities going.

COMMUNICATION: GENERAL

126. I think the communication about [redacted]'s treatment was actually okay. We knew what was going on and what was next on the protocols. We always knew what should be coming next so were quite happy with that aspect.

127. Communication about other things that were happening at the hospital was really just poor, non-existent. The communication about issues with the hospital and the water was really poor. Why were we even in that hospital?

128. During the time when there was a lot of news reports and when parents were speaking out about their concerns, I remember that there was a meeting hosted by Jeane Freeman, who was the Health Minister at the time. I didn't arrange the meeting personally, I think one of the other parents did and I was able to attend along with other parents. I think it was in 2019 in a big Glasgow hotel. I went to that meeting. She made out as if she was really shocked about what was happening but later we found out she already knew about all the problems. All the parents were there. It was like a big circle time with the parents. She said she didn't know about the issues. These things were all going on and we didn't know anything. Jeane Freeman came across as if she'd never known but we found out later that she already knew all about the problems. To be honest, we just came out of that meeting feeling even angrier, and the same with the meetings with people in the hospital.

129. Shortly after that I went to a meeting with the Labour MSP Anas Sarwar. It was a group of parents who were concerned about what was being reported in the news, and who had concerns about the hospital. The purpose of the meeting was so we could tell him about our concerns, and he said he would bring it up in Parliament for us. He did raise our concerns in Parliament, I saw it on the TV a few times, on the news.

130. We met higher up people in the hospital too. I think it was the Health Board. It was a panel of people and we could ask questions. [redacted] was an inpatient in ward 6A at the time. It was held in the university part of the hospital so we went down there. It would have been 2018. It could get quite heated and some parents got upset that their kids were on these preventative medicines. All they could say was ‘we’re sorry’.

131. At the meeting with the Health Board, it felt like they came armed with spreadsheets. They had a PowerPoint, to go through this and that. They couldn’t really answer the question, not about *why* it had happened. It felt like it was just them just saying sorry, they can’t really answer the questions. They told us *nothing* about *why* it happened. They told us things about the building of the hospital, water supply, ventilation and all that kind of stuff. I didn’t understand a lot of the stuff about building’s construction. It was well over my head. I think unless you were a builder you probably wouldn’t have understood; some of the parents did though.

132. I feel that the communication about what was happening with the hospital should have been a lot better. When this was all in the news, I feel they should have spoken to us. Someone who knew what was going on should have told us about it. I feel that even the nurses didn’t understand what was going on. They didn’t know what to say. When it was going on those higher up in senior management in the hospital, or those on the health board should

have told us exactly what was going on instead of them lying about what was going on with water and ventilation and covering it up. We just never knew. That stress felt as stressful as your child having cancer. They made out that they didn't know; that there was nothing wrong and we were just not to use the water. I felt the medical staff didn't always know what was going on with the water and ventilation.

133. I do not feel communication has changed that much. The hospital have set up a Facebook page and a help board there. It goes directly to the hospital. One of the men whose daughter's in the Ward is good at going forward with anybody's concerns, John Cuddihy. If there's anything going on, he'll take it forward.

134. I'm a member of the Facebook group. You get a lot of information from it, especially as an outpatient. Like when they expect ward 2A to re-open. Parents can ask questions but I'm not sure who replies. To my knowledge it's from NHS GGC, Haematology. I've not asked any questions but have seen other people's questions and read the responses. The Facebook group is a positive thing, definitely. For example some complaints about the food have been taken on and they've introduced a lunch cart with wraps, snacks and things, so really helpful for things like that.

135. The hospital still hasn't really told us things about the building. They direct us to reports, to see the findings and things like that. Professor White has been involved. I haven't had direct contact with him but concerns are made like a collective group on email. He'll get back to them. I'm not sure if that's done through the Facebook page. I really don't know if that kind of contact has improved.

136. The press coverage affected me greatly. I would also see things on Facebook. I'm on the STV news link. It's scary hearing about kids dying.

Loads of people comment saying ‘this is all fake’. You could reply saying it isn’t fake but they’d just think we’re overprotective parents. If they were in the position we are, they’d be exactly the same. It felt like it was never off the news at one stage. It’s hard reading it and stuff on TV as well.

137. It can feel like there’s something new in the press all the time, like the pigeon droppings. It felt like we were living a joke and were getting no answers from anybody except from the news. I never heard anything from the hospital before it was in the news. The first I heard was on the news and then we started seeing things happening, like when we started seeing the water coolers disappearing and the tap filters.

138. I think communication in relation to the staph infection, the water issues and the move from ward 2A could all have been better. I think communication is better now that it was. Now we are not there as much, we are not in throes of the treatment and we don’t need as much communication with the hospital. What we’ve got is sufficient for us. I cannot speak for people that are going through treatment now.

COMPLAINTS

139. I did not make any complaints to the hospital. I was scared. These people were saving your child’s life. At the end of the day, you just take it and that’s it. I would not want to compromise care in any way. It was one of the hardest bits, not knowing what was going on. You didn’t want to feel like they were keeping things from you. These were people that we trusted with my child’s life, I didn’t want to think they were keeping things from you that they shouldn’t have been.

OVERSIGHT BOARD / CASE NOTE REVIEW / REPRESENTATIVE GROUPS

140. I have heard about the Oversight Board but haven't been part of it. I'm not part of any family representative groups either but I am a member of the Facebook group.

141. [redacted] was not included in the Case Note Review. I do not think we will ever know what caused the staph infection.

CONCLUDING COMMENTS

142. If someone asked me if I wanted to go to that hospital over any other one, I was say absolutely not. If we could be finished and done with that hospital forever and I never needed to step foot in it again that would be the best case scenario for me and for [redacted].

143. It is described as a "super hospital". I don't see any kind of resemblance to a super hospital there. The staff, you could not fault them in the slightest. But the problems that happened at the hospital, it doesn't bear thinking about. Even just talking about it, it is not nice opening up those memories and remembering what actually went on at the time and the fears you had. I don't think it is fit for purpose and it should never have been opened.

144. I feel that the Health Board and hospital management lied to us. They made things a million times worse when they didn't need to. They could have told us what was going on and just been honest. I would rather they were honest. I was shocked at what I heard, but I would have been better knowing that I had been told the truth rather than sitting there not knowing anything, and being told nothing. I would rather have had the truth and dealt with it, and not them covering things up and not telling anyone anything.

145. I have ongoing concerns about the safety in the hospital. In Ward 6A they are still zipping up and sealing off rooms. They still have filters on the taps. We are not in the hospital much anymore especially up in the ward, but if I am in there I still wouldn't use the water even if they told me it was safe. They told me it was safe in 2017.

146. I really don't know how they could make us feel any different about the concerns I still have. It may be different for new patients and families who have not gone through all this. They might believe them more. But I was there at the time and I don't think they can do anything to make me feel any better now. I don't believe anything that was said, so I still would not use the water. I would still be wiping [redacted] down to get him washed because I have absolutely no trust in that place at all. It is scary to think that is a children's hospital. It is somewhere that you are supposed to feel safe. It is somewhere you are supposed to go to get better.

147. I believe that the facts stated in this witness statement are true. I understand that this statement may form part of the evidence before the Inquiry and be published on the Inquiry's website.

APPENDIX 1 – SB/01 – Timeline

2016 /2017

30.12.16 - 21.2.17 - ward 2A inpatient

2017

14.03.17 outpatient ward 2B

21.02.17 outpatient ward 2B

22.02.17 - 05.03.17 - ward 2A inpatient

07.03.17 outpatient ward 2B

10.03.17 outpatient ward 2B

05.04.17 outpatient ward 2B

11.04.17 outpatient ward 2B

19.04.17 outpatient ward 2B

02.05.17 outpatient ward 2B

19.05.17 - 22.05.17 - Ward 3 A,B,C inpatient

21.03 17 outpatient ward 2B

28.03.17 outpatient ward 2B

09.04.17 outpatient ward 2B

25.04.17 outpatient ward 2B

15.05.17 outpatient ward 2B

25.05.17 outpatient ward 2B

31.05.17 outpatient ward 2B

07.06.17 outpatient ward 2B

12.06.17 - 13.06.17 ward 2A inpatient

20.06.17 outpatient 2B

22.06.17 - 28.06.17 ward 2A inpatient

03.07.17 outpatient 2B

11.07.17 outpatient 2B

18.07.17 outpatient 2B

27.07.17 outpatient 2B

08.08.17 - 10.08.17 Ward 1E/1A inpatient

08.08.17 outpatient 2B

22.08.17 hydropool

01.09.17 outpatient 2B

11.10.17 outpatient 2B

28.10.17 - 31.10.17 ward 2A inpatient

14.11.17 - outpatient ward 2B

14.11.17 - 15.11.17 ward 2A inpatient

16.11.17 - 18.11.17 ward 2A inpatient

20.11.17 - 24.11.17 ward 2A inpatient

06.12.17 - 09.12.17 Ward 1E/1A inpatient

11.12.17 - 13.12.17 CDU admission - inpatient

12.12.17 - 14.12.17 Ward 3 A,B,C inpatient

2018:

09.01.18 outpatient 2B

06.02.18 outpatient 2B

27.02.18 outpatient 2B

27.02 18 hydropool

17.03.18 outpatient 2B

18.03.18 - 20.03.18 Ward 3 A,B,C inpatient

21.03.18 - 24.03.18 - Ward 3 A,B,C inpatient

21.03.18 outpatient 2B

24.03.18 - 06.04.18 ward 2A inpatient

13.05.18 - 15.05.18 Ward 3 A,B,C inpatient

20.05.18 - 22.05.18 Ward 3 A,B,C inpatient

29.05.18 outpatient 2B

31.05.18 outpatient 2B

19.06.18 - 21.06.18 ward 2A inpatient

03.08.18 - 07.08.18 ward 2A inpatient

08.08.17 hydropool

31.08.18 - 04.09.18 ward 2A inpatient

31.08.18 outpatient 2B

02.10.18 outpatient 6A

10.10.18 outpatient 6A

30.10.18 - 05.11.18 Ward 6A inpatient

13.11.18 outpatient 6A

2019

26.03.19 outpatient ward 6A

27.03.19 outpatient ward 6A

03.04.19 outpatient ward 6A

23.04.19 - 25.04.19 Ward 6A inpatient

28.05.19 outpatient ward 6A

06.06.19 - 10.06.19 Ward 6A inpatient

18.09.20 outpatient ward 6A

01.11.19 - 04.11.19 Ward 6A inpatient

18.11.19 outpatient ward 6A

10.12.19 outpatient 6A

16.12.19 outpatient 6A

2020

08.01.20 outpatient ward 6A

20.02.20 outpatient ward 6A

Scottish Hospitals Inquiry

Witness Statement of

Graeme McCandlish

WITNESS DETAILS

1. My name is Graeme McCandlish. I was born on [redacted]and I am [redacted].

2. I am the step-father of [redacted] [redacted] who is the son of my partner, Suzanne Brown.

3. I live with Suzanne and our three children, [redacted], aged 11, [redacted], aged[redacted]and [redacted], aged [redacted]i [redacted] [redacted].

OVERVIEW

4. My step-son, [redacted] [redacted] was 6 when he was diagnosed with ALL (“Acute Lymphoblastic Leukaemia”). That was in December 2016.

5. He was treated in the Royal Hospital for Children (“RHC”) and the Queen Elizabeth University Hospital (“QEUH”) in Glasgow between December 2016 and March 2020 when his treatment finished. He still attends the hospital in Glasgow for check-ups.

6. Suzanne has provided a timeline for the dates when [redacted] was in the hospital as an in-patient and an out-patient. I am aware that [redacted] was treated in several wards in the RHC and the QEUH including wards 2A and 2B which are in the Schiehallion Unit in the RHC, several other wards in the RHC and ward 6A in the QEUH. Suzanne was with [redacted] for all of his admissions as I was taking care of our other children and she will be able to confirm all of the wards he spent time in. [redacted] had over twenty in-patient admissions over the entire period

of his treatment; it was over 100 nights in hospital and he stayed in lots of different wards.

7. There are some specific events that I would like to mention. [redacted] contracted a "staph" infection in February 2017. There were issues with the water throughout [redacted]'s treatment at the children's and the adult's hospitals. I believe that [redacted] was prescribed preventative antibiotics in 2018 which may have been connected to issues with the water supply. I thought that the communication about what was going on with the hospital building was poor. I will come on to talk about these events in more detail.

FAMILY BACKGROUND

8. I live with my partner, Suzanne Brown and our three children [redacted], aged 11, [redacted], aged [redacted] and [redacted], aged [redacted] in [redacted], [redacted]. [redacted] is really into playing with his PlayStation, playing fortnite and football. As a family we like to go to the cinema and going out to trampoline parks.

SEQUENCE OF EVENTS: December 2016 – March 2020

9. [redacted] was admitted to ward 2A of the RHC in December 2016. Ward 2A is part of the Schiehallion unit and it treats children who have cancer. I stayed on the ward the first night and then went home. The second night I went home because I had to get the kids but when I took them to school the next morning I went back up to the hospital during the day. Ward 2A was miserable, especially when [redacted] was in isolation, he wasn't allowed out the room. Some of the blinds didn't work in the room and being in there felt like being confined.

10. [redacted] was discharged from hospital in February 2017. We came home but he was re-admitted the next day. We went into ward 2B where [redacted] was getting a check-up. We ended up back in because he had a temperature spike when we got home after the check-up. I went with him that day when he was re-admitted to 2A. When you go back in with a temperature spike the first thing they do is put you straight onto antibiotics. After he was re-admitted I went home every night to look after the kids. That was the way it mostly was. Sometimes Suzanne's mum and dad would help when they weren't working. My mum would take [redacted] when they weren't working as well. I only ever stayed overnight once. That was in ward 2A about the start of 2017. Otherwise, it was mostly Suzanne that stayed overnight.

11. When [redacted] was readmitted in February 2017, he was diagnosed with a staph infection. He was put on antibiotics but I don't know what kind.

12. During 2017 [redacted] had various in-patient and out-patient appointments.

13. After [redacted] was discharged and he was an out-patient, I would take the kids to school then me, Suzanne and [redacted] would come through to Glasgow to the RHC to his clinic appointments. Some days you could be in and out and other days you could be there for hours, it all depended on how busy the hospital staff were.

14. When [redacted] was in in-patient care I went to the hospital every day, but I mostly had the kids and had to come back before 3 o'clock for the kids. Suzanne was with him for all of those admissions and she can give fuller details in relation to these admissions.

15. In 2018, [redacted] was in daycare in Ward 2B at the time we began to notice that the hospital staff were packing up stuff in the ward. He was in receipt of weekly treatment as a day patient. We could see big wooden boxes being put

up outside rooms in the ward. Rooms were bring shut down. We were told "they were being fixed" but no one explained why or what was wrong with the rooms.

16. Shortly after that, we were told we were moving to 6A in the QEUH for a couple of weeks while some work got done in 2A in the RHC. [redacted] spiked a temperature shortly after Ward 2A was moved to ward 6A in the QEUH. On this occasion we went to A&E, passed through CDU and then [redacted] was admitted to ward 6A. It was an adult ward. It was the same admissions process as going to Ward 2A. Once he was assigned a room he was given paracetamol to control the temperature and other medications. Suzanne stayed with [redacted] during this admission. I was at home taking the other kids to school and looking after them. I'd come down in the evenings when I could. I had some experience in Ward 6A but Suzanne had more.

Experience in Ward 2A

17. When [redacted] was an in-patient in the Schiehallion Unit in ward 2A of the RHC, we used the parent kitchen quite a lot. It was quite a good wee place to just get away to collect your thoughts for a couple of minutes. It was like a place to go and sit and talk to the other parents, a place for you to go and have some time and collect yourself. It was like a wee meeting point for parents.

18. In Ward 2A, [redacted] used the play room quite a lot and played with the volunteer, painted and drew pictures. He quite enjoyed it when he could get out and do stuff like that.

WATER: EVENTS INVOLVING WATER SYSTEMS

19. We thought there was nothing wrong with the water from the taps when was first admitted to ward 2A. We were putting him in the bath and the shower and brushing his teeth. He was using the hydropool to help with the pain in his legs too. We were using it and washing with it as well. We thought things were fine, we didn't know any different. When we first went in we were able to use the tap water and the taps were normal, there was nothing fitted on them. There was a water cooler that I always used to get a drink of water from but it was then out of order.

20. One day we went up to day care and that water cooler was out of order as well, I can't remember the date but it was when [redacted] was getting outpatient treatment so it might have been in 2018. The next time we went up all the water coolers were away.

21. We started noticing all the filters were getting put on all the taps. In 2018, during a clinic appointment in 2B, we were in one of the rooms with a nurse and all of a sudden a guy walked in and started fitting a filter to the tap so we asked what was going on. The people that were fitting the filter just said it was to try and get clean water or something.

22. Shortly after that things started to change. During one of [redacted]'s admissions to ward 2A in the RHC we were told by the nurses not to use any of the water for showers. I can't remember the nurse's name or when this conversation took place. There were 'out of order' signs on the door of the room where the bath was. We were told not to use any of the water to wash our hands, brush our teeth or a have shower. We were handed a bottle of water for washing and brushing our teeth. This also happened in wards 3A, B and C in the RHC during all of the admissions during 2018. We were initially allowed to drink the water out of the taps as normal in other wards, but over time we became aware there was an issue and so stopped drinking from the tap.

23. The water in the adult part of the hospital was just the same. In ward 6A there were filters on all the taps and we were told not to use the water. It was the nurses who told us not to use any of the water. This was in all wards of the hospital. There were no signs up, it was just the nurses that told us.

24. Using the bottled water wasn't the best thing, you were using to wash and it was freezing cold, it wasn't ideal to get a proper wash. We couldn't even heat it up.

Water: Communication

25. We weren't told anything about the water. As I have said, the nurses told us not to use the water, but we weren't told why. The filters were on the taps at the time the information about the hospitals water was in the news, and we started thinking that the filters might have been on the taps because of this. Everything we know just now, we heard on the news. The news knew before we knew what was going on. What we know now from the news is that the water is contaminated and that this had led to infections. The children were put on antibiotics to protect them from the infections, [redacted] was one of these children.

HEALTHCARE ASSOCIATED INFECTION

HAIs: events and physical impacts and communication

26. I never knew much about the 'staph' infection. In February 2017, they told us there was a 'staph' infection in [redacted]'s line. That was all we were told. [redacted] had been an out-patient for less than a day. We got home, went to sleep, got back up and went back through to Glasgow. It was the nurse that told us about the infection but the source hadn't been identified. The Doctor does a round in the morning and you get swabs taken. You get the results back after 48 hours

and the second day we were in he told us it was a ‘staph’ infection. He didn’t go into any detail about it really. [redacted] was put on antibiotics at that point but I don’t know what kind.

27. I’m not too sure how long he had the “staph” infection for at that time. [redacted] was quite sluggish. He was shaking and he had a high temperature; he was basically unwell. In terms of the impact on his treatment, I can’t remember exactly what happened on this occasion but an infection would take [redacted]’s counts down and that would force staff to stop the chemo. It would depend on how long he had the infection, and that would affect how long the chemo stopped for. The staff would need to give his blood counts a chance to come back up before they could start with the chemo again.

PREVENTATIVE MEDICATION

Physical Effects and Communication

28. Suzanne told me that [redacted] was on Ciprofloxacin (“Cipro”). I recall that she told me that they were putting him on a new medicine that was part of his treatment. They said that all the kids with lines were getting ciprofloxacin and it was part of their treatment. We didn’t know what it was at all but Suzanne was talking to some of the mums about it. What she heard about side effects was quite worrying. Suzanne Googled it and discovered that it was for infections that you can get through contaminated water. This was obviously quite worrying at the time because we had heard there was contaminated water in the hospital. Then all of a sudden we’re getting this medicine that we were told was part of his treatment and everybody gets it and it’s nothing to worry about. This was around the time we were seeing things on the news and it was the one and only time the hospital spoke about it but I can’t remember the details now.

29. Suzanne found out from her own internet searches that it is an antibiotic used to treat infections and one of the things it can be used to treat is infections in contaminated water. It can cause a long list of side effects. The internet search suggested that it was not a drug for long term use. [redacted] was on it for over a year. The hospital didn't tell us that, we found out for ourselves. It goes to show that there was no compassion and no consideration of the impact on [redacted]. At the time, we took the hospitals word for it.

30. Suzanne saw on the internet that the side effects of Cipro included nausea, vomiting, stomach pains and heartburn. There were other ones as well that could result in complications. These were all things we had to find out ourselves. It was Suzanne that told me about all of [redacted]'s medication. Atovaquone was another one. I don't remember any of the other medications, Suzanne will be able to tell you more.

<u>OTHER ISSUES RE HOSPITAL CONSTRUCTION</u>

31. If there was no room in 2A in the RHC we were told we would need to go to 3A, B or C in the RHC, or wherever they had a spare bed in the children's hospital as there was not enough space in ward 2A for [redacted] to be admitted there. There was a bit of concern when we were not in Ward 2A and when we were in other wards.

32. The difference was that in other wards there was nothing for [redacted] to do. There was no play room, the televisions didn't work, he couldn't connect his tablet to the Wi-Fi, he had nothing to do at all. We were sitting there all day and night just staring at the walls. We couldn't even look out the windows because most of the blinds were broken. That had a big impact on [redacted] as well because we would be there for two days sitting looking at four walls.

33. The possibility of being put on other wards was the worst part of the admission for Suzanne. We did not know where we were going to be. We felt

comfortable in 2A because the nurses are all fully trained to look after children with cancer. They know what they're doing. When we had go to another ward and would be basically left to do it all ourselves; we had to look after [redacted]. When [redacted] was to get his medicine me and Suzanne were telling the nurses what medicine he was to get and when he was to get it. We were actually telling them how to do the job because they didn't know anything about kids with cancer and it was really, really scary. That was the worst part of the admission: not knowing where we would be and then worrying when we were admitted to another ward about making sure he had the correct medicines. It was a combination of both these factors that made it so bad. Suzanne is worrier and it affected her.

Closure of RHC and move to QEUH – experience

34. Ward 2A and 2B in the RHC were closed and the children were moved to Ward 6A in the QEUH. There wasn't a parent's kitchen in 6A in the QEUH. There was just a wee room that you could use the microwave so we went down the stairs to Marks & Spencer and WH Smith. That's where we got breakfast, lunch and dinner but there were times when we could order meals when we were in 6A.

35. When we were in 6A [redacted] was allowed out but there was a couple of times when he was in-source which is where you're not allowed to leave your room at all. That's when you notice there's no telly that worked, no proper Wi-Fi, it would either not work at all or it would be extremely slow, there was nothing for him to do. Suzanne couldn't leave the room either and had to buzz for a nurse and rely on other people to do things for her. I don't think 6A was really equipped for children. When we were there, 6A had all the kids from 2A that had been moved. It was still all the same protocols in place so when you were in source you weren't allowed out your room at all.

36. The rooms on 2A were just the same as the adult hospital. You had televisions that the picture was upside down. [redacted] couldn't connect his tablet or his iPad to the Wi-Fi, it was just ridiculous. There was a lot of boredom in wards 2A and 6A. Sometimes in 2A we would have got the television working if we were lucky but there was none of that on 6A. Suzanne was trying to think of things for [redacted] to pass the time but he slept most of the time because he was just lying in his bed with nothing to do. It was worse when [redacted] was in 6A.

CLEANLINESS

37. The children's hospital in general had big clumps of dust floating about the corridors throughout the hospital building. There were wrappers and crisp packets left in the lifts and bottles jammed down the back of the handrail. There was dirt and dust and chewing gum stuck to the floor. It's not what you would expect from a hospital. I would expect it to be cleaner, not spotless but cleaner than what it was.

38. Ward 2A was the same. There was dirt and dust. There were fingerprints on the glass in the doors. It just looked like there was nobody cleaning at all.

39. When we were in source, in 2A, we couldn't leave the room, not even to put a tray back in the rack or take dishes to wash them in the kitchen, so we had to buzz to ask somebody to take our plates away. We were told somebody would collect them but no one turned up so the plates kept piling up. We said to them to take them away because there were two or three days-worth of plates sitting there. We asked again but got fobbed off again. Infection Control was in that day and we got a row because we had all the dishes piled up. We explained that we had asked for them to be taken away for two or three days. We didn't have any other contact with Infection Control after that. Eventually someone removed the dishes a few hours after they had left.

OVERALL EMOTIONAL IMPACT ON [redacted] AND HIS FAMILY

Overall impact on [redacted].

40. I think [redacted] has anxiety now, mainly about using taps outside of our house. That's one of the main effects it's had on him. [redacted] refuses to use taps outside our own house. When he goes to hospital or school, he refuses to drink out the taps at all. [redacted] still goes to the hospital for check-ups but he's still got anxiety when he goes. He's still really bad with heartburn and a sore stomach that we fear may be linked to the prophylactic medication he was on. He is still on medicine for all that. He's getting referred to gastro.

Overall impact on witness

41. During this period, it was quite hard. There was a lot of travelling, trying to get here and there for a certain time and then back. I had to make sure Suzanne and [redacted] were alright in the hospital. I had to leave them to come back and get the kids, do their after school activities, get them dinner, all that sort of thing. Then I had to get them to bed and to school Travelling back through was really, really tiring. Travelling one way is about 45/50 minutes and I could be doing that more than once a day. It had a really bad impact on me.

42. During [redacted]'s treatment it had such an effect that I ended up going to my Doctor and they referred me to a mental health nurse and I was diagnosed with depression. It was all the stuff on the news about the water and the people not telling you about things that made me a bit worse. Even to this day I'm still on tablets for it all. What we were going through was hard enough without being kept in the dark about all this. We had the news on every night and we were hearing about the water and how they found this and how they found that in it. They were talking about it when we were actually sitting in that place. It's scary to even think about that and there's nobody telling you anything. It was just scary. This was all in 2018 when [redacted] was an in-patient as well as an out-patient.

43. Every time I go near the hospital (RHC) now, everything starts running through my head again. I ask myself, are we going to be safe in here? Is [redacted] going to catch anything in here? Because of his immune system he could easily contract any infection. When we were in the adult hospital (QEUH) it was a complete worry in case he came into contact with someone who had an infection. Also, with hearing all the stuff on the news as well, I don't know what to think.

44. There was always more and more to worry about. Suzanne is a worrier. I was trying to put on a brave face. Every time I see her I act like everything's fine to try and relax her a bit and calm her down. When there's times I need to leave her I know she's still worrying about it and there's nothing I can do to make it better. Because I felt so helpless, that was having an impact on me as well. It was hard on everybody.

COMMUNICATION: GENERAL

45. There were no real problems with communication relating to [redacted]'s treatment. The only time they didn't tell us anything was when it came to [redacted]'s Cipro. That was the only time. We didn't know any different. We just went along with it but Suzanne eventually found out it was a medicine to stop you getting an infection from contaminated water. It was quite worrying that they were able to lie to your face about that. We were told that [redacted] had to take the medication he was put on because it was part of his treatment protocol, when in fact it was because it was the hospital environment. It's quite scary when you think about it. I'd rather they had just told us the truth and told us what was going on at the time. There would have been more respect if we had some clarification about what was going on, instead of getting all our information from the news.

46. When it came to the hospital building and issues with it, the communication was non-existent. We weren’t told anything, nothing at all. It was concerning that everything we know now about the infections and the environment, we had to hear it all from the news and not from the nurses or people higher up. It’s still non-existent.

47. In relation to the water, that was another lie that was told by the NHS, that the water was safe. They were hoping that was another one that wouldn’t get out and I don’t think it was dealt with properly, going about changing filters and not saying it was because the water was contaminated. They still let us go about brushing [redacted]’s teeth or having a bath, having a shower or whatever. It was just terrible. The bottled water was terrible as well. It was a case of, here’s a bottle of water and use it to brush his teeth and wash with and that was it. They didn’t say it was because of this or because of that.

48. It was like a lottery, with the water, whether you caught something or not. Knowing what I know now, that the water was contaminated it was like a lottery with his life basically.

49. When we were in 2A in the RHC, around 2017, they were boxing off rooms, building wooden boxes, workers going in and out. The blinds were covered and you couldn’t see in at all. You had no idea what was going on. When you asked they said it was just getting cleaned but I’ve never seen cleaning where you have to close down a whole room and everything was taken out. The people who were doing the work were wearing suits, like overalls and were wearing masks. I saw it happening with a few rooms in 6A (QEUH) and a couple in ward 2 (RHC). All the staff told us was that the room was getting cleaned. By the time we went to 6A (QEUH) when we saw a room was getting boxed off we knew what was going on, the room was getting a deep clean, that there was something wrong with the water and ventilation. But we were still getting told the room was getting cleaned. We suspected that there was

problems with the water and the ventilation and I've come to understand this through the news and from other parents at the hospital as well.

50. The issues with the water in RHC started around 2018, I think. When it first all came out we asked if [redacted] was allowed to have a bath or a shower and we were told "no" by the nurses and told to use a bottle of water to wash him and brush his teeth.

51. I'm not a member of any of the Facebook groups and I've never had any contact with Professor Craig White. I've seen the press coverage about the hospital and it's made us worry because you're sitting in that hospital and they're telling you it wasn't fit for purpose. It's constant worrying and constant stress.

52. I attended a meeting with Jeane Freeman at a hotel in Glasgow city centre. We went there and listened to her and some of the parents got to tell the stories about what they went through and about what their kids went through. Jeane Freeman listened and she acted like she was shocked. She said "oh, that's terrible" but she knew everything that was going on in that hospital and she basically just lied to everybody in that meeting saying she had no clue what was going on. It then came out in the media that she actually did, she knew everything about it. I say that because it was on the news that she knew about the problems the hospital was having, like with the contaminated water. Basically the hospital should never have been opened in the first place. We went away from that meeting knowing exactly what we knew when we went in to it. There was never any follow up from that meeting.

COMPLAINTS

53. We didn't make any complaints about the hospital on the wards, to a nurse or a Doctor. I think the communication could have been handled a lot better. We

trusted the nurses with [redacted]'s life and I think they could have been a bit more informative.

OVERSIGHT BOARD / CASE NOTES REVIEW / REPRESENTATIVE GROUPS

54. I don't' know anything about the Oversight Board and [redacted] isn't included in the Case Notes Review. I'm not part of any family representative groups.

CONCLUDING COMMENTS

55. I thought the hospital was a good thing when it was getting built but after having had the experience I've had with it, I don't think it should have been opened. I don't think it was ready to be opened at all. I feel like it's ruined our life. I don't trust anything that Greater Glasgow and Clyde Health Board say now. I don't think the people on the Health Board should be on the board, knowing what they knew about the hospital. It wasn't ready to be opened given the problems they were having with the water and the ventilation, but they just went ahead and opened it anyway with no thought or concern for the people who were in there. I think if was one of their kids in there it would be a completely different story.

56. My ongoing main concern about the hospital is the water and the ventilation. Do we even know it's safe now? Even if they came back and said it was safe now, I still wouldn't use the water because we've been told that before, that it was safe to use when it actually wasn't safe to use. I probably still wouldn't believe them.

57. The hospital have never told us what was happening with 2A (RHC), all we were told was we were moving to 6A (QEUH) for a couple of weeks while some work gets done in 2A and I believe to this day, they're still in 6A. I feel like we've been lied to again so I'm not really shocked. I think the hospital

should tell the families the truth. They should let us know what’s going on instead of all this secret keeping.

58. I believe that the facts stated in this witness statement are true, that this statement may form part of the evidence before the Inquiry and be published on the Inquiry's website.

Scottish Hospitals Inquiry

Witness Statement of

David Campbell

1. My name is David Taylor Campbell. I was born on [redacted]. I am [redacted] years old. I am a [redacted].

2. I am the Father of [redacted]. [redacted]'s date of birth is [redacted]. He is 6 years old and due to turn 7 years old [redacted].

3. Completing this statement has been a gruesome emotional experience. Many dark painful moments have been relived and attempted to be put into some kind of context. A difficult thing to grasp, as I am still in a form of emotional limbo, not knowing what to feel 3 years on from my son's first cancer diagnosis. The reason for that being, there are still many questions left unanswered from what we experienced in that place and so a form of purgatory remains.

4. Some things are clearly evident though and what is the most fundamental to me, is that my son and the other children with their families should not have set foot in that building when their lives were so perilously ill as it was.

5. People chose to ignore recommendations that the building was not as it should have been, even back in 2015. This was highlighted by an independent report and the fact they continued to let these children continue to be admitted to this hospital, ignoring qualified substantiated advice is totally unacceptable and unforgiveable.

6. My sincerest gratitude to [redacted]' fantastic consultant and his team, I will be forever in your debt. Also the surgeons who operated swiftly removing the

tumour successfully and their theatre staff, anaesthetists, play workers and the nursing angels who are so very brilliant, we owe you his life and will continue to be ever grateful for saving him. CLIC Sargent Marion House and CCLASP, thank you. Without that support I could not have done it.

7. To the SNP Government that let this hospital be handed over and deemed fit for purpose and then let the Health Board continue to operate so inefficiently, the contracted people responsible for building a death trap for the country's most vulnerable children causing so much distress and added psychological cruelty to us all. I hope karma finds you all soon and this inquiry brings you all to task and accountable.

8. The staff who do all they can to protect these children every day deserve so much better than a Board devoid of any compassion, candour and accepted responsibility. To the Health Board, shame on all of you.

9. To the beautiful little people we met in there that are heartbreakingly up in heaven now and not suffering in pain anymore, thank you for inspiring me, showing me how to be fearless and how to fight to be the best I could for my son as back then I had nothing left to give. Cancer is so cruel. You all deserve so much more, God love you all, thank you.

10. Finally, to all the parents, bloody well done, we won't hear that enough as no one really knows how much we go through.

OVERVIEW

11. My son is [redacted] [redacted]. [redacted] was diagnosed with rhabdomyosarcoma in August 2018 when he was 4 years old. [redacted] was treated in the Royal Hospital for Children (RHC) and Queen Elizabeth University Hospital (QEUH) between August 2018 and February 2019, when he finished his treatment. He

attended both hospitals as an in-patient and an out-patient regularly for six months. [redacted] still attends the QEUH for MRI scans which were three monthly and have just been extended to four monthly.

12. [redacted] spent time in ward 1A, which was a surgical ward, 2A and 3B of the RHC. Ward 2A was known as the Schiehallion Unit. Following the closure of the Schiehallion Unit in 2018, [redacted] was treated on ward 6A of the QEUH. I stayed with [redacted] on a regular basis during his treatment when he was both and in-patient and an out-patient. I can speak to the experience and I had on these wards.

13. There are some specific events that I would like to mention. I believe was prescribed preventative medications in September 2018, which may have been connected to the issues with the water supply and the then rumoured bacterial problems in the hospital. There were always ongoing construction works going on at the hospital through-out [redacted]'s time there, which I believe impacted on him. I will come on to talk about these issues and events in more detail.

FAMILY BACKGROUND

14. I live in [redacted] . I work for three weeks on a rotational basis. [redacted] stays with me at weekends when I am [redacted] and during the school holidays. If I get a day off from my work, I go to visit him.

15. I live near the water-front so when [redacted] is staying with me, we like to do a lot of things outside, including catching crabs. He used to see his grandparents most days when we stayed in Mull of Kintyre but he now sees them about once a month [redacted] just before the diagnosis.

16. [redacted] doesn't really like school just now, which I feel is a consequence of being in hospital, not being allowed visitors and separated from his peers. It's difficult for him to blend in now and do group tasks but the school have been supportive with this. He was used to being on his own at the hospital, just as we were getting him back to school, we ended up being in a similar situation, due to the country being put into lockdown as a result of Covid.

17. [redacted] has a set of friends he plays with and is adapting to school starting [redacted]. We are still very wary of him getting a bump to his head after remission. is also wary of climbing etc. just now so we are just taking everything slowly and let him find his own pace

SEQUENCE OF EVENTS: THE FAMILY'S EXPERIENCE AT RHC AND QEUH

Admission to hospital: August 2018

18. On 5 August 2018, I noticed that [redacted]'s eye was swelling up. He had just returned from holiday and had suffered a bump to the eye when he fell, while he was away. I decided to get it checked at A&E at the QEUH in Glasgow. This was the adult part of the hospital we went to. [redacted] was given antibiotics and we were sent home.

19. On 19 August 2018, I took [redacted] back to A&E at the RHC this time as the swelling had increased. Dr Sastry, [redacted]' Consultant, requested that Ophthalmology take a look at him. He was admitted and placed on IV antibiotics. The next day, [redacted] was given a CT scan, a tumour was identified and that evening he underwent an excision of the left orbital tumour by Mr Clements, the ENT consultant surgeon.

20. [redacted] was admitted on to ward 1A of the RHC, which if I remember correctly, was a pre-theatre or pre-diagnosis ward. He wasn't in there very long,

maybe three or four days. [redacted] got out for a night before being re-admitted to ward 3B on 23 August 2018 as ward 2A was full.

21. On 26 August 2018, [redacted] was moved to ward 2A at the RHC where he was admitted as an in-patient. Dr Sastry confirmed a diagnosis of a Rhabdomyosarcoma malignant tumour in the soft tissue of the left orbital lobe area. Although this was a rare cancer, there were possibilities of effective treatment.

[redacted]'s initial treatment: August 2018 – late 2018

22. [redacted] had, his Central Venous Line (CVL) fitted on 27 August 2018. His CVL was a Hickman Line. This was done in theatre under sedation. He also had a bilateral bone marrow aspirate and trephine biopsies done on this day too.

23. On 30 August 2018, I agreed to the treatment plan with the doctors and I signed the consent form. His treatment plan consisted of nine courses of ifosfamide, vincristine and actinomycin which were given to him intravenously. This included a mix of in-patient admissions where his chemotherapy was administered over three days, every three weeks. Some of the chemotherapy was delivered by injection and that meant that could go to CLIC Sargent House afterwards. [redacted] started the treatment on 31 August 2018.

24. [redacted] was discharged for a few days to CLIC Sargent on 3 September 2018 after being in ward 2A from 26 August 2018.

25. Between approximately 10 September 2018 and 14 September, [redacted] had his feeding tube fitted. My dates for this are approximate as he accidentally

pulled this out a couple of times. I believe the CVL was fitted earlier as his medications were all administered to him through the CVL. I originally thought he had his earlier treatment through cannulas but the medical records do not support this.

26. Throughout his treatment, [redacted] was in and out of hospital a lot, I couldn't really keep track as it was pretty constant. He would be admitted because there was a suspected infection or a temperature spike and then he would be discharged after the infection cleared up. They didn't keep him in unless there was a valid reason. I often felt that he was released quicker because of the ongoing building problems.

27. The procedure for a temperature spike was that whenever [redacted] spiked a temperature, which I think was anything above 38.2 degrees and we were at home, I had to phone the Schiehallion ward for advice. I bought an in-ear thermometer to have at home and we were given strips from the hospital that go under the armpit that the nurses used every hour to take a temperature. I would use the strips first and then check if it would coincide with the in-ear thermometer. This was to see the complete picture and any trend. The nurses told me that I could gauge if there was a bigger spike this way. When I phoned, they would go through everything with me and ask me to check his temperature again. I had to give the ward some notice because sometimes they wouldn't have a bed for him so they would have to source one in wards 2B or 2C until one became available in ward 2A. Sometimes we were given our own little room in A&E before we could be taken up to the Schiehallion Ward. It used to be the case that when you called, you were told to bring your child in via A&E or ward 2B and then you would be admitted in ward 2A. After the move, you would still come in via A&E but if my memory serves me right, it was always ward 6A we went to in the adult hospital.

Experience on ward 2A: August 2018 – late 2018

28. When [redacted] was first admitted to ward 2A on 26 August 2018, I noticed there were other families living out of suitcases. Maybe they didn't know how long they were going to be in there or maybe it was psychological that they wouldn't be in the hospital that long. I knew [redacted] and I were in for the long haul so I wanted to make our room on the ward as comfortable as possible. Immediately when we were in our room we noticed a few different things. You couldn't make the room like home. For example, if you go on holiday for a week, you can make your accommodation your own. You couldn't do that here as there were other things in the room which made it difficult to set it up. It was like a cell. It was just a bland space. There was absolutely nothing [redacted] was familiar with. You'd like to make it homely but it was very difficult. You didn't want it to be a home in the first place so it was psychological too. Most young children like to play on a floor. You can't keep them off a floor when they're playing with cars and other toys but that wasn't possible on this floor as it was dirty. The only playing options he had were in the bed or on a chair.

29. There was a playroom in ward 2A which [redacted] used a lot when he wasn't neutropenic. He wanted to go there all the time because that was where he saw toys or he could interact with other children. A lot of the time it wasn't possible to take him to the playroom because there were things like chickenpox going around. My dad used the playroom with him too when he visited as you could go in with [redacted] and speak to other parents or grandparents. It got [redacted] off his iPad for a while. The games in there were really good and well stocked. The corridors in the RHC were wide enough that we could go for a walk and get some exercise with the trollies [redacted] had attached to him and not have to worry about getting past anyone else doing the same with their child. It was set up with the focus on the children. had two trollies, like giant coat hangers attached to him, one was for his diet through his nasal tube and the other one was for his central line. If I

was on my own with him, I had to use a hand for each of the trollies with him going ahead. If he took off, I had to drop the trollies and catch him because if he pulled his central line out, he would be dead.

30. [redacted] would sometimes start fighting with me if I tried to rein him in for a many matters. He would scratch me and hit me and he became really strong when he couldn't go home. He would try and throw himself on the floor, I would try to pick him up to stop him from hurting himself with the cable that was attached to his chest. He would try and pull it out so he had bands put on it round his chest to stop him doing that. He became reliant on "wiggly" the name the kids give to the central line as it stopped a lot of painful cannulas having to be inserted in the back of his hands to administer anything.

31. There was a play worker there that was really good with [redacted]. I wish I could remember her name. She would come in to the room and brings toys with her and interact with him. Some of the charities would come up and do puppet shows and that really helped. He was stuck to his iPad otherwise and eventually he just went into himself.

32. [redacted] responded well to the play leaders. When he was allowed, he would go down to the hospital Radio Lollipop room and would interact with the staff there. That helped him cope with the difficult aspects of treatment. The play leaders would also do things with teddies as well to show him his central line and engage with him about this.

33. Another benefit of the playroom was that it gave children the chance to bond with the other children. Meeting older children was good for [redacted] too. He was able to see how brave they were and it helped when he was getting some of his treatment as he'd want to be seen as being brave too. It was almost like a competition.

34. There was a parent's kitchen which I used quite a lot. It had a sofa, radio and a TV. I could speak to other parents there who were going through the same thing as we were and could relate to how we were feeling. It would depend on who was with me, how long I used it for. Any time I was there, [redacted] wouldn't let me out of his sight, but when he was sleeping and the nurses came in to do their tasks, they used to tell me to take five minutes. If my brother was visiting, I'd get a bit longer.

35. There was a fridge in the parent's kitchen too so whenever I needed to make dinner for myself or [redacted], I could keep that in the fridge. Visitors would sometimes watch [redacted] for me when I went to make a tea or a coffee. You were able to bring your own things in and you'd be allocated your own space in the fridge and cupboard for it.

36. There was a cinema on the ward. It showed all the new films. [redacted] loved the cinema and it was a huge thing for the other children too. Adults could sit at the side and you would see all the children's faces light up when the music started. It was their treat. Their chance to be normal. The kids could still go even if they were attached to units containing medical equipment as there were power sockets there where they could plug them in. The battery packs they were issued with for keeping their machines working, if they left their bedside, didn't last very long so the sockets made it accessible to all the kids. I think they had input from people who knew what to expect as it was all centred round the kids.

Closures of ward 2A and the move to the adult hospital: Late 2018

37. The Schiehallion Unit was named after a famous mountain. Ward 6A wasn't equipped for us climbing that mountain. In fact, the Schiehallion Unit died when it was moved from the RHC. We saw it getting further and further away from us every day. With all that was going on with the cancer

and now an unfit place for him to receive treatment, put his survival chances at a definite disadvantage.

38. There was no communication at all about the reasons for moving ward 2A to ward 6A. We were told the move was a temporary precaution. They had to get all the kids and families out so they could inspect the space. When we got to ward 6A they were putting up child friendly art work up on the walls and setting the ward up in a way that I knew it wasn't going to be a temporary thing.

39. We were told on the morning of the move, that we were being moved. A lot of the other families said, "Oh, you're going home?" because it was great seeing kids get out for a few days when you saw them going past with the suitcases. The reply was, "No, we're going into Ward 6". All the parents were asking what was happening on ward 6. We asked the nurse in charge of the ward and she told us, "Yes, there's going to be a move into the adult hospital but, everything's alright, trust the process." We weren't told why the move was happening. We asked some of the other nurses and one of the nurses unofficially told me that ward 2A and 2B had been condemned and it was "riddled". That was the word she used. It was riddled from top to toe, drains, ventilation and crumbling walls.

40. The families on ward 2A were moved to the adult hospital a week after the news report about the pigeon droppings on 19 September 2018. [redacted] and I were one of the last families to be moved from ward 2A to ward 6A. I thought our room must be okay since we were the last family on the ward. I asked the nurses, if [redacted] was ok, could we stay, but they said no and moved us. No explanation was given. I was told by a nurse that we were moving to the adult hospital and that was all the information I was given. I saw other parents leaving with suitcases and asked the nurses if they were moving too or if their child had been discharged. They said they weren't

allowed to discuss other patients. I asked other parents if they knew anything but they had been given the same answers as me from the nurses.

41. I questioned how these children with life-threatening illnesses could just be moved like that. The Schiehallion Ward is a renowned name and they were just taking them out of that place and putting them into a random ward. I would have rather taken my chances staying in ward 2A which is why I asked if we could stay. That was until we actually found out about the reason behind the moves, then we were glad to be clear of it.

Experience in ward 6A QEUH (adult hospital): late 2018 – 2019

42. When we moved to the adult hospital it was awful. There were no facilities. To leave 6A to go for a walk outside to relieve stress, it would take around 15-20 minutes just for the lift, as it was used by the general public; a confined space with all walks of life and ailments after leaving a secure ward of vulnerable neutropenic children. There was nowhere to heat a meal up for yourself. You had what was left of your child's cold dinner if they didn't want it, however [redacted] was on a liquid diet at that point so sometimes this was what was left over for me. Staff would come around in the morning and ask him what he wanted for his dinner that night. How was he supposed to know in the morning what he was going to feel like having at dinner time? None of the food was appealing. I couldn't always get to Marks and Spencer's, which was the only decent option in there. It was a long complicated journey to get there, walking past a number of people who may have been carrying infections themselves, that I could have brought back to [redacted]. I was already living on limited sleep, so journeys like this were sometimes too much. There was only one access lift and it took about 20 minutes to get down because it took so long for the lift to come. Ward 6A didn't give any of the parents meals, it was only the kids that got meals. You couldn't take stuff in with you from home because you

didn't know how long you were going to be in for. You were living off Marks and Spencer's sandwiches and bottles of water. You were taking up three or four at a time. There was only one access lift at that hospital so you had to mix with everybody going to all sorts of wards. I would have to leave a neutropenic boy to go down in a lift I had to share with other people. This is more relevant now with Covid for the two metre spaces, but back then, that was the kind of journey I was expected to take every day so I could eat.

43. After a while, I just didn't have the patience to do it; or by the time I got back up, I didn't even want anything anyway because I was so tired and sweating because of all the exertion. But even then I couldn't use the showers because they had to be run for five minutes according to the hospital policy and the warning signs on the wall. I also didn't trust the water. So what was I supposed to do? [redacted] was asking for a cuddle upon my return so I was having to use wet wipes, or have a shower so I could ensure that I wasn't passing on any potential bugs from the journey to Marks and Spencer's first. It was a lot of effort for a sandwich and a bottle of water so I often ended up eating what was available on the ward.

44. I asked the staff where the adult room was on 6A where I could go and get a cup of coffee. I was told there wasn't one but that I shouldn't worry, as we'd be back in ward 2A soon enough. I didn't feel too inconvenienced because I was being told that the move was only going to last a couple of days; at least that's what we were told. I was hoping in the back of my mind it was a temporary move but I really knew that this was where we were going to be now.

45. There wasn't a parent's kitchen in ward 6A and the loss of the fridge and freezer had a huge impact on [redacted]; we used to keep his favourite ice lollies in the freezer. He hated getting cannulas inserted so we used to bribe him

with an ice lolly. If he was having to get a procedure like that done to him, there had to be a reward but that was taken away when we moved to 6A.

46. The lady that came around with the tea trolley twice a day was a godsend in ward 6A otherwise I wouldn't have had a cup of tea all day. There was nowhere to make a cup of tea and you couldn't bring tea, coffee or soup from the canteen up to ward 6A as it was a hazard.

47. Not having a playroom on ward 6A was a massive loss. [redacted] was stuck in his room, isolated from everyone else. There wasn't even enough room for him to exercise in the corridor because it was too narrow. He would ask to go and see some of the other children, to be told by staff that he wasn't allowed to. You had the same bridge to cross every day, the same battles, trying to get him to understand he couldn't see other children.

48. The loss of the cinema had a huge impact on us too. The kids used to love being able to go and see a film on ward 2A. There was nothing like that on ward 6A.

49. We had the same room twice on ward 6A. It was room 1, when you first came in, it was the first door on the left. I heard a wee girl's mum crying one night. She had been told there was nothing else that the hospital could do for her daughter. I saw her through the window in room 1 but I couldn't go to her as I couldn't leave [redacted] on his own. There was no privacy there and nowhere she could have received support from other parents.

50. We had made the room as comfortable as possible on ward 2A. It had been our home and [redacted] had made some friends there but the move to ward 6A was unsettling. [redacted] wanted to go back to 2A as he was familiar with his surroundings and it was comfortable there. He was also able to see other children which he couldn't do on ward 6A.

51. Ward 6A was like a prison, an institution. There was a mobile bedding unit that you would go to get yourself and bedding for the fold out bed. In the morning, there was a breakfast trolley. You would have about 15 minutes to go and get something off the breakfast trolley and put your used bedding in the bin beside the bedding unit then you were back in your room. It really was like a jail. The televisions didn't work. They eventually got a coffee machine put in after parents in one of the groups fought for it.

52. Another thing about ward 6A was that day care was at the very bottom of 6A. You had kids, visitors, people who were picking up prescriptions and everyone else coming from outside and walking right through the ward to their day care appointment at the bottom of the ward. So everybody was traipsing through. It was just like a waiting room and it was chaos. There would be all these wee bald kids wandering about with tubes in their nose, barely standing and other kids running about past them, and going home. That would then start [redacted] asking why he couldn't go home.

[redacted]' ongoing treatment: October 2018- February 2019

53. [redacted] started cycle 3 of his chemo on 12 October 2018. This was as an outpatient in ward 6A Day Care.

54. [redacted] began cycle 4 of chemo in ward 6A on 4 November 2018. He was an in-patient as the chemo was administered through IV over a 24 hour period. He then got an injection of vincristine after that. You had to wait until he was responsive after the IV chemo and good within himself before he got discharged to CLIC or home. I changed my work from three weeks on, three weeks off to a Monday to Friday. [redacted]'s chemo fell on weekends which was good for this schedule. When he was given all of the cycles, I would stay on a Friday or a Saturday night, but usually a Saturday, with him and he would be released on the Sunday.

55. [redacted] was admitted on the 8 December 2018 as he was neutropenic and was feeling sore so I was told to take him in. The 8th to the 14 December he would have been treated with antibiotics because he wouldn't have started his chemo on the 14 December unless his bloods were good and the infection had cleared. I told Dr Sastry that [redacted] was sore and he said that it was a side-effect of the antibiotics. He could only have been in for an infection, so there would have been mention of an infection. I honestly don't know, but my gut and everything tells me that the infection was from the hospital because they wouldn't have him on all these anti-fungal drugs otherwise.

56. [redacted] was admitted on 26 December 2018 to ward 6A for an IV infusion of antibiotics. I think it was an infection although I wasn't told what he was being given and why. It would have been an infection because wouldn't have been admitted without having either an infection or constipation. That would have been the two critical reasons he would have been admitted. If he wasn't eating, that leads to the constipation so you would try a different food with him to take. When he was with me, I had to share the same bed with him because he would get tangled up with the food machine going 24/7 beside the bed. He couldn't turn over. He had to only sleep on one side so when he turned over you had to move him again. Sometimes the machine would get clogged up or it wouldn't work and you had to change the batteries. The machine had to be kept going non-stop. [redacted]. The hospital would try a different bag so [redacted] would have to go into hospital for that. There was a dietician that did everything for [redacted]. All that stuff had to be done at the hospital because that was where the team looking after him were and all his records. So, if he was going to the toilet too much you would have to take him into the hospital then too. The reason for him passing so much or being clogged up, was apparently down to an infection

of some kind or a side effect of the drugs. [redacted] stayed in hospital until 4 January 2019.

57. On 11 January 2019, [redacted] was admitted to ward 6A again with what I think was an ear infection, although I can't say that for sure. The temperature in one ear was higher than it was in his other ear. I had a briefing with Dr Sastry about [redacted] on 13 January 2019. He had a blood transfusion for platelets on 14 January 2019 to prepare him for his next round of chemo. In [redacted]' medical notes for this admission, there's an entry on his admittance notes for posaconazole, septrin and co-trimoxazole. I don't remember being told anything about these at the time. I wasn't aware of any of them being administered and I wasn't aware of the names of them until I got [redacted]' medical records. I asked what these drugs were but was told that they were just part of his treatment plan.

58. On 25 January 2019 [redacted] started cycle eight of his chemo. On 4 February 2019, there was an MRI scheduled but [redacted] had gone under the bed and wouldn't come out. I had a hell of a job getting him out. I think he was picking up on my anxiety as I felt I couldn't protect him from the stuff going on in the rooms about the environment and there was a lot of tension on the ward with everything that was going on. Knowing he was going for a MRI would have made him anxious too as he knew he would be getting put to sleep under general anaesthetic as the MRI takes about an hour. He can't lie still for that long and he was worried he wouldn't wake up again because when he had his first MRI he woke up and his eye was all bandaged up. He thought someone had stolen his eye so he thought they were going to steal the other one, so he didn't want to go to theatre because of this. The doctors eventually said that they would postpone it as he was going to end up hurting himself. I can't recall when he actually got the MRI after that, but it wouldn't have been longer than two weeks as

he had to get the MRI to see the state of the tumour that was removed and to see if anything was still there or coming back.

59. [redacted] had cycle nine of his chemo on 15 February 2019. He received platelets again in day care of ward 6A which was an overnight stay. They had to balance the platelets with fluids so it was a long, drawn-out process for the body to absorb them. They've got to test the bloods when all the cultures come together and make sure they've all levelled out. They have to check that his body hasn't had a reaction to anything in the blood.

60. During the rest of 2019, [redacted] was attending regular out-patient appointments for MRI scans. These were every three months to start with and are now every six months.

WATER: EVENTS INVOLVING WATER SYSTEMS

Water: incidents

61. We noticed as soon as we were admitted to our room on ward 2A that there were prompts in the bathroom such as signs on the wall telling you to run the water for five minutes. These signs were in every room on ward 2A. The bathroom was a wet-room and there were signs up on the walls telling you to run the shower for five minutes before you used it. If you did run the shower for four of five minutes before using it though, it would flood. There's no tray. It's a wet floor with no partition. Water would be running to the entrance of the room. You can't have a flooded room when you're trying to get in and out and dealing with your child who has been sick.

62. You were giving your child close comfort care so if they did have an accident or were sick, you had to be quick. [redacted] had a Hickman Line which

was attached to two machines so if he had been sick on his top and had other accidents, you had to try and get his pyjamas off whilst he was attached to a line and a nasal tube. To get him into the shower, you had the two trolleys to take with you. Running the shower for five minutes before using them wasn't an option.

63. The cardboard bottles containing the urine samples were kept on the bathroom floor waiting to be collected. If you ran the water for five minutes, then the water was very close to touching them and they may have been damaged from the water. Bearing in mind his urine was radioactive, I'm not sure of the impact that would have had if the urine mixed with the flooded water. If you did run the shower for five minutes, there would be chaos as the shower and toilet is all in one, so water would have run right up and you'd have swimming pee bottles all over the floor if you ran the shower for five minutes.

64. I did ask staff why we were to run the shower for five minutes before using it. I was told that it was normal practice for legionella. Other staff told me it was a standard thing that happened with all showers of that type. I asked if this was the same in a hotel so everywhere was the same. I was just given a look in response.

65. The silicone fittings in the shower were loose and the drains bubbled. There were no proper seals and with the drains bubbling too; I think this might be part of the issue connected to the infections.

66. I became aware of issues with the water in August 2018, after [redacted] and I had been in the hospital for two or three weeks. One of the cleaners was the first to mention it and she said she wouldn't let her dog drink the water in the hospital. She told me to ask for bottled water. Other parents had said not to drink it, not to bathe [redacted] in it or use it to brush our teeth. There

were loads of rumours going round that we shouldn't use the water and the nurses never confirmed that the water was actually fine to use. They also didn't address the rumours so it left me with a resounding fear that there was something being covered up.

67. There was also another father I used to speak to quite a lot. He said to me that I could ask the nurses for sterile water to bath my son with as he wouldn't use the shower on his child. He said I can buy water wipes at Booker and to get as many as I could. I didn't think anything of it at first, but when you start to see things yourself, like the water not draining away, or the filters on the taps, then you do start to think about it more and question if there is actually something wrong with the water.

68. Before all the horror stories started about the water, when I asked nurses for a drink for [redacted], they would bring in a jug of water or a jug of diluting juice for him. The nurses used to make ice lollies and ice poles on the ward as well. I'm now wondering about the impact of this if they've used tap water.

69. When we were moved to ward 6A, the staff started bringing in big bottles of water. I asked some of the nurses about the water and was told it was fine. Where [redacted]' bed was in the room there was a sink directly opposite it and there was a sign on that that said, "Water not for drinking, for washing hands only". We asked if the sink in [redacted]' bedroom was okay to use because it didn't make sense to us that one sink on the ward couldn't be used but others could. Surely they were all connected?

70. If you asked the nurses about the water, some of them never used to give you a straight answer. I said I didn't want to bathe [redacted] in the water and one of the nurses said I could try using the sterile water they provided. If there was nothing wrong, why wouldn't she just have said that and not

suggested the sterile water? Nothing was said. It was mostly sterile water I asked for to clean [redacted] with. You get little bottles of sterile water for cleaning out syringes and things like that but anything else to clean with, I would bring in myself. That was never questioned. I got the impression the nurses didn't want to say anything bad about the water.

71. It was pretty widespread that the nurses would tell us to watch what we were doing with the water. We were told not to put him in the shower because that was critical for his central line. I had to wipe [redacted] down with wet wipes. Unless he was really bad then I would shower him quickly and afterwards I'd put gel and stuff over his legs and clean it all up because I was told that was the best kind of form of defence after anything, to stop it getting on him.

HEALTHCARE ASSOCIATED INFECTIONS

HAIs: events and physical impact

72. [redacted] was admitted to ward 2A again on 16 September 2018 with sickness. He usually always presented with a temperature first. If your child develops a temperature, you have to phone the ward to at least seek advice. There were three things you looked out for: temperature, pallor and responsiveness. We were at CLIC Sargent and I was told to take him in so he was admitted to the Schiehallion Unit but I can't remember the number of the room we were in. There was no indication of what the infection could be but he was given fluids through IV. I think it would have to be a bacterial infection that [redacted] would have as IV antibiotics are not used for viral infections.

73. [redacted] was admitted from CLIC Sargent on 1 October 2018 with an infection. This was to ward 6A and he was put on IV antibiotics but I was never told what the infection was. The information was always very vague. The term,

"A wee infection", was used a lot and it would sometimes be used when had a temperature spike. It's the terminology they used for it. That's all I was told, "There is something. It's a wee infection". This was the phrase that was continuously used. [redacted] was neutropenic at this point meaning he had no immune system and this lasted for about four weeks. He was discharged on 5 October 2018.

74. [redacted] developed an infection on 7 November 2018. He was taken to QEUH by ambulance. The infection turned out to be influenza A and he was treated for this with an IV infusion of antibiotics, then discharged. I think he was possibly given other medications at this point but I can't remember.

75. When [redacted] was admitted to hospital on 8 December, I understand that was because of an infection. I believe this was hospital acquired, but his medical records are very vague in how they describe what he was treated for.

76. [redacted] was admitted to the hospital again on 26 December with another infection. [redacted] wasn't supposed to be out of hospital but we wanted him home for Christmas as we didn't know if it was going to be his last one or not. He wasn't right all the way through Christmas. He was admitted and given IV antibiotics but we weren't given any information about the infection.

77. [redacted] was admitted to hospital again on 11 January 2019 with what they thought was an ear infection. It could maybe have been a build-up of wax from this chemotherapy treatment, we don't know.

78. I had difficulty in obtaining [redacted]' medical records. I eventually had to go to a solicitor to help me. I now have them, but there are 38 blank pages and the notes are very vague for the details that I think should have been

included. It’s taken me a long time to go through them, even for someone who’s not been through what we have, it would be painful to go through medical records and try to figure them out but it was worse for us. For all the critical dates I’m trying to get information from, there’s nothing I can take from them. From the information that is there, I don’t know what a lot of it means but it doesn’t say what I think it should. I think they are far from complete and I have challenged the records through my solicitor.

79. There must be records of blood tests [redacted] had and that is what I have asked to see. When I got a screenshot from Dr Maguire, that said that could not be tested because of the effects to his body, they are very intrusive tests. So in [redacted]’ whole stay in hospital, they’re saying that he was only tested twice or three times for gram A and gram B negative cultures. I think this is really bizarre and I think he should have been tested every few days or every week to see if he was reacting while staying in the hospital. I think it’s a complete lapse of treatment that he was not tested for these cultures that went on to apparently have catastrophic results for these children. They are not divulging the records so I think one of two things must have happened: They did test him and he was found to have these infections because he was treated with the drugs or; the antifungals stopped these things from developing because he was already covered.

80. I have found out from [redacted]’ medical records that he was prescribed Tazocin which I have found out is used to treat gram positive and gram negative bacterial infections. [redacted] was given this between 12 January and 15 January 2019 as well as Gentamicin, which is used to treat several different types of bacterial infections, on 12 January 2019 and January 13 2019. I wasn’t told about any of these. On 15 February 2019 to 17 February 2019, [redacted] was given Tazocin again. This was in his medical records too. I wasn’t told about this at the time.

PREVENTATIVE MEDICATION

81. [redacted]'s medical notes show that on 21 September 2018, co-trimoxizole was added to [redacted]'s treatment plan. I remember at the time he was given another medication and I asked the nurse what it was for but I was just told it was better he took it and it was now part of his treatment plan. I didn't question it as I trusted the staff. The information I was given at the time was vague. I was also shown by the nurses how to administer this to [redacted] through his feeding tube. It was later on when I was researching it, that I found it was used to stop the growth of bugs that cause infections.

82. Within [redacted]'s medical notes, there is also a letter from the pharmacy providing information about [redacted]'s antifungal medications. It's in relation to a prescription for posaconazole suspension 92 mg. The letter advises that was due to have vincristine chemotherapy on 4 January 2019 and to start the posaconazole on 6 January 2019 which would have been 48 hours after his chemotherapy began. He was then to start the vincristine with every course being administered at 21 day intervals, so the plan would be that he stopped posaconazole 48 hours pre and started it again 48 hours post vincristine.

83. I can see from [redacted]'s medical records that posaconazole was only given to him for seven or eight days but you can see from the letter from the pharmacy, he was on it as part of his treatment plan. The medical notes don't reflect it correctly; he was given it more times than has been recorded. I am currently challenging [redacted]'s medical records as I think they are incorrect and I don't think they show everything. [redacted] was on the posaconazole constantly from what I can recall and it was explained to me that it was part of his cancer treatment. I saw it being injected into him. I think the medical notes are only showing a three month period but they're

difficult to work your way through and read as they are out of order and only record partial information.

84. One of the other parents was telling me that her daughter had lost one third of her hearing in one of her ears. She said everyone should have a look at the impact of the prophylactic antibiotics so I started doing my own research too. Posaconazole is recommended for those aged 13 years or above and not for long term use, only as minimum use. I'm now wondering if [redacted]' leg muscles have been impacted by its use; he's also under audiology just now for his hearing although his hearing is showing to be normal at the moment. None of the side effects were ever explained to me at any point. I googled all the medications and got my information about them from there.

85. I remember asking one of the nurses about the posaconazole, how to administer it, and about the dosage he was receiving. Some of the nurses were pregnant and others were worried about their own health issues so I wondered if they were on it too. I asked one of the nurses in ward 6A if she was on it and she just smiled at me, but didn't answer. That was a common trait in a lot of the nurses. You could tell with their body language that they were uneasy when you asked them a question about the building or the medication.

86. I may have not been told that [redacted] was getting posaconazole. However, if I ever was, then it was not fully explained why and what the gravity of taking it would be. All we got was a generic handout put under the door to say that it was a medication that the children were going to be put on as protocol, it was better to be safe than sorry. The posaconazole probably did save his life and stopped him contracting some infections. I am complaining about protocols that the hospital implemented around this drug which resulted in [redacted] having to take it. I also feel torn about the fact

he was on it to begin with as I recognise that it saved his life, but he shouldn't have had to have been put on it to begin with. He should have been in a sterile safe environment.

87. We were told that [redacted] was given all these anti-fungals and prophylactics as a precaution. It was all about them only being given as a precaution in case anything should crop up and he was never in any danger, and lo and behold, what happens after the kids are all put on these medications; the whole place is condemned. So it was utter nonsense that they didn't expect anything to happen. It's like dealing with a snake, they gave the kids these anti-venom prophylactics but let them keep having all these bugs and bacteria attack them like snakes all the time. It doesn't make it right, giving them an anti-venom and letting the snake keep biting away at them. It's absurd and that's what they've done because in that environment it was all wrong. So they seem to think by giving them the prophylactics it made it acceptable.

OTHER ISSUES RELATING TO HOSPITAL CONSTRUCTION

Hospital build issues: impact of construction works

88. The area around the windows was really cold in the winter. You could leave your food there and it would be fresh to use the next day because of the chill. [redacted] used to like sitting at the windows looking at outside life and day dreaming about getting out of hospital. I had to stop him though as it was too cold for him. This was the same in both in the RHC and the adult's hospital.

89. In the summer, the windows had the opposite impact, the room would be really hot. There was an air-conditioner in the room that looked to be operated digitally, but you were too scared to turn it on due to the rumours

about the ventilation, such as dead pigeons being in the ventilation shafts. So you had to sit in the room with no air. There were rumours about a lot of things via both staff and other parents. I overheard two ladies talking one day when I was out for a walk in the hospital grounds and they were talking about the pigeons. Sometimes you would hear people talking about pigeon droppings but then people were saying there were dead pigeons in the ventilation not just pigeon droppings. The dead pigeons in the ventilation were causing the smell to go through the hospital and because you do see a lot of pigeons at the hospital, you think that's what caused some of the issues and nobody has told you anything about it. You believed the rumours as nobody has told you anything to dispel these rumours. I did ask what was happening with the ventilation, staff just said, "Don't worry, I'm sure it's only a precaution". They were referring to the air filters.

90. One of my mates worked on the hospital when it was being fitted. He said there was a high turnover of people working on it so that the building standards were poor. It was knocked together under pressure. There were rumours about things being wrong with the water at this point too. Nothing was done by the hospital to dispel any of the rumours so when you start seeing air filters coming in and filters on the taps, you believe the rumours.

91. When I had mentioned the silicone coming off the bathroom to another parent, they said to ask maintenance to fix it. I discovered though that the maintenance person on the ward tended to not fix things when I asked them and would avoid me afterwards.

92. The move to the adult's hospital impacted [redacted] and I as there were no facilities, but even to get to the ward, you had to go in via the main entrance where the main lift was and where people were standing smoking or other people were carrying out drug deals. You used to see them at the door exchanging money. We had to go through those people and if you asked

them to move, they wouldn’t. Even the security guards wouldn’t move them. Other parents would wrap their children up in their arms and try to get past. There were neutropenic children trying to get into the hospital, having to go through all these people smoking and then waiting 15 minutes on the lift. It was the only way to ward 6A though so you had to go that way.

93. To get to Day Care on ward 6A, you had to go right through the adult hospital and through ward 6A too as the Day Care ward was at the back of 6A. You had to pass members of the public who were in visiting so there were lots of people in the corridors coming in and out.

94. Air filters were placed in ward 6A after a short while of us being in there. There were industrial machines that are taken into your room on the ward. They’re huge machines, not like a Dyson one you’d have in your living room. They were they the size of a mini fridge. Each individual room in the ward had at least one or two and in the corridors, there was one every five metres. The nurse’s station had one too. They were standalone and they were on 24 hours a day. [redacted]. Having one of these in an enclosed space is more dangerous to the kids than it is without it because it’s just recirculating things. They’re just drawing in and it’s recirculating again. It’s blowing out the other end. They weren’t attached to any kind of extraction system or anything. I don’t ever remember any of the filters being changed or cleaned. I asked the nurses why we had to have them on if we have the air conditioning on. I was told it was a precaution as they thought infections had been brought in from the kids’ hospital.

95. The noise from the air filters used to annoy [redacted]. He would ask for them to be turned off. Every little irritant annoyed him and got him grumpy because it was making him uncomfortable. Any acute smells or noises really got to him. [redacted] asked one of the nurses that came in if the air filter could be

turned off but she said they couldn't. I asked her if we could even turn it off for a couple of hours but she said they had been told to keep them on 24/7. We could have turned them off ourselves but we had been told not to. I thought the air conditioning was alright in ward 6A until all that carry on with the air filters started as well.

96. There was always something getting done to the hospital when we were there, even when [redacted] was discharged and was only attending his MRI appointments. I still witnessed windows being replaced. The fact all the work isn't finished yet; leaves you wondering what on earth is going on. Two years have passed and they still haven't fixed whatever is wrong.

Hospital build issues: impact on [redacted].

97. There were massive physical impacts on [redacted]. What was previously normal for him, he now had to be shielded from. It was stressed to you by staff that it won't be the treatment that will kill them, it will be an infection so this is a constant worry as the chemo leaves them with no immune system.

98. [redacted] couldn't get much exercise when we moved to the adult hospital and there was nowhere for them to play. He was bed bound and had to lie on his left hand side because of the trollies and his lines.

99. I think his development has been affected to an extent due to being kept in a room all the time and nowhere really to go for exercise. There's no fluidity with him when he's running. He can't run more than 100 metres and is slightly disjointed when he does run. His shoulders are forward because he was hunched for so long in his bed.

100. There were issues with the toilet seat in the en-suite bathroom we had in ward 2A and it wasn't fixed for a while. It was loose so I couldn't sit [redacted] on

it properly. He started going in his pull-ups so that he didn't have to use the toilet. This put him back a few steps regarding his toilet training.

CLEANLINESS

101. I had some issues with the cleanliness in ward 2A. The cleaner would use a dry mop. It was the same one the cleaner used for both the bathroom and the bedroom. I'm not sure what sort of products they were using to clean with but there were never any strong smells of chemicals. Any smells like that used to make [redacted] sick. I'm not sure if they were maybe using scent free detergent. The floor was never wet and slippery either. I think someone used to go in with the big mop and clean the floor properly if we were out of the room. Even after a shower, you would still feel dirty after walking just a few steps on the floor. There was high footfall and they just never felt clean. I would never let [redacted] play on the floor. I did raise this with the staff but there was never any improvement.

102. There was a wee white board on the back of the bathroom door a bit like the ones you see on public toilets to tell you when the toilets were last cleaned and who by. The one we had sat in a plastic pocket, but the same squiggle used to stay on it for days. Sometimes it would be removed and you would just be left with the plastic pocket. There was nothing filled out regularly as there is in other places like a shopping centre or a restaurant.

103. [redacted] was in nappies and pull up pants. I was putting these in a pedal bin within the room on ward 2A. The bin wasn't emptied regularly so it used to be full and the smell would hit you straight away. It would sometimes sit for a whole day. I didn't want to be a nuisance and ask the nurses to empty it though as they were busy enough so I brought in scented nappy sacks.

104. Sometimes we could have up to seven urine samples to be collected which would be lying on the bathroom floor. I spoke to nurses and cleaners about this. They would always say “Oh, God, I’m sorry. This should have been seen to”. They would say they would make sure it didn’t happen again but then it would just carry on the same way. You weren’t angry at the nurses but you asked who you could speak to about it. When the cleaners with the green clothes came in, you didn’t want to give them a hard time either as I understand that they have their own work remit. It’s not like you’re in a hotel and you’re going down to complain about something not being right. I didn’t want to be one of these people but eventually I had to say, “Look, this is not right”. If it was a normal hospital and it was me that was in it, aye, fine. But not for a child that’s neutropenic. Eventually you had to say something. There was one younger guy that was there the majority of the time and another lady but no matter how many times I raised it, there was no improvement.

OVERALL EMOTIONAL IMPACT ON [redacted] AND HIS FAMILY

Overall emotional impact on [redacted].

105. By keeping [redacted] in solitude in Ward 6A, away from the other kids, he was in solitary confinement. Apart from the kids that came to his door to say hi, he would only be seeing them in passing, whereas before in the children’s hospital they could all play together and the parents could speak too. Because he couldn’t mix with other children, particularly when he was in ward 6A, he has struggled at school in social settings. He’s going into [redacted] and he finds it difficult to interact now because he’s been used to being on his own for that length of time resulting in him going into himself. He was home schooled for part of the week and the school have been trying to help to get him mixing again.

106. When [redacted] was visiting my dad at my dad's house, my dad was getting a wet room installed. [redacted] wanted to come home as it was like the hospital bathroom. It's wee things like that, which will pop up every so often. I've tried to just let him be a little boy and if he brings anything up, then I reassure him.

107. [redacted] still sleeps with his back to the door. He's very wary of people now. In the hospital when my dad came to visit him, because my dad wouldn't take him home, it had a negative impact on their relationship.

108. When [redacted] stays with me now, he will not go into his own bed. He has to sleep with me. In the hospital, he had to sleep on his left hand side to avoid his line and he still sleeps that way.

109. When [redacted] has an MRI scan, I have to tell him the day before and bribe him to go. If I tell him any further in advance, he just won't go. He doesn't want to go back.

Overall emotional impact on witness

110. I found it hard to speak to anyone at the hospital as it was mainly mums that were staying there. Some of the nurses would ask how I was but I would just tell them I was fine. I couldn't say how I was feeling.

111. I have severe trust issues now because of the lies that have been told about the hospital and the fact that no one was answering the parent's questions.

112. The overall silence regarding the hospital has led me to being paranoid and having it all on your mind all the time is dangerous. It was a stressful

situation and it became as stressful as it was dealing with the cancer, which made it too much.

113. I have been attending CCLASP counselling sessions which were organised by the Edinburgh Hospital Charity. The counsellor thought I was maybe suffering from Post-Traumatic Stress Disorder (PTSD) after my experience at the hospital, everything that happened and the fear of relapsing.

114. I had to tell my work that I was getting contacted by reporters when the issues at the hospital started appearing in the media. [redacted]. [redacted]

115. I [redacted] now but due to everything that has gone on with the hospital, I have to stay in the background. It's left me too nervous.

COMMUNICATION GENERAL

116. When [redacted] was first admitted, I didn't take everything in that Doctor Sastry told us about his treatment. I had contacted his secretary at a later date and Doctor Sastry had a meeting with me to explain everything which was really good of him.

117. You would ask the nurses what was going and you would get the impression that you weren't getting the full story. The example about the water; they would offer that you can bath your child in sterile water but you never got any clear answers from them that there was anything wrong with the water.

118. Some of the nurses who were in [redacted]'s care team told me they were exhausted. They appeared to be doing a lot of extra tasks. Some of the other parents used to have the nurses doing everything for them rather than do certain tasks themselves. A lot of the nurses when we were in ward 2A said they'd rather be at Yorkhill and that didn't fill me full of confidence. They would be chatting when they were in our room and a few of the nurses would say it was awful here, take us back to Yorkhill. They just didn't have a good feeling about the place and didn't like the new hospital. They wouldn't expand into why not.

119. Nurses maybe felt they couldn't stand up to the Board, even with their Union Reps. It's as if no one is willing to speak out. Like a lot of the parents, they're worried to go against the Establishment. I wonder if the nurses didn't know either or whether they were just scared for their jobs, scared that they won't work for the NHS again, never mind in the QEUH.

120. There were never any regular planned maintenance checks so when you needed something done in the bedroom, you had to speak to the nurses. The nurses were often really busy so when you asked them for something and an alarm went off, they would run to see what it was then forget to come back and speak to you or you were told someone would come and speak to you later but they never did.

121. I wasn't told everything about all the environmental preventative medication either. I was told that posaconazole was part of his chemotherapy treatment plan. I signed a consent form at the beginning of his treatment but that was from the information that this was for his cancer treatment. There were a couple of references to posaconazole in [redacted]'s medical notes. I can only remember being told that it was being brought in as part of the treatment plan and it was better for [redacted] to have it than not as it would protect him from infections but they didn't go into details about

the infections or where they were sourced from. I think this was on ward 6A and it was one of the nurses on duty who told me this. I just accepted what they told us at the time as we didn't know any better and [redacted] being put on them was to us a good thing.

122. There was a photocopied note, a flyer, put under the door that the hospital were taking measures regarding the things reported in the news and that was to reassure everyone but nobody said what the exact issues were or what the measures were either. I threw the note away. I think the note mentioned that patients were being treated with posaconazole. I asked staff what this meant and was told someone would come in and speak to me but nobody ever did.

123. On 19 September 2018, one of my friends text me to say they were closing the RHC due to wide spread infections. My friend had said it had been on the news but I knew nothing about it. I fell out with a lot of people at that time because I accused them of rumour-mongering. I said. "I'm fed up with all these rumours. I'm here and I'm trusting these people. They would have told me if there was anything going to put [redacted] in jeopardy." I did lose a lot of friends over this and all they were doing was telling me what was on the news. People believe the news. I asked some of the nurses and other parents about it but nobody knew anything. Eventually I was told by one of the nurses that someone would come and speak to me and that's all I was told. Nobody came to see me though.

124. Dr Sastry and one of the nurses came to see me in [redacted]'s room on 13 January 2019. Dr Sastry explained that there were certain things going on in the hospital and that they had been in the news. He said this meeting was to reassure me that everything is still being done for [redacted]'s care. There were things that he didn't even know that were happening but just to be rest assured that he and the nurses were doing their best for [redacted]. I can't

remember all the details. I was left assured that there was a level of care being given to [redacted] but there was nothing about the building or anything. Just reassurance on the level of care.

COMPLAINTS

125. I raised several complaints but the only written one I raised was straight to Jeane Freeman. I emailed her on 11 January 2019 and asked her to tell me what was happening with the hospital. I got a reply the same day saying she was going to ask for an update from her Senior Advisor. Surely she shouldn’t have had to ask for an update when she was the Health Secretary? I never got an update and when I asked for meetings with her, I’ve heard nothing back.

126. When I realised that the medical records that I had been sent were incomplete, I complained to the board again and to the Case Note Review and they sent me through some screenshots of certain things that happened. The medical records were set out in a way that only a medical professional would understand. It made it difficult for me to decipher what had happened. I thought, if they can give me screenshots, what else is there, where is the evidence? There must be a record of his bloods, his urine, what he had infection-wise. I think I have copies of these.

127. I raised the environment issues and the closure of the ward with my local MSPs and MPs, Maurice Corry and Brendan O’Hara, who was the SNP one. Brendan came back to say his assistant will look into things and get back to me, but no one ever did. Maurice just wanted a photo opportunity and he declined to help when I said no.

128. My local Argyll and Bute councillor, was really good too when I raised the issues with him. He was really supportive but as I knew him, he couldn’t

take on a personal case. He was going to make sure there was pipeline open to discuss things though but by that time, Jennifer Haynes who was liaison with the hospital had all been in contact with me to give me direct correspondence. After the response I got from Jonathan Best, I've not bothered to respond as I don't know how to. I've got no faith in opening up a line of dialogue with the hospital.

129. I spoke to the labour MSP Monica Lennon on 5 December 2019 about the environmental issues and the ward closure and she was the best one I dealt with. She invited me to Parliament on 10 December 2019, to the public gallery to listen to Jeane Freeman speak about issues surrounding the hospital. All she said was that the Health Board was being investigated, that the Health Board was going to be overseen by another board. She didn't even say anything about the matter, again. I'm disappointed that Jeane Freeman has said to trust the nurses and the processes. If those people we have on the Health Board are the best we have and you can't replace them, then there's no point in Scotland going for Independence. I've not got any faith in any of them now. I feel palmed off.

130. Before I went to Parliament on 10 December, I met Monica Lennon at Anas Sarwar's office in Glasgow. I think there were about 12 other families there. This is when we first saw the whistle-blower documents that were given to Anas Sarwar. He reached out to the families involved when he got hold of the documents and then I think one of Monica Lennon's constituents asked her to intervene and that is when the parliamentary stuff happened with Jeane Freeman. I don't know if the information he gave us has been made public but it's damning of the whole hospital and about records that completely disappeared from the health board computers.

131. I wrote to Jonathan Best, who is the Chief Operating Officer at NHS Greater Glasgow and Clyde, on 6 January 2020 about the secret use of prophylactics and other environmental issues. He wrote back to me and said that the first they were aware of any issues in the wards was in 2018. He said that when the hospital first opened in 2015, there was no indication of infections out with the normal realms of what you would expect to see. I believe the other independent review that looked at the issues further back than what Michael Stevens did, shows a different version of events though as there was a spike in infections in 2018 in ward 2A of the RHC and on testing the environment and the water, they found organisms that can potentially cause infections in the water supply. Mr Best told me the first indication they had that there was anything wrong in the hospital was in 2018. That's what I have in a letter from him. I think he was trying to hoodwink me as he failed to mention the evidence from the whistle blowers that Anas Sarwar shared with the parents. Mr Sarwar also told us that senior clinicians made wrong decisions prior to the closure of RHC. Apparently there was paper work showing that issues had been raised in 2015 about the hospital but it was still signed off. How can Jonathan Best assure me [redacted] didn't have a hospital acquired infection when what I witnessed says otherwise? It is difficult to expand upon this as I don't have a full set of medical records to refer to.

132. When I got Mr Best's response, alarm bells were ringing. He said [redacted] did not have any hospital acquired infections. He was quite categorical about that, but I don't know how he can say that categorically when the blood records are not there that show if he had infections or not. He stated in his letter that he was alarmed to read my concerns about [redacted] being put on prophylactics secretly and that families should have been spoken to by whoever was with the child at the time. He said all the parents were spoken to about the use of prophylactics and he was sorry for the concern and worry this had caused. He went on to explain that no patient should be

placed on medication secretly and that all families were spoken to about the appropriate use of the medication. Regular discussions were taking place and we were given a letter. I know the letter he means; it was the photocopied one about the use of prophylactics but I can't remember the exact content.

133. I also asked Johnathan Best for evidence [redacted] didn't have a hospital acquired infection but I haven't had anything back. I've stopped engaging with the Health Board. If they were carrying out testing on [redacted] for this, I wasn't aware of it so they should be able to provide his test results. I think it would be good for the kids any way to be tested for certain infections when they are due to be discharged so the parents know they're safe and what to look out for.

134. I asked an independent company to come in and test the water for me. They told me on the phone that they couldn't because there was a conflict of interest. They also told me that the NHS had the best infection controls and that the NHS was the best at testing for bacteria disorders in the water.

135. I saw Jane Grant, the Chief Executive, at the hospital on one occasion. Her and another two people in suits. I approached them and asked them about the issues with the hospital. They looked at me as if I was begging in the street and asking them for money. She didn't answer me and walked away. Now look at her on the TV, no compassion, nothing.

OVERSIGHT BOARD / CASE NOTE REVIEW / REPRESENTATIVE GROUPS

136. [redacted] was not involved in the Case Note Review. I don't know how it was decided that [redacted] wasn't part of the Case Note Review. What if [redacted] had been put on antibiotics before the blood tests had been carried out so any

bacteria didn't get the chance to grow? I don't think anyone can prove didn't have a hospital acquired infection.

137. I wrote to Professor Stevens on 27 May 2021 asking him three questions; here is a bit of what I said:

"Can the following questions be answered and backed up with hard, factual evidence, please? Number one, what were the actual testing procedures used to determine any daily infection or indeed as you say, for his non-infection as you claim in your last email and what was the frequency of this testing throughout his and indeed our own hospital stay? Number two, when was the testing regime changed to account for impending possibly infected due to other unexpected variables in the water, air or structural inadequacies presenting a danger to my son? Was testing changed after the deaths and serious illness of other children? Why wasn't I told by the hospital first that we should be extra vigilant in caring for our children instead of by the news? Three; many of the different strains of bacteria and other dangers came to light afterwards when the review published its findings. Can you tell me what actual bacteria strain or any other found anomalies my son had been tested against? All I was told about the showers was possible E. coli risk and is it not possibly a new strain was developing all the time until we were moved out of the condemned wards in the children's hospital? If he wasn't in any danger or didn't have any infection, why was he moved to the adult wing when the ward was deemed unfit?" So I've gone on like that. I can't read it all out but I'll send it to you.

138. Professor Stevens told me that Professor White would explain everything to me and that's when Professor White got Dr McGuire, who I didn't know, to go over the medical records with me. She also sent me two screen shots of [redacted]'s blood samples that I'd asked for. That's the only records of blood tests that they have for him. I asked my solicitor how to reply to them. Why are these blood tests not contained in [redacted] records?

139. I think Craig White was just trying to keep the peace so I wouldn't speak to the Inquiry. I think Craig White was appalling. His whole approach to the inquiry, the Board, meeting with families, I don't think he's reflected accurately on all of it. It's as if he's reading off a sheet. He's recommending who I speak to. They apologise for what's happened, so to me that's an admission of guilt but at the same time, they should just come out and say what's actually happened because they're saying sorry but they're not really sorry. The distress wasn't our fault. Somebody's got to take responsibility here and that goes for Craig White and Jane Grant.

140. I did ask Professor White for [redacted]'s individual medical records and he said I'd have to write away for them as per the process. I'd originally thought that when he became involved and was one of the 'big guns', that we'd be taken seriously and get answers. He's just been a puppet though. He's passes the buck.

141. I was involved with the Oversight Board but eventually these groups all roll into one and become the same thing. I did think it was effective but I think a lot of people are scared to show their hand and come forward with information while the Inquiry is going on. One of the other girl's dads is really good at getting answers from them. He's experienced in this kind of stuff and he was getting answers to some of the questions. In fact, the questions you're asking me just now, I've been asked those already by that girl's dad.

142. I'm involved with a number of groups and sub groups. I get all the notifications when there are updates. There's so many of them now. Some parents speak independently but we decided it would be better if we formed a group and discuss everything as a unit with Professor White. We felt stronger together and we might get more answers and get taken seriously as there would be less chance people could brush us off.

143. There was one lady that was very good. She was the Nursing Officer but she stood down. She was really good and you could speak to her. She was the only one I felt gave sympathy to what was going on and she didn't speak in official terms. They'd have been better having someone that knew what was going on rather than Professor Craig White's nonsense.

144. I am a member of the parents closed Facebook Group and I feel that's really a really good help. There's support available for anyone struggling. There's lot of rumours appear on it but they have someone, professional people that answer those and give you the facts.

145. I was a member of the Schiehallion Unit Support Group. It's a closed Facebook group that has been set up by parents themselves that have been involved with the Beatson or the Schiehallion ward. This group was outstanding and I got to know one of the ladies that runs it quite well. It was good for sharing information and also if you needed to offload anything on your mind. It was set up for new parents coming in and finding themselves in the same situation. At the start, you're lost and this group tells you what you need to know and what you need to do. I'd say this group was essential. If it wasn't for these groups, a lot of the parents would be left high and dry a long time ago. It's been a lifeline for us. You could also offer to help each other with shopping. It's been taken up a bit by the Inquiry though and new parents are now reading the information and that's scaring them so they're asking questions rather than being reassured.

CONCLUDING COMMENTS

146. The fact that is has taken two years to sort two wards is concerning me. The cinema is still closed and there's a vast amount of space that has all

been neglected. Something is going on. It can’t just be that one section that has been condemned.

147. I think the smell from the carpark is the bullshit coming from the Health Board’s offices. I have absolutely nothing positive to say about the Health Board.

148. I would like to thank [redacted]’s medical team, especially Doctor Sastry, [redacted]’ consultant. I am so grateful to him for giving [redacted] the scan on 19 August 2018. He told me if we had waited another two weeks, the normal time, then the tumour would have been all through [redacted]’s eyes and nose and that would have been him. He saved my son. He’s God in my eyes and can’t do anything wrong. I trust him with everything. I had really good relationships with [redacted]’ doctors. We were fortunate enough that ours were good. I know some of the other parents didn’t get on with their consultants.

149. I noticed when I attended the hospital with [redacted] for a follow up MRI scan, that due to Covid, people were no longer allowed to congregate and smoke at the main entrance. The hospital is now taking the infection risks seriously as a result of Covid-19 but when there was a risk to child cancer patients relating to infections, they didn’t.

150. As far as I’m concerned, there’s people at the very top of the government who knew about the issues with the water. I’m not making direct accusations however the impression I am left with is that the First Minister of Scotland can’t give straight answers. She must have seen the documents. The hand over and process have been done as there’s been pressure to get SNP’s flagship hospital open.

151. Due to the type of cancer [redacted] had, if he relapses, that’s it for him. I don’t want him dying in that place. The environment isn’t clinically fit for children.

152. There are a few children no longer with us and those children were heroes. They were the ones that [redacted] and so many others going through treatment, looked up to. They did so much for the children following behind in their treatment and who have been more fortunate.

153. [redacted] sometimes mentions other kids he met on the wards. He asks if we can have them up to play. Some of these kids aren't here anymore, how do you tell a 4-year-old that these kids have died? How do you tell him the wee girl he was friends with died of an infection? It's heart-breaking. Sometimes I've just told [redacted] that they're on holiday as you can't tell a 4 year old their friend has died.

154. I believe that the facts stated in this witness statement are true. I understand that this statement may form part of the evidence before the Inquiry and be published on the Inquiry's website.

Scottish Hospitals Inquiry

Witness Statement of

Kimberly Darroch

WITNESS DETAILS

1. My Name is Kimberly Darroch. I was born on [redacted] . I am [redacted] years old. I work as [redacted] and live with my son, [redacted] ,who is [redacted], in [redacted].

2. I am the mother of [redacted] [redacted]. [redacted]'s date of birth is [redacted] . She was 10 years old at the time of her death on [redacted] .

OVERVIEW

3. My daughter is [redacted] [redacted]. When [redacted] was 5 years old, in September 2012, she was diagnosed with Acute Lymphoblastic Leukaemia (ALL). She was treated at Yorkhill Hospital in Glasgow and entered remission in 2015. She relapsed in January 2017 and was admitted to the Royal Hospital for Children (RHC) on 16 January 2017 where she was predominantly an in-patient until her death on [redacted] .

4. [redacted] spent the majority of her time in wards 2A and 2B of the RHC which are known as the Schiehallion Unit. I stayed with [redacted] for the duration of her admission along with her father, [redacted]. My mother, Christine Horne also helped out and came to the hospital with us. I can speak to the experience which [redacted] and I had on these wards.

5. With the assistance of my solicitor I have prepared and provided the Inquiry with a timeline showing [redacted]'s experience with the hospital. The timeline

is attached to this statement as an appendix (**KD/01 – Appendix 1**) and I confirm that it is accurate to the best of my recollection.

6. There are some specific events that I would like to mention. [redacted] contracted an infection, stentrophomonas maltophilia, which contributed to her death. As her family, we were given no information in relation to this infection and that it might have been related to the hospital environment. I will come on to talk about these events in more detail.

FAMILY BACKGROUND

7. I had a very close relationship with [redacted] after the death of my husband in 2016. She really looked after me.

8. Although her brother, [redacted], was much younger than her, she was really good with him and just loved him. They were always playing together and she would take him for walks just to give me five minutes

9. [redacted] had a wonderful personality and was a bit of a character at times. She had a great sense of humour. She had some temper on her and she had a death stare that would look right through you.

10. She had loads of friends and she cared about everyone she met. She always had a big smile on her face. It didn't matter how she was feeling at the time, she had one thing and that was to make other people feel better. She cared a lot. She was always reassuring her friends and family.

11. She had a very close relationship with my mum, Christine Horne. Her and would watch the dancing on a Saturday night, even though [redacted] hated dancing, she watched it for her gran. She would also go swimming with my mum quite a lot. They would go to the shops together.

12. [redacted] also used to like going to my mum and dad's caravan in Ayr and as a family we would often make trips down there. We also used to have family trips to places like the Five Sisters Zoo which she enjoyed.

13. [redacted] liked to go out on her bike and scooter but she wasn't really into sports. She had taken a long time to recover from her first lot of treatment for leukaemia and was often quite breathless.

14. She did love animals, especially foxes and she would often feed the foxes at night at my mum and dad's house. She also liked going out into the garden and finding snails.

15. She loved life and was full of beans. She was a joy to be around.

SEQUENCE OF EVENTS

Initial treatment at Yorkhill between 2012 and 2015

16. [redacted] was initially diagnosed with Acute Lymphoblastic Leukaemia (ALL) in September 2012 and she was treated at Yorkhill Hospital in Glasgow. She was treated as an inpatient and an outpatient and received chemotherapy and steroid treatment. [redacted] was mostly an outpatient after the initial five weeks. She did really well on the treatment, although the steroid treatment did affect her mental health and she had to work with a psychologist to help her, but we got through all of that and she was in remission.

17. Yorkhill Hospital was a really nice environment to be in and I wish it had never closed. You were able to speak with the other parents and the kids were able to mingle in the playroom. It was a lot bigger than the playroom in ward 2A in the RHC. There was a lot more to do and it was more age-appropriate for a lot of the kids. It was always really busy and the nurses

would be enjoying time with the kids in the playroom as well as in the ward and the bedrooms. The kids were able to go up and down the ward and speak to each other. [redacted] used to enjoy going there.

18. When we went to the new hospital, it didn't feel as nice an environment. It felt like it was more for younger kids and the playroom was smaller. There wasn't a lot of room to do anything. There was hardly ever anyone in it and it felt like more of a prison. We weren't allowed to congregate in the halls or the kitchen to talk to anyone and the atmosphere couldn't compare to Yorkhill. All of the children had to be kept in their own rooms.

[redacted]'s relapse: January 2017

19. Between [redacted] entering remission and her relapse in 2017 she was having regular check-ups, I think every three months. She had actually been for a check-up in December 2016 and nothing had come back from that.

20. In the couple of weeks leading up to her relapse she had been having a lot of diarrhoea and had a pain in her leg so I took her to her GP. He said that it was nothing to do with her leukaemia but I felt there was something wrong. I also spoke with my parents. I called ward 2A and they told me to bring her to A&E of the RHC, which I did.

21. We were in A&E for a couple of hours and then Professor Gibson came and told us that [redacted] had relapsed. I think this was on 15 January 2017 and Professor Gibson told us that [redacted] could have one last night at home and then she would be admitted to ward 2A on 16 January 2017, which is what happened. [redacted] was aged 9 when she relapsed.

Description of Ward 2A

22. [redacted] was admitted to ward 2A. To get into the ward you have to go through two sets of double doors. The first thing you come to is bathroom and there's a kitchen. There are isolation rooms at the start of the ward and then single bedrooms on either side of the corridor. An isolation room is a double door room. You go in through one door and there is an area with a sink and then you go through another door into the patient's bedroom. Then there's the nurses station and the playroom was straight across from that. Further up the ward there is another set of double doors and that takes you into the teenage unit and then another set of double doors to take you out of the ward.

23. All the bedrooms are single rooms and I think they were a bit better than the rooms in Yorkhill as they had fold away beds for the parents that could be put in a cupboard which was better than them being in the room the whole time.

24. There was a playroom, but it wasn't as big and didn't seem to have the same facilities as there had been in Yorkhill. There didn't seem to be as many activities to keep the kids entertained. There were no arts and crafts, no small tractors, or lights they could shine on the floor and dance around It was a shame.

25. There was a parents' kitchen, but it was often closed because there were infections going through the ward like norovirus. The kitchen was closed to stop the spread of infections. So a lot of time we didn't actually use the kitchen and would only go there to get water then leave straight away.

26. There seemed to be plenty of nurses around the ward all the time, although I did notice that there was a difference in the amount of time they were able to spend with the kids. When we were in Yorkhill the nurses seemed to spend a lot more time interacting and playing with the kids, but in the new

hospital they would come in to see the kids then leave straight away. It was maybe because they had more paperwork to do.

27. I was really happy with the care that [redacted] was given by the nurses. They were really good and I don't have anything negative to say about them. I think they were specially trained in dealing with oncology and there were certain ones who were trained to administer chemo and they were the only ones who were allowed to do it.

28. As I said, Professor Gibson was [redacted]'s consultant, but she wasn't on the ward as much as she maybe could have been. We saw her about once a week. There were loads of different doctors in the ward. A lot of them were just learning and they would change every six months

29. I wasn't really aware of any specific protocols on the ward in relation to infection control. The only thing that stands out is that, if [redacted] was in an Isolation Unit which had the double doors, then the nurses would wash their hands and gown up and things like that, but if we were just in a normal room then they didn't do this. My dad made a comment that there didn't seem to be any barrier nursing.

30. In relation to medication, I felt that we as the parents were left to give most of the day to day medications, except from the steroids. We were also left to do most of the day-to-day care.

[redacted]'s first admission to ward 2A: January 2017 – March 2017

31. During [redacted]'s admissions me and her dad, [redacted], did night about staying with her so that I could look after [redacted]. My mum also helped with looking after and staying in the hospital overnight with [redacted].

32. When she was admitted on 20 January 2017 she was seen in ward 2B first of all, the daycare unit, and a bone marrow aspirate was taken. That is a sample of bone marrow. That confirmed that [redacted] had relapsed.

33. [redacted] was then admitted to a room on ward 2A. I can't remember the number of the room. All the rooms were much the same. When you went into the room, [redacted]'s bed was on the left hand side and the bathroom was on the right. The bed that parents could sleep in was on the right hand side of [redacted]'s bed and we just folded that down. I think they were smaller than the rooms in Yorkhill. In the first room we were in, I don't think the blinds worked, so we couldn't see out the window. I am not sure if [redacted] stayed in the same room during this admission or if she was moved about.

34. The treatment plan for the relapse was chemotherapy and steroid treatment again. I was given a written copy of the treatment plan. I think that [redacted] got chemo every second day. I can't remember exactly what the chemo treatment was that she was getting, but I am sure it was every couple of days. I do remember that the doctors had a meeting with me before they started the treatment and said that the treatment was really intense and might not survive it so that was a bit of a shock. But she sailed through it. She wasn't really ill during that first admission.

35. The doctors' main goal was to get [redacted] into remission within that month with the chemo. Then they would decide whether she would need a stem cell transplant or she could just continue on the chemo. A stem cell transplant is the same as a bone marrow transplant. [redacted] did not go into remission after the first round of chemo and it was at this stage the doctors knew she was going to have to have a stem cell transplant. Once they realised she had not gone into remission after this first round of chemo they started trying to find a stem cell donor and they kept going with the chemo until they found one.

36. [redacted]'s chemotherapy was administered through her Hickman line. Her Hickman line was inserted under general anaesthetic into her chest. I think she got this line put in the day after she was admitted and then the chemo started the day after that. I can't remember the specific dates.

37. [redacted] had a Hickman line when she was treated in 2012. The nurses showed us how to look after the line and clean it. We were advised to change the plaster covering the line once every week, but we did it every day because [redacted] didn't want to get an infection. Infections in the line were very common, but [redacted] never had one, until the fatal one.

38. There was a plaster over the line where it went into [redacted]'s body to keep it covered. We would change that and then we had wee alcohol sticks that we would rub over it. We would then use another liquid to swab round where the line actually goes into the body as that can be quite gunky. Then we would cover the line back up again and with alcohol wipes we would wipe the end of the tubes and that was it. There were two tubes on the line and one would be used to administer chemo and the other would be used for fluids and other stuff. These tubes were loose and [redacted] use to wear a wee bag, "wiggly bags" we called them, round her neck that her gran made her and the tubes were put in the bag so they didn't flap about.

39. This first admission lasted until March 2017. I think [redacted] got out for a week just before her birthday. I remember as she had to go back in for a jag on her birthday and she was not happy. At this stage the first round of chemo had been done and she hadn't gone back into remission, so we knew that was going to have to have a stem cell transplant. The relapse treatment protocol continued whilst a donor was found. This was really maintenance treatment until the transplant could take place. She would have continued with the relapse protocol, which was the chemo, even if she had gone into remission.

40. I think [redacted] was let out of hospital to give her a break from her chemo. She hadn't had a temperature so she was well enough to go home. She would go back in to ward 2B for bloods to be taken and for her antibiotics to be administered. She got those three days a week. The antibiotics were called Ambisome. Professor Gibson told us that it was because it was a new hospital. I'm sure that's what her words were. I never thought to question her about it any further. I trusted her. I think she said it was to protect against bacteria of some sort but I'm not quite sure. I do not know when [redacted] was started on these antibiotics.

41. [redacted] was also on another prophylactic medication. I think it was called Septrin. I think she was on this to protect her lungs. I think she was prescribed that in February 2017. She wasn't given it straight away. Any time her blood counts came down she would be taken off that one. I didn't know why she was on this or why she was taken off if her blood counts were down. I just accepted it especially as she had been on Septrin during her treatment the first time in Yorkhill.

42. Throughout [redacted]'s first admission, and during subsequent admissions, would often have spikes in her temperature. There was a protocol in place if kids had a temperature as it could mean that they had an infection. If had a temperature, she would be put onto general antibiotics for 48 hours. There would then be some tests carried out. [redacted] would get a swab up her nose, bloods and cultures taken and then we would find out if she had an infection that needed different antibiotics. That happened a couple of times. It wasn't always an infection that caused her temperature to spike, some of the time I think it was just because of her treatment.

43. I don't think [redacted] spiked that often during her first round of treatment in 2012, but she did seem to spike more often during the relapse treatment. If it was an infection, sometimes the doctors and nurses didn't really know what it was and it was just one of those things that happened. I do

remember that she had the norovirus, but that was more sickness and diarrhoea. I think the doctors and nurses also mentioned the adenovirus and rhinovirus, which is just the cold. Those were the most common ones I think.

[redacted]’s second admission to ward 2A: March- April 2017

44. After her week at home, [redacted] was readmitted to ward 2A in March 2017. I think this was because her treatment was starting again. I think it was the same regimen as the first admission where she got chemo every couple of days. I think she also had another chemo medicine added in this time, methotrexate. I know she was having quite a few different chemo medicines at this point.

45. [redacted]’s treatment was all done as an inpatient as it was so intense. She had no immune system so was at high risk of getting an infection. I think this round of chemo lasted for about a month. I think I have the protocol paperwork somewhere. I don’t think she was on steroids in this round. I think she had just been given them in the first month of treatment. I do know she was also getting an injection of chemo once or twice a month. It was called a PEG. The PEG jag was in her leg. She hated that one as it was injected into the blood and it was really painful. I think she got this during the first and second round of chemo. [redacted] reacted alright to the chemo. She maybe had a few temperature spikes, but she wasn’t really ill.

46. I can’t remember what room [redacted] was in during this stay. It wasn’t an isolation room; it was just one of the normal rooms. I can’t remember whether we got moved during this admission. She got home after the round of chemo in April 2017, around Easter time.

[redacted]’s third admission to hospital: April-May 2017

47. [redacted] was home for a few days and then had to be re-admitted to ward 2A with stomach pains. I wasn't able to take her so my mum and dad took her to the hospital. I'm not sure what was causing the stomach pains. From there on in she had diarrhoea quite a lot of the time. The medical staff kept telling me that she was positive for norovirus all the time.

48. [redacted] then got another round of chemo during this inpatient stay. I think she was on up to five different kinds of chemo at this point. It was around this time that she got mucositis which are ulcers caused by the chemo. It must have been caused by one of the new chemo treatments. It is really painful and [redacted] was given morphine and ketamine to treat this.

49. She recovered from the mucositis and was allowed home for a few days at the end of May 2017 before she was re-admitted on 4 June for her stem cell transplant.

[redacted]'s admission for stem cell transplant: 4 June 2017

50. Once we knew that we had a donor for [redacted]'s transplant, she was admitted so that her body could be prepared for the transplant. [redacted] was admitted on 4 June 2017 for this to be done.

51. We got a letter from the hospital explaining what the stem cell transplant was as well as the risks. I think Professor Gibson probably had a discussion with us about it, although I can't remember that. We decided to take the chance. The transplant did work. We were told about the graft versus host disease where the body rejects the transplant and we were probably told other things as well, but I can't remember.

52. Before the conditioning treatment began, a number of tests were carried out on [redacted]'s heart and lungs to check their function. They were fine so the conditioning treatment could begin.

53. The conditioning treatment consisted of radiation, which was total body irradiation, and chemo. [redacted] was an inpatient in ward 2A throughout this treatment, but had to travel to the Beatson Clinic to get the radiation treatment. The Beatson Clinic is the only place that offers radiation treatment in Glasgow. It is on Great Western Road. It is a 20 minute drive from QEUH. This started on the 6 June 2017 and she got it twice a day for four or five days. She would be transported back and forwards between the RHC and the Beatson by a private taxi for this treatment.

54. [redacted] then had intense chemo of different kinds in ward 2A. The chemo and the radiation gets rid of all your bone marrow and all of your cells out of your bone marrow so that the new donor bone marrow can go in. None of this treatment made her ill, she came through it okay.

55. When [redacted] was first admitted on 4 June she was in a room behind the nurses' station and this is where she stayed whilst she was getting her radiation treatment. She was then moved into one of the isolation rooms, one of the rooms with the double doors, for the transplant, although she was moved out of it into another room briefly whilst the isolation room was cleaned. I think this is something they do before the transplant takes place. She then returned to the isolation room and was there for the transplant taking place.

56. On 12 June 2017, [redacted] had some blood cultures taken and antibiotics were started. She normally had blood cultures taken every day just to check she was alright. On this occasion she must have had a spike in temperature and the antibiotics were introduced automatically as a precaution because she had no immune system whatsoever. I don't think

this was standard testing that was carried out in advance of the transplant. I think it was just that she had a temperature. There was no infection on her blood cultures anyway.

57. [redacted] got her stem cell transplant on the 15 June 2017. She was in the isolation room and it was done intravenously through her Hickman line. Once it was done, the nurse stayed with her for three hours and checked her blood pressure every 15 minutes. Then they came in every four hours to check her and carry out observations. Then after that we were just left to see if it worked. [redacted] remained in isolation. The expectation was that she would remain in isolation for about 8 weeks, although it was only about 15 days before [redacted] got her first neutrophil, which was a sign that her body was accepting the transplant.

58. After the transplant, [redacted] was very low and wasn't herself for at least three weeks. She got mucositis again and was sore with that and had to get ketamine and morphine again. Once that settled down she got back to her normal self and started trying to eat things, although I think it tasted awful and she wasn't up for eating very much. From her second month of treatment, [redacted] had been on a feeding tube, which was a milk feed, but after the transplant she couldn't tolerate that either and she had to be fed intravenously through her Hickman line. She continued to have diarrhoea and, had she not got her line infection, the plan had been to carry out investigations into why this was the case.

59. On 16 June 2017, [redacted] experienced some respiratory difficulties. I don't know what caused that, although I thought that it might have had something to do with the transplant. I think they maybe gave her an injection to boost her neutrophil counts, that was something she was given quite a few times.

60. On 20 June 2017 [redacted] was given antibiotics as she was unwell. She was having temperature spikes and she was given the antibiotics. I don't know if she had the adenovirus infection at this point.

Adenovirus Infection: 30 June 2017

61. [redacted] had blood cultures taken on 28 June 2017 and on 30 June it was confirmed that she had adenovirus. I think Professor Gibson and maybe another doctor, Mark, told us about the infection. I think they told me that it is quite a common infection and it lives in everybody, but obviously with having no immune system it just appeared and made her unwell. I don't remember if I was told how they thought she had caught it. She was given antibiotics and she improved.

62. On 6 July 2017 [redacted]'s fever had settled and about a week after that she was allowed out of the hospital. This was the second week in July 2017. She was allowed out on a few occasions. She was allowed to go home for a couple of hours, although she wasn't too keen about this as she still didn't feel great. She still had diarrhoea and wasn't really up for eating things. She had been sick when she was on her way back to hospital one time and her feeding tube had come out so she was bit wary about going anywhere with the tube in.

63. On the ward, [redacted] was still in the isolation room with the double doors, but she was no longer in isolation. She was allowed out. She mainly stayed in her room and played her PlayStation and watched the iPad or TV. She didn't really use the playroom because she didn't want to. As I have said it wasn't really for her age group. She didn't really interact with any of the other kids, but there wasn't really an opportunity for her to do so.

Stenotrophomonas maltophilia infection: 25 July 2017

64. The Friday before [redacted]'s Hickman line was removed she was complaining that it was sore around where the line went into her body. She never complained, so it must have been sore. I mentioned it to the transplant nurse. I can't remember his name. He had a look at it and said that it was fine and that was it. There was nothing obvious, the infection must have been in the line. Nothing else was done at that point.

65. Around about this time, [redacted] was spiking quite a few temperatures and she was telling me that she was feeling rotten. She was still telling me that her line was sore. Blood cultures were taken again on 25 July 2017 and they found she had a line infection. [redacted], [redacted]'s dad, was in the hospital that day. He was told that her line was infected and that she needed to go to theatre to get it removed. We were never told what the infection was. In fact, Professor Gibson kept telling us that they didn't know what the infection was. She said it might have been the adenovirus, or it could have been because of the chemo. I don't know when she first said that they didn't know what the infection was, but the hospital staff maintained throughout [redacted]'s treatment for the infection that they didn't know what it was.

66. [redacted] was taken to theatre on 25 July 2017 and they couldn't get her temperature under control. Her blood pressure was either high or low, I think maybe low. But they got the green light to go ahead and take the line out. This was after blood cultures had been taken from [redacted] and they showed that she had a stenotrophomas maltophilia infection in her line, although we were not told that at the time. I actually thought I was going to lose [redacted] that day after the line removal. Whilst they were removing the line, there was a septic shower from the line and the PICU doctor explained to us afterwards that it was the infection running through [redacted]'s blood. On 26 July 2017 [redacted] had further blood cultures taken from her and they were still positive for stenotrophomonas, although we weren't told that at the time either.

67. After this surgery to remove the line, we thought that [redacted] should have been admitted to the Intensive Care Unit (PICU) but she wasn't. She was taken back to ward 2A and was being monitored closely by the nurses. We were told that she would be admitted to PICU if her lactate levels fell below a certain number, although even when the numbers did fall, she wasn't admitted.

68. [redacted] wasn't admitted to PICU until 4 August 2017. She had just been at the toilet and her lips were blue. One of the doctors came into her room and saw her and it was then that the decision was made that she should go to PICU.

[redacted]'s admission to PICU: 4 August 2017

69. The decision to admit [redacted] to PICU was made because she was blue in colour and her heart function was at 17 per cent. Her lungs weren't coping either. She had severe infection in her lungs, which I didn't know about either. I wasn't told anything about why she was so unwell. I put it down to her heart function and her lung condition. I remember when she went into PICU and she was ventilated, Professor Gibson came down and I asked her if [redacted] would survive and she said she didn't know. So at that point I knew it was serious. But I was still under the impression they didn't know what was wrong with her.

70. [redacted] had to be put on a ventilator on 6 August as her lungs weren't functioning. We were told this by the PICU doctors. We rarely saw Professor Gibson once [redacted] was in PICU and I think she was away on holiday until the week before [redacted] died. The PICU doctors were amazing, but they still didn't say [redacted] had stenotrophomonas. They were telling us everything they were doing for [redacted]. They were giving her lung massages and they were clearing out her lungs as well. The doctors

were telling us that they were trying to find out what the infection was and they even checked to see if her leukaemia had returned. They kept trying her with different medication when she was in PICU. One of them they had to get from America. I can't remember what it was called, but they thought it was this other infection that they were going to treat her for. They kept telling us that virology was involved. And all these different doctors, infectious disease doctors. But if they knew what the infection was, I don't understand why they would tell us these things. Maybe the PICU doctors didn't know. I don't know. Somebody knew but maybe they didn't.

71. On 12 August 2017, [redacted] was put on the ECMO machine which is a heart and lung bypass machine. It takes all the blood out of the body and does the work for it. Just after she was put on the ECMO machine, Professor Gibson and the Head of PICU spoke with me, my dad, [redacted] and his wife. They told us that [redacted] was very poorly and was the sickest child on the ward and they didn't know what the outcome would be.

72. After that they were just trying to keep her comfortable. They tried taking her off the ECMO one night. She was okay and then they put her back on it again. They were doing physio on her lungs and still clearing her lungs out. We had been told that there was a high risk of her bleeding because she was on so much warfarin with the machine. They took her off her medication which had sedated her and she was able to speak to me a couple of times. It wasn't much but it was nice. At one point we were told that they were looking into getting her a heart transplant down in Newcastle. They were always giving us hope. There was always something that they could do. And then they said that they couldn't do the heart transplant because she was so poorly. I think that it had already been established that if she couldn't have the heart transplant then there was nothing more to be done. They then took her for a CT scan and they found she had a bleed on the brain. [redacted] passed away

on [redacted]. At the time of her death we knew that the stem cell transplant had been successful and the leukaemia had gone.

73. After [redacted] died, one of the doctors in PICU certified the death. I wasn't there to collect it. [redacted] and his wife did that. I think they were advised against having a post mortem as they wouldn't find anything that they didn't already know. I didn't look at the death certificate until about five or six weeks after [redacted] had passed away. I saw the stenotrophomonas infection on the death certificate and I had never heard of it before. I Googled it and saw it was an infection found in water, but I never thought anything untoward. Maybe I should have at that point but I had just lost my daughter and I trusted everyone in the hospital. I didn't expect an infection found in water to have killed my daughter. I didn't ask any questions at that point. There was no further information from the hospital about [redacted]'s death.

74. I didn't start to question the information about the infection until everything came out in the press in November 2019. I had heard about ward 2A closing in September 2018 and I did have a niggling feeling at that time, but I am not the sort of person to go out and get answers, I am actually quite shy.

Meeting with Professor Gibson: February 2018

75. In February 2018, Professor Gibson and one of the outreach nurses from Schiehallion, Karen Marshall, came out to my house to meet with me. My mum was there too. I was in touch with Karen quite a lot and I think I had had a card sent to me by Professor Gibson saying she would be happy to talk to me. So I told Karen I thought that would be a good idea and she arranged it. They came out to see if I was okay and if I had any questions. I did say to Professor Gibson that I had Googled the stenotrophomonas and thought it was found in water, but she didn't take

the conversation any further. I think she just nodded her head and that was the end of it. We didn't really discuss [redacted]'s death at all. Professor Gibson was saying how lovely [redacted] was and what a nice family we were. She was just really sorry that [redacted] had passed away. She seemed to be particularly affected by [redacted]'s death which I thought was strange. I remember that Karen told me that Professor Gibson hadn't gone to the memorial service held in September 2017, for all the children that had died, as she was too upset about [redacted].

76. After this meeting in February 2018 I didn't really have much communication with the hospital. I kept in touch with Karen now and again and I raised some money for the ward. I used to get invited to the memorial service I just mentioned. I didn't go in 2017 as it was too soon after [redacted]'s death, but I did go in 2018. I also went to the Christmas event held by the children's hospital charity and I went to a few counselling group meetings. After everything came out in the press I wasn't invited to anything else.

Hospital Acquired Infections and water contamination reported in the press: November 2019

77. Throughout 2018 I wasn't aware of anything happening in the hospital and then I read in the papers that ward 2A was closing in September 2018, but that was the only information I had at that point.

78. Around November 2019 I must have seen something in the press about the hospital which made me think that the issues at the hospital were linked to [redacted]'s death. As a result of that I emailed the Health Minister, Jeane Freeman's office. I think this was in September or October. I was asking whether there was a link between the issues at the hospital and [redacted]'s death. I had a suspicion that something wasn't right. I did get a response from Jeane Freeman's office about three or four weeks later

which said that someone would be in touch in due course, and then I got a further email to say it was being looked into. By that time the press articles had come out about the whistleblowers and the water contamination and I instantly knew that the child they were talking about in the press was [redacted]. The press article came out in November 2019. I didn't have any meetings with Jeane Freeman as a result of my email to her.

79. After all the information appeared in the press, no one from the hospital contacted me.

Involvement of Police/Procurator Fiscal

80. Although [redacted]'s death wasn't initially reported to the Procurator Fiscal, they are looking into it now. I spoke with the police and they went over [redacted]'s medical records. They didn't really ask me questions about the ward or anything, just about [redacted]'s care. I gave them two bottles that used for drinking water which hadn't been washed, just in case there were any signs of infection, but I haven't heard anything back from them.

81. I also had a meeting with the Procurator Fiscal. I think it is the Health and Safety Unit who are looking at [redacted]'s case. I received an email a couple of weeks ago to say that a team has been appointed to investigate [redacted]'s death so they are looking into it. I have asked them to contact me every six months unless there has been a development so I will just wait to hear from them.

HEALTHCARE ASSOCIATED INFECTION

82. The only line infection that [redacted] had was the one linked to her death. We knew that it was a line infection. That was the reason that she had to have her line removed and that led to the septic shower.

83. At no time were we told what the line infection was and, as far as we were concerned, the doctors had no idea what it was. The death certificate was the first we knew that the infection was stenotrophomonas and was related to [redacted]'s death. The Case Note Review says that there is a record that this infection was discussed with us as her family. That did not happen. We have never discussed the infection with the hospital, at the time, or in the aftermath of [redacted]'s death. No one in the hospital has ever discussed with us the cause of [redacted]'s infection.

PREVENTATIVE MEDICATION

84. I am aware that [redacted] was prescribed Ambisome as a prophylactic when she was admitted to ward 2A in January 2017. Professor Gibson told me that it was because it was a new hospital and mentioned something about bacteria but that was all I was told.

CASE NOTE REVIEW/ OVERSIGHT BOARD/ REPRESENTATIVE GROUPS

85. [redacted] was one of the children who was included in the Case Note Review and I have her individual report. The Review states that [redacted]'s infection was linked to the hospital environment. The Case Note Review Report states [redacted] caught an infection on 23 July 2017 and it was caused by Stenotrophomonas maltophilia. The report states "*based on the information available to us, we consider that this infection was probably related to the hospital environment.*" They refer to another case of the same infection which occurred in the same ward 10 days earlier, and they mention that [redacted] had been on ward 2A for 7 weeks prior to the contracting this infection, in support of their view. They state on balance, that they believe the Stenotrophomonas infection must have made a contribution to [redacted] passing away. There is one comment in the Review that is false. It says that there was a meeting between us

and the doctors and the infection was discussed. The only meeting we had was the one where they told us that [redacted] was really poorly. That was the meeting with Professor Gibson and the Head of PICU. My dad was there too and neither of us remember stenotrophomonas being mentioned. It's something that we would have remembered, especially when we saw it on her death certificate. I was quite into all the medical side of things, and I would Google everything as I always wanted to know what was happening and what things were, so I am sure I would have done this if I was told at the time.

86. This information was in the Review as one of the questions I had asked the Review Team, through the Oversight Board, was why [redacted]'s parents had not been told about the stenotrophomonas infection. In the Review it says: "*The case records document that the stenotrophomonas infection certainly featured in discussions with members of the family once had been admitted to Paediatric Intensive Care. It's not exactly clear when the issue was first raised with the family after the blood culture was confirmed on 25 July.*" That never happened.

87. I haven't had any further discussions with the panel who were involved in the Case Note Review. They did offer to speak with me, but I didn't feel able to. I asked them questions through the Oversight Board prior to the Review concluding. I met with Fiona McQueen to do this. She was helpful and we had quite a positive meeting and I felt she wanted answers as much as I did. She took all of my questions back and they have all been answered in the Case Note Review, although not all accurately. I haven't heard from her since that meeting. I did find the Oversight Board and the Case Note Review to be helpful processes.

88. I also had some email contact with Professor White. He would email now and again with things that we needed to know or things that came out, and I did find that helpful, but I haven't heard from him in a while,

certainly not since the meeting I had with the Oversight Board. I thought he would have emailed once the Case Note Review was out but he hasn't.

ISSUES WITH THE HOSPITAL BUILDING

89. When we were in the hospital with [redacted] I was not aware of any issues with the building. I was not aware of any work being done in the building, I wasn't aware of any issues with the water or the drainage in the bedrooms, the ward, or elsewhere in the hospital and none of the staff ever mentioned anything about the water. I think[redacted], [redacted]'s dad saw shower heads being changed on a couple of occasions but I never saw anything myself.

COMMUNICATION

90. When [redacted] was in the hospital, I didn't have any issue with the communication that I was getting about [redacted]'s infection, but now, knowing what I know, they should have told us what it was at the time.

91. I don't think that any of the staff on the ward knew at that time that there were any issues with the safety of the hospital or the buildings. I think that if they had they would have said something as I'm pretty sure none of them would have wanted a child to be in any danger.

92. I feel really let down by the hospital. [redacted] didn't need to die. When she was in hospital, we kept getting told that we needed to keep her clean. I would have been happy for her to have been dirty if it meant saving her life. The bottom line is that I believe that she caught the infection from a shower or bath as that is the only time her line was near water. Since the link between the water and [redacted]'s infection all came out I think that the hospital has been burying its head and hoping it all

goes away. They're not communicating with the families at all. They keep saying in the media that they are more than happy to meet with the families but they've never once invited me personally to have a meeting with them. So their communication, or lack of communication, is absolutely shocking. I think it would be really good for them to meet families that have gone through this unnecessary pain but they're staying away from all of us as much as they can.

OVERALL IMPACT ON WITNESS

93. It has been really difficult. I was never one for accepting help, or medication or anything, but in January 2021 I felt I couldn't continue and was suffering flashbacks. Prior to everything coming out with the building issues at the hospital and the link to [redacted]'s death, I was kind of putting my life back together, although of course I will never get over [redacted]'s death, she never leaves my thoughts. All of this coming out in 2019 has brought all of the demons up with it and I am now on anti-depressants and have had numerous days off work as I am just not able to cope. It's not a nice situation at all and gets so stressful that it's horrible to actually deal with.

94. I would have preferred that the hospital staff had been honest and told me about the infection at the time. Instead, I found out about it in the press. I would have preferred it was not public knowledge. I think it could all have been dealt with better.

OVERALL IMPACT ON OTHER FAMILY MEMBERS

95. When [redacted] passed away, [redacted] was very young, he was under two. But when all of the information came out in the papers in 2019 I wasn't myself and this made [redacted] very anxious. He didn't want to go to school and leave me and he was crying all the time. We were on the verge of having him

see a psychologist but then COVID and lockdown hit and I think that actually helped him. He has been much better since he went back to school after lockdown.

CONCLUDING COMMENTS

96. My view is that the hospital should be closed. I don't think it's safe. I've since heard other reports from nurses that there's fungus growing in walls and adult patients are now dying and they're covering that up.

97. I feel like the health board need to be punished for all of this. In my eyes, what happened to [redacted] is murder. She should still be here and I am trying to come to terms with that after coming to terms with losing her initially. I don't know that I'll ever be able to. I would never go back to the hospital, never.

98. I believe that the facts stated in this witness statement are true. I understand that this statement may form part of the evidence before the Inquiry and be published on the Inquiry's website.

KD/01 APPENDIX 1- TIMELINE

- [redacted] - [redacted]'s date of birth.

- 19 September 2012- [redacted] was diagnosed with Acute Lymphoblastic Leukaemia. She was treated at Yorkhill Hospital with chemotherapy. [redacted] was switched from regiment A to regiment C treatment.

- January 2015- Regiment C treatment completed.

- 15 January 2017- [redacted]'s Leukaemia relapsed.

- 16 January 2017- [redacted] was admitted to Ward 2A at Queen Elizabeth University Hospital. [redacted] received chemotherapy and radiotherapy treatment.

- March 2017- [redacted] discharged from QEUH and allowed home for a week. This was just before her birthday.

- April 2017- [redacted] was discharged from QEUH and allowed home for a few days.

- May 2017- [redacted] was discharged from QEUH and allowed home for a few days. She was re-admitted on 4 June 2017.

- 4 June 2017- [redacted] commenced pre transplant conditioning.

- 5 June 2017- [redacted] commenced total body irradiation (TBI) followed by further chemotherapy treatment.

- 12 June 2017- Blood cultures were taken and antibiotics started. No infection was identified on the blood cultures.

- 15 June 2017- [redacted] received donor bone marrow stem cells.

- 16 June 2017- [redacted] experienced respiratory difficulties.

- 20 June 2017- [redacted] was given antibiotics as she was unwell.

- 28 June 2017- Blood cultures were taken.

- 30 June 2017- The results of the blood cultures confirmed [redacted] had an adenovirus infection
- 6 July 2017- [redacted] started to improve and her fever started to settle.
- 25 July 2017- Blood cultures were taken and were positive for Stenotrophomonas maltophilia. The clinical team removed [redacted]’s central line. ’s family were not told this at the time.
- 25 July 2017- The removal of the central line triggered a septic shower of bacteria from the infected central line. [redacted] was visited by a PICU consultant.
- 26 July 2017- Blood cultures were taken and they were still positive for Stenotrophomonas. [redacted]’s family were not told of these results this at the time.
- 4 August 2017- [redacted] was admitted to PICU.
- 6 August 2017- [redacted] required artificial ventilation.
- 12 August 2017- [redacted] was transferred to ECMO (Extra Corporeal Membrane Oxygenation)
- [redacted]- [redacted] passed away
- February 2018 - Professor Gibson carried out a home visit
- November 2019- a whistle blower reported there had been 26 cases of patients contracting hospital acquired infections in 2017.
- 18 November 2019- Water contamination at QEUH journalist briefing published.
- 22 March 2021- publication of general independent case note review and oversight board report commissioned by the Scottish Ministers

Scottish Hospitals Inquiry

Witness Statement of

Christine Horne

WITNESS DETAILS

1. My name is Christine Horne. I was born on [redacted] . I will be[redacted]years old in about 2 weeks. I am a [redacted].

2. I am the mother of Kimberly Darroch and grandmother of [redacted]. [redacted]'s date of birth is [redacted] . [redacted] passed away on [redacted].

3. I live with my husband, Derek Horne in [redacted].

OVERVIEW

4. My Grand-daughter is [redacted] [redacted]. [redacted] was diagnosed with Acute Lymphoblastic Leukaemia in 2012 (ALL) when she was 5 years old. After two and a half years of treatment, [redacted] went into remission. [redacted] then relapsed in January 2017 when she was 9 years old. [redacted] was treated at the Royal Hospital for Children (RHC). She attended the hospital as an in-patient and as an out-patient although it was mostly as an in-patient.

5. [redacted] spent time in ward 2A, which was known as the Schiehallion unit, of the RHC. She received treatment from January 2017 and had a successful bone marrow transplant on 15 June 2017. On or around 5 August 2017 was admitted to PICU in the RHC for six weeks, due to an infection, which we now know was connected to the water supply at the hospital. passed away at 3am on 31 August 2017, aged 10 years old.

6. I was with [redacted] during some of her admission and can speak of the experiences which my family and I had on these wards of Yorkhill Hospital and RHC/QEUH.

FAMILY BACKGROUND

7. I live with my husband, Derek Horne in [redacted]. We are [redacted]'s grandparents.

8. [redacted] loved animals. She wasn't a girly girl and played in the garden with all sorts of insects and loved doing that. She had her own wee bit in the garden and she would collect snails and name them.

9. [redacted] loved climbing. If she went on holiday, she would find somewhere to climb. At the caravan site, Haggerston Castle, when Kimberly took her, had talked me into letting her go on this climbing thing that was really, really high. She promised me she would only go halfway and I should have known better! I had to walk away and leave her mum watching her because I couldn't watch it any further; half way wasn't enough for her and she just kept going and going to the top. She was such a tomboy. Climbing was definitely her thing. She loved football too but she wasn't very good at it.

10. [redacted] usually stayed with us a couple of times a week. She was always here one night at the weekend. Whenever she came, she would stay for the night. We had midnight feasts and watched television until midnight. She made me watch all of the Disney films, but she would watch anything, even films you wouldn't think a girl would watch; spy films, Jaws, everything. She watched anything to do with an animal, it didn't matter what kind of animal it was. There was Jurassic Park too. It didn't matter how scary a film was. We usually sat up late at night.

11. [redacted] could give you the look, the "[redacted] look", if she wasn't happy with you. She didn't have to say anything, you just got the look. She was very witty too. We miss her very much. We miss her terribly.

[redacted]’s experience in Yorkhill: 2012-2015

12. [redacted] had previously had treatment for ALL. In September 2012 Kimberly took [redacted] to Wishaw General a few times as she had a really sore leg but the hospital kept putting it down to growing pains. It got to the stage where she was having to get carried everywhere as she just couldn’t move her leg. Then Kimberly phoned me one morning and said that [redacted] had come out in wee spots on her neck. I told her we should bypass Wishaw and go to Yorkhill. Kimberly’s sister had leukaemia when she was younger so we had experience of it. Nothing was getting better with [redacted] and now there were more symptoms so we went to the old Yorkhill, through their A&E department. When Kimberly was out of the room I said to the staff that [redacted]’s aunt had had leukaemia and I had my suspicions that [redacted] might too, but I hoped it wasn’t.

13. [redacted] had some tests carried out which confirmed that she had leukaemia and she was admitted to the Schiehallion unit in Yorkhill. [redacted] then underwent chemotherapy treatment and after two and a half years she went into remission in 2015.

SEQUENCE OF EVENTS: THE FAMILY’S EXPERIENCE AT THE RHC

Admission to Ward 2A (Schiehallion) at RHC: January 2017

14. [redacted] relapsed with ALL in January 2017 when she was 9 years old. had been in remission for just over two years I think. She had been in the hospital for a check-up in December 2016 around Christmas time, and everything was okay but obviously acute things can come on very quickly. It’s not that anything was missed in December. It’s just that it comes on so quickly. [redacted] was fine at Christmas but just after it, she had started to take headaches and she had a nosebleed. Kimberly took her to the doctors, but the doctor just said she was probably like every other child having colds and whatnot.

15. On 19 January 2017, which was a Sunday, we decided that we would just take [redacted] straight back into what was the new Yorkhill, which is the RHC, to have her checked again for our own peace of mind. We went in through A&E of RHC and then were taken to the triage.

16. Staff took blood tests. Dr Gibson, [redacted]'s Consultant, came down that night, at about six o'clock I think, and told us that she thought the leukaemia was back. She wanted [redacted] to stay in that night but we didn't have anything with us. We asked if we could just go home and be back for seven o'clock the next morning because she was going to go to theatre. We contacted [redacted]'s dad and he wanted to be there, we couldn't stay there without him. So we went home that night and we picked [redacted]'s dad up in the morning of 16 January 2017 and headed back to the hospital.

17. [redacted] went to theatre for a lumbar puncture and this confirmed that the leukaemia was back and she was admitted to ward 2A, or the Schiehallion ward as I call it, that same day.

Description of Ward 2A

18. The RHC was a super hospital. It was a big hospital and it was absolutely beautiful. Inside they had loads of things for kids to do. This was at the front entrance of the hospital building. There were lots of things for kids to do while they were waiting for clinic. There were novelty mirrors which made you look much bigger or much smaller and there was a ball game. On the ward, the bedrooms were a good size. They were bigger than the Yorkhill ones and they had the fold down bed, so you weren't squeezed in as much.

19. Down the right hand side of ward 2A were the transplant rooms. I can't remember how many transplant rooms there were. There were two in the old Yorkhill but I think there might have been four in ward 2A. They're maybe a little bit bigger than the usual bedrooms and they have filtered air. There is the bedroom where [redacted] would be in her bed and then the parent bed as you are still allowed to stay with them. There is a door from the

bedroom into an outer room with a big sink and the medicine cabinets. There's a stand because you've got to put your coat on as you can't walk into the bedroom with your outdoor coat on. Your shoes have to be changed and you've got to scrub up. There is then a door from this outer room onto the ward. If the door from the bedroom to the outer room is open, then you can't open the door that goes onto the ward. You would have to wait until the bedroom door was closed. It's like an airlock. The cleaners go in and they clean the room before you move into it. I think it's a spray or something like that and then you are allowed to go into that room.

20. Anything that was brought in to the transplant room had to be brand new in packaging. It had to be wiped down and opened and then [redacted] had to pull it out so that she wasn't actually touching the packaging. That outer room was where you did all that before you went in to the actual bedroom. That's the difference; in the normal bedrooms on the ward you went straight in from the ward, there was no outer room.

21. There were no windows open; you can't open them in any of the bedrooms. You're not allowed to. If you're in for transplant, the whole room is air filtered and it's supposed to be a certain air that goes in and out. When [redacted] was in one of the transplant rooms she was moved and I remember wondering at the time why she was getting moved. You do not go to the transplant room until you are ready for the transplant treatment. You are only in the room a few days before it. When you're in a room to get a transplant you're meant to stay in the same room. She was moved to another transplant room just up from the one she was in and that was where she stayed until she was moved to PICU. I don't know why she was moved or if it was before or after her transplant.

22. Back 30 years ago, when my daughter was going through a bone marrow transplant, she was never allowed to be moved. They said once she went into a room, you had to stay in that room. One of us would be in and gowned up to deal with her. Before you entered the room, you had to

change your shoes and make sure you were scrubbed up. It was infection control. To take [redacted] out of that room and put her in another room, I always thought that was quite odd but then, I had to say to myself that maybe things have changed in the 30 years since my daughter went through it. Looking back now, I think there was maybe something wrong with the room [redacted] was in but they didn't tell us that.

23. After the transplant rooms, you had rooms to the side where you took the toilet and things, yucky things, like bedpans. And then there was the laundry room and after that there was the desk where nurses sat. When was well enough she actually sat with the nurses at night. There was a wee nurses bit outside [redacted]'s room too. It was a wee box thing that came in front of her room. We never went past this because that was the teenage area.

24. There were bedrooms on both sides of the ward and because of the layout of the hospital building, rooms on one side of the ward would have a view looking into the atrium, and the rooms on the other side of the ward would have an outside view; you would look out and see people coming in and out of the hospital entrance. The outside view was better. Kids with leukaemia and tumours do spend quite a lot of time in their bed. You're there with them 24/7 whether you're sleeping or not, in case they wake up. So it was good to have something to look out to.

25. If you were on the other side, then you were looking out to the outside doors and could see people coming in and out and you could see the car park. There was a smell on that side, a sewage smell. I thought that it would be really bad in the height of summer but I got used to it if I'm being honest. I don't know where this smell was coming from. You couldn't open the windows in the rooms so I don't know if it was coming from outside or from inside.

26. I never really passed [redacted]'s door. One time I took her up to the teenage area as she was desperate to see what the teenagers had. They had

everything that she didn't. They had their computers and everything all set out and they had a great big room to be in. I took her up to see it but that's the only time I was up there. Most of the time we were in [redacted]'s room. I can't recall any of the numbers of the rooms that [redacted] was in.

Facilities

27. There was a playroom on the same side as the transplant rooms. I always felt that they didn't actually accommodate [redacted]'s age. They accommodated for younger ones, up to maybe seven years old, in the wee playroom. They had their play lady and their wee arts and crafts things. Things that the younger ones could do. But nothing that [redacted] would want to do. She was nine, she was nearly ten. I don't think they've accommodated for that age group, from your eight-year-old to your 13-year-old. They had the teenage unit and I know that money had been raised and that's why they had the teenage bit.

28. To me, eight to 13 is quite a difficult age and it should maybe have been accommodated; that's the scared age. Up to the age of seven, the mum, gran, papa, they're the ones that know everything. Then they get to 13 and think they know everything. You then have your eight to 13 year olds where something big has happened to them and they're taken away from their family and friends. They're taken away from school and they're scared. Schiehallion really didn't accommodate them. So the parents try and deal with the kids. We could with [redacted], she would listen. She would take it all in. But there should have been more things there for her and people going in to speak to her more about what was happening. To me, that is a really, really hard age. It was a fantastic hospital but they hadn't thought about this middle age group. That's quite a scary thing they're going through. You could see it in [redacted]'s eyes that she was scared.

29. There wasn't much for her to do, so we entertained [redacted]. We played monopoly and other games. We watched films. We asked if we could have a PlayStation and we got one so I went out and bought her some games for it. She had her iPad which she was on quite a lot. We could sit up until

midnight playing monopoly. It was her game. She loved monopoly. Everything worked in the room: the TV and the Wi-Fi.

30. We never wandered up and down the ward. It wasn't quite like Yorkhill where they would go out and play in the corridors. Some of the kids did go up and down on the wee toys. I saw this in Yorkhill hospital and RHC but I saw this more frequently at Yorkhill. I agree that it's best to have kids in their own rooms but I also think if they're well enough and they've not got an infection then they should have had another bit to mingle and play in.

31. To be honest, you didn't really mix and see everybody that was in the rooms in ward 2A. The old Yorkhill had a sitting room. Parents would maybe sit in there, and they had a wee kitchen as well. So you could go and make yourself a cup of tea if somebody else was in visiting [redacted] and you could sit in the sitting room. In ward 2A they only had a kitchen area that wasn't really that big. It did have a couch in it but it was a bit wee if somebody was in using the microwave and the fridges. There wasn't anywhere else to go in the ward. You could go downstairs to the canteen but that was away from the ward and away from [redacted] for too long.

32. The kitchen area would have been okay if you'd had another bit to go and sit. Some families came in to see their kids and they would quite like to sit together and eat. If they were there, then that was the room taken up and there was no room for anyone else. I'm not knocking anyone for this as this is what they wanted to do. It did mean that, if someone was in to see and you were trying to disappear from a while, you couldn't sit in the kitchen and watch other people eating so you just had to wander around the ground floor.

Staffing

33. The nursing staff were lovely on ward 2A. I actually can't say anything about the nursing staff. [redacted] loved some of them, and she had her favourites. They had a way of working with her. They actually got the gist

of her. They knew how much pain she could handle and when she wasn't able to take anymore.

34. [redacted] was getting laser treatment on her mouth ulcers because it was really, really bad and it was incredibly painful. She was feeling really crap. I spoke to the doctor who was doing the laser treatment, and told her that if she had a dog she should talk to [redacted] about that and she would have a friend for life. The doctor did this and she was fantastic. After that they would always talk about the dog. It was just the simple things like this that could make it so much easier because [redacted] actually trusted her then.

Protocols

35. There were special protocols in place if [redacted] was in the transplant room that I have already described, and, as far as I know there were protocols in place for infections more generally on the ward. There was always supposed to be barrier nursing if there's infection. But obviously nurses go in and out rooms. That's a hard one to call, to be honest with you, because while you're coming in and out of rooms you don't actually see if the nurses have gone and scrubbed. They'll come and wash their hands but you don't know if they're dealing with somebody else that's maybe had another infection. It wasn't as good as Yorkhill. No one had any masks on, and the cleaners and nurses would come in and out of the rooms. No one was wearing gowns. That was the main difference we saw between Yorkhill and the new hospital. The first month [redacted] was in Yorkhill, everybody was gowning up. We didn't see this as much at the new place.

[redacted]'s Initial Treatment: January 2017 – June 2017

36. [redacted] had chemo again and they did bone marrow tests throughout her chemo. It was maybe April, when the doctors said that [redacted] would need a transplant as the leukaemia just wasn't going into remission the way they were hoping.

37. When we were told in the April that [redacted] would need a transplant, the doctors started the process of looking for a donor and they found a really,

really good match. She was getting the transplant on 15 June 2017 and she started her conditioning for her transplant on 4 June 2017. This happens two weeks before the transplant because it floors you. The chemo is so severe that it takes away all your immunity. [redacted] also had to get radium treatment at that point too so she was sent over to the Beatson for that from the Schiehallion. She went there twice a day for about ten days for this treatment. She would get picked up in a taxi and taken between Schiehallion and the Beatson. [redacted] had to go to the Beatson Hospital for radiotherapy treatment. They did not have the facilities for this at the new hospital. The Beatson Hospital is another adult's hospital in Glasgow. It is a 20 minute taxi drive from QEUH.

38. [redacted]'s transplant was on 15 June 2017. She had done really well and fought all the way. She had a sore mouth because of the treatment and struggled with eating though. These are all the normal things that we've gone through before with both [redacted] and my daughter and it was always a battle to get them to eat and drink things. My daughter never had a feeding tube, but [redacted] did. [redacted] didn't want the feeding tube; she didn't like it. She was just like every other child. They fight these things.

39. [redacted] was quite poorly for a couple of weeks because she had no immunity but Kimberly did everything by the book. [redacted] was showered. Her bed was changed daily. Kimberly took in her own bedding. It was all brand new and was done the way it should have been done. The only thing they really used was the hospital sheets and a couple of pillow cases. Everything else, she took in herself. She made sure everything was super clean. We had to go and buy new shoes; you had to change your shoes before you went in her transplant room. We kept ones that we could wear in the room. We made sure we had everything as you weren't allowed to wear your outdoor things into a transplant room.

40. [redacted]'s transplant seemed to be working and some of her levels were coming up really well. This included her blood levels and white cell count. We started to go out for a wee while because her levels were improved. I

can't recall how long after her transplant she was allowed out of her room. It started off we just went round the hospital grounds and I took her round the back bit where there was a wee park where she could see her mum drive out of the multi-storey car park to wave to her as she left the hospital. Then we could go to Braehead Shopping Centre and then she was getting home for two hours. Everything was positive. Her eating and drinking still wasn't good but everything else was positive. We went on holiday expecting [redacted] to be home by the time we got back but obviously that wasn't the case.

[redacted]'s admission and time in PICU: July 2017 – 31 August 2017

41. We were away on holiday in July 2017 and Kimberly told us when we were away that [redacted] had been saying for a couple of days that her Hickman line was sore. She wasn't really one for complaining so I think the doctors should have listened to that. They did eventually say that they were taking her down to theatre to take the line out. Kimberly phoned to say that she was going down to theatre and they were going to check her tummy at the same time because she'd had quite a bit of diarrhoea. Then she phoned us to tell us that the line was out and [redacted] had gone into septic shock.

42. I think it was a septic shower that the doctors called it but we had spoken to [redacted] and she sounded okay. By the time we came back from our holidays, I went straight in to see [redacted] and her breathing was not good then. Her colour was not good. She did not have a lot of energy. She was lethargic. She had no line in. She had the one cannula in her hand but not what she normally had. She normally had a line in her chest. It could be put on either side of the chest. I think it's called a Hickman Line, that's what it was called when my daughter had one. So it sticks in my head that it was a Hickman Line and that had been taken out.

43. I asked Kimberly when the Hickman line would be getting put back in and Kimberly said that will maybe be a week or two before they can put it back in. I can always remember when my other daughter was in, if they took the line out from one side because there was an infection, they had to put it in

the other side so it went straight back in. That wasn't happening and I thought maybe things are different now and obviously our trust was in the doctors. So I thought it was fine. [redacted] just had her cannula in her hand at this point.

44. At this point [redacted] just kept going downhill. I remember thinking she should be in ICU and I think she went too late. I might be wrong but I thought she should have been in ICU. The Schiehallion staff would come into [redacted]'s room to take her blood pressure and I would say to them she was poorly They were sending requests for ICU doctors who were coming up, but nobody was doing anything about getting a line in her and giving her more antibiotics, or whatever she needed. I didn't say anything to the doctors as you just trust that they are making the right decisions, but things just went from bad to worse. [redacted] did not have a Hickman line in. The patients get all of their medication through their Hickman line. She only had a cannula. A cannula can break down the vein more easily. When that happens, another cannula has to be inserted into another vein. It is not pleasant for the patient having to have multiple cannulas. All of the kids get Hickman lines for cancer treatment. Once the Hickman line is in it does not come out again, unless it gets infected. They don't need to get jags when they have a Hickman line in like they do with a cannula. They go to theatre for a Hickman line to be fitted. With a cannula they just apply some cream to the skin before it is fitted. A cannula is not as secure as a Hickman line.

45. Eventually [redacted] was admitted to PICU early August 2017. I think her dad was with her when it happened and a nurse or doctor had come into the room and had seen [redacted] going to the toilet and her lips were blue and that was when the decision was made that she had to go to PICU. That had been happening quite a few times. [redacted] had been struggling to get to the toilet and walk back. Her chest was sore as she was really struggling to breath, and she was having to have oxygen on her when she was sleeping. That's why I think they were too late in moving [redacted] into PICU.

46. Once [redacted] was in PICU things just deteriorated and she was on a ventilator within a couple of days. Kimberly wasn't actually there when the doctors came to tell me and [redacted]'s dad that they wanted to ventilate her. We had to phone Kimberly and tell her to come straightaway so she could spend some time with [redacted] before they put her to sleep.

47. I told [redacted], that she was being put to sleep as all her veins were gone and it would be easier for her when they would be putting in the cannula so that she wouldn't feel it. She did not know she was being ventilated. Only her mum and dad and me got to speak to her before she was put to sleep. It was just heart-breaking. She never got to speak to her brother or any other members of the family. She was sedated from that point until she passed away.

48. That day, we asked how long she would be ventilated for because she wasn't able to communicate in any way and we were told by the doctors that they weren't sure, maybe a few days. Then she was on all these other different machines, one that shook her all the time. She was on one that I think is called an ECMO machine and then there's one that's trying to hoover all the infection and mucus out. It's a very deep suction and they're put on a board thing and it just shakes and rattles all the time. The physios were coming in too. She was also on a kidney dialysis machine. They were trying different things.

49. The nurses kept saying to us, "She'll be fine." They said that the ECMO machine was wonderful and that everybody's that's on it, comes out of it. They're the doctors. They're the professionals and we were emotionally involved. You don't always see the bigger picture. You just think she'll be okay. We were being given hope that she would pull through. Looking back the doctors were probably admitting that things might not go the way we were all hoping but no one ever said that at the time.

50. [redacted] had been on the ECMO machine for the maximum number of days. There's only so long you can go on that. I think it's 21 days. Staff were

talking about giving her a heart transplant down south but she would never have been able to go anywhere for a heart transplant. I don't even know why staff were saying that but they did try to take her off the ECMO. There's something I think they do before she would be off it altogether so they tried to take her off it for a couple of hours and I think she did actually manage to breathe, but the mucus in her lungs just kept coming back. The doctors tried absolutely everything but none of it worked. Every part of her body was failing.

51. At one point, Derek and Kimberly were called into a side room with Professor Gibson and a consultant. They told Derek and Kimberly that was a very sick girl. We all knew that though. I think this was later on in the August when [redacted] was still in PICU.

52. We tried to go to the hospital as often as possible but we also had to ensure [redacted] was looked after. I stayed with Kimberly a couple of times as she wasn't really leaving the hospital at all at this point. After she had been ventilated, [redacted] was sedated the whole time until she passed away, but there was always someone with her and we kept talking to her.

53. On the night that [redacted] passed away, Kimberly had come home for her tea and was going to go straight back in. [redacted]'s dad was with [redacted]. He phoned to say they think there's a bleed on [redacted]'s brain. I think she actually died at that point if I'm being totally honest. Me, Kimberly and [redacted]'s dad headed back in.

54. Her aunty on her dad's side drove up from Leicester to see her but she didn't make it in time. We'd gone in and so had her other gran and papa so we could say bye. The specialist doctor to turn off the machine was supposed to come, I think around midnight, but we were told by another doctor who was present, that there was an emergency which is understandable. It was three o'clock in the morning when the specialist doctor we had never met before, came in and turned the machine off. I

think [redacted] was away earlier than that, but once the machine was turned off she just passed away.

55. We had no idea what the infection was that cause [redacted] to become unwell. We knew that it was from her line, but we were never told what it was and there was never any indication that it was related to the water in the hospital. Nobody said anything about what had caused the infection.

COMMUNICATION: GENERAL

56. The day after [redacted] went down to PICU, I came up to Schiehallion to get her slippers. When I said to the nurse that I was there to get [redacted]'s slippers she told me that [redacted]'s room had been emptied and her stuff was in a store cupboard. I couldn't believe it. I thought it was strange and heartless as she had only just left the ward. No one on the ward had come down and told us that is what was happening and they didn't give us a reason why that was done. It is like they had already decided she wasn't coming back to the ward. I just think it was a bit heartless the way it was handled.

57. When [redacted] passed away we weren't told anything about why she had passed. The doctor who came in to switch off the machine didn't tell us anything and we had never met them before.

58. We weren't there when [redacted]'s death certificate was being issued. It was her mum and dad. They had to go back to the hospital the day after [redacted] passed away and Derek took Kimberly in. We were just functioning. We weren't taking anything in. We did see the death certificate but I don't know when we saw it and I didn't know what it said. They were all big words to me. I couldn't have told you what any of the infections were. Nobody has ever said it was from the water or anything. When we read it, we just thought she had an awful lot of infections.

59. As far as we are aware, there weren't any meetings with anyone from the Schiehallion just after [redacted] died. Usually Kimberly would tell us if there was anything but I can't remember her saying that she was going to meet with

anybody until Professor Gibson and an outreach nurse from the Schiehallion came out but that was a while after [redacted] had died. I think it was a few months later as I was back at work, possibly February 2018. I had to get time off my work to be with Kimberly for the meeting with Professor Gibson. During this meeting, Kimberly did ask about the stenotrophomonas infection but it was brushed away as a hearsay question. She was asking about this infection because it was on the death certificate, I can’t remember exactly what she said, but I know that Professor Gibson brushed it aside. It wasn’t answered. Professor Gibson didn’t elaborate on any of the questions. She was just asking things like, “How are you coping?” I can’t remember fully what was said but Kimberly was trying to find out what that infection was and we didn’t get any answers. I expected more from the meeting, even after all those months. The big question is why were her parents not told face-to face what the infection was and how [redacted] got it? We didn’t know about some of the information at the time but the infection actually started before [redacted] got her line out. I did not find this out until I read this in the independent case note review report. The report was prepared by a consultant who reviewed ’s medical records. Then she had the septic shower. I can’t believe that it has actually gone on and they hadn’t told us. Why not tell us? They’re always going to say it was an infection. We didn’t know what kind of infection [redacted] had. We knew it obviously had to be a line infection or something to do with the line as when it was removed, that’s when she started to go downhill. Nobody said anything about what caused it.

60. With her experience of dealing with [redacted], Kimberly was very good with medics. I don’t know how she managed to remember all the medicines and infections and what the doctors were doing to [redacted]. She was always on the ball with everything and that is how I know that Kimberly didn’t get an answer to her questions as she would have said something at that meeting.

61. Until this actually came out in the papers, we had no idea at all about the water and it hit us like a ton of bricks. After the meeting in February 2018

the next thing I was aware of was when Kimberly phoned me at work saying it was in the papers. Anas Sarwar had gotten in touch with her and told her about these whistle blowers. Kimberly said it was a water infection that [redacted] had. This was November 2019 so a lot of time had passed. It just brought absolutely everything back and then we were worse than what we actually started with; all of a sudden, we realised [redacted] could be here. It brought up so many emotions, we were so angry and disappointed with the hospital. At this point there was no name in the papers but Kimberly knew it was [redacted]. She just instinctively knew it was [redacted] they were talking about when they said a child had died. She knew instantly. It is thanks to the whistle-blowers that this was all brought to everyone's attention because they don't want to live with the feeling that they're letting something go. It's understandable but I wish they'd done it earlier.

62. Between August 2017 and then this all coming out in November 2019, we were not contacted about the circumstances of [redacted]'s death, but we did have some communication from the hospital regarding a memorial service that we were invited to. Karen, the outreach nurse from Schiehallion, and some of the nurses from the Schiehallion were the ones that would get up and speak so I think it's through them that we got the invites. I can't say for sure though but we did get an invitation. At the service, they had the children's names up on a screen and you go and set off balloons and light candles. [redacted]'s name was on the screen with all the other kids who had died. Kimberly and I always tried to go. When this all came out in November 2019, we weren't asked to attend again. We weren't invited to anything. This was very disappointing as well. I don't think it's a coincidence that we weren't invited after all this came out in the press. I know that the children's names go up on the screen for at least five years and there were families there whose kids had died several years ago and they were still invited even though their kid's names weren't up on the screen.

63. I found out about the Schiehallion ward being shut through Kimberly. She called me and let me know that the ward had closed. I think there was a

Facebook group because she kept in touch with some of the parents so that's probably how she found out but I'm not 100 percent sure. When we heard about it we thought things were getting worse in the hospital and we worried about the kids there that needed treatment and wondered what was going to happen to them. I didn't know the reason for the ward being shut.

64. When I heard about the ward being closed, I had my suspicions that this maybe had something to do with [redacted]. We were also hearing about the infections from the pigeon droppings too and when we started to put things together and form a picture of what was happening; we realised things weren't working in that hospital. We started to think; "Why all of a sudden are they closing and not opening up again?". There must have been problems. There must have been a big problem.

65. We didn't receive any direct communication from the hospital but we weren't really expecting it anyway as it would be to the parents, not the grandparents. We sat in on things with Kimberly if she was having to make statements, or talking to reporters, or if she went to Edinburgh, but we never spoke to the press or anyone else, we were just there for support. Derek went with Kimberly to a meeting at Holyrood, I think with Anas Sarwar, but he was just there to support her. We sat in a few times with her when the reporters spoke to her. When she did that documentary with Lisa Summers and the other one that came out, we only sat in. We weren't asked anything. We were just there to support her.

66. I do remember that maybe the Chief Executive at the hospital did contact Kimberly and gave her the opportunity to speak to them if she wished to. Her attitude was that it was too little too late and that it should have happened before all of the information came out in the press. I don't know when this was.

ISSUES WITH THE BUILDING

67. Derek wasn't really in the hospital as much as I was as we also had [redacted]'s brother to look after so that Kimberly could be at the hospital and he did most of that. Sometimes I would drive to the hospital and we would swap over [redacted]'s brother and Kimberly would come home. At the weekends, Derek would be at home looking after [redacted]'s brother until I would go to the hospital and let Kimberly or [redacted]'s dad leave. Kimberly would then come home to look after her son. We had a wee rota. So I was at the hospital more than Derek.

68. The building was brand new and it was immaculate. I did notice that there was always some work being done on ward 2A. They were always fixing things like the doors: the doors coming into the ward and things. It's a new build, so you're always going to get wee problems and wee things that have got to be sorted. So I didn't really give it any thought.

69. One of the times the wee kitchen area was closed because there was an infection somewhere in the ward. I can't remember what the infection was but the only thing we were allowed to do was go in and get water from the wee machine which was connected to the taps. It was like a filter of some sort.

70. I never noticed anything in relation to the water in the ward. [redacted]'s dad always said he thought there was something but I don't know if Kimberly actually thought about the water. I think she read it and googled it later on but [redacted]'s dad thought there was something, even at the time. He had noticed they changed the shower heads. They didn't do it when I was there but her dad said that the showerheads in [redacted]'s room had been replaced two or three times and that there had been workmen in the room. He's a tradesman himself so was more suspicious of these things but nothing like that was done when I was there. We don't know if it's something they had to do routinely. We never saw this; we were just there to look after [redacted]. The only time we left the room was to go to the toilets, they had a toilet in the room but I preferred to go out as she was using that toilet. We would maybe go and get a drink or something to eat for ourselves but most of our

time was spent in [redacted]'s room. I even slept in the room. You were basically in the room 24/7 other than being up and down the stairs to get something from M&S or the soup place.

EMOTIONAL IMPACT ON [redacted]'S FAMILY

71. Part of me thinks, "*hats off to the whistle-blowers*". But I wish they had done it at the beginning, in 2017 not 2019 when the grieving process had already started. We were trying to get through every day as it was. I almost feel it would have been better if they had just kept quiet because it brought so many emotions back. We are so angry and disappointed in the hospital. We've known Dr Gibson for over 30 years. I'm not wanting to believe that she knew any of this. It was just devastating. Every time it came up, every time it was on television, you saw pictures, it was in the papers, your heart just broke even more. You get a tightness in your chest. You don't want that sadness or pure anger. Because we just want her here and that's never gone away. Even though now we know that can't happen, it's just still something you want. We've all been robbed of [redacted].

72. Derek doesn't think the hospital should have opened when it did. They seem to want everything now up and running and they're not doing the right tests. It's a case of we want this built, we want this running, open. I wouldn't take my child to the hospital. I don't feel it's safe. We have a family member due an operation there and I'm terrified.

73. The grieving process, when it started in 2017, was bad enough. We supported Kimberly every way we could. She's our daughter so we're trying to do this, support her and grieve all over again. That's what has happened, the grieving process has started again and it brings it back every time we talk about what happened to [redacted]. It's not that we don't talk about [redacted]. We talk about her like she's still with us but it's stories of [redacted], happy stories, before she passed away.

CONCLUDING COMMENTS

74. We've not had any communication from the hospital. There should have been communication. The hospital should have been open and transparent. I wish they'd told us right from the beginning all about the infection and not kept it to themselves. At the end of the day, they've got to live with this. We're living through it but they've got to live with it for the rest of their lives. Somebody has made a big mistake. Someone's passed something that they shouldn't have passed. Somebody's not checked things that they should have checked before that hospital opened.

75. We don't want this to happen to any other family; for somebody else to die, and then two years down the line it's exactly the same thing, where there are whistle-blowers revealing more problems and it's all back to where it was. There's loads of families out there that are probably terrified to take their kids to the hospital now. Personally, if I was watching the news and listened to this, I would be petrified to take my child there. People need the hospitals and unfortunately children still get ill and they still get cancer. The need to be reassured that everything is all right and nothing is going to happen to them. I know that can't be guaranteed because nobody can guarantee tomorrow but they shouldn't be losing someone through something like this.

76. We hope one day we'll get the truth. I think the Health Board have just crossed their fingers and are hoping for the best. It's not been the best for us. I think they've all known that there were issues and they've just kept going and hoped it would maybe clear itself.

77. [redacted] is no longer here. That's the main thing. She should be here. The hospital building was at fault. That's it as far as I'm concerned. She should be here with us now.

78. I believe that the facts stated in this witness statement are true. I understand that this statement may form part of the evidence before the Inquiry and be published on the Inquiry's website.

Scottish Hospitals Inquiry

Witness Statement of

Derek Horne

WITNESS DETAILS

1. My name is Derek Horne. I was born on [redacted]. I am [redacted] years old. I am a [redacted].

2. I am the father of Kimberly Darroch and grandfather of [redacted].

3. I live with my wife, Christine Horne in [redacted].

OVERVIEW

4. My Grand-daughter is [redacted]. [redacted] was diagnosed with Acute Lymphoblastic Leukaemia in 2012 (ALL) when she was 5 years old. After two and a half years of treatment, [redacted] went into remission. [redacted] then relapsed in January 2017 when she was 9 years old. [redacted] was treated at the Royal Hospital for Children (RHC). She attended the hospital as an in-patient and as an out-patient although it was mostly as an in-patient.

5. [redacted] spent time in ward 2A, which was known as the Schiehallion unit, of the RHC. She received treatment from January 2017 and had a successful bone marrow transplant in June 2017. [redacted] was then admitted to PICU in the RHC for six weeks, due to an infection and septic shower, which we now know was connected to the water supply at the hospital. [redacted] passed away at 3am on [redacted], aged 10 years old.

FAMILY BACKGROUND

6. [redacted] even the name says it all, a fun-loving girl, beautiful and wild and loved mixing with other kids. She was intelligent and sharp and was clever at school. Everybody seemed to enjoy [redacted]'s company and liked her. She was never away from our door and we had holidays in the caravan on a regular basis. She was just a normal, fun-loving girl. She seemed to love nature and was never out of the garden.

7. She loved animals and loved the zoo. We've got a plaque up in the zoo at the Five Sisters in Livingston now with her name on it in the wolves' enclosure. She loved the wolves.

8. She wasn't a girly girl. She played in the garden with all sorts of insects and loved doing that, to be honest. It's horrible but snails, believe or not, she loved the snails in the shells, not slugs, snails. She'd collect them and feed them and things. She had a wee bit in the garden, [redacted]'s garden and her wee brother, [redacted] is now looking after that. [redacted] tells me "Papa, look at this, look at the wee stones with [redacted]'s name on it and my name on it". would have loved that, to be honest.

9. She had a great relationship with her other papa, I can say that much. They were always out walking the dog on a regular basis.

10. She just loved her wee brother too, [redacted], when he came along, they just hit it off. They loved each other and well they still do and she had a great relationship with her dad, they were so alike.

11. [redacted]'s always in our thoughts every day. She never goes away, I am always thinking about her and missing her. We couldn't have asked for a better granddaughter, to be honest; just perfect. I miss her so much.

EXPERIENCE IN THE RHC

12. I didn't spend a lot of time in the hospital whilst [redacted] was getting her treatment as I was helping to look after [redacted]'s brother most of the time. I did spend a bit more time at the hospital once [redacted] was transferred to the PICU and we knew she was very sick.

13. We knew [redacted] had a line infection and her line had to be taken out and she had had a septic shower. Even once she was there we thought she was going to be okay. She was put on all these machines and the nurses were telling us that they were wonderful machines and that [redacted] would be fine. We put our trust in them, the hospital, what else could we do.

14. Late on in August, when [redacted] was in the PICU, Kimberly and I got called into a side room, the times and dates escape me. Professor Gibson and another consultant took us into a room and basically told us that [redacted] was a very sick girl. They didn't go into great detail of the outcome but that was their comment. We were shell-shocked at the news and I can't remember exactly what was discussed. At that time we knew that [redacted] had an infection, but we weren't told what the infection was and there was never any mention that it was a water borne infection.

15. After that, things seemed to deteriorate quickly and every part of [redacted]'s body was failing. The consultant had come through and spoken to us and said they had done everything they could. It was a female doctor during the night, at three o'clock in the morning, who switched [redacted]'s machine off and she passed away.

OBSERVATIONS ABOUT THE HOSPITAL BUILDING

16. At the time, there was nothing obviously wrong with the hospital building. It was a brand-new building, the ward looked immaculate, the room looked immaculate, and the facilities looked immaculate. It looked the part.

17. I think the infection control was quite basic, what I noticed. No one was wearing masks or anything like that. Cleaners, even nurses were coming in; you'd think when treating someone with their immune system being so low, infection prevention and control policies would have been better than that, to be honest. But we certainly scrubbed up when we came in, the family did. This is what I observed when I was in the hospital, it wasn't as good as other hospitals we've been in. When [redacted] was in Yorkhill all the staff would gown up, but we didn't see that much in the new hospital.

18. Knowing what we know now, they shouldn't have opened the hospital when they did. The things that are on my mind were whether the tests carried out on the water systems, gas systems, electrical systems were done right. It then leads you to think about why the Edinburgh hospital was closed for another year; why the bricks fell down at that primary school; and why Grenfell happened. All that stuff seems to be going the wrong way. To look at it, it's a super hospital. But there's obviously other issues that they're covering up. The whistle-blowers have come out and there are various stories going about.

19. If it's a water borne infection, the first question you ask is: where did it come from? There must have been an investigation done, there must have been some readings taken.

20. There's a lot of information out there about the hospital; bad information, good information, whatever you call it. There's a lot of bad vibes about the hospital out there. My daughter-in-law works in the Ambulance Service and she'd taken a patient to the hospital who worked in the Queen Elizabeth. She said

that the people in the hospital, running the hospital, knew what was going on. She told my daughter-in-law, it's just unreal, the things they're hearing. So it's like they've known about it from day one and it's just a big cover up from start to finish so far. Hopefully we'll get to the bottom of it. It's a long, drawn out process. It's a long way to go yet but hopefully we'll get there.

CONCLUDING COMMENTS

21. The hospital was a super hospital, is a super hospital, and at the time was in we didn't think anything else other than that. When [redacted] became seriously ill, it goes through your mind, "could it have been this, could it have been that, why were they doing this, why were they doing that?" You don't think for a minute that it's been a cover-up. That's how you're feeling.

22. The whistle-blowers have opened a can of worms. We don't know where it's going to end but we're looking for the truth and for somebody to admit that it was the water that's caused this.

23. Whatever happens, [redacted]'s not going to come back but we have to get the answers we're looking for and help other people, and hope they don't go through what we have.

24. I believe that the facts stated in this witness statement are true. I understand that this statement may form part of the evidence before the Inquiry and be published on the Inquiry's website.

SCOTTISH HOSPITALS INQUIRY

Hearing Commencing
20 September 2021
Bundle 3 – Programme and Witness Statements for Week Commencing 20 September 2021