SCOTTISH HOSPITALS INQUIRY

Hearing Commencing
20 September 2021

Bundle 4 – Witness Statements for Week commencing 27 September 2021

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SCOTTISH
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Scottish Hospitals Inquiry

Witness Statement of

Annemarie Kirkpatrick

WITNESS DETAILS

1. My names is Annemarie Kirkpatrick. My date of birth is [redacted]. I am [redacted] years old. [redacted].

2. I am the mother of Stevie-Jo Kirkpatrick. Stevie-Jo's date of birth is [redacted]. She has just turned 17 years old.

3. I live with my husband, Steven, and our daughter, Stevie-Jo, in [redacted].

OVERVIEW

4. My daughter is Stevie-Jo Kirkpatrick. Stevie-Jo was diagnosed with Acute Lymphoblastic Leukaemia ("ALL") for the first time on 28 February 2014 when she was 9 years old. She received treatment in Yorkhill Children's Hospital in 2014 and 2015. When Yorkhill closed and the services were transferred to the Royal Hospital for Children ("RHC") in Glasgow, she received outpatient treatment there for a few months before being discharged on 1 July 2016.

5. She relapsed on 3 July 2017 when she was 13 years old. Stevie-Jo was treated in the Royal Hospital for Children ("RHC") and Queen Elizabeth University Hospital ("QEUH") between July 2017 and May 2019 but her treatment had to finish 6 months early due to an infection. She attended both hospitals as an in-patient and an out-patient for almost two years. In the main, her care has now transferred back to Dumfries hospital and she has regular check-ups there but she continues to have some contact with the doctors at the QEUH in relation to an infection that she caught at the hospital.

6. Stevie-Jo spent time in wards 2A and 2B in the RHC. This is the Schiehallion unit and it treats children with cancer. When ward 2A was closed, she spent time in Ward 6A in the QEUH. She also spent time in a number of other wards throughout the hospital, namely 1C in the RHC and also 3C which is the cardiac ward in the RHC. She was admitted to other wards if there was no bed for her in the Schiehallion unit. She also received surgery in the theatres in the RHC and she was admitted to the Paediatric Intensive Care Unit ("PICU") in the RHC.

7. I was with Stevie-Jo when she attended the hospital. I stayed with her most of the time as Steven was working back in [redacted]. We also had access to and used the facilities at CLIC Sargent house. I can speak to the experience that Stevie-Jo and I had in the hospital.

8. There are some specific details that I would like to mention. Stevie-Jo contracted listeria meningitis in 2018 when in ward 2A and 6A. She contracted a line infection in February 2019, not long after being discharged as an in-patient from ward 6A. She contracted a mycobacterium chelonae infection in March 2019 after surgery to remove her line in February 2019, at the QEUH. She was prescribed anti-fungal preventative medication which I believe was connected to issues with the hospital environment. There were all sorts of issues with the hospital throughout our time there which, in my view, impacted on Stevie-Jo's treatment and on our family's experience. I will talk about these in more detail.

FAMILY BACKGROUND

9. I live with my husband, Steven, and our daughter, Stevie-Jo, in [redacted]. We have lived here for eleven years, prior to that we lived in Australia where we stayed for two years before relocating to [redacted].

10. Stevie-Jo is at high school, [redacted]. She is going in to S5. She has just passed all of her Nat 5 exams, she achieved As and Bs. Due to her treatment

she had not been in school for a number of years and taking that into account, she did really well. Stevie-Jo wants to be a children's nurse and she wants to work with children with cancer; she is really focussed on that.

11. Stevie-Jo is a bubbly individual. She's just full of fun and carry on all the time. She's got a good group of friends, there are five of them and they're really close. Her favourite pastime is football. She is a Celtic supporter. She plays too and has started getting back to training for [redacted] girls football team. She plays centre left or striker. She has started her driving lessons and she got a car for her birthday.

12. She also plays the bass guitar. She goes to her room to play but she's not allowed to do it on amp in the house.

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

Transfer from Yorkhill to the RHC: March 2015 to July 2016

13. Stevie-Jo was diagnosed with ALL for the first time on 28 February 2014. She received treatment in Yorkhill Children's Hospital in 2014 and 2015. Some of the services were transferred to the RHC in around March or April 2015. At that point she received outpatient treatment at the RHC before being discharged on 1 July 2016. During that period she had some in-patient admissions if she had a temperature spike, for example.

14. After that she began maintenance treatment and she attended clinic monthly She was about to switch to three monthly appointments when she relapsed in July 2017.

15. Maintenance treatment is where all of the chemotherapy is complete and at that point the cancer is away. The kids start taking a daily tablet at home, and it's to keep the cancer at bay. Because cancer is acute it can come back really quickly. Maintenance gave her a period off the intense chemotherapy

but kept her treatment at a level to reduce the chances of the cancer coming back quickly.

16. Clinic is in ward 1A in the RHC, it is to the right when you are in the atrium, so it's before you get to any of the wards. Clinics were all on the bottom floor and there were many different clinics. There was loads of chairs up the centre of the waiting area, everyone waited outside on the chairs and then the doctors would come and shout each of the children one by one. The doctors have separate rooms, just like in a doctor surgery. The kids get checked over and then they would sit back outside on the chairs and wait for their prescription to be provided to them.

17. Stevie-Jo saw Professor Gibson at clinic. She is a haematology consultant. She'd also see Anna-Marie Ewins who was the bone marrow transplant specialist, she was next in line from Professor Gibson. If neither of them were available she saw Doctor Story the registrar, or Doctor Heney, who was the oncology teenage consultant, but that was only really early on.

18. There was a bit of concern from parents that the kids were all sitting with just the general public. Those who are going through cancer treatment tend to have low immune systems. At clinic in the RHC before any of the kids have seen the doctors they were all mixing in together in the waiting area, which is quite a concern as the kids were there for lots of different types of clinic. The general public were able to just walk past the waiting, coughing and maybe with bugs.

19. At that point when Stevie-Jo was going up to clinic at the RHC, two days later we'd be in Dumfries Hospital with a temperature. We didn't really think much of it at the time. We just thought it's because she was coming to the end of her treatment. But every month that we were up there, two days later she'd be admitted to Dumfries and Galloway Royal Infirmary for about a week on antibiotics. She was always fighting temperatures.

20. Her liver was damaged too, so she always had jaundice, and her bilirubin was always really high. All her liver functions were always off. She went yellow in colour it had gone yellow including in her eyes, she used to say she was like a Minion. Nobody could ever fathom it out, because at that point Stevie-Jo wasn't actually getting intense chemotherapy. That treatment had stopped and she was just on her maintenance of check-ups at that point. No one could ever understand. The doctors did quite a lot of tests to see if her liver was actually failing or if there was anything wrong, but it always repaired within a couple of days, maybe about a week after being in Dumfries and Galloway Royal Infirmary (" DGRI") on antibiotics and she began to recover.

21. The clinicians didn't know why this happened during that time. They just kept putting it down to the amount of treatment that she had had over the two and a half years, they thought that maybe it was having an effect on her liver. They weren't sure.

22. Doctor McKnight was the consultant in the DGRI and she did remark that it was really strange that every time Stevie-Jo was up in the RHC within two days she was admitted with a temperature and her liver to the DGRI. Doctor McKnight was in contact with Professor Gibson a lot regarding Stevie-Jo's health and all of her treatment. At one point they weren't sure if she was going to need a liver transplant: her liver levels were already really high and she was on antibiotics frequently which they considered posed an additional risk. The doctors were always trying to balance things up.

23. Professor Gibson said that it could have been scarring from all of the chemo that Stevie-Jo had over time, but none of them were really sure what had happened.

Relapse: July 2017 - admission to the Schiehallion Unit, Ward 2A of the RHC

24. Stevie-Jo finished her treatment in 2016. Stevie-Jo's blood levels usually increased after chemotherapy, the blood levels would return back to normal.

At this time Stevie-Jo's never went back to normal. Her platelets and her white blood cells always stayed really low. We had check-ups at DGRI monthly for Stevie-Jo where she saw Doctor McKnight who checked her bloods. She started getting tonsillitis again and that was one of her symptoms when she was first diagnosed in 2014; it was how it began in the first place. She also had a high temperature. At that point nothing was showing up in Stevie-Jo's bloods that were concerning, but Doctor McKnight wasn't very happy with the way she was presenting. She got the labs to dig deeper into the blood samples. She asked them to look at it underneath the microscope to see if there was any abnormal cells. When those results came back it confirmed that there were abnormal cells in the blood.

25. On the 3 July 2017 we got the results and Stevie-Jo was immediately transferred by ambulance from the DGRI to the RHC in Glasgow to begin treatment. She was okay but she was a bit scared and unsure how things were going to go. At this point her colour was really good. She didn't actually look like she did previously when she had the leukaemia. This time she appeared to be absolutely fine and apart from the tonsillitis and a high temperature; you would never have thought she was ill.

26. Doctor McKnight told us that there were abnormalities in the blood and she suspected that it was a relapse. This was confirmed by Professor Gibson up in Glasgow who carried out a lumber puncture and blood tests to confirm that it was leukaemia. A few hours after performing the tests it was confirmed.

27. Stevie-Jo was admitted to ward 2A in the RHC. Professor Gibson was her consultant. She was not given a treatment plan at that point due to the liver problems and infections that Stevie-Jo had been acquiring throughout maintenance treatment, so it was a bit of a concern. She started a course of intense chemotherapy for four weeks in the hope that she would go into remission. If she didn't go into remission then the proposal was that she would need a stem cell transplant.

28. Luckily Stevie-Jo went into remission in the first four weeks following intense chemotherapy. At that point, the treatment plan was to just carry on with chemotherapy and go through the chemotherapy stage by stage. The doctors monitored Stevie-Jo's liver and modified the treatment to accommodate Stevie-Jo's body. Professor Gibson jiggled things about and played it by ear pretty much month to month. Normally, when a child is diagnosed with ALL they are given a treatment plan which sets out the protocols and treatments that will be followed. Girls are on the treatment plan for two and a half years and boys are on the treatment plan for three years.

29. From the 3 July 2017, Stevie- Jo was admitted as an in-patient and she stayed in ward 2A in the RHC for about 8 months. She had a line fitted straight away on the 4 July. It was a surgical procedure under a general anaesthetic. It took place in the theatre in the RHC which is 1B.

30. Stevie-Jo's line went in through a vein in her neck and sat on her chest. It was on the right side of her chest, and it was attached on to the skin. It had two tubes that hang out of it with clips on it, one for blood and one for treatment. The clips on the tubes are to stop the blood coming out or anything going in. The medical staff have to open the clips when they're taking blood or putting anything in. There was one tube going into her neck, and then it had a little box like a little square clip, and then it had two tubes coming out of that: a red one and a white one. The red one was for taking blood, and the white one was to administer treatment. The separate tubes were so they didn't contaminate the blood or the treatment lines. The clips were actually in the middle of actual tubes like little pegs, they gripped the tube to stop anything coming out for the blood line and sealed it off. When medical staff were taking blood or putting anything in they had to open that first then connect to the tube onto the line. On the end of both the tubes there was a connector which the blood bottles could be connected to.

31. It was maybe a few months following Stevie-Jo's relapse, at some point in 2017, the hospital introduced a little green cap for the end of the lines. I can't

be certain of the date. The caps had little disinfectant cloths inside them, which then screwed on to the end of the line and it was to keep it clean. Every time the line was used a new cap was placed on the end of the line.

32. It was one of the nurses who first fitted the caps onto Stevie-Jo's line. All of a sudden she came in Stevie-Jo's room with them. We asked what they were as we'd never seen them before and they were not used in Yorkhill. She explained that it was a new thing that was being introduced because a lot of the kids were getting line infections and infection control thought that the nurses weren't cleaning the ends of the lines properly.

33. The nurse said that a lot of the kids' lines had been getting infected, but they didn't know if it was because the lines were lying open. Infection control had thought that the kids were getting dirt or dust into the lines. One of the other nurses told us that infection control were blaming them saying they weren't cleaning them properly when they were using them. The cap was supposed to take away the risk of infection because the suggestion from infection control was that the nurses hadn't cleaned them properly with the disinfectant wipes. But the nurses were cleaning the ends of the lines and this would have kept the ends clean.

34. The nurse also said that the nursing staff didn't understand what they were supposed to do, because they were cleaning them. Unless the clip was open nothing would be able to get up the line because of the clamp, and the nurses always flushed the line with saline before they put anything in or took anything out of it. They didn't really understand what the purpose of the caps was; but they were told to use them. Everyone was just really confused about the caps and no one understood why all of a sudden these were introduced.

35. When Stevie-Jo was discharged from the RHC, she went for check-ups and monitoring at the DGRI. The staff in the DGRI had never seen the green caps before either. They didn't have a clue what these caps were. We ended up

having to get some from Glasgow to keep at Dumfries so that they had some for when we were running out at Dumfries. They were kept in a drawer in the DGRI and we collected them from the RHC whenever we were up at the hospital in Glasgow.

Description of Ward 2A in the RCH: the Schiehallion Ward

36. Ward 2A is part of the Schiehallion Unit. It is the in-patient ward and it treats kids with cancers, bone marrow problems, tumours or haemophilia or other conditions where the blood doesn't clot. The name "the Schiehallion ward" was what it was called in the old Yorkhill, so it carried over.

37. Professor Gibson was Stevie-Jo's main consultant. Shazia Chaudhury was one of the other consultants and was coming in to take over from Professor Gibson because she's near retiring age. It was pretty much at the end of Stevie-Jo's treatment that we saw Shazia, and it wasn't very often. She saw Dr Heney and Jacob quite a lot, he was a trainee doctor. Jacob liked football and I think he liked to come and talk to use when the football was on. I do not know his surname.

38. When you go into the ward you go through a set of double doors. The ward is in a big, massive curve and the corridor goes round. The patient rooms are all single rooms. The ward itself is quite dull, a dark purple on the walls. Not like old Yorkhill where they had loads of kids' drawings and things on the walls. There are no windows looking out to the outside. Everything was inside and internal to the building. In total, I think there were about 32 patient rooms in the ward. They went down both sides of the ward.

39. Walking down the corridor into the ward, there is the parents room with a kitchen at the beginning of the ward. Half way down the corridor is the nurses' station which is in the middle of the ward. As you go further into the ward you come to the Teenage Cancer Trust ("TCT") unit which was a long corridor off the ward. The TCT unit had a room for the teenagers, it is chill area. The room

has a jukebox, a pool table, Sky, comfy chairs and a kitchen. Only the teenage patients can use that room, and their families could use it too but only if there weren't too many teenagers using the room; it is a facility for the teenagers. Off of that as you come out the TCT common room through a side door the unit has five TCT patient bedrooms. The TCT unit had another glass interior wall, so it separated it off the main ward, and it was its own little unit. It had the specialised TCT nurses in there.

40. The parents room in the main part of 2A had a kitchen with a microwave, coffee facilities, fridges and a freezer. It was a place where parents could store some food. There was a nice big table and couches, it was a place where parents could sit and just have five minutes. It was a comfortable and relaxing area. There was a little Costa coffee machine. I think there was a small TV in that room as well. There was a nice big window so you could just look out onto the parking area but it was still nice just to look out, you could see everyone coming in and out of the hospital.

41. The nurses station in ward 2A was half way down the corridor and it was a big half circle desk. All the children's monitors were there and that meant that the nurses could visualise them when they were at the desk. There were two patient bedrooms right behind the nurses' desk. We were unfortunate enough to stay in there before Stevie-Jo relapsed on two occasions during 2016. At night you can hear all the monitors going off; you can hear the nurses talking. You can hear all the private conversations about other patients as well, to be honest. That's obviously no fault of the nurses but due to the layout of the ward, they had their station and there were two rooms right behind it.

42. In July 2017 Stevie-Jo was admitted to a room the TCT unit, it was either room three or four. She stayed in that room for most of that admission. The room was awful. It looked out into the atrium of the main hospital building; it had no daylight whatsoever. It had some plugs, but nowhere near enough plugs for the kids considering the amount that they need in order to power all the medical equipment that they use. For example, various drips and

monitoring equipment. The blinds were inside the window, inside the glass. There was a knob on the outside of the glass but when that knob breaks you couldn’t close or open the blind. The lights stay on in the atrium constantly, the room was lit up all the time. The room also had what looks like a wardrobe but it’s actually a pull out bed for parents and carers; it is a single bed and a mattress. Then there is the patient’s bed. There was a TV above it but the TV never worked. None of the TVs worked in any of the children’s rooms. All rooms had an en-suite bathroom as well. There was also a separate sink in the bedroom next to the patient’s bed.

43. The TCT unit was really good and organised a number of activities for the teenage patients on the ward. Ronan was the TCT coordinator, he always had a lot of people in the unit to lead on activities and he was in the unit Monday to Thursday. For example, he had people in doing pyjama making. That is also how Stevie-Jo got into the guitar. He always tried to have things throughout the day. He sat and played games with the kids or pool; anything to keep them entertained. We were quite lucky that we had TCT in that sense.

44. As regards her school education, there was absolutely nothing for Stevie-Jo. During her first treatment in the old Yorkhill, they had a primary teacher who come along every now and again. It wasn’t daily and they didn’t really push them at that age; they were only in primary school and they could catch up. Stevie-Jo used to always kid on that she was sleeping when she came in to see her in Yorkhill.

45. In the new hospital, during the whole time we were there we did not see a teacher until the day that we were getting home. The other kids on the wards had teachers coming in quite often and they were doing the work with them. We weren’t sure if this was because of the different local authority areas, and that [redacted] local authority hadn’t been in touch with the hospital. I don’t know what happened. On the last day when Stevie-Jo was discharged the teacher came round to the room and said he was here to see Stevie-Jo. I told him that we were actually going home today. He said that as Stevie-Jo

had been in hospital for longer than seven days, it was against the law for her not to have education. I said that we’ve been here for eight months, and I asked who I should contact because we had not seen anyone. We didn’t see him again after that.

46. Stevie-Jo had a close relationship with many of the staff, in particular a number of the nurses. She has pretty much grown up with the nurses that treated her, so she’s got a very close relationship with them. When the services transferred from Yorkhill to the RHC, a lot of the nurse moved into different departments but they still worked in between Schiehallion and the new departments, so a lot of the nurses were still working in the ward.

47. The heating in the bedrooms was not great. Sometimes it would be absolutely roasting in the room and you were far too hot, especially on a hot day. At night the temperature would really drop and it was pretty much freezing cold. You couldn’t regulate it. There were thermometers inside each of the rooms but they never worked; it was like one of the central heating controls that you get in a house. You should have been able to move it up and down to regulate the temperature but they didn’t work. The staff couldn’t regulate the heat either. The nurses came in and tried to help, they also got maintenance staff up a few times to see if they could fix it but they couldn’t fix it. I don’t think the thermometers in the room were connected properly.

48. One of the things that we noticed straight away when we got there was that infection control staff were constantly on the ward. There wasn’t a day went past when infection control wasn’t on the ward. The infection prevention team wear burgundy uniforms, it is different from the Schiehallion staff so they were easy to spot. I didn’t really speak with them. In the old Yorkhill the kids were allowed to draw pictures and put them up in their rooms. We weren’t allowed to do that in the RHC. The kids were allowed to put posters up to make it more homely and bring in their duvet covers at Yorkhill.

March 2018: Day pass to CLIC Sargent House

49. Following six to eight months as an in-patient, Stevie-Jo was given a day pass from ward 2A around the start of 2018. That meant that whilst she was able to leave the ward, we were not able to go home. She started a treatment plan of 3 days inpatient chemotherapy treatment at the hospital and then would go over to CLIC in between times. Even though she was at CLIC she was still in 2A officially and had to stay very near to the hospital.

50. We moved into CLIC Sargent house which is just off the hospital grounds. It is a house with separate rooms for families and patients, and it has a shared kitchen and sitting area. It is only for use by patients and families of the Schiehallion ward. Professor Gibson wasn't very keen on sending Stevie-Jo home to [redacted]. She was concerned because she had relapsed and it's not very often that the kids go through two lots of chemotherapy. When she was first diagnosed she had two and a half years of chemo, and then following relapse she was going through another two and a half years of treatment again. It's quite a lot on her immune system over a five year period. Professor Gibson was concerned about her immune system so we stayed there for a bit before we were able to go back home to [redacted].

51. A day pass meant that Stevie-Jo still kept her bedroom in the hospital. We could leave her belongings there and her room was always there for her. We would get to go over to CLIC Sargent throughout the day, and the odd time they would let her stay over there at night just to try and get to sleep. She couldn't sleep on the ward due to the light from the atrium and the noise.

52. CLIC Sargent House can accommodate up to six families at a time. It is a massive house with an upstairs and a downstairs villa. It has two big kitchen areas, one downstairs and one upstairs. In the kitchens there are two cookers, two fridge freezers, so as much as it was shared there was still plenty for everyone to use. In each area, there were two sitting rooms. There was a laundry area to wash and dry clothes and that was a god send. CLIC

Sargent house is about a three to five minute walk once out of the hospital grounds. It is literally just across the road.

53. At that time, Stevie-Jo was getting chemotherapy at night through her drip and her central line. She was also getting eye drops every hour and the eye drops were given for about a month. I think that she had finished the high intense dose of chemo and we were moving onto the consolidation phase. Her treatment was reducing down and was not quite as high intensity.

54. We stayed at CLIC Sargent until around May 2018. When the treatment finished she was discharged from ward 2A and we were able to go home to [redacted]. After that we attended clinic in ward 1C of the RHC for check-ups.

Maintenance Treatment: June 2018

55. In June 2018, Stevie-Jo moved onto maintenance treatment. This was administered as an out-patient at clinic in ward 1C. Her bloods were checked weekly and she got her prescription of oral maintenance chemotherapy. She took the oral chemo tablets daily. Once a month she was given Vincristine which is chemotherapy that goes through a cannula and not a central line, it's more intense rather than just a tablet that they take daily.

56. Stevie-Jo began to get headaches in June 2018 and they carried on for months. Between June 2018 and November 2018 Stevie-Jo was up and down to the hospital with temperature spikes. She was admitted as an in-patient on a few occasions.

57. There was one occasion in August or September 2018 when Stevie-Jo had been up at clinic. We came home and she wasn't feeling very well. So I phoned Glasgow and was told to bring her back up to the hospital. All of a sudden her breathing was really bad. She was given oxygen as her oxygen levels had dropped significantly. She was wheezing, she had a high temperature and was not feeling very well. She was admitted to ward 2A

RHC. The hospital worked through the procedure when the kids present with a high temperature. They took the usual blood tests and started her on IV antibiotics.

58. When she was lying down she couldn't breathe properly, but when she was standing up she wasn't too bad. Over time she began to get better but she still needed oxygen; this went on for a couple of weeks. The hospital carried out a lot of scans. They could see clouding in Stevie-Jo's lung, but they couldn't fathom what it was. Nothing was coming up on the tests or the swabs that they'd taken.

59. Stevie-Jo went to surgery in 1C of the RHC and the surgeons suctioned out some of the cloudiness in her lungs. They tested that but nothing ever came back to confirm what it was. From that point and throughout the whole of Stevie-Jo's treatment, up until a couple of months ago her oxygen levels always sat really low. They were just on borderline. If she got an infection she needed to go onto oxygen, prior to that this had never been the case.

60. Around about that time the five kids that were in TCT unit were really not well. Two ended up in PICU and another two of the patients had been preparing to go home when all of a sudden they had line infections. This all happened in that three week period when Stevie-Jo was admitted. All these kids had to get their central lines taken out at this point. That is when the infection prevention control team had visited the ward and they had turned off the water. We couldn't use the TCT kitchen, the water was off and we weren't allowed to use the dishwasher.

61. At first, staff said that the dishwasher wasn't working, but we asked why we were not allowed to use water from the taps either. We couldn't wash our dishes in the sink either. It pointed to an issue with the water. Staff told us that they were investigating the drains. Someone else said that the water needed cleaning agents put through it. They said because the kids were getting the line infections, they thought that there was something in the water.

62. After that the maintenance staff began putting cleaning agents through all the taps and all the sinks in the bedrooms as well. They poured a liquid down the drains, it was like a bleach. After they did that we weren't allowed to use the sinks for about three hours. They did try and do it at night. We couldn't use any of the sinks once they'd poured it down, or flush a toilet. The nurses gave us that information. The nurses told us that they were cleaning out the drains and they'd had quite a lot of issues with the water on the ward. The nurses were quite open, to be honest. I think because we'd known quite a lot of them for a lot of years they were quite good in just giving us information. The nursing staff told us that that the water's not right. They said that a lot of the kids had been getting really ill from the water and the hospital was trying to figure out what it is. We weren't allowed to wash in the showers at that point.

63. Infection control were in ward 2A a lot during that time. It was around this period that the Dyson fans were removed. The Dyson fans were removed because of the dust in the ward. Staff said that there was too much dust floating about. I pointed out that we used old fans at the old Yorkhill and it was never an issue, the old fans had the blades. I would have thought they would pose more of a concern than the Dyson ones which did not have any blades. Staff said it was too much of a risk and by removing the fans from ward 2A they were trying to eliminate that risk.

64. I noticed that every time the nurses came into the room they wanted to clean the kids' lines. Up on the area where the line enters the body, there is a dressing over that. Stevie-Jo didn't clean hers. Every day staff wanted to clean it. During her first set of treatments in 2014/2015 in the old Yorkhill, she had the central line in for the two and a half years and we had never once heard of a child who contracted a line infection at the old Yorkhill. This was all new to us.

65. During that admission we were able to go to on a day pass to CLIC Sargent throughout the day as long as Stevie-Jo's oxygen levels were at safe levels. Staff checked her before we left and if they were okay then she could go for an hour, but she'd have to come back just to check her levels again to make sure that she was safe enough.

66. During that admission she was still having headaches and she began to say that her eyes were flickering. Stevie-Jo was discharged after about three weeks as an in-patient. We went back to weekly check-ups as an outpatient.

November 2018: PICU and Ward 3A RHC

67. In November 2018, Stevie-Jo's headaches grew more intense. One particular evening around about the 19 November 2018 we were at home and Stevie-Jo was complaining of really bad headaches, she couldn't look into light. I gave her some paracetamol and I phoned DGRI for advice. They told me to give her some paracetamol and see if it settled. She took paracetamol, during the night she woke up and came through to see me. She said her head was absolutely thumping and she felt sick. She'd been sick. When I looked at her face looked like she'd had a stroke. One side of her face was all level, the other was drooped and she couldn't see properly out of her eyes. We phoned DGRI and took her up.

68. She stayed in there overnight, but she started deteriorating. She really wasn't well at all, and the nurses were really concerned about her. The doctor was convinced she had an ulcer and I don't know why. An ENT saw her and said it was a mouth ulcer. She was sent for a scan. I thought it would be an MRI or a CT scan, but they sent her for an ultrasound on her mouth thinking that she had this ulcer. I tried to explain with Stevie-Jo's treatment that in the past she had her whole mouth covered in ulcers but never had these symptoms.

69. Throughout the night the nurses suggested we ask for a second opinion because she wasn't right. We thought she maybe had a blood clot or something. You could tell it was something in her brain. In the morning her own consultant, Doctor McKnight, sent her straight down for an MRI scan. It confirmed that there was a mass on the back of her brain. She did say it wasn't cancerous. She didn't think it was cancer; she thought that it looked more like an infection. Doctor McKnight called Professor Gibson and they decided between them to send her straight back up to Glasgow.

70. Stevie-Jo was taken by ambulance straight back up to the QEUH. That night she ended up in PICU, because the part of the brain that had the infection controlled her swallow and the movement in her face. That's why the muscles were so relaxed on one side of her face.

71. She was in PICU for two or three days. The problem was that because she hadn't been so well they begin the sepsis protocol of giving them lots of antibiotics. She went for a lumbar puncture to determine what the infection was, but the antibiotics masked the infection at that time.

72. No one was sure what it was at all. They thought it was maybe an auto immune thing. She was given really high doses of steroids which seemed to improve her.

73. After a few days she was moved up to 3A, which is the neuro ward in the children's hospital. We stayed in there for three weeks. She did improve but I could still see in her face that there was something not 100 per cent right. She was a lot better than what she was.

74. The layout of ward 3A was similar to 2A. All the wards are pretty much the same with patient rooms going down both sides of the corridor and the nurses' station in the middle. I can't remember what room she was in or what the room was like. it's just a bit of a blur given everything that was going on at the time, She was in for about three weeks.

75. There wasn't a kitchen and things like there was in 2A. It wasn't equipped for the long term patients, and the Schiehallion was. The nurses could make you a cup of tea or coffee but you still had to go down to Marks and Spencer or something to get food. It didn't have the facilities that had been available in ward 2A. There was no parent's lounge. They had a play room, for the younger kids but Stevie-Jo was too old for that.

76. Stevie- Jo was pretty ill during that admission and she didn't use any of the facilities. There was nothing for parents. If I wanted some time to myself, I had to walk down to the atrium and maybe to the front door. Stevie-Jo was so ill I rarely left the room, apart from going for food and even then it was straight back up to the room. I stayed with Stevie-Jo the entire time. Steven came up to stay two nights through the week and also at the weekend. We were not able to use CLIC Sargent at all at that point as technically we weren't Schiehallion patients.

December 2018: PICU RHC and ward 6A QEUH

77. Stevie-Jo was discharged about two weeks before Christmas, around the middle of December 2018. She began to get really bad headaches again as doctors had begun to reduce her steroids. It happened a day or so after she was discharged from the RHC.

78. I took her to the DGRI who sent us straight up to ward 6A in the QEUH. Upon arrival the neurosurgeon examined Stevie-Jo, but he wasn't concerned; he thought it was just the effect of the steroids reducing. She was examined by a consultant from neuro and another from the PICU. They had a look at her eyes and checked her with the light and reactions. The neuro consultant said that really severe headaches was a common side effect from reducing down

steroids, and he believed that this was the cause. He wasn't concerned. They sent us back home that day.

79. Over the next few days, she still had really bad headaches and she was taking a lot of pain relief. We tried to manage her pain with co-codamol, morphine and paracetamol.

80. On early morning Christmas Eve 2018, Stevie-Jo was really not well again, she had bad headaches and was being sick. She had a bit of a temperature and she was screaming in pain. Steven and I took her back up to DGRI. The doctor who we saw there originally in the November, was just going to send her for an eye test. However one of the other consultants who'd seen Stevie-Jo before said that she had to go for an MRI straight away. She was seen by Doctor Ecclestone. Luckily she went for the MRI. The scan showed that the mass on the back of her brain had got bigger.

81. On Christmas Eve Stevie-Jo was transferred up to daycare on ward 6A in the QEUH where more tests were performed. Then throughout the night into Christmas morning she deteriorated again. Her breathing was reduced and she could not eat. On Christmas Day Professor Gibson asked for the PICU team to come up and have a look at Stevie-Jo. By this point Stevie-Jo's swallow was gone, so the theory was if her swallow was gone her airways would collapse as well. They phoned for the rest of the PICU team to come up to transport Stevie-Jo from the adults hospital to the children's hospital. It was a mission in such a rush.

82. The PICU team arrived in ward 6A. They had to make a plan of how they were going to get her from the adult hospital to the children's hospital. They had to make up plans for what would happen if Stevie-Jo crashed; they had to work out how and where they might be able to resuscitate her. I speak about this event later on.

83. As soon as Stevie-Jo got on to PICU another lumbar puncture was preformed, this time before she had any antibiotics. It was too much of a risk to put her under anaesthetic with her airways closing and her swallow gone. PICU staff told us that they weren't sure if they would have to put her on life support during the procedure, they were not sure what was going to happen because they weren't sure how quickly she was deteriorating. Professor Gibson actually took the lumbar puncture and took it to the labs herself and tested it.

84. After they performed the lumbar puncture they started Stevie-Jo on a lot of antibiotics just to try and fight whatever it was. From Christmas Day to the 27 December we didn't know what it was. No one did. None of the results were coming back with anything that they thought it was.

85. On the 27 December 2018 it was confirmed that Stevie-Jo had contracted listeria meningitis. She was put on IV antibiotics for 4 weeks. The antibiotics that she had been given up to that point were not the ones that fight the meningitis. So they stopped all the other antibiotics and put her on the one that actually fights the listeria. The nurse in PICU actually told us first then Professor Gibson came in and officially told us. She said that it's something that's ingested. We went over if she had been near anything, went through all her food; but she hadn't really eaten anything that might be a risk. We didn't really know where it had come from.

86. Once she was taking the proper antibiotics she started improving within about 48 hours. She was in PICU until New Year's Eve. On the 1 January 2019, Stevie-Jo was moved to ward 6A. She was there for approximately 4 weeks in room 5.

87. In January 2019 Stevie-Jo had a new central line fitted so that she could receive her IV antibiotics. It was a replacement, because her line had actually split so they had to take that one out and put a new one in. This was in surgery in the RHC. When she got out of theatre, she really wasn't well. She needed oxygen, which had never happened before when she had surgery. After surgery she

kept coughing up massive blood clots. We were quite concerned about it. The nurse looking after her said she'd never seen that from someone getting a line in before. Each day the doctors checked her over and she seemed fine.

88. Stevie-Jo's cancer treatment was stopped completely all the way through this period, from November 2018 right through till New Year's Eve. In January 2019 when she came out of PICU, Professor Gibson decided to give her weekly Vincristine just to try and hold the leukaemia until she could sort out a new treatment plan.

Description of Ward 6A QEUH

89. Ward 6A in the QEUH is a big straight ward. The nurses' station was a bit better, because it wasn't in front of any patients rooms; it was on the corner. You walk straight down a massive corridor and the ward has rooms on either side. There is a big room at the bottom of that corridor and that was day care, which was formerly ward 2B in the RHC. To get to day care people walk right through the entire in-patient ward. There was a wall in the middle of the ward, it was in a horseshoe shape, and there were rooms round the other end and up the side of the ward.

90. There were about 40 odd rooms on the ward. Stevie-Jo was in room 5. It was very basic. It was worse than ward 2A in the RHC. It is an adults hospital; it's not equipped for parents staying. The hospital had to bring in fold out beds for the parents rather than having the beds that pull out from the wardrobe. There were no TVs. There was an en-suite with a toilet and shower, and a sink next to the kid's bed.

91. There was no kitchen facility. I couldn't even make a cup of tea. For tea, coffee and food I had to use the canteen or Marks and Spencer.

92. There was nothing for the kids. There wasn't even a play room for the small kids. They just had a tiny little table sitting in the corridor with some colouring

sheets on it. It was right outside Stevie-Jo's room, at the entrance to the ward. The table was so small that it could only accommodate one small child at a time, one 2-4 year old. There were no play leaders or educational specialists. There was a play specialist, but she was never on the ward.

93. The temperature in the rooms was just as bad as in ward 2. It was really hot through the day and cold at night. I couldn't control the temperature, there were thermostats but they were not working.

94. Overall, the layout of the rooms in ward 6A was probably a lot better than in 2A, because you could see round the corners. The nurses weren't having to be really cautious with trollies, they didn't have to worry about kids who were playing and running into them. The ward is brighter and some of the rooms actually look outside. Day care has a nice big, bright window so you could actually get some daylight in that ward.

95. Before entering ward 6A there is a room off it. It is a massive room and it had a nice big table. I asked Emma, the ward sister if parents could have that as a parents' room or a play room for the kids. Emma asked management but she was told "no" and that it was not possible because some of the bosses use it for meetings.

96. The hospital food is bad and the kids wouldn't eat the food. It was really hard without a kitchen, we didn't have a microwave or a fridge. I didn't really have anything hot to eat when we were staying there.

January 2019: Events on Ward 6A QEUH

97. Once Stevie-Jo was moved back to Ward 6A, I noticed that there were air filter machines in the corridors. I asked the staff on the ward what the filters were for. They told me that they were HEPA filters for the air. I was told that the hospital tested the air quite often and they just wanted to fit these in to purify the air. At first I thought that was fine.

98. Gradually each day the staff started turning up the filters; up and up and up. They were really noisy so you could tell when they'd been turned up. The kids were really dry from it in their noses and their throats. Everyone was getting a really sore throat. The nurses were the same, they were not feeling very good around the air filters either.

99. Then they moved the HEPA filters into the bedrooms. This was around the end of January 2019. One was moved into Stevie-Jo's room. I asked staff why the HEPA filters was being moved into her room. I asked if there something wrong with the air in her room? They said, "no, no, we're just putting them in some of the rooms". Later on that day, around nine o'clock at night Professor Gibson and the microbiologist came round the patient bedrooms and they were looking in the showers. I thought it was very strange and so I asked if I could have a meeting with them both to find out what was going on. At this point Stevie-Jo was really vulnerable and was recovering from the meningitis.

100. The next day Steven and I had a meeting with Professor Gibson and the microbiologist. I cannot remember the name of the microbiologist, but she's had quite a lot to do with the investigations of what happened. She has actually left the hospital and she spoke out publicly about all the issues in the hospital.

101. During the meeting I asked them both "what is going on in the ward?". I pointed out that I noticed that HEPA filters had been brought into the ward, and that I saw them both looking at the showers in the bedrooms at 9 o'clock at night. Things weren't right. They told me that mould had been found in the wet rooms as the flooring had come away the water was getting down the back of it, sitting in it and was causing the mould. They said they were a bit concerned about that having an effect on the transplant patients. They told me that they were going to move some of the transplant patients from ward 6A down to ward 4 in the adult hospital, just until they got the mould sorted. I then asked "is Stevie-Jo safe in this hospital?". She was recovering from meningitis and

the last thing we wanted was for her to end up back in PICU. The microbiologist replied by saying, “well she's as safe in here as she is outside”. I responded by saying that we’re not in the middle of a war, she's not being treated in a desert; rather we’re in a hospital, it should be clinical. I was quite angry about that. They reassured me that she was safe enough, that there were no issues and that Stevie-Jo’s was not at risk. They said that the HEPA filters were there because of the mould, to disperse the spores coming from the mould to reduce any contamination.

102. The next morning, Professor Gibson came to speak to us in Stevie-Jo’s room. She told us that she was driving home last night and that she had been thinking about the best way to keep Stevie-Jo safe. She told us that she I could send Stevie-Jo back down to the DGRI in Dumfries, as long as Doctor McKnight in Dumfries was happy. She trusted Doctor McKnight with Stevie-Jo’s care. She said she could send us back to Dumfries, and then that would mean that Stevie-Jo is out the hospital and she would be safe down there and she could finish her course of antibiotics there. We were happy with that; we’d prefer to be closer to home anyway.

103. The next day Stevie-Jo was transferred to DGRI and we were glad about it. Even with the transfer, there was no communication between Glasgow and Dumfries hospitals. We just drove down to Dumfries, Stevie-Jo was well enough for me to take her in the car. We arrived at the DGRI, and no one knew that we were coming. They didn’t have a bed for us, they didn’t have any notes. The staff were angry. Communication between the hospitals was bad anyway, but that was quite a bad example.

104. Stevie-Jo remained in DGRI until she was discharged at some point between the 12- 16 February 2019. She noticed that the area around her central line was going red, it had begun to get red before she was transferred back to the DGRI from the QEUH.

105. Shortly after that Stevie-Jo was re-admitted to the RHC to get her central line taken out, and the area around the line was still red. The line had been fitted so that she could receive the IV antibiotics for meningitis. After her line was removed the area of her skin where she had her line started going really puffy. Around about the 27 February 2019, we went back up to the RHC and Stevie-Jo went back into surgery and they cleared out the area. The surgeons had to cut into the area and it was filled with green pus. They cleaned it out and packed it. Samples were taken and tested but nothing came back at this time. Stevie-Jo was discharged.

106. I asked to speak to the sister of the ward, Emma. It was obvious that there was an infection in her line. She had not long had that line put in, and it seemed that it had come from surgery. She only agreed to speak to me because I wanted to put in a formal complaint. She had agreed it definitely looked like it had come from surgery, but asked that I wait until we get the results and then put in the complaint, but that just never actually happened and as there was so much going on with Stevie-Jo; I found myself caught up with that.

107. Around about that time Stevie-Jo started getting sores on her arm. It came up in a big lump on her arm. We just thought it was a big bite on her arm. Stevie-Jo was in the DGRI to have blood taken and we asked the doctor to have a look. They gave her some medication in case a bite had become infected. She had this lump for about two or three weeks, and then it had started to burst open, it was bleeding and really sore. Around about this time we were in the QEUH for a check-up with Professor Gibson. She said that it was really not right and had phoned the dermatologist, Doctor Beattie.

108. Stevie-Jo was sent for a biopsy that day. We went to the old Yorkhill as that’s where dermatology is based. The biopsy was taken and the doctor who took it looked really intrigued by it. She had an assistant with her and she was saying “look!”, and she was pulling out all this orange stringy stuff from it. It was weird.

March 2019: Healthcare Associated Infection: Mycobacterium Chelonae

109. It took ages for the biopsy results to come back. First of all we were told that Stevie-Jo had tuberculosis. That was what they thought had come back on the test results. Professor Gibson had phoned us one Saturday morning, this was about three weeks after Stevie-Jo first originally got the biopsy taken from her arms. We knew that the biopsy results would take a bit of time to come back. Professor Gibson phoned the house to say that the results had come back and that Stevie-Jo had tuberculosis. She wanted us to go back up to Glasgow because we had to re-look at a plan for Stevie-Jo. We went back up to Glasgow and Stevie-Jo was admitted to the neuro ward which I think it Ward 3C. We stayed there for about a week because Professor Gibson was off and we had to wait for her to come back.

110. From our perspective, that was really stressful. We didn't know if Stevie-Jo would be going back on chemotherapy. We didn't know what the other options were. We didn't know what was going to happen. We stayed up in Glasgow for a week, not knowing. None of the doctors would speak to us because they were waiting for Professor Gibson to come back. They couldn't authorise anything without her. Stevie-Jo did not continue on with her chemotherapy treatment.

111. When Professor Gibson returned to the ward the following week, she came to speak to us with Conor Doherty. Conor is the infectious disease doctor. They had literally just got the test results back which confirmed that Stevie-Jo actually had mycobacterium chelonae. They told us that the infection was very rare. As it was so rare they had to send the biopsy to a specialised lab up in Dundee or Aberdeen, I can't remember where. By this point Stevie-Jo had lesions and scars all over her body.

112. At that point, we still didn't know what the plan was for Stevie-Jo. All we knew was that there was only one antibiotic which could fight the infection. The side effects were really severe, and given the cancer treatment that Stevie-Jo had

already undergone Conor was reluctant to give her that antibiotic. Instead the doctors hoped that they could bring Stevie-Jo off her chemotherapy completely. This would allow her immune system to kick back in, and the hope was that would start fighting the mycobacterium chelonae infection itself.

113. Conor was very open with us. He said that it can take up to three years before we even start seeing any improvement. This was due to the nature of the infection; it's so slow-growing, that it can take a while to show as clear. It is now two and a half years since that infection was confirmed and Stevie-Jo's still got the infection in her body. She still has big marks from the lesions on her body: she will be scarred for life.

114. Professor Gibson held a multidisciplinary meeting with other clinicians to discuss Stevie-Jo's case. This is when there's a complex case; all the professionals attend and discuss the best course of action. During that meeting they decided that that because the infections that Stevie Jo was contracting were becoming more rare, the concern was that they wouldn't have an antibiotic that would fight the infection. If Stevie-Jo relapsed she still had treatment options available. She still had a stem cell transplant, and CAR-T therapy, which could be used. The concern was that if she developed another infection there wouldn't be an antibiotic to treat it, but there were still options for her cancer treatment if she relapsed.

115. A few days later, Professor Gibson then called us back to Glasgow as a family. She wanted to discuss the infection with us. On the 29 March 2019 we met with Professor Gibson and the microbiologist. They had confirmed that the infection that Stevie-Jo had come from the operating theatres in the RHC. Microbiology had traced it back to the time when Stevie-Jo wasn't really out the hospital. They knew that it had come from the hospital.

116. Mycobacterium chelonae has a long incubation period. Once the infection was confirmed, the microbiologist knew how long the incubation period was. She was able to trace that back to when Stevie-Jo had her line removed in surgery.

They had found the infection it in the water, in surgery in the RHC. They had tested the water.

117. Stevie-Jo did receive antibiotics to begin with. Originally, when they thought it was tuberculosis she was given some IV antibiotics for about a week. I wasn’t sure if she had anything else. When the people who did the Case Notes Review looked back she had antibiotics right at the beginning, before they knew what the infection was. It was confirmed, and these antibiotics just continued on after that.

118. I was really angry when the infection was confirmed and when I was told that it had come from the water in surgery in the hospital. Like a lot of the parents, I'd had concerns for quite a long time. Everyone knew that there was something not right with the water. I remember being in the old Yorkhill when the new hospital was being built, and at that time a lot of parents were really anxious about it being next to the sewerage works. We couldn’t actually believe that a hospital that was treating kids with cancer, could actually have issues with the water, and that this was actually making the kids more sick than they were already. Your kid is going through cancer treatment, your biggest worry should be the cancer, not what infection the hospital is going to give your child. For a lot of the families, I think the infections from the hospital were worse than the cancer, especially for us. We knew that if Stevie-Jo relapsed, that there's treatment available to fight the cancer. But when you're told that they might not have medication to keep fighting the infections that are coming from a hospital, it is a bad situation. The hospital should be keeping her safe. It was and continues to be really stressful for me, and for us as a family. The risks of her relapsing are still there. She gets regular blood tests.

119. Stevie-Jo saw the doctors in Glasgow: dermatology; the skin nurses; and Professor Gibson, just in the hope that the lesions would start improving. It took a long time and although it has improved now it's still there.

120. Once we found out that Stevie-Jo had the mycobacterium chelonae infection on her skin, communication from the hospital staff was okay. The breakdown in communication from our perspective, was before that when no one knew what it was that was making Stevie-Jo unwell. When the clinical staff were trying to work out what was wrong with her, we had quite a lot of back and forth from [redacted] to Glasgow. She underwent a lot of tests.

121. The pros and cons were weighed, along with the risks for Stevie-Jo. On the 12 May 2019 the decision was taken to completely stop her chemotherapy. It was concerning. Stevie-Jo had already relapsed. At this point she had already missed six months of maintenance chemotherapy due to the meningitis and being ill with this infection, and she was going to miss the final six months of chemotherapy. When she relapsed, instead of two and a half years' treatment she had about a year's treatment of chemotherapy.

OBSERVATIONS ABOUT THE HOSPITAL BUILDING

122. On one occasion there was water in the atrium, I think it was sewage. There's a linking corridor between the atrium, heading through to the adults' hospital, which takes you to the food court. There's an x-ray room on that corridor as well. I was down in the atrium and the link corridor had been closed off. There were little barricades around it and the sewage was coming up through the floor tiles. The tiles had burst, and all the sewage was oozing up through the tiles. It was disgusting, the smell was awful. This was in the November or December of 2018 when Stevie-Jo was in PICU.

123. There was an occasion when part of the roof blew off in the adult's hospital. I think this happened around October and December in 2018. We were down in the food court, and we heard a big almighty crash. On the way back to ward 6A we looked up, there was a corner at the left-hand corner of the food court where part of the roof had actually blown off. I had tried to take a photograph

of it, but a security guard approached me and he was shouting at me to stop. I didn't actually get a photograph of it. I was a bit too scared to try.

124. There was an issue with the windows. The whole front of the adults' hospital, and the children's hospital is coloured glass windows. At least twice the windows have fallen out, near the front entrance. Now there is scaffolding with netting round it, so if any windows fall it protects the public underneath.

125. In the children's hospital there was the issue with the cladding. I understand that I had to be removed and changed due to the issues highlighted by the fire at Grenfell.

126. The front door into the main entrance of the adults' hospital is glass. The door goes round and round, it revolves. The door shattered because the wind blew it in. I think this happened because of the shape of the hospital; the wind just seems to catch in that shape and the whole door shattered. The hospital has put up a false wall up behind the moving door, just to protect it from the wind and to save it coming in. The ladies who were sitting at the reception area, always had big massive blow-heaters on just to keep warm.

127. There were not enough plugs in the bedrooms for the kids' equipment. This was a really a big issue, especially through the night, when I had to get up every half hour and change the plugs round to power the equipment. The batteries in the equipment didn't hold a charge either. Stevie-Jo was often on morphine or ketamine, and her chemotherapy. During the night if she needed the toilet I had to unplug all her medication and drips from above her bed, carry her to the toilet, with her drips and monitors on wheels. In the bathroom there was nowhere to plug in equipment, which is not great when your child is receiving medication. You couldn't just unplug it from the bedroom and plug it into the bathroom, like I could at Yorkhill. The cables didn't stretch enough into the bathroom. When she was on fluids and she needed to pee, this could happen a lot during the night.

128. As regards the design of the rooms, the rooms on the external part of the corridor had a view outside. The rooms on the internal part of the corridor, looked inside to the atrium. The atrium lights are on all the time, so the bedrooms never get dark. It's like trying to sleep through the daylight but all the time. Within the atrium is where they had the adults' NHS out of hours, service is located, so at nights it was really noisy, people who were drunk were coming through the children's hospital, shouting, screaming. On a Friday and Saturday night, it was worse. It was really awful.

129. The ventilation in Schiehallion ward 2A was different from that in the old Yorkhill. It was one of the things that we noticed as soon as we went into the children's ward. In the old Yorkhill, you entered the ward through a set of doors and then those doors would close, then you would go through another set of doors and into the ward. This was for the ventilation and to keep the air clean. They didn't have this in the new hospital, in either the kids or the adults hospital. I have already mentioned the heating in the bedrooms and that the temperature regulator didn't work. I'm not sure if that was connected in any way to the ventilation system. I think it was Ronan, who's the TCT Coordinator, who told me that when they had carried out tests on the ventilation in ward 2A before they actually moved the kids into the hospital, that for a normal person it was sitting at 50 per cent lower than what it should operate at, and for a cancer patient with a low immune system it was sitting at 70 per cent lower than the average of what it should operate.

130. In both wards 2A and 6A the rooms were hot. We used to have old fashioned fans in the old Yorkhill. In the new hospital, a charity had actually donated loads of the big Dyson fans and these were in the patient rooms which was lovely. Once the infections all started, hospital staff took the fans away. When the kids have a high temperature, the fans could be placed around about them to help them cool down; but that stopped. If the kids had a temperature, and the room was boiling, sometimes we questioned if they did actually spike a temperature, or if it was the heat in the room that was causing it. It was awful.

131. The design of the building meant that dust gathered all throughout the building. It was a big issue. The design of the building is that there are lot of different layers and ledges, but you can't actually get into the layers to clean them. I could see piles of dust sitting on all around the building, on different parts. There were little gardens on the roof of the buildings, but no one could get to them so the grass was overgrown and there were weeds were everywhere.

CLEANLINESS

132. The cleanliness of the hospital was not great. The cleaners would use the same bucket of water for every room. When we were in the old Yorkhill the rooms were cleaned three/four times a day. It was only ever in once in the new hospital and it was just a quick mop round the floors, and a quick wipe down. Whereas in Yorkhill they would have the beds off and have the mattresses scrubbed down; the whole room would get a deep-clean. Provided the kids were ok, we had to leave the rooms whenever it was cleaned.

133. I don’t think they have enough cleaning staff in the RHC and QEUH. In Schiehallion ward 2A and ward 6A, there were two cleaners and quite often only one cleaner at a time who was doing all the rooms. Whereas in Yorkhill they had four or five cleaners.

IMPACT OF THE MOVE FROM WARD 2A RHC TO WARD 6A QEUH

Distance from other services in the RCH

134. One of the biggest concerns that we had when the children moved to ward 6A was when Stevie-Jo needed to be admitted to the PICU. On Christmas Day in 2018, Stevie-Jo had to go to PICU which is in the children’s hospital. Ward 6A is six floors up in a different part of the building in the QEUH which is the adults hospital.

135. The staff wanted to take her in the patient lifts as it is a bit more private but their keys wouldn’t work for the lifts. They then tried to use to the cleaner’s lift, but there were other people coming up and down in beds in there. We ended up having to go all the way around the hospital. We had to come through where the public were, using the public areas to try and get Stevie-Jo from the adults’ hospital to the children’s PICU. It must’ve taken a good 10/15 minutes to get from the adults’ hospital to the children’s. In that time there was a lot of concern from the staff about Stevie-Jo's airways closing or her crashing. The team had to make a lot of plans for this journey, and they had to change their plans really quickly when we had to change route.

136. If she crashed, they didn’t want to be attempting to resuscitate a child in the middle of an atrium with members of the public present; but there wasn’t really anywhere else that they could go to make that journey. If she did crash the plan was to run to a room, any room, which most likely wouldn’t be equipped, or to an office just for a bit of privacy if anything went wrong. Thankfully, it didn’t. On the way down we were discussing this with the medical team. They had a lot of concerns about a child crashing up in ward 6A, it was their view that there was no way that the PICU team could run from the children’s hospital to the adult’s hospital, up six flights of stairs carrying the crash equipment, and then be able to resuscitate a child when they got to ward 6A. They thought that it wouldn’t be possible; they'd be absolutely exhausted, and they wouldn’t have the energy to be able to resuscitate a child once they got to the ward.

137. The teams need to carry a lot of crash equipment. They’ve got massive bags which contain oxygen bottles; a defibrillator; adrenaline shock plates; a heart rate monitor; a blood pressure monitor. It is big kit bag that staff carry on their backs, and they run with it to get to wherever is needed. In the adults hospital the lifts don't work, but even when they are working, the lifts are at the back of the hospital and are quite far away from ward 6A. Even if all the lifts were working the staff had to run from PICU in the children’s hospital to the adults hospital in the QEUH; wait for and then get the lift up six floors; then run from

the back of the hospital to ward 6A. Either way, it wasn't going to work with the distance and the lifts. Staff were really worried about that.

138. There tended to be six to eight staff members in a crash team. It was a big team comprising the ICU doctors; cardiology depending on the issue; and an anaesthetist. They had to try and fit six to eight staff, the kit, parents and the patient plus their bed into the lifts. Lifts that were often full and sometimes not working.

139. That experience and having these conversations with the doctors was terrifying. In that situation your quite heightened anyway, as your child needs intensive care. But then the added stress of not knowing how they're actually getting your child from the ward to ICU; it was terrifying.

140. PICU is on floor one in the RHC. Schiehallion in on floor two in the RHC. It is literally down the lift and you're there in PICU. When the kids were in ward 2A, the doctors, the crash team, everybody could run up a flight of stairs to the ward.

141. When the kids were moved to ward 6A, they were not situated near any of the services and departments in the children's hospital. These are services that need to be accessed very frequently. For example, the pain nurses were still over in the children's hospital. If the kids are really unwell and they need to go on morphine, or ketamine, a specialised nurse attends and prescribes that medication. They set the kids up with the machines and the medication. When we moved to 6A there was always quite a bit of wait for that nursing care, particularly when you add in that they had to travel across from the children's hospital.

142. The kids needed to go for regular surgeries for bone marrow and lumbar punctures, and that was all situated in the children's hospital. The porters had to come over from the children's hospital, try find a lift that was working, collect the kids from the adults hospital and get them back to the RHC. A lot of the

time the porters would just actually walk them back via a link round the back of the hospital. There was a corridor that you could go through. It was a very long way round; it is about a 15/20 minute walk.

Lack of amenity

143. When the kids were in the children’s ward the young kids had a playroom, and the teenagers had the TCT unit. When the kids moved to the adult’s hospital, they had nothing. Especially the little ones, they had a tiny little round table with two little plastic chairs, the proper kiddie ones. This was set up in the hallway in the corridor; they didn’t have any playroom at all.

144. The lack of a TCT room had a huge impact on Stevie-Jo. The TCT common room is a place for the teenagers; it's away from all the little kids. It's a chill out room and they can come out their bedroom and they can talk to each other. When kids are going through treatment, it's okay for them talking to their parents, but you don't understand what they're going through. Really, they need other teenagers who are going through the same thing, because they have an understanding. The common room gets them out their bedroom as well.

145. We found that Stevie-Jo was fine going through her treatment in ward 2A; her and a couple of teenagers were always in the common room within the TCT. In the adult’s ward they were never out their bedrooms. A lot of them started getting really bad depression, and I would say that was probably when Stevie-Jo had to start going to see a psychologist. The kids are sitting in their room thinking about everything; all day, every day. Whereas, at least with the TCT room, they're out with other teenagers. They’ve got their juke-box, they’ve got their pool table, and they’ve got their Sky, Xboxes. Whereas in ward 6A they had nothing; they were just in their room. I know a lot of the kids ended up on anxiety medication because of that.

146. In terms of the impact on me and Steven, we don't stay in Glasgow so we don't have family local who could bring us food. The lack of a parents kitchen or TCT common room meant that when we were in ward 6A we had to go to Marks and Spencer’s to buy food daily, because we couldn’t even keep anything in a fridge. It is not as if we could nip into Asda and get a couple of bits, and keep it in the fridge. There was no fridge.

147. There was no microwave on the ward either. If we wanted anything hot, we had go to Marks and Spencer’s and buy microwave meals then wait until after 3pm which was when we were allowed to use the staff microwaves. The staff microwaves are in the atrium. Stevie-Jo was the same because she wouldn’t eat the food in there, so we'd have to heat her food up in the microwave that was down in the area for the staff. There were three microwaves there, but they were never cleaned. The staff would just run in, put their food in, and go away. For Stevie-Jo, that was quite a big risk, with her immune system.

148. If Steven was in [redacted] and I was up in Glasgow myself, I couldn’t just nip out if Stevie-Jo wasn’t well. That would mean going all the way down to the canteen, or to Marks and Spencer’s in the atrium to get food. The lack of facilities meant that I couldn’t just nip into the kitchen and just grab something from the fridge. Instead I had to wait until she was either sleeping, or feeling a bit better so I could leave the ward and actually get some food. Even to get a cup of coffee, I had to go all the way down to the canteen and leave the ward.

149. It wasn’t too bad on the days that Steven was up, but he was at home working quite a lot of the time. Through the week, I was there on my own.

PHYSICAL IMPACTS

150. There have been physical impacts on Stevie-Jo. She is self-conscious about the scars on her body from the mycobacterium chelonae. A prime example is that the other day it was 24 degrees, and Stevie-Jo was out with jeans, a tee-shirt, and a jacket on; she won't wear anything that shows any of the scars

whatsoever. She won't go swimming, which she used to love. She doesn’t want to go abroad on holidays, because she won't wear shorts or tee-shirts due to the scars on her arms.

151. She hardly takes part in PE now, because she doesn’t like getting changed in front of people. She had loads of steroids because of the infections, so she put on six stone because of that. That has had a big impact on her self-image, and she's really struggling to get the weight off because of it being steroid weight. She's got issues with her knees related to the steroids and as well. Stevie-Jo has a lot to deal with.

EMOTIONAL IMPACT

On witness

152. The experience at the hospital has definitely had a big impact on our lives. I suffer from really bad anxiety and panic attacks, now. I have been seeing a psychologist. My triggers for my panics were on the motorway. Every time I got on the motorway driving to Glasgow, I'd have to stop about four or five times with panic attacks. My psychologist has said that’s related to the trauma of what’s happened at the hospital, and the thought of going back there.

153. Luckily, I've not been back for two years, so that’s not an issue now. But at the time, when we were going up for clinics, Steven would have to take the day off work just to come up with us because I couldn’t drive up the motorway. That wasn’t very good.

154. As a family, when Stevie-Jo had her first diagnosis and her first round of treatment at Yorkhill we were fine: but this time, we've really suffered given all the issues at the hospital. Stevie-Jo sees a psychologist regularly now. I have really bad anxiety. I suffered with panic attacks and PTSD this time round. I think it is because of the additional stress of everything that happened at the hospital. The impact on our family has been huge this second time round,

especially when compared to the first time that Stevie-Jo was diagnosed. The difference is because of the things that were going on at the hospital, it added to the stress and worry. Things like moving from the children's hospital to the adult hospital. Things like losing the parents rooms in ward 6A.

155. When your child's really ill, some days you're not out their bedroom for days. When they're on morphine, or ketamine, or they are really ill; you don't leave the room. When I was in that situation, sometimes it was nice just to go into the parents' room and just have five minutes. Have a cup of coffee; just take a step out and take a breather. But you couldn't do that up in ward 6A, because there was nowhere to go. Even if I was upset and I didn't want to sit in the room and be upset in front of Stevie-Jo, I could go to the parents room. But in Ward 6A all I could do was go out in a corridor, with everyone else walking past as well. It was really quite hard, there was no time or place just to gather myself.

156. The number of additional hospital visits added to my worry and anxiety too. I can't even count how many more hospital visits we've had. Stevie-Jo definitely had more hospital visits this time round, especially with all the infections that she had. I don't think there was a week that we weren't up there either two and three times a week, or alternatively we were having to stay long periods.

On Stevie-Jo

157. Stevie-Jo used to be a very bubbly child; she's got [redacted] as well, so she used to be constantly on the go. Now, she's very reserved. She takes quite a bit time to build up trust with people. She's quite shy. When she goes into new situation, she used to just go; for example she would just go to a football club and that would be her, she'd be away. But now she hangs back and stays with her dad until she can sort of get used to people. The experience has definitely impacted her confidence, and her trust of other people.

158. She's like that at school as well, when she finally got into school. Stevie-Jo hadn’t been to school from primary six to S3 simply because of all the time that she was in hospital. She didn’t have a teacher in all that time.

159. She should have had a teacher the whole time that she was in the hospital. The week that we were getting out of the hospital, the teacher came to visit Stevie-Jo, and he said, oh I'm here to give Stevie-Jo some education, and I said, oh we’re actually going home today. And he said, oh well, I need to inform you that Stevie Jo has been in for seven days, so it's the law that Stevie Jo should have some education. And I said, well that’s funny, because we’ve been here for eight months, and we've never seen a teacher, so who do I phone to find out about this. And then we never seen him again from there. Stevie-Jo was due to start in S1 [redacted] when she relapsed but the school just left it. I think their thoughts were her getting better would have been the better option. The other kids in the ward had teachers coming in daily, but Stevie-Jo never had any teachers whatsoever.

160. There was bit of an issue when Stevie-Jo went into S3. We paid for private tuition for her for maths and English. We were getting a bit concerned about her education, so I had contacted the Education Department, who had no idea that Stevie-Jo had leukaemia. They were going to put supports in place but COVID hit and nothing actually happened with that. But she has just passed all her Nat 5 exams and got As and Bs, somehow.

161. Stevie-Jo [redacted]. She has seen a psychologist quite a lot, and it has really helped her. It has also helped that she's not been at the hospital for such a long time.

162. Stevie-Jo was petrified. Every time we had to go to the hospital, she was crying and she didn’t want to go. Before the experience in the RCH and QEUH, Stevie-Jo pretty much grew up in a hospital environment as she was in treatment from a young age; she used to love going up to the hospital, it was

like going up and visiting family when she went up. But after all this, every time we had to go, she was crying and petrified of what she was going to catch in that building.

OTHER IMPACTS

163. I estimate that it costs us around £18,000 in fuel and other costs to travel. Through it all, the hospital didn't understand that we don't just live five minutes round the corner. The staff wanted us up at the hospital three and four days a week for check-ups, or appointments. Me and Steven took time off work. I don't think that there was any understanding from the hospital. We were trying to live up in Glasgow and run our house in [redacted].

PREVENTATIVE MEDICATION

164. Stevie-Jo was on preventative medication called posaconozol. It was an anti-fungal antibiotic. We were told that was part of the treatment, but obviously we knew it wasn't part of the treatment as she was not on it at Yorkhill. It was something that was introduced at the RHC. Steven and I spoke with Professor Gibson about it. We knew that it wasn't part of the treatment. Professor Gibson said Stevie-Jo was on it because of all the work that was going on around about the hospital. She said that she would rather prevent the kids from getting anything, rather than trying to fight something if they got it. She said they were giving it as a prevention rather than trying to then cure anything if they caught it from the works that was going on.

165. We have a really good relationship with Professor Gibson, we trust her with anything with Stevie-Jo. She's been Stevie-Jo's consultant for quite a few years. We've always taken the approach that what she needs, she needs, and you make that decision on that basis. But if she doesn't need it, obviously we would rather that she wasn't on some of the medication.

THE INDEPENDENT CASE NOTE REVIEW

166. Stevie-Jo was one of the patients that was included in the Case Note Review. The Case Note Review took a closer look at what happened with the circumstances of her mycobacterium chelonae infection. We have received a copy of Stevie-Jo’s individual report. We weren’t surprised with the outcome of the review into her case. The panel found that it was very highly probable that the mycobacterium infection that Stevie–Jo contracted came from the water supply in the operating theatre in the RHC. It concluded that the infection has had a severe impact on Stevie-Jo's life, and it is continuing to have a severe impact on her life.

167. We’ve had quite a lot of engagement with the Case Note Review through one of the parents, John Cuddihy. He's been really good and he has communicated between us and the review group. I think he goes to a lot of meetings. He simplifies and shares a lot of the information with the parents; it has been really helpful. It has been good having him do that, sometimes things can be a bit hard for us to understand in terms of the legal terms used. Personally I have not had a lot of contact with the Case Note Review directly.

168. In terms of the impact on my family, the process of going through the Case Note Review has been quite emotional. I have had to revisit what happened. As a family, we have gone through the treatment for seven years now; we tend just kind of get on with it. We don't usually get involved in things; we usually just get in, get the treatment done, and go home. But with this, I have had to a connect more with my feelings; I can't really just shut it out.

COMMUNICATION

Communication: water

169. We were told that the kids weren’t allowed to use the water. It was never really explained why. All of a sudden, the kids had to have bottled water and these were introduced to ward 2A. The kids weren’t allowed to brush their

teeth with the water, but they could have a shower – that was in the beginning – they were allowed a shower, but they couldn't brush their teeth, and they couldn't drink the water.

170. Staff said that they were having some issues with the water. They said cleaning stuff had been put down through the pipes, and they didn't want the kids drinking it in case it wasn't safe. I think the kids still drink bottled water on the wards. It was never explained why. We saw people coming into the rooms putting stuff down the sinks; it was constant. There was one point it was almost every day they were putting stuff down the sinks. For us the most serious thing was the water situation when Stevie-Jo was on another ward. Sometimes there were not enough beds within the Schiehallion Ward for the kids, or sometimes if your child had an infection they would go to another ward to protect the rest of the Schiehallion kids on the ward.

171. A couple of times Stevie-Jo ended up in Ward 3A or 3C in RHC. The staff weren't told that the Schiehallion kids weren't allowed the water. Each time we went into another ward, we had to tell the nurses that the kids in Schiehallion aren't allowed to drink the tap water. Nine times out of ten we'd have to go and buy Stevie-Jo bottled water, because the nurses never went and got water for her, or if they did they couldn't find any within the hospital. It was really concerning. Some of the families whose kids began treatment after the move to the adults' hospital might not have known that there were water issues in the children's hospital too. They might not have known what had happened in ward 2A RHC. They might have thought that it was just an issue confined to ward 6A. They might have thought that their kids could drink the water in the children's hospital; that they could face a risk. There was no communication between the wards in the hospital.

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

172. We were at home in [redacted] when the move happened. But the following day Stevie-Jo had to go up to clinic, which was in ward 2B or 2C in the RHC. When we arrived in ward 2 in the RHC, nobody was there apart from workmen. I asked the workmen where the ward was. The workmen told me that the ward had been moved up to the adults' hospital. We went back down to reception and asked where the Schiehallion unit had gone. Staff on reception told us the ward was moved to the adults' hospital, up in 6A. That is how we found out that they had moved. That day there were quite a lot of families who were going up to day-care, and didn't actually know the ward had moved.

173. I was really angry finding out in this way. The most concerning thing was that, if we needed to get to Schiehallion in a rush, we wouldn't have known where to go. When it is something like a temperature spike, or your child's not well, you need medical treatment quickly.

Communication: Cryptococcus event

174. Throughout my experience at the hospital communication has been awful, right through from the top to the bottom. It was particularly bad when the kids got moved out the children's hospital up to the adults' hospital in September 2018. I felt that everyone in the hospital just closed down; no one was being told anything. The nurses were in the dark a lot too. I remember when they started bringing in the HEPA filters, up to ward 6A. This was when there was the Cryptococcus outbreak on the ward but just before everything started kicking off in the media about that. I think it was around the end of December 2018 and the start of 2019. We didn't know what was going on in the ward.

175. The nurses were really concerned about the HEPA filters being put in the wards. When this was happening a couple of the nurses came into our room and asked us to go to the media. They told us that they had been told nothing by management, and they felt they could not go to the media because it would risk their jobs. They felt that there was something seriously not right in the

ward. During that whole week, the nurses were in and out of meetings with hospital management. A lot of the nurses were really upset during that time. That's when me and Steven started asking for meetings with the hospital.

176. Our family have been on the Schiehallion ward for around seven years; first in in Yorkhill and now in the new hospital. We've got quite good relationships with many of the nurses. A number of them came to our room to talk, and they were in tears. They said things like they knew that there's something serious going on, but they didn't know what. They felt terrible because they couldn't tell us. They felt like they were fighting against something but they didn't know what they were fighting against; it was a big concern to them and to us. A few of the staff were pregnant at the time, so they were concerned for themselves and their babies. All they knew was that there was an issue, and a couple of people had died on the ward in December 2018. It was really quite scary at that time.

177. The hospital said that if any parents wanted to arrange a meeting to address their worries, we could arrange a meeting with Professor Gibson and the microbiologist. I asked for a meeting. Stevie-Jo had just come out of PICU; Steven and I were really concerned. At that meeting I asked if Stevie-Jo was safe is she stayed in this hospital. I said that over the past couple of months she'd fought meningitis; she was just out of PICU; her immune system was not great. I asked if she was safe here?

178. I found out about the Cryptococcus event in ward 6A on the news. It was only when it hit the news that we knew that that's what the actual issue was within the hospital. No one from the hospital had said anything to us. When it had hit the news, I think that we were all sent a letter or we were told at clinic but I'm not a hundred per cent sure. We were told that Professor Gibson and the microbiologist would be holding meetings with any of the parents who wanted to speak with them, but only meetings of up to three families at a time. A meeting was held with our family and another two families. We met to discuss the Cryptococcus and what that meant for the kids. We never really got much from the meeting. We were told that the patients who had got the

Cryptococcus and died were already very ill, and their immune system was really low before they got the infection. During that meeting I said that Stevie-Jo's immune system was almost at zero and said that would suggest she might be at risk. I was told that she was not at risk, and although Stevie-Jo's immune system was at zero, the ones who had passed away from this were even lower than zero.

179. We felt like we got nothing at that meeting. During the meeting I asked about the infections. I pointed out that when I looked up the infections that all the kids were getting, they were from soil, water, and environment. I asked if there was any link between these issues and the infections? The microbiologist said, that she had questioned it herself but that she had got a separate answer for each infection and therefore she was not linking them together. I didn't really understand what that means, but it turns out that they are all from the water.

Communication - Meeting with Jeane Freeman: September 2019

180. I was involved in setting up the meeting between Jeane Freeman, the Cabinet Secretary for Health, and the patients and families of the Schiehallion ward. I started realising that things weren't right in the hospital. I'd emailed Jeane Freeman in 2019, and explained the whole situation about Stevie-Jo. I told her about the infection and set out the concerns that I had with the hospital. I asked her to clarify why the hospital was opened earlier than planned, and whether they opened the hospital too soon. I asked why someone was willing to take a risk with these children's lives and I asked her who had signed everything off. I was quite angry, so it wasn't a very nice letter that I wrote. Someone must have signed off the building without doing the proper checks; you don't just put sick kids into a hospital without there being loads of checks done. In my view, someone must be held liable, there must be someone who said that this hospital was okay for these kids to go into. Clearly they hadn't done the proper checks of the building.

181. I then spoke with another couple of the parents in the ward, and told them that I'd emailed Jeane Freeman. Following that a few of the other parents had emailed her as well. She must have received quite a few emails from parents. All I got was a letter back from her, the letter pretty much said the same thing for everyone: that she was really sorry, and she was going to do what she could to find out what happened, and try and find out the answers. Pretty much the usual response from politicians. However I think because the parents kept pushing her by correspondence she decided that she was going to have a meeting with us, rather than everyone messaging her at different times. I think she thought it would be easier having a meeting with whatever parents wanted to go.

182. The meeting took place at a hotel in Glasgow Central in around September 2019. The head nurse for Scotland was there too. Around 8 or 9 families attended that meeting. When she started hearing the stories of different families she seemed shocked. I don't know whether she was or not, but she said she was shocked. She genuinely seemed like she didn’t know half of the concerns that were raised during this meeting. She said that what had happened at the hospital wasn’t acceptable, and that she was truly sorry for the pain, and the heartache, and the trauma that it had caused to the families. During that meeting we explained that “sorry” is not really going to cut it. Something needs to happen; someone needs to look into this properly and find out what’s happened; what’s gone wrong. This was so things could be fixed for further families who attended that hospital; because there are still families who will need to access treatment at that hospital. If they are starting treatment, their kids were going to be really vulnerable at certain stages in their treatment.

183. As a result of that meeting, we did not get any answers to our questions. I felt that she was there because she had to be there. I didn’t feel like she was really listening. It was not very helpful. She couldn’t answer anything that we asked her and I don't think she'd done much research prior to the meeting. I think it was a quick option she tried to use to make the peace. My general

observations from that meeting were that it wasn't her fault and she didn't have any answers to give us.

184. At the end of the meeting she said that she was going to look into it further. Once the media started getting involved it put pressure on. Our family had quite a lot of media coverage. It think it was from a journalist at the Sunday Mail. The journalist had messaged me to see if she could come down and speak with myself and Stevie-Jo about our experience. She had been given documents which had been leaked, someone had left them on her desk. She said, "*look, I know that sometimes in the media things can get spiralled out of control, and your story is not told the way that it should be, but I'll bring down the papers that I've been given, left on my desk, and I'll show you them, and then we can take it from there. If you don't want anything published, then that's absolutely fine*".

185. The journalist came down to [redacted] and we met with her at our home. She showed us the papers she had which showed that things had been missed, way before the hospital was opened. They had tested the ventilation, and they knew it wasn't fit for purpose within the hospital. There were issues with the water before they opened it, and there had been lab test results that had went missing as well. It seemed that they couldn't get the test results either. The hospital's microbiologist was really concerned about the levels on the water, and she had asked a few times for to get reports on it, but they kept saying that they didn't have the reports.

186. From there the journalist did a piece on us in the Sunday Mail. Not long after that Jeane Freeman announced a public inquiry. I think that she knew a public inquiry was the only way to get the answers. Jeane Freeman said it was for the parents to get the answers that they needed, but to be honest, she didn't have any other option.

187. I think that the media coverage has really helped raise the profile of what was happening at the hospital. At the point that we went to the media things

started spiralling. That was when more parents started questioning what was happening at the hospital. In the new hospital, the parents weren't socialising with each other like they used to in the old Yorkhill. Nobody was really talking to each other due to the way the ward was set up, and following the move to ward 6A this got worse. Whilst my child had this infection, none of the other parents really knew about it. Once the media started to publicise the issues with the buildings, and the fact that kids were getting infections parents began to ask questions. At that point we were using the Facebook group that was set up and run by parents of Schiehallion patients. I was a member and still am a member of that group. Things started spiralling from there, people were talking and were realising their child had the same infection as another child on the ward. Others began to question why their child had X amount of line infections. For the first time, I think the media actually really helped us as parents. People began talking, sharing and realising that our kids were getting the same infections.

COMMUNICATION: GENERAL

188. Communication was awful. Even now, especially from up the hierarchy in the hospital. We always said that we felt really sorry for the doctors and the nurses, because you could tell that they weren't allowed to tell us what was going on. I think they were really held over by concern for their jobs.

189. I was a member of the closed Facebook group which was run by NHS GGC, but only when it was first set up. I am no longer a member of the Facebook group. I didn't really see the significance of it. The board said that it was to keep families up to date with what was going on before it hit the media, but things were still going in the media before the families found out. I left the group as I didn't really see the point of it. NHS GGC didn't like the Facebook group that had been set up by parents for the parents, this was because they had no control over what was being said there and they didn't know what was being said or discussed. I think they were trying to move it onto a group that could be monitored by staff and by NHS; but that wasn't going to work.

190. I did have some engagement with Professor White at the Scottish Government. I think Professor White was just an intermediary between the NHS and the parents. A couple of times I emailed him to ask if the listeria meningitis that we were told Stevie-Jo had on December 2018 was ever proven to have come from the water. The reason I asked that question was because Stevie-Jo was drinking loads of water out of the water cooler in the ward and then she began to get the bad headaches. I've asked a few times if I could get the water sample test from that period of time. We emailed back and forth, four or five times, and I was sent some water samples but they were just regular ones that had just been done, some standard water samples that had been taken at the time, nothing that showed if the water had been tested for listeria meningitis. It was not what I was looking for. I wanted samples from a specific period of time when Stevie-Jo was in Ward 2A, but they were never received.

191. For me, one of the things that really annoyed was when the head of the board at the NHS was on the news recently. It was when the Oversight Board Report and the Case Note Review report were published and they had found that there were faults. The microbiologist, whose name I cannot recall had said, “sorry”, and that was it, just that she was sorry. But she has blatantly lied and covered up, all the way through. She is happily sitting in her job putting these kids at risk, without actually doing anything, about it. Then she just said, “sorry”.

192. I am aware of the Oversight Board and the Report that was produced, but I did not have any contact with the Oversight Board.

CONCLUDING REMARKS

193. I do not want Stevie-Jo being treated in that hospital, whatsoever. Prior to the experience in the RHC and the QEUH, we had never had concerns before.

Our medical team is still amazing, but we certainly wouldn’t want Stevie-Jo being in that hospital again. We've asked that if is it possible for Stevie-Jo just to go to DGRI for anything that she needs, rather than going to the hospital in Glasgow. I don’t feel safe in the hospital, and I know for a fact that Stevie-Jo certainly doesn’t feel safe. It is not just the infections, I don't even feel the actual building is safe. I don’t feel that the structure of the building is safe. Taking that together with the infections, the water, and the actions of the Health Board; I actually don't feel safe. I don’t feel that the Health Board has got the kids’ best interests, or their care is at the centre of it.

194. In terms of the Health Board, I am angry and disgusted that they’ve actually just covered up so much. They knew what the situation was at the hospital, and they did not tell parents how much risk the kids were exposed to. I feel like they're still just trying to cover up and save themselves.

195. The only way that my concerns about safety can be addressed is if they knock the building down and start again, somewhere else. We've been down the line of trying to get the Health Board to be honest, of trying to get them to build up the trust with the patients and the families, but it's not happened. I can't see that happening any time in the future, either.

196. Communication from the Health Board and the hospital has not improved. They said that they were going to be more transparent, and be honest with families. They said families would find out anything before it went through the press. But it's been going through the press before families are finding out. We feel they're only telling us what they think we’re going to find out from the press. I know a few other parents feel that way too. It's not that they're being transparent and being open with us. Rather, they only tell us what they think we’re going to find out anyway.

197. Personally, I don’t think there is anything that the Health Board can do to gain my trust. Maybe for people using the hospital in the future, they might be able to build up a bit of trust by being more transparent. They actually need to be

open, and not just tell them the basics that they feel they can get away with telling them.

198. Even now when we were finding out things about the hospital in the media, it made me so angry with the Health Board. Sometimes I think, “right, that’s fine, we’re here, we’re at the public inquiry, things will start improving” and then there is something else about the hospital in the media and it's just straight back to square one with them. I feel like I’m constantly fighting a losing battle with them.

199. I believe that the facts stated in this witness statement are true, and 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

Stevie-Jo Kirkpatrick

WITNESS DETAILS

1. My name is Stevie-Jo Kirkpatrick. I was born on [redacted]. I am 17 years old.

2. I am a pupil at [redacted], [redacted], [redacted] and have recently started S5.

3. I live with my parents, Steven and Annemarie Kirkpatrick in [redacted] , [redacted].

OVERVIEW

4. I was diagnosed with Acute Lymphoblastic Leukaemia (ALL) in 2014 when I was 9 years old. I was originally treated in the old Yorkhill hospital in Glasgow until it transferred over to the new Queen Elizabeth University Hospital (QEUH), where I was treated as an-outpatient until 2015. I relapsed in 2017 and I was treated in the Royal Hospital for Children (RHC) and the QEUH between July 2017 and March 2019 when I finished my treatment. I still attend at the QEUH for check-ups.

5. I was treated in ward 2A at the RHC, which is the Schiehallion Unit. It treats children with cancer. I also spent time in ward 3A at the children's hospital. After the Schiehallion Unit closed in 2018 I was treated in ward 6A in the adult hospital; this was where the Schiehallion ward was moved to. I was treated there as an in-patient and an out-patient. Both my mum and dad stayed with me in hospital when I was there but it was mostly my mum as my dad was working. We also stayed at CLIC Sargent house too.

6. There are some specific events that I would like to mention. I contracted a line infection in late 2017 when I was an inpatient in ward 2A. I also contracted listeria meningitis in December 2018. I contracted another line infection in February 2019, not long after being discharged as an in-patient from ward 6A. I contracted a mycobacterium chelonae infection in March 2019 after surgery to remove my line in February 2019, at the RHC. There were issues with the water supply throughout my time at both hospitals. There were ongoing construction works at the hospital throughout my time there which, in my view, impacted my experience. I will talk about these events in more detail.

FAMILY BACKGROUND

7. I live with my parents, Steven and Annemarie Kirkpatrick near [redacted].

8. I am a pupil at [redacted], [redacted] , [redacted]. I have recently finished my S4 exams and have moved up to S5. One of my hobbies is football. I support Celtic and I also play for [redacted]. I play the bass guitar. I taught myself because I can't get lessons in [redacted]. I like listening to music, I like 80s, 90s and more modern music, a real proper mix.

9. When we do things together as a family we'll go to football matches or the cinema. My dad plays golf so we do things together whenever that is not taking up too much time!

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

Initial diagnosis and treatment: Yorkhill and transfer to RHC: 2014 – 2017

10. I was diagnosed with ALL (Acute Lymphoblastic Leukaemia) in 2014 when I was 9 years old. I was treated at Yorkhill Hospital in Glasgow up to 2015 and

then I moved over to the new Royal Hospital for Children (RHC). I was an out-patient there for a couple of years at the RHC.

11. I attended at the clinic, down in the atrium, when I was there. The clinic is for the patients in the children's hospital and it's where you go when you're on maintenance which is when you get tablets and a monthly check-up from the Doctor. Day care is when you're still on IV chemo and things like that. The same Doctors that work in the clinic and day care in ward 2B of the RHC. I went to clinic once a month. I went there to get my chemo tablets, a check over and get bloods done. I was in maintenance at that point.

12. The clinic had a really big waiting area. All the clinics are together so everybody is mixed in the waiting area and there could be three or four different clinics on at the same time, and the patients all sit next to each other. The clinics serve lots of different departments in the RHC, there was the heart one that was often there but I can't remember all of the other clinics. There were usually three or four Doctors from the Schiehallion clinic there. Pharmacy is down there as well.

13. There are two rooms for bloods but they cover two or three clinics. We would usually try and get there for 10am in the morning when it was quiet but you would still have to wait for three or four hours for the bloods coming back. A lot of the time the bloods in the samples were clotted because you were waiting that long for them to be tested. That was really quite annoying especially because of the amount of time we had to travel from [redacted] to get there. If the bloods were clotted, you would have to get them done again and then you'd have to wait another three hours on them coming back. The bloods would get sent through the chutes to the labs and a lot of the times the chutes would break down which would make it even worse and make the wait longer. Sometimes the staff had to draw 3 or 4 times due to bloods sitting for a long

time and clotting. For young kids who were scared of needles this was really bad.

Relapse and admission to ward 2A, RHC: July 2017

14. My blood had never recovered after the first time I had ALL. We always knew there was something there. In July 2017 I started getting really bad shooting pains up my legs and I was getting tonsillitis a lot. I was also tired quite a lot, which was usually one of the first signs; it was one of the first symptoms.

15. On the 3 July 2017 I went up to Dumfries hospital for a routine check. Nothing was showing up on my routine blood checks. My Doctor, Jean McKnight, took my bloods and she made sure the film of the bloods was checked as well. A film is a deeper look at the bloods. Because she did that, that’s how we found out I had relapsed.

16. I was transferred by ambulance to the Royal Hospital for Children in Glasgow. I got admitted to ward 2A at the Schiehallion Unit. Professor Gibson was my consultant, when we arrived she took my mum and dad away to discuss my treatment plan. The doctors started my chemotherapy treatment straight away to see if they could get me into remission. It was intense chemotherapy treatment. If they couldn’t get me into remission, then I would need a bone marrow transplant. After my first round of chemo I did go into remission so that was fine. I remained an in-patient in ward 2A for about 6 to 8 months and I received chemotherapy treatment during that time.

17. I got the treatment through IV which went in through a central line into the right side of my chest. I had to get surgery under general anaesthetic to get that fitted. The central line is used to take bloods and give chemo and medicines through it too. There are two separate lines, one is white which is

for chemo and the other is a red one for getting bloods put in and taken out. The medicines can be antibiotics, platelets and bloods. The line has a dressing over it. I have always been really bad with cannulas with my veins, and I was going to need too many treatments, so I needed a central line.

Experience on ward 2A of the RHC: July 2017 – December 2017

18. The first thing I noticed about ward 2A was that it only had a single door whereas the old Yorkhill had double doors to ensure the air on the ward was purified. After you went in to ward 2A, the ward was in a curve so you couldn’t see what was coming which I found quite weird. There was quite a small playroom for the little ones but everybody was in their rooms. There were not a lot of patient rooms; less than Yorkhill. The nurse’s station was right in the middle of the ward. In the old Yorkhill all the kids were out of their rooms, up and down the corridors or in the playroom, or in and out of each other’s rooms.

19. Being ‘in source’ is when patients are kept in their rooms for infection control purposes. At Yorkhill the only time you were in source was when you had a cold. In the new hospital you were never out of source because you were always getting infections.

20. I was in the TCT (Teenage Cancer Trust) unit on ward 2A and it is funded by the Teenage Cancer Trust. I think I was in room 3 which is a TCT bedroom. There are about five rooms in the unit. It’s a separate unit away from the younger ones and it’s just for teenagers. In my room there was a bed and there was a small TV above the bed that never worked. There was a three-drawer unit, a fold down bed for my mum or dad to stay and some of the rooms had a big wardrobe. There was also the bathroom which had a shower, sink and plastic drawers, which were brought in later. I stayed in that room for

the first year I was there. My mum or dad could stay over with me and use the pull out bed.

21. The unit has a common room which is like an adult version of a playroom. It's got a pool table, a TV, X-boxes, a full Sky package, and quite a good mini kitchen. There are comfy couches and board games; it's a pure chill out area which can be used by teenagers and their parents.

22. The TCT coordinator, Ronan, got a few people in to do things with us. There was pyjama making, guitar lessons and he would come in and play board games and the X-box with us. There wasn't too much going on and I never had a teacher the whole time I was there. Some people did get a teacher but I didn't and it wasn't until I was getting ready to leave that he decided to come round. The teachers were all primary but I think there was a secondary teacher. I was in S1 at that point.

23. One day I was sitting in the unit and I was talking to the TCT coordinator. We were talking about the ventilation and how it felt different. He told me that it was only up to 30% standard for a normal person and 70% lower should be for what it was for us. It was really humid and stuffy in the unit. It didn't feel right or what it should be. You were warm anyway, you were spiking temperatures and the thermostat in the bedrooms didn't work; it was horrible. It was boiling in the patient rooms but at night it went freezing, it was either one or the other and there were no windows to open. If you were warm, you stripped down and if you were freezing you got all the covers. The old Yorkhill had a bit of a breeze and it was quite cold and different to what it was like in the rest of the hospital. In Yorkhill we had Dyson fans to keep cool, when I first arrived in Ward 2A we had Dyson fans. Then one day they took them away; they randomly disappeared and no one told us why. We were not allowed to use the fans and the rooms were too hot. It was not nice.

24. My first lot of treatment lasted six months. I had chemotherapy every day, the whole time I was there. Sometimes it was stopped when I got infections and I would then get antibiotics in place of the chemo, for however long it took for the infection to go away. The first sign of an infection was when I had a temperature, which was above 38 degrees, and then they tested it through my bloods and swabs. That’s when I would get started on antibiotics. I had infections a good few times during that admission but they could never find out what they were.

25. I was in isolation during my time in ward 2A. There was ‘isolation’ and there was ‘in source’. Isolation was when you weren’t allowed to leave your room and the nurses would bring everything to you and ‘in source’ was when you had a temperature or a cold or cough and you weren’t allowed out the room. You tended to be ‘in source’ if you had an infection. I was mostly in source rather than isolation but that was later on though. I wasn’t in isolation during my first admission but I think that it was in 2018 when I got the RSB virus that I was in isolation. I was more annoyed in source, I was really lonely and things play on your mind and there’s no escaping it when you’re in source.

26. The water coolers were like rectangular white boxes with a blue bottle on top. There was one in the parent’s room in ward 2A. I would use it a couple of times a day and I was drinking quite a lot of it. I would stand and chat to the nurses. There was one week in December 2017 when I drank a lot of it and by Thursday or Friday I had to go on oxygen because I couldn’t breathe properly. I had x-rays and it showed up a bit of cloudiness so I had to go to surgery for suction to get whatever it was, out. I stayed on oxygen for quite a while because it was really low, around 93 or 94 and sometimes when I was sleeping it was around 91 or 92. It never really recovered properly and they never understood how or why it was like that. My oxygen should be around

98; that was the lowest it should ever be sitting at. One or two months after that all the water coolers started disappearing from the hospital. The doctors were never able to work out what caused the cloudiness in my lungs.

27. There were never enough sockets and the nurses told them when they were putting them in that they needed at least eight. I was hooked up to at least six machines that were bleeping all the time and they never held charge so when I got up for the toilet I would switch all the plugs around. The machines were for chemo, bloods, platelets, morphine, ketamine and antibiotic fluids. If you were already ill and not sleeping then you had all the bleeping on top of that, it wasn't good. The bleeping came from the battery packs, it didn't matter how long they were on charge, they just didn't hold it. It wasn't very good if you were halfway through bloods or chemo and the battery runs out.

28. My mum and dad didn't really use the parent's kitchen much in the ward. It had a microwave, a kettle and a coffee machine too. It also had a fridge, a freezer and a table. It also had daylight from a window. We used the TCT room instead.

29. The TCT facilities in ward 2A were all internal, including all the bedrooms. My room, (room 3) was also internal. If you turned off the lights it didn't really make a difference because the lights never went off in the main atrium and the blinds were always broken. They were internal so you couldn't get in to the window to fix them. The cleaner would come around at 4 o'clock in the morning to clean the atrium, pulling all the chairs that were squeaking on the ground and then there was the cleaning machine screeching and squealing. They had the out-patient adult clinic down there as well so weekends were stressful with adults walking about the hospital and kids screaming. They had a 24 hour, out of hours thing, with drunk folk entering in the atrium. This was all near to my room window and because the atrium is so big it echoes, so

you're up all night basically. I was always wondering if I would manage to get a sleep.

Discharge from ward 2A, CLIC Sargent and day care, ward 2B: January 2018 – November 2018

30. I got out in approximately January 2018 and went to stay at CLIC Sargent for a few days a week. I had to keep going to day care in Ward 2B for chemo every day I started a treatment plan of 3 days inpatient chemotherapy treatment at the hospital and was allowed to go over to CLIC in between times. I was still in 2A officially and had to stay very near to the hospital.

31. Over time at the weekend I would get home to [redacted] and then back up on the Monday to go again. I think that lasted for a couple of months but a few times I ended up spiking a temperature so I ended up getting put in the ward.

32. CLIC Sargent is a two minute drive from the hospital grounds, it is two minutes around the corner. It's kind of classed like being a little bit of an out-patient. It's a little house and there's a couple of families that live in it. There's a kitchen, a living room and your whole family can stay there. It's got a drier, a washing machine and a wee garden. You can make proper meals and you can have it as long as you need. It's like a home from home and it's only Schiehallion patients that can use it and you can talk to other families. It's not like Ronald MacDonald house, because that is for the whole hospital and that's always busy. That is why CLIC was good, it has communal areas and we could talk to other families who had children who were Schiehallion patients. I could stay there with my mum and dad.

33. I went to day care for my IV but sometimes I spiked temperatures so I ended up getting put back into ward 2A as an in-patient. That happened three or four

times during that period. I also remember towards the end of that, I had a problem with my eyes and I had to get admitted to get eye drops every two hours, day and night. It was because of the chemo that I had problems with my eyes. We were still staying at CLIC Sargent then.

34. I was never told why I spiked temperatures but when I got them my chemo had to be stopped. Professor Gibson wouldn’t let me home to [redacted] because I had too many infections and a relapse so she wanted to keep a close eye on me. It’s an hour and half drive from the hospital to my home. She was just over-protective of me.

35. Maintenance treatment lasts for two years. It’s a treatment and is basically chemo but in tablet form. You also get vincristine through a cannula although I still had my line in. You get regular check overs from the Doctor and get your bloods checked as part of it. I got home kind of half way through maintenance treatment but not at the start of it because I was still in CLIC.

November 2018: PICU and admission to ward 3A in the RHC

36. In June 2018 I began the maintenance phase of treatment. I started getting really, really bad headaches and my eyes were flickering. The treatment can cause headaches but I told Professor Gibson and she told me to take some paracetamol and I would be fine.

37. This lasted up to November 2018 when I had been at home for a short time. I woke up the morning of 19 November 2018 and couldn’t lift my head off the pillow. I couldn’t handle the pain at all so we went straight up to Dumfries hospital. I stayed in overnight and in the morning it looked like I had a stroke. I couldn’t talk and I couldn’t swallow.

38. My Doctor at Dumfries hospital gave me a CT scan and I got taken straight up to Glasgow. That night I went into PICU in the RHC and spent two days there. I had loads of steroids pumped into me. I then spent three or four weeks in the neuro ward which is 3A. They were trying to figure out what was wrong. I started picking up after they put me on a high dose of steroids which reduced inflammation in my body. During this time they did a lumbar puncture, which is a surgical procedure where they drained fluid from the spine. I started receiving high dose chemotherapy and was released home again around the start of December 2018.

39. I was mainly under the care of the neuro Doctors and it was only once a day one of the Schiehallion Doctors would come up to see me on Ward 3A . My maintenance treatment stopped while I was in 3A. My mum thought that I had leukaemia in my brain. One of the doctors thought it might be a neural disease. The steroids made my headaches mild, my eyes were still squint and I couldn't speak properly. My balance was off and it never really went back to normal. Some of my face is still numb and I've still got scarring on my brain. Sometimes I can't see too many people, my sight is a bit blurry. My mouth is squint, I still can't chew on the left side of my mouth.

December 2018 – January 2019: PICU and the move to ward 6A QEUH

40. I got let out in the middle of December 2018 and I came home but a couple of days later we went back to Glasgow because I had really bad headaches again. My mum and dad took me up in the car. We went to day care which was now in ward 6A in the adult's hospital, and one of the neuro Doctors and Professor Gibson came to see me. They had a look at me and said that it was fine because they had been reducing my steroids. We went back home to [redacted] . My chemotherapy was still stopped during this time.

41. On Christmas Eve the same happened again. I couldn't lift my head off the pillow; it was even worse than before. We went back up to Dumfries hospital where I saw Doctor McKnight and they did a CT scan. I went straight back up to Glasgow by ambulance again and was admitted to ward 6A in the QEUH.

42. I can't really remember much about the night of that admission. I remember watching TV that night I was admitted but that's about it. A couple of days later I was in PICU, ward 1B.

43. It's quite hard to get to PICU from ward 6A. When I was going down, I had the crash team with me. It's a team that has resus, a defibrillator, oxygen, medicines and adrenalin, that kind of thing. It's a lot of kit, it's huge backpack. The medical staff had their staff cards for the lifts but some of the lifts were broken down or full of people so they had to put me in the public lifts and take me the long way round the whole of the adult hospital to the children's side. I then had to go all the way round the children's side to get to the ward. It could take 15 minutes to get through it all. If I had been in the children's hospital, it would have been nearer, down one floor, instead of down six and up one floor. The staff had to make a plan of what to do and where to go if I crashed during the journey to PICU from ward 6A.

44. The resus teams for kids and PICU for kids is on the children's side of the hospital. So if I crashed and needed my resus team, they had to run from the children's side of the hospital. When they got the adults hospital they had to run up flights of stairs to get to the 6th floor where we now were. It is not suitable to provide care like this when the children are in the adult side of the hospital. That's where the problem came in for the resus team, if there was an emergency in 6A, it would take them too long to get there and then to try and resuscitate somebody. They were always saying that, with all their equipment

to carry that it was dangerous. It was tiring, and they probably wouldn’t have been able to resuscitate a child once they got to ward 6A. Only the resus team for kids can resuscitate kids; adult resus teams cannot resuscitate children. It is just too different.

45. At that point they didn’t know what was wrong with me. It wasn’t until 27 December 2018 that they could actually figure out what was wrong. The first thing Professor Gibson said was not to give me any steroids whatsoever because that would mask whatever I had. My maintenance chemo treatment was still on hold at this point. When I was in PICU they took a lumbar puncture and Professor Gibson ran it to the labs herself. When it came back my mum and dad were told that I had listeria meningitis. I got treated with IV antibiotics for eight weeks. I had a cannula in because I had my line removed half way through my maintenance treatment, which was more surgery in late summer 2018. Because the antibiotic treatment took so long and my veins were so bad from my previous treatment, they put another central line back in, at the start of January 2019. That was also surgery under general anaesthetic and I was in ward 6A.

46. Connor Docherty is an infection disease Doctor. I started to see him the second time I went to PICU which was in December 2018. It was Professor Gibson and Connor Docherty who were not too sure what it was and they thought I got the meningitis through something I had eaten.

Experience of ward 6A

47. I stayed in 6A until the end of January 2019. That’s when they started bringing in the HEPA filters and all the Cryptococcus happened with the pigeons and the ventilation. The microbiologist and the Professor were also coming around at 9 o’clock at night to the patient bedrooms to check the drains in the shower.

48. The Schiehallion team from both wards 2A and 2B are on ward 6A in the adult hospital. Ward 6A is in two parts. You go through two doors and there are five or six rooms on the left hand side. The nurse's station is on the right hand side at the corner, it was like a triangle. There were another seven rooms and then you go through a door to day care. You had to walk through 6A where all the in-patients were, to get to day care; it was quite a long ward. The transplant patients were not in the ward though, they were in ward 4 in the QEUH. That was the children who were getting bone marrow and stem cell transplants.

49. I was in room 5 when I was in 6A. It's in front of the nurse's station, at the corner. The room had a bed, a unit and a bathroom but I don't think it had a window. It was really basic, a lot more so than the rooms in the children's hospital. There was a fold down bed for my mum or dad to sleep on. There was no kitchen for parents; they had one but it was only for staff. You weren't allowed to use it all, if you wanted a cup of tea or coffee, you had to get one of the nurses to make it. You didn't have a fridge and the only place you could heat up food was in the adult's atrium, in the communal microwave, but you couldn't use it until after 3 o'clock because it was for the staff for their breakfasts and lunches. Whilst we could use the microwave in the Atrium, staff and members of the public passed through that area and used it. It was not good for an infection prevention point so we didn't use it.

50. In general the food was not nice in the hospital. They had stuff that I liked but it was cold. When I had meningitis, I was on a soft diet, and it was actually better than the solid diet. I was given burnt soup at one point though. The canteen food was not good, and it was such a shame as the Yorkhill food was good. We got food at Marks and Spencer and it was expensive. Lidl is across the road but it is difficult to get out to the shops.

51. The ward didn’t have a playroom or a TCT (Teenage Cancer Trust) facilities. The only room it had was a meeting room for teenagers to play a game or something like that but sometimes you couldn’t use it for a couple of hours. All the younger children had was a table and two chairs, in the middle of the ward corridor outside one of the rooms. That was literally their play area.

Emotional effects of move to ward 6A QEUH

52. It was a depressing and lonely experience in ward 6A. I found that with all the teenagers, they were all on anti-depressants and they didn’t even want to leave their room. One of my friends was anxious, it was really bad. The TCT staff could come to your room if you weren’t in source, but it was very limited. Before moving to 6A I knew all the other teenagers but when I was on ward 6A I never knew any of the other ones that were in at the exact same time as me. I ended up seeing a psychologist later on in [redacted].

53. When we moved to Ward 6A, we had nothing. We lost our community. We were isolated because we had nowhere to go meet each other, and that was a hard thing. We didn’t have a place where we could just meet and talk about stuff: where somebody else is going through something and they tell you, and you’ve went through it and you can talk with them. Even if all you want to do is talk about something completely irrelevant, and try and take your mind off it. Or if somebody is upset, there wasn’t any place where we could do that, where we could meet and speak to each other. It was hard, especially if you're just starting treatment. I'd already been through that but if you're just starting treatment it can be a really daunting time anyway, and then adding that on top: it's just hard.

Ward 6A QEUH and Dumfries Hospital: Late January 2019 to March 2019

54. In January 2019 I was made aware of the Cryptococcus in the ward and the possible ventilation issues by one of the nurses. I would rather not say what the nurse's name was. We already knew there were things going on around the hospital anyway and we were being told quite a lot of things from the nurse. We were talking to the nurse about HEPA filters that had been brought into ward 6A. We asked what they were for and she said it was for the Cryptococcus that came from the pigeons and the ventilation in the hospital. It was in the main ventilation for the whole hospital.

55. At that time it started coming out on the news and infection control were in and investigating what was going on in the hospital. Anytime my mum tried to find out what was going on from hospital management they, just didn't tell her anything.

56. In January 2019 I went to a meeting with my mum, Professor Gibson and the microbiologist whose name I cannot recall. This meeting took place in a room in ward 6A. There were also two other patients and their parents. The meeting was a chance for us to ask questions, but every question we asked the microbiologist, she just averted away from answering it. We were asking if it was safe for me, and she said "yeah, it's fine". We asked if the building was safe, if the patients were safe. The microbiologist never really had an answer, to be honest. The microbiologist came down to clinic to have these meetings, and everybody that wanted to talk to her went and spoke to her. The meeting came about because everybody was up in arms about what was happening throughout the hospital. The Cryptococcus in ward 6A was in the news at the time, and the news reported that two patients had died from it.

57. At the end of January 2019 my mum and dad had a meeting with the microbiologist and Professor Gibson and my mum asked if I was safe in the hospital and they said “yes”. I wasn’t at that meeting. My mum was also told that there was mould in the showers by Professor Gibson and the microbiologist. I don’t know the name of the microbiologist but it was a female.

58. After that meeting, the next day Professor Gibson came to my room and said she was driving home that previous night after that meeting, and she was thinking of how she could keep me safe. She said the best way to keep me safe from all the infections in the hospital was to transfer me down to Dumfries hospital. I wasn’t surprised to hear that to be honest, and I was relieved. My mum was with me when she told me that. We packed up my things and my mum drove me down to Dumfries hospital that day. The reason I was moved to Dumfries was to take me away from the QEUH and the issues there.

59. At the end of January 2019 I was transferred down to the hospital in Dumfries and was there for five or six weeks until the end of February 2019. I was fine. I was still getting my antibiotics and my chemo was on hold. I felt safe in hospital because I knew I wouldn’t catch any weird infections in there and that their water was clean. They had good ventilation as well because they’ve got a special isolation room for me with proper double doors and purified air. It had a door, a sink then doors again. You could feel the difference; it was very cool, their windows open and you can see outside.

60. The skin around my line had already begun to go red before I'd left ward 6A in January 2019, but we never really thought anything of it at the time. It wasn’t until I was in Dumfries for a couple of weeks and the line started to come out, this was about mid-February 2019. I went back up to Glasgow and was admitted to ward 6A in the QEUH. I saw one of the general doctors on the ward and the decision was taken to remove my line, he just looked at the line

and didn’t do any other tests. The next day I was down in surgery in the first floor in RHC for a line removal. I had a general anaesthetic and the line was removed and scar stitched up.

61. As I didn’t have a central line I continued to get my course of antibiotics by cannula. I was in Ward 6A for about a week until the scar scabbed over and then I was transferred back down to Dumfries. I finished my course of antibiotics at Dumfries hospital and when I finished the course I was able to home around about the beginning of March 2019.

62. Around about this time which was the end of February 2019/start of March 2019 I was starting to get a red lump on my right arm, at the top of my forearm. I didn’t think too much about it at the time.

63. After I was discharged, I was back to school for a bit. In March 2019 not long after I was discharged from Dumfries, I went up for a routine check-up at Hospital. Where my stitches were, it looked like something was happening. It looked like one of my stitches were still left there and the area turned red again. I had a little pocket of pus where my line had been removed; the area was really sore.

64. I was sent immediately back up to the Glasgow hospital again and was sent straight to day-care in ward 6A. One of the nurses took out a bit of stitch and the whole area just blew up into like a big ball; it was just like a huge ball of pus. I was then admitted as an in-patient to the cardiology ward in RHC as there were no beds in ward 6A. The area of pus just kept getting bigger and bigger.

65. I stayed overnight and then the next day I went to surgery to get the area cut out. It was a surgery under general anaesthetic and the surgeon removed an

area about the size of a 50 pence piece. I was in hospital for a couple of days. I was then transferred back to Dumfries Hospital for a while, because the area had to be packed every day. I was in Dumfries hospital until the surgery scar healed a bit more and then I went home.

66. After I was discharged from hospital I gradually got more lumps on my arms, my legs and chest. The lumps were sore. They would burst and bleed, there was pus coming from them. It was sore to touch. I ended up with ten altogether and they appeared gradually over one to two months.

67. The lumps were at the worst about two to three months after they began to appear. It took about six months for the lumps to actually stop bursting. Only then did they finally start to heal a bit.

68. I had a routine clinic appointment in March 2019 at Ward 6A in QEUH. At the appointment I showed Professor Gibson the lumps on my body. She sent me straight over to the old Yorkhill hospital for a biopsy on them. At Yorkhill hospital they took a biopsy from a big lump on my arm. The lumps were bad at this point. They were bursting and bleeding all the time.

69. I was given a dressing for the bleeding but it just made it worse. I went back home to [redacted] after the biopsy and nothing really happened for a while.

70. A couple of weeks after I had the biopsy, Professor Gibson phoned to say that they biopsy results were back and it that it was TB. She asked us to go back up to Glasgow. Me and my mum went back up to Ward 6A and met with Professor Gibson and Conor Doherty. They explained that my immune system was so low, and they said that I had to come off chemo to let my body recover. They told me that I couldn’t have an IV antibiotic, the side-effects were so severe that they didn’t want to put me through that on top of

everything else. At that point the doctors decided to stop my chemo for now, and hope that my body can fight the infection itself. They didn't tell me how I might have contracted TB. We went home and we thought that was it about the infection.

March 2019 – June 2019: Confirmation of Mycobacterium Chelonae infection and impact on treatment

71. A short while later we got another call from Professor Gibson. She asked to speak to the family. On the 29 March 2019 we all attended a meeting with Professor Gibson and the microbiologist whose name I cannot recall, in Glasgow. The microbiologist confirmed that the infection that I had was actually mycobacterium chelonae. It is related to TB but is not TB. She told us that she had traced it back to the water in surgery when I had my line removed in February 2019. She apologised and said she was sorry. I had caught the infection in the hospital. We went back home to [redacted] after the meeting.

72. Around June 2019 I was going for a bone marrow and lumbar puncture to Ward 6A. One of the main Schiehallion consultants called Annamaria came and spoke to me and mum. She told us that the doctors had decided to completely stop my cancer treatment altogether. At that meeting she told me, her and Professor Gibson and doctors from all over the world had discussed my infection. They agreed that the best option would just to be to stop my chemo altogether, so I finished treatment six months early. They said this was to try and keep the mycobacterium chelonae infection gone by allowing my immune system to recover.

73. The doctors were worried that I was getting so many rare infections, and they didn't know what they were or how to treat them. They were worried that one

day I might get an infection that they might not be able to treat and that would reduce my cancer treatment options. Whereas, if I were to relapse again now, I've still got bone marrow, stem cell, and CAR-T therapy: I still have options open for cancer treatment should it be needed. It was a safer option just to stop my chemo for the time being and let my body recover.

74. After this I began to see a psychologist in [redacted] to help me given my experience at the hospital.

WATER: EVENTS INVOLVING WATER

Water incidents in RHC and QEUH: 2017 to 2019

75. For the first couple of months in ward 2A there was never anything said about the water. That was in 2017. I was drinking from the water cooler but not the taps. I was taking showers and brushing my teeth with tap water. After that first two months they came round and said that we weren't allowed to use the showers because there was a problem with something in them and they had to put filters on the taps in the shower. A lot of people didn't have a shower for about seven weeks and we were given some sort of foam spray to clean ourselves with. There was nothing we could really do, it is not like we could go home or go to CLIC and get washed. I was lying on a hot bed, the mattresses are covered in blue plastic and I couldn't wash unless I used bottled water. I think it was the nurses who told us not to use the tap water. After that it all went back to normal and then it happened again around August/September 2017.

76. Around November 2017 they were coming round and putting bleach or something down the sink at night so you weren't allowed to use the sink or the

toilet for a couple of hours. That was never explained; what they were doing or why.

77. They brought in portaloos for the Doctors and nurses and put them outside the hospital so if they needed the toilet they'd have to go all the way outside because the water was turned off. They were there for a couple of days. I remember the nurses saying they would go in a group because in the middle of the night in Govan, it wasn't exactly safe. It was obviously taking a lot of nurses out of the ward which was bad if an emergency happened in the ward.

78. Around about that time they brought in bottled water and we used it since then; it was constant. I still use my own bottled water and bottled water is still used in the ward now. Around this time I noticed they put filters on the taps and showers.

79. Being on chemo I had to keep my fluids up. I mentioned that I drank a lot of water from the water cooler. Not being able to drink the water in the ward, we had to buy bottled. Families had to find time to go to the shops. If I was ok and feeling up to it, I could go if I was allowed out and if I was not in isolation. If not it was my mum who would have to find the time to go down to the shops in the atrium for it. If we ran out someone had to go get it.

80. In 6A there were the same issues with 2A, with the showers and the water. You weren't allowed to use the water in 6A either. I think they still drink bottled water now. You were only allowed to use bottled water to drink, and I used it to brush my teeth. I did go for a shower in ward 6A because my mum asked if it was safe to go for a shower and the staff on the ward said it was.

Zone 12 flooding: 2019

81. In 2019 I was up in ward 3A, the neuro ward, between the teenagers and the kids bit. I was in zone 12. It was like TCT (Teenage Cancer Trust) but for younger people. I remember the tiles from the ceiling fell in overnight and all the water flooded the room.

HEALTHCARE ASSOCIATED INFECTIONS

HAIs: events and physical impact

82. At the end of 2017 it was all happening with the water and everyone was getting line infections. Infection control said it was the nurses fault and that they weren’t using the central lines right, which was a complete lie because they did it the exact same way as they always had. They introduced the green caps to keep the lines clean. Every time it got taken off to get whatever done, they would give it a clean and put it back on, and it had to stay on the whole time. Nobody had ever seen them before, they didn’t have them in the old Yorkhill and Dumfries (hospital) had never seen them before, so that was quite a weird thing. I had a green cap on my central line from the end of 2017 and it stayed on for the rest of the time I had a central line. They didn’t help as everyone kept getting infections anyway.

83. In the old Yorkhill I barely ever changed my dressing. I would leave my dressing on my central line for about a month until I went back up to Glasgow and got it changed because they could give it a proper clean and I never got a line infection from it. It was when I went to the RHC and got my line put in, every couple of days they wanted to change the dressing. The green caps got changed every time the line got touched, and then the green cap was disposed of. I think they cost quite a lot of money. I got told by the nurses that

the reason for the green caps was because there was so many line infections. I had never had a line infection until I was in with Meningitis.

84. When I contracted the mycobacterium chelonae infection it gave me lumps on my arms, legs and body. These burst and have left me with scars. As I mentioned the lumps were at the worst about two to three months after they began to appear. They were sore, they burst and bled constantly. It took about six months for the lumps to actually stop bursting. Only then did they finally start to heal a bit. I cover up my arms and legs now.

85. I did see a few doctors about the scars on my arms and legs, but even with all the doctors opinions about what to do, nothing was really happening. It was just a case of waiting, and letting my body heal itself.

HAIs: Emotional Impact

86. For half a year I was going between Glasgow and Dumfries constantly, with infections and I think they were related to either water or soil. Some we know about, others we don’t know the causes. We didn’t always know what the infections were. It got to the stage that I didn’t want to go up to the hospital in Glasgow: I was having anxiety and panic attacks as I didn’t want to go up.

87. I felt annoyed that I was getting infections and they were getting harder and harder to treat. When I was told that my treatment was stopping early because of the mycobacterium chelonae, I felt worried and anxious about that. I caught an infection so rare that I cannot get my cancer treatment.

88. When my mum was at one of the meeting with the microbiologist, she asked if I was at risk in the hospital. The response from the microbiologist was that my

body would cope outside. But I was inside the hospital, I should have been safe in the hospital. I was being treated inside that hospital.

89. I still see the psychologist and I've still got all the scars from the mycobacterium chelonae. It's made me feel self-conscious and I get panic attacks when I go up to Glasgow. I still go up to the clinic every two weeks because Professor Gibson keeps an eye on me but since Covid I've not been up for a year, which is not a bad thing. I now only go to Dumfries hospital for routine checks, every three months. I still have contact with Connor Docherty, we don't meet but he checked on my progress at the end of last year.

HAIs: communication

90. When the microbiologist discovered I had mycobacterium chelonae, I think the communication of that issue was probably alright. They didn't leave out anything. When the doctors found out about it they told us, and they didn't really have to do that.

91. Prior to that I was hearing things about the water, the ventilation, the infections. Parents and staff were saying the hospital wasn't safe. The staff were getting fed little bits of information and they were telling people. The staff were trying to get us to talk to the media because they obviously couldn't. Everybody was talking about the infections and then the Cryptococcus came to light. They were talking about the infections constantly occurring and how they were weird infections, and if someone went to day care, how they got an infection from there. People would talk about how they picked up infections and others would say how they got them as well. I knew the infections were coming from the water because when I was on the oxygen I had been drinking the water. All the infections I got were linked to the soil and the water environment and they all had the same links to that so that was the reason.

92. I only found about the Cryptococcus through one of the nurses, otherwise I wouldn’t have heard about it apart from through the news. Any time you asked the hospital about what was happening, they never gave you anything. We would ask the Doctors, infection control, the microbiologist.

OTHER ISSUES RELATING TO HOSPITAL CONSTRUCTION

Hospital build issues: impact of construction works

93. In 2017, when I had relapsed, the window panels on the outside of the hospital were falling out. A few of them fell out and they put scaffolding over the main entrance of the hospital. There was a net also so they wouldn’t land on somebody. At the children’s side, they took out all the window panels and replaced them.

94. The shape of the main QEUH building is like a star. When you’re walking up to the entrance of the hospital, there’s an unbelievable amount of wind that flows in your face. It doesn’t matter the time of the year, it can be a really nice day but it can still be the same. I think it’s because the shape of the building that drags the air in. They had to put up a false wall inside the doors to try and break the wind a bit. At reception they were sitting with heaters underneath the desks to try and keep them warm. Later on in 2017 there was one day when the doors swung open and smashed so the entrance got shut and you had to go the long way round. In December 2019 the roof in the adult’s atrium came off. It blew off and left a gap.

95. The lifts in general were always breaking down, they were really dodgy. When we got moved to the adults you’ve got to share the lifts with the general public,

like drunks, folk out their face and coughing their lungs up. If you're neutropenic it's not a good place to be.

96. The hospital was next to the sewage works and that's all you could smell walking up to the hospital. On a windy day it's worse but then on a hot day it's terrible. That's all you could smell throughout, even on the wards. You could go as high as you want but you could still smell it. When I had the RSB virus I was in 2A for a week. I was stuck in source and the only place I was allowed out was to the park but even at that, you couldn't go to the outdoor park. I was up there for five minutes and I was just about sick. It's not nice, you're feeling sick anyway and then you add that onto it as well, and then you're trying to eat and all you can smell is that, it's not pleasant. They had a problem as well, in that the sewage was coming up through the ground. My mum saw that in the atrium, in the corridor between the adults and the children's hospital.

COMMUNICATION: GENERAL

97. When I was down in clinic I had heard from the TCT coordinator, and from other people, that they had moved all the patients out from 2A to 6A, to try and fix the ventilation in the ward. More problems kept on occurring with the likes of the water, the move back to 2A was delayed about four times. The communication aspect of it was pretty poor. After the move to 6A happened, when I was sitting in clinic in 6A, there were still people going up to ward 2 because they hadn't told anybody about the move.

98. The communication around the water and other issues was terrible, there was none whatsoever from senior management. If it wasn't for the nurses we wouldn't have known about half the stuff that was going on in the hospital. When my mum emailed infection control about general issues, they wouldn't

reply or they would give you as short answers as they could or something that was completely irrelevant to what you were actually asking.

99. The staff were getting blamed for a lot of things, like the line infections. It was really taking its toll on a lot of them, the stress in general. A lot of them were seeing psychologists for it. With all the Cryptococcus coming out, it was really getting to the staff, you could see that but they couldn’t speak out about it because they worked within the NHS. They were constantly pushing for us to try and speak for them. We were already sick of what was going on anyway so that gave us all the more reason why to do it.

100. My mum contacted the media, the newspapers and BBC as well. I think we were on Reporting Scotland. We talked about the hospital in general, like all the problems with the water, because the hospital wasn’t doing anything about it. If we brought more things to light then they couldn’t deny as much as they were. It had an impact; a lot of people started coming forward and a lot of things were brought to light and the hospital weren’t holding onto as much information as they had been doing, and they started talking to people. It improved communication with us but not drastically, but it changed a little bit. The Health Board started giving us bits of information and didn’t deny as much as they were. They then promised we would find out information before the media. A lot of my friends were only finding out things from the media or the news before that.

101. I feel that communication between us and the hospital has changed a little bit for the better. They could be more honest about it, even now they’re holding back information about issues in the hospital.

102. I don’t use the closed Facebook group. The press coverage hasn’t impacted me at all.

Meeting with Cabinet Secretary for Health and Sport

103. I went to the meeting with Jeane Freeman. I went with my mum and dad and there was about six different families there who were all asking questions about why so many things had happened and why were there so many problems with the hospital and why it had opened so early. Everyone was sharing stories and saying things like, “that’s happened to me too”. We never really had that many answers at all. We were promised the world but it wasn’t a long meeting. It lasted about half an hour and took place in the Central Hotel in Glasgow but I can’t remember when it was.

OVERSIGHT BOARD / CASE NOTE REVIEW / REPRESENTATIVE GROUPS

104. I don’t know anything about the work of the Oversight Board and I’m not a member of any of the representative groups.

105. My medical notes were part of the Case Note Review. I don’t think I had contact with them but I think my mum did.

CONCLUDING COMMENTS

106. I don’t like the hospital building at all. I don’t know what I feel about the Health Board, but I think there’s too many problems to solve. I think they should knock it down and start again. You’re never going to get rid of the sewage for a start which means you’re never going to get rid of the water problem.

107. The experience has had a really big impact on me. I still have scars. I still have panic attacks when I go up to Glasgow. I still see a psychologist. I didn’t

mind going to the hospital before but now it’s a fight to try and get me to go. I get panic attacks every time I go there. I don’t know what I’m going to catch next. The stress and the anxiety from it impacted me quite a lot. From the scars, I’m very self-conscious, I wear jeans and a hoody when I leave the house; it doesn’t matter how hot it is.

108. 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

Steven Kirkpatrick

WITNESS DETAILS

1. My name is Steven Kirkpatrick. I was born on [redacted]. I am [redacted] years old. I am [redacted].

2. I am the father of Stevie-Jo Kirkpatrick. Stevie-Jo's date of birth is [redacted]. She is 17 years old.

3. I live with my wife, Annemarie Kirkpatrick and my daughter, Stevie-Jo in [redacted] .

OVERVIEW

4. My daughter is Stevie-Jo Kirkpatrick. Stevie-Jo was diagnosed with Acute Lymphoblastic Leukaemia ("ALL") for the first time on 28 February 2014 when she was 9 years old. She relapsed on 3 July 2017 when she was 13 years old. Stevie-Jo was treated in the Royal Hospital for Children ("RHC") and Queen Elizabeth University Hospital ("QEUH") between July 2017 and May 2019 but her treatment had to finish 6 months early due to an infection. She attended both hospitals as an in-patient and an out-patient for nearly two years. Her care has now transferred back to Dumfries hospital and she has regular check-ups there. Between 2017 and 2019 Stevie-Jo had shared care with Dumfries and Glasgow.

5. Stevie-Jo spent time in wards 2A, 3A and ICU in the RHC. Following the closure of ward 2A, Stevie-Jo spent time in ward 6A.

6. It was mainly my wife, Annemarie, who was with Stevie-Jo when she was admitted. I would visit at weekends and whenever I wasn't working. Annemarie and Stevie-Jo are better placed to give you dates.

7. There are some specific details that I would like to mention. Stevie-Jo caught a number of infections during her time as an in-patient in ward 2A, during surgery to get her central line removed and on 6A. Due to one of the infections being so rare and the antibiotic used to treat it having such severe side effects, Stevie-Jo's chemotherapy was ended six months earlier than it should have been. There were issues with the water supply during her stay in both hospitals. I believe that Stevie-Jo was prescribed anti-fungal preventative antibiotics which may have been connected to the water issues. I will come on to talk about these events in more detail.

FAMILY BACKGROUND

8. I live with my wife, Annemarie and my daughter, Stevie-Jo in [redacted].

9. Stevie-Jo is currently in year five at [redacted], which is just [redacted] miles from where we live. Stevie-Jo is outgoing and easy going, a 'mini-me'. She has a lot of pals, likes watching and playing football and is a Celtic fan. She plays as a centre mid-fielder for [redacted] Ladies, Under 17's Football Team in [redacted].

EXPERIENCE AT YORKHILL

10. When Stevie-Jo was first diagnosed with ALL in February 2014, she attended the old Yorkhill hospital for one and a half years before transferring over to the new hospital for clinics and monthly check-ups.

11. Yorkhill was fantastic. The nurses and doctors couldn’t do enough for you. It was a relaxed, and a good place to be to be honest. There was always laughter and people doing stuff. Even the meals were really good. The differences show how bad the new hospital really is.

12. Everything was straight forward. There were no infections. I didn’t even know there was an infection control team there as we never saw anyone from Infection control. There were double doors at Yorkhill. When you opened the door, you felt the wind, it felt like it was blowing oxygen into the department. The new hospital only had single doors and there was no air.

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

Admission to hospital: July 2017 – June 2018

13. Stevie-Jo was first diagnosed with ALL on 28 February 2014. She was admitted to Yorkhill Hospital on 1 March 2014 and was treated there for one and a half years. She attended clinics once a month as an out-patient at the new RHC when it opened in 2015 where she would have a check-up and collect oral chemotherapy in tablet form.

14. Stevie-Jo relapsed on 3 July 2017. She had never been right and kept getting infections. I don’t think her cancer ever went away and it was possibly the tablets she was taking that were keeping her levels at an undetectable level. Her platelet levels had never recovered. The QEUH and Dumfries had shared care of Stevie-Jo. She had bloods taken at Dumfries hospital, that day and they transferred her by ambulance to the RHC, ward 2A where she stayed as an in-patient for a while. She was then discharged to CLIC Sargent, but still had her bed available in ward 2A. After that, she was discharged home while still receiving chemotherapy. I can’t remember exactly how long she stayed in the hospital for as an in-patient but her treatment continued for about a year.

Stevie-Jo's initial treatment: July 2017 – June 2018

15. Stevie-Jo was put on intense chemotherapy. As it was a relapse, they go in harder the second time; she was on a really high dose of chemotherapy. I think it was Vincristine she was on. She was quite sick then because of the chemotherapy.

Experience on ward 2A: July 2017 – June 2018

16. Every time Stevie-Jo was due to get out of hospital, she would get an infection. The staff never knew what they were though. She either got an infection or didn't take well to the chemotherapy. There was no noticeable difference between the reaction to chemo and potential infections. I did not notice a clear difference and staff never clarified the difference. At the end of this period, we got over to the CLIC Sargent House and stayed there for a few days. She was to attend the hospital for three days per week to get her chemotherapy.

17. At one point, Stevie-Jo had a green cap fitted to her line. They'd never used these at Yorkhill. All the kids appeared to be getting line infections though. These green caps appeared. You had to make sure the green caps were on all the time. I think these were being used as a scapegoat because they didn't know what was going on and they thought they'd use the green caps to try and stop the infections. We asked the nurses about them and they told us it was to try and stop infections. I think these were introduced about three or four months after Stevie-Jo got her central line in. We had to attend Dumfries one night and they asked what the green cap was for. We told them that the RHC had told us that Stevie-Jo had to keep one in but we couldn't tell them why. Staff at Dumfries had never seen them before and had to order them in.

Other admissions after the closure of RHC

18. Stevie-Jo had been getting a lot of headaches but they got worse around about the start of November 2018. We took her to Dumfries who scanned her. Doctors found a mass in the back of her brain so she was blue lighted by ambulance to the QEUH.

19. She was admitted to ICU. Stevie-Jo was really ill at this point, she was really very poorly so she was put on high dose steroids. It was probably the steroids that were keeping her alive.

20. Stevie-Jo deteriorated but the doctors and nurses didn’t have a clue what was wrong with her. She had a lumbar puncture and all sorts of tests but nobody had a clue what it was. Her face was drooping, she looked as if she’d had a stroke. She was in PICU for two nights then moved to ward 3A for three weeks. 3A was a neurology ward in the children’s hospital. Neurology came to see her but they didn’t think anything was wrong. She got home after this but in the following days Stevie-Jo started getting the headaches again.

Experience in the QEUH (adult hospital): late 2018

21. We’d been back home for one night and had to attend Dumfries again as Stevie-Jo’s headaches were getting worse. We were in 6A this time, the Day Care part. It was Professor Gibson who sent us to 6A. Neurology came to see her again and thought it was maybe the reducing of steroids that were causing the headaches. The Doctor put her back on full dose and sent us home again. This continued for about four weeks. She kept spiking temperatures.

22. On 24 December 2018 she was admitted to Dumfries and they carried out another scan. She was then blue lighted by ambulance up to Glasgow again. The mass at the back of her head had grown. She was admitted to ward 6A.

23. In the morning she was admitted to ICU as she had lost the ability to swallow and she had reduced breathing. A lumbar puncture was carried out.

24. On 27 December 2018, we were told by Professor Gibson that Stevie-Jo had listeria meningitis. The hospital didn't know how she had contracted it. Stevie-Jo was taken off chemotherapy for eight weeks and given IV antibiotics. She stayed on ICU until 1 January 2019 when she was moved to ward 6A. She was there for four weeks.

25. We started noticing things such as Professor Gibson and a Microbiologist coming down at night to check the showers and there being HEPA filters in the room. During the meeting in January 2019 with Professor Gibson and Dr Inkster, we asked if Stevie-Jo was safe in the hospital. We were told that she's as safe here as she is outside but she wasn't outside, she was in a hospital. The next day, we were transferred back to Dumfries. We were told she would be safer there by Professor Gibson. It felt as if there was stuff going on at the hospital out-with her control.

26. At the end of January 2019, Stevie-Jo had itching and the site of her central line was irritating her. We'd only been in Dumfries hospital for two days. Dumfries sent us back up to Glasgow to get her line removed in surgery and then she was admitted to ward 6A. The area round her line had ballooned up and she was still on IV antibiotics for the listeria meningitis. Once the line was removed, she was transferred back to Dumfries.

WATER: EVENTS INVOLVING WATER SYSTEMS

27. There used to be water coolers through-out the hospital. They were removed rapidly from ward 2A but I noticed they were slowly getting removed from the rest of the RHC and the QEUH. There were two or three up and down the ward, they were removed.

28. Staff tried to provide you with bottled water. They were stored at the edge of the ward and you were to help yourself to water when you needed it. Nurses told us we weren't allowed to drink the water from the taps. I can't remember when this was.

29. The water was okay for Annemarie and I to use for showering but the kids weren't to use it. Other parents chatted about their children only being able to have baths.

30. The water was slow to drain away. That could be to do with drainage or anything though.

31. There were filters on the taps in ward 6A when we were there. This was to filter the water when you turned the tap on. You weren't supposed to drink it, just use it for cleaning. No one told us this information, we just worked this out ourselves from what we could see was going on with the filters. We were aware generally there was a problem with the water.

32. You weren't allowed to use the dishwasher in the kitchen at one point. I think this was to do with the water. Again this was to do with us generally being aware of the problems that were going on with the water overall, no one told us this exclusively.

33. When Stevie-Jo was admitted for listeria meningitis, Professor Gibson and a Microbiologist had been in checking the showers at about 9 pm at night. Annemarie told me that she asked what was happening and she was told it was nothing to worry about.

34. When Stevie-Jo had been admitted to ward 6A, we were having to source bottles of water for her as the message hadn't been passed on to the staff from ward 2A that she was to use bottled water. In fact, this happened in all other wards she was in, 3A and 4 too. Staff weren't aware she wasn't allowed

to drink from the tap. There were no filters on the showers or taps in the other wards at that time either, only in 2A.

Water: communication

35. We received a letter from infection control about the water. It was just an A4 page but I can't remember when this was or the exact content of the letter.

36. We were told that Stevie-Jo's infection, mycobacterium chelonae, was linked to the water in the theatre in the RHC, and likely to have been contracted when she had her central line removed in January 2019. They'd traced it back due to its incubation period.

HEALTHCARE ASSOCIATED INFECTIONS

HAIs: events and physical impact

37. We knew Stevie-Jo was getting infections. Nobody was forthcoming with information about what they were and how she'd caught them though. There's some things we've heard that she had but we didn't even know she had it at the time. Some things are still coming to light, but I cannot recall all of the particular names and details now. She was always needing oxygen. We'd have her at the QEUH then a few days later, she'd had to visit Dumfries with a temperature spike and needing oxygen. Nobody could put a finger on what was wrong with her.

38. At the end of February 2019, Stevie-Jo had started getting lumps on her arms so we were sent back up to Glasgow. She was admitted to ward 6A Day Care but Professor Gibson sent her to Yorkhill to get a biopsy done. I think there were still parts of Yorkhill that hadn't moved over, possibly dermatology. Professor Gibson said the abrasions didn't look right; they were all pus filled and bleeding. When this was happening, Professor Gibson stopped Stevie-

Jo's chemotherapy at this point until they found out what the abrasions were. Stevie-Jo was never able to start back on her chemotherapy again and lost out on 6 months of chemo treatment in total as a direct result of the infections.

39. Three weeks later, I can't remember the date but it was March 2019, Professor Gibson called to say the Stevie-Jo had Tuberculosis (TB) so we had to go back up to Glasgow. She was admitted to ward 3C at this point as there were no beds in 6A and she was admitted for about a week. While we were there, another doctor, Doctor Docherty, who was from infectious diseases, came to see us with Professor Gibson. He told us that Stevie-Jo actually had mycobacterium chelonae. Dr Docherty went through everything with us as it wasn't Professor Gibson's area but she wanted to be there. There was only one antibiotic that could treat mycobacterium chelonae but because the side effects are too severe, with Stevie-Jo's immune system, she wouldn't handle it. They didn't treat it and they stopped her chemotherapy too. Stevie-Jo has about ten scars from mycobacterium chelonae that are on her legs, arms and chest. When she had the abrasions, she had to get them cleaned and bandaged at the time. It may take two years or even more for this infection to come out her system. Stevie-Jo ended up having to stop her chemo six months early as a result of this. She couldn't get any antibiotics due to the side effects. Given all she had been through with her cancer treatment they were not keen to give her any antibiotics.

HAIs: Communication

40. After Stevie-Jo being admitted for a week in March 2019, we got home but after two or three days, Professor Gibson called us to go back up to Glasgow. She had a meeting with us and the microbiologist. They said they were really sorry but they found the bacteria in the water. The infection that Stevie-Jo had, they found it in the water. During that meeting we asked if it could be treated and they said they didn't know. Mycobacterium chelonae is so rare. Before this meeting though, they tried to blame Stevie-Jo's body not taking to

the environment. They said her body wasn’t adapting as the infections she was getting were rare. This was before they found the cause of the infection.

41. We then got a call in May 2019 to say they would be stopping her chemotherapy. Professor Gibson had been in touch with doctors all over the world discussing Stevie-Jo’s case trying to find a treatment plan. If she got another rare infection, there would be nothing they could treat her with if she was to have a relapse.

PREVENTATIVE MEDICATION

42. Stevie-Jo was on anti-fungal medication but I can’t remember the name of it. Annemarie will be better placed to speak about this.

43. Annemarie and I asked why she was on it and staff told us it was just part of the treatment protocol. She wasn’t on it at Yorkhill though. Some of the nurses told us it was because the new hospital was dirty. I can’t remember any of their names though.

OTHER ISSUES RELATING TO HOSPITAL CONSTRUCTION

44. In all the wards, there were problems with the plugs in the rooms that were needed for the machines. Sometimes Stevie-Jo would need six, seven or even eight machines but close to the bed, there were only four plugs. You could have eight machines beeping and they wouldn’t hold charge: IVs, chemo, pain relief, things like that so there was an issue with the lack of plugs. I even thought of bringing in my own extension because it was that bad!

45. You couldn’t open the windows. Even the blinds inside them were all broken. There was no daylight and it was so stuffy in the rooms. There’s no ventilation when there’s three of you in the room. At one stage, the hospital did have fans. They’d been bought by one of the hospital charities. They were those big

Dyson fans. Most rooms had them but when all the stuff started to come out about the hospital, infection control came and took all the fans away.

46. One of the rooms in ward 2A which, Stevie-Jo was in faced the atrium. The lights were on there all the time so you couldn't really sleep.

47. The adults out of hours service was moved to the children's ward. During the night you could hear everyone coming in and going out at all hours. It was difficult to sleep when in the rooms in ward 2A.

48. There were issues with the ventilation in ward 2A. I think it was only 30% up to standard. The only way you could cool down, was to take clothes off. They had machines that looked like bullets, checking the air quality. When rooms were empty, they sent the machines in. I was told by nurses that the machine was checking the air quality but not why.

49. There was a general smell of sewage all the time and it was really bad on a summer's day, really, really bad. I didn't know there was a sewerage works until I was right out in front of it. The site is right out the front gate. The smell follows you on the way in. You could smell it everywhere in the hospital, through the toilets and the drains too. You got a whiff of it every now and again. It came in waves. I thought it was maybe lack of drainage or water backing up. I asked about it and the nurses just said it had been mentioned. It's one of the largest refuge sites in Europe and when I was in ward 3C with Stevie-Jo, I could see them outside the window mashing up the waste.

50. There were loads of pigeons around the hospital. Anything to do with food and they were swooping down. They even sat on the window ledges of the ward rooms.

51. In wards 6A there were HEPA filters in the room and in the corridors. The filters were to bring in clean air.

52. Transplant children had started being moved to different wards. They were going to ward 4. Annemarie and I attended a meeting with Professor Gibson and the microbiologist who told us the kids were going to be moved.

LOSS OF AMENITIES IN WARD 2A AND LACK OF AMENITIES IN WARD 6A

53. To start with, it was really good in ward 2A. On the Teenage Cancer Trust (TCT) side, there was a kitchen with a microwave, fridge and places to store food. Parents of children in this part could use the kitchen.

54. They started closing down the kitchen in the TCT area. At first it was the dishwasher then they started removing food after three days even if it was still in date. You could only keep food in it for three days. This was a decision made by infection control. The kitchen was eventually closed for a while to fix the water then it got reopened but they closed it again.

55. There was another kitchen on the ward that we sometimes used for cups but that started to get closed down too. Nurses told us it was to flush the taps through and clean them.

56. The TCT area also had a huge room with a pool table, juke box, Sky TV, X boxes and play stations. It was really good to start with but when we moved to ward 6A, there was nothing. There was no kitchen and nothing for the children to do.

57. There was no parent kitchen on ward 6A at all. You couldn’t even step out to get a cup of tea or coffee. You had to buy food and bottles of water. When I came up to visit I took Annemarie to buy microwave meals from Marks & Spencer’s which were more expensive. Stevie-Jo didn’t like the food on the ward but to make sure she had a meal, we had to go to the main area behind the shops to use the microwave used by the nurses. It was in a main atrium

area of the hospital; everyone used and it wasn't clean. You then had to take the meal back up in the lift to ward 6A so she could eat it. The food the hospital provided was disgusting. Stevie-Jo was on a soup and soft diet but the hospital even manage to burn the soup!

CLEANLINESS

58. There was a lack of cleanliness in all of the wards. In 6A, the room would get cleaned once a day and it would be at a time they wanted to do it, whenever the cleaner was on the ward.

59. The ward only had the one cleaner, maybe sometimes two. The same mop was used to do every room and the same mop bucket. Sometimes the cleaner would come in at 4 AM to clean.

60. Stuff would be left lying. We were on top of the cleaning. If something like plates was left there too long, I wouldn't let them lie around. I would deal with it. I would wash plates so Stevie-Jo could get her dinner as sometimes she would have it in the room. I wouldn't let things like plate lie around too long. If there was bedding that needed to be changed or was in the washing basket I would take it along and sort it out for Stevie-Jo and Annemarie. We didn't let things pile up.

61. There were issues with dusting. With three people in the room, you're not getting everywhere. The top of the TV was never dusted. You could see dust in the corners of the room. The cleaner basically just wiped the sinks and mopped the floor and it was the same in all wards.

OVERALL EMOTIONAL IMPACT ON STEVIE-JO AND HER FAMILY

62. Stevie-Jo had to see a psychologist, [redacted]. This was at the [redacted].

63. It’s bad enough when your daughter is going through cancer. All the other issues were just added stress. You don’t need them when you’re going through enough already and it causes you to lose trust in the hospital.

COMMUNICATION GENERAL

64. There were no issues with communication regarding Stevie-Jo’s treatment. Professor Gibson is one of the best ones in the world so you just left it up to her as she knew everything. At Yorkhill she was phenomenal. We just knew that she looked after Stevie-Jo and she still asks for her. I just didn’t trust the hospital.

65. In relation to the infections that Stevie-Jo contracted, we were never told the names or source of any of them. We found out about some of them later on. Staff weren’t forthcoming with information about them. We found out information in our meetings with Jeane Freeman and with the hospital. Annemarie will be able to expand on this point.

66. You’re looking for answers but people won’t give you them so you feel as if you’re banging your head against a brick wall. It’s nothing to do with the staff. They can’t relay the information. We were asking about what was going on in the hospital with the water, what were the infections, what was wrong. The staff would give vague answers and even Professor Gibson wasn’t clear about what was going on. The only ones that spoke were nurses but they’re limited to what information they can give you. I think the situation was stressful and emotional for the doctors and nurses too. I saw nurses breaking down. It was the way the hospital was being run but the nurses were getting the blame. Their hands were tied but you could see how they felt in their faces. Nurses pleaded with us to go to the press. They said to Annemarie that something needed to be done. They couldn’t do anything because of their jobs but they knew there was a big problem. Annemarie can tell you more about the press.

COMPLAINTS

67. We asked quite a lot of questions. My wife, Annemarie put a formal complaint in and was told it would be dealt with later. The complaint was about the cleanliness of the hospital and Stevie-Jo's care in general. I didn't put a complaint in. Annemarie was better at dealing with that side of things.

OVERSIGHT BOARD / CASE NOTE REVIEW / REPRESENTATIVE GROUPS

68. I've heard of the Oversight Board but can't really remember much about it. There were a few emails between us and the hospital with Craig White as the go between. It was hard to talk to him. Annemarie is the best one to speak to about this and she still has the emails on her phone.

69. We were really happy with the Case Note Review. Stevie-Jo was part of it. We got quite a lot of information from it and had a meeting with them afterwards. We got a whole copy of the report, they sent it to us. Stephanie (my legal representative from Thompsons solicitors) was at the meeting too.

70. Annemarie was involved with a group where another child's dad would give us updates. He knew what he was talking about and was very thorough. He attended the meetings and wrote them all up. I think he was involved with the Oversight Board. He was quite informative. He was fighting a cause.

71. We were part of a Facebook group too. There was one set up that was a closed group and run by the hospital. Emma, the Lead Nurse, was involved with this. There was a lack of information though. They thought they could take that on and see what was getting said. The doctors and nurses didn't like the parents talking to each other about what was happening. I think, Professor Gibson said it was a "witch fest", with people gossiping and creating stories about individuals to destroy their character. She hated it anyway and openly said this. It was better as at least you were getting some information but you could only say so much on it.

72. There was a parents Facebook page too where parents could share information. I don’t know how many families were members on it but they were all involved with the hospital. More came to light on this page about the underlying issues at the hospital. They made us aware of issues around the hospital and we made them aware of any issues we found.

CONCLUDING COMMENTS

73. There are still problems at the hospital now that I don’t think they’ll ever fix. They should take the cancer unit out of there and make it a separate unit. It’s built on cheap ground and it’s not fit for purpose. People call it the ‘Death Star’, and they’re probably right.

74. The hospital won’t ever be right. It opened too early and there wasn’t enough checks with whoever built it. There are always going to be underlying problems with it. They’d be better knocking it down and starting again on a different site. I’d hate to be going through treatment there just now.

75. The Health Board, that’s not good. They’ve got their issues too or their hands tied. It looks like they’re protecting a scapegoat. They’ve not said anything. They admitted it and that’s as much as we’ve got which is pretty poor. The Health Board clearly know more than what they are letting on and protecting themselves as it is clear to the world that the hospital was not fit for purpose.

76. 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

Witness 6

WITNESS DETAILS

1. My name is Witness 6. [redacted]. [redacted].

2. [redacted].

3. [redacted]

OVERVIEW

4. My [redacted]. [redacted] was first diagnosed with Acute Lymphoblastic Leukaemia ("ALL") in [redacted] [redacted] [redacted] was originally treated at Yorkhill and then at the Royal Hospital for Children ("RHC") between [redacted]. [redacted] attended the hospital as both an in-patient and out-patient for [redacted]. [redacted]. I have been unable to provide the Inquiry with a timeline showing the dates in which [redacted] attended hospital due to the time period between [redacted] last treatment and present date. I can't access any dates via [redacted] medical notes either as they are not in chronological order. [redacted].

5. [redacted] spent time in ward 2A, which was known as the Schiehallion Unit. Ward 2A took over the treatment and purpose of the old Yorkhill Schiehallion Unit. I stayed with [redacted] during most of [redacted] admissions to the hospital as an in-patient and out-patient. [redacted]. I can speak to the experience [redacted] and I had within ward 2A.

6. There are some specific events I would like to mention. When we moved over to the new RHC, we lost a lot of services that helped both parents and children, some of the facilities that were built for the move to enhance the RHC, were never even opened. Parents were isolated as were children as a result of this. [redacted] had a number of infections during [redacted] stay but I cannot recall a lot of the details and I was not told what they were at the time. I was never given information about the infections and it was always dismissed as being part of [redacted] treatment. I found out [redacted], that [redacted] had been on preventative medications. I will come on to talk about these issues in more detail.

FAMILY BACKGROUND

7. [redacted].

8. [redacted].

9. [redacted].

10. [redacted].

11. [redacted].

AMENITIES AT YORKHILL

12. [redacted] was diagnosed with ALL in [redacted] and was initially treated at the Schiehallion Unit at Yorkhill hospital for [redacted].[redacted] had [redacted] port-a-cath fitted there which lasted [redacted] through-out [redacted] treatment. Yorkhill was a lovely hospital. It was a bit run down and needed a bit of a face lift but it was a functional hospital.

13. The service at Yorkhill was great. One example would be the blood tests and the time they took. Children would go to Day Care, to receive any treatment that was not required to be administered overnight. Before they went to Day Care, they would have to go and get their blood tests done at the blood clinic. This was a thumb prick test and by the time you had walked from the blood clinic to Day Care, the results were sitting waiting for you.

14. Everything in Yorkhill was quite compact. They had a canteen nearby. It doesn't sound important to other people but when you have a child on steroids, a canteen is very important. You need to be able to feed yourself too. The canteen was reasonable, not too expensive. If the children didn't like

what was for dinner or what was on the dinner trolley, they were given a wee yellow slip that they could take to the canteen and choose a meal.

15. There was a sense of community at the Yorkhill hospital. The Unit was called the Schiehallion Unit and we took the name over to the RHC with us. We didn’t use ward numbers at Yorkhill.

16. The Schiehallion Unit was a sociable ward although we were aware the children were immunocompromised. They had wee cars and tractors for the children to play on. The children would toddle up and down the ward on a tractor. There was a great big play room too with lots of stuff going on in there. They used to invite external people in to do activities with the children. They had balloon makers, clowns, various different things going on. The children spent quite a lot of their time in the play room.

17. The children were encouraged to come out of their rooms and play. That’s why there were activities put on in the playroom. It was a really sociable ward and had a strong sense of community.

18. There was a parent’s kitchen at Yorkhill which was vital when you have a child on steroids. You could make a pot noodle, or heat something else up for them whenever they needed it. This was also where a lot of the parents supported each other too. It was a place you could cry, shout or get a cuddle if it was needed. There was a big family room too with couches, a television and books.

AMENITIES AT RHC

19. At the RHC blood test results took ages to come back, sometimes hours. You became 1 in 4000 patients compared to Yorkhill where you were 1 in 400

children. This was because the children's blood tests were then processed at the same place the adult patient's blood tests were processed.

20. I've mentioned the canteen at Yorkhill, there was nothing like that in the RHC. They had a canteen but it was in the adult hospital. You had to walk through the RHC then through the adult hospital to get to the canteen. If you're a [redacted] on your own, you're not going to leave your extremely sick child in the RHC to walk all the way to the canteen. The canteen was also very expensive. They did have a coffee shop in the RHC which was great for sandwiches and things but it was also expensive. It closed at 4 PM and wasn't open at weekends. There was a Marks and Spencer's there too but it was expensive.

21. The canteen doesn't seem like much but we were used to having a canteen, and relied on it. We missed having one, when we moved to the RHC. There were financial implications as everything was more expensive.

22. Having a child in treatment is expensive anyway. Running up and down to the hospital, fuelling your car, buying food as your child is on steroids and constantly eating, you've got yourself to feed, toys to buy to keep them amused. All these things matter while your child is going through treatment.

23. There was no sense of community at the RHC. The playroom the children had was tiny and could maybe only fit three children in it. My home bathroom is bigger. There were no external activities or people that came in to do things with the children. There were no cars or tractors. No children playing up and down the corridor. Children weren't encouraged to come out of their rooms and socialise. In fact, most of the children were locked in their room in isolation. They had nowhere to congregate. It was quite isolating for them and indeed the parents. They did have clown doctors and a balloon lady that came and made stuff outside your room window but it wasn't the same, especially if you'd been treated elsewhere like Yorkhill and had all these things previously. The play girls tried their best but there is only so much drawing and gluing

glittery things that children can do. [redacted]. The way the ward was shaped didn't exactly allow for socialising either.

24. Originally there wasn't a parent's kitchen on the plans for the RHC. Three of the parents at Yorkhill joined a committee to fight for one to be put in. We all knew we needed it but it wasn't included. The parents that fought for it went up to the new site before it was established and the building work was still being carried out on ward 2A to see the kitchen being installed. When we did move over to the RHC, the parent's kitchen was often closed or sections of it were closed. There would be a big yellow sticker on the door telling you it was closed or out of use but nobody ever told us why. We just accepted it was closed and didn't question it.

25. At the time, it did not seem like a big deal, the kitchen being closed, it was an inconvenience and there was a workaround; as long as [redacted] was okay, that was the main thing for me. It seemed petty to complain when your child is fighting for their life. However, these things were invaluable as that's where you got your support, from the other parents. You worried about how you were going to feed your child that was on steroids so it was important.

26. We were told there was a play park attached to one of the wards at the RHC as well as the play park further out nearer the car park. The one attached to the ward was never opened. They had one event in it but it never opened for the children to be able to play in. They had one event in it and the play leaders had been sent up beforehand to clean up all the pigeon droppings. That's the only event that I know of. The playground is something [redacted] would have used and we would have used as a family. There were wee gardens there too that the kids were meant to have access to but they never opened either. Children would've really benefitted from being out in the wee gardens or being able to use the park.

IMPACT OF MOVING TO RHC

27. There were a lot of changes when we moved the RHC.

28. It may not sound much but the loss of the services had a huge impact on us. The increased time waiting on blood results, the lack of things for children to do, the financial implications of having to buy food when the parents kitchen wasn't available, the impact on [redacted] when the parents kitchen wasn't available and [redacted] wanted something to eat. All of these services were invaluable and there was a massive impact on [redacted] and us when we lost them.

29. When we were moving from Yorkhill, some of the staff moved to the new RHC with us but a lot of the staff left. I don't know the exact reasons why but I had heard the general consensus was that the RHC was very different to Yorkhill and had no sense of community, possibly due to the shape of the building or where it now was.

30. There was a huge impact on us when the staff left. We lost relationships which were really difficult to lose. Those staff members were our support. During one of the worst times in our lives, these staff members supported us and some became our friends. They had new staff members at the RHC but they didn't all have the same level of experience as some of the nurses who had left. We didn't have any 'go to' people. It also took time to build new relationships whereas at Yorkhill, all the staff knew [redacted] and they knew the family too. The fact you were moved to a different hospital where you didn't know your surroundings, you didn't know where you were going for treatment or what you were doing, losing those staff members had a huge impact on us. It made a difficult situation even harder.

31. Staff at the RHC rotated quite a lot too. You had the odd few that were always there but we were seen by different doctors and nurses quite a lot.

WATER EVENTS INVOLVING WATER SYSTEMS

Water Incidents in RHC

32. The first thing I noticed about the new hospital was that there were filters on the taps and the showers in 2015/2016 in ward 2A. We had just moved to this new, state of the art, all singing and all dancing hospital, so I didn't understand why the filters were needed.

33. There were signs up, advising the water was for washing only and not for drinking. I recall it was 2015 onwards. You were given bottled water for drinking by the staff. I wish I could remember the exact wording. [redacted] took a photo of it so I'll likely have it somewhere. We were washing our immunocompromised children in this water that you can't drink.

34. The showers were constantly flooding too. I had to get extra towels and fold them round the door so the water wouldn't get into the bedroom. There was never any plumber or staff who came to look at the showers after they flooded.

35. [redacted] hadn't been very well so we were in source but there were urine and stool samples in the bathroom when it flooded. I couldn't get out to take them anywhere and sometimes you could wait quite a while until a nurse was free to collect them. Sometimes they could sit for 24 hours.

36. You had to run the shower for five minutes before using it which was odd. I found that really difficult as if you have a child who's had an accident, you need to get them cleaned up. I didn't have the time to run the water for five

minutes before cleaning [redacted]. Even if [redacted] hadn't had an accident, the chemotherapy made [redacted] skin extra sensitive. [redacted]. [redacted] was really anxious about getting showered and this would've been worse if I ran the shower for five minutes before using it.

37. At one point, we had to use bottled water on [redacted] to wash [redacted]. This was another level of drama. We were not told to use bottled water to wash [redacted], we decided to do this for personal reasons as we were aware of all the problems with the water and if it wasn't safe to drink, it wasn't safe to wash in.

Water Incidents: communication

38. Sometimes I raised concerns with staff. I would speak to nurses, auxiliary or the cleaner and show them something but they just used to agree with me and say, "I know, it's terrible". A lot of staff weren't happy at the new hospital but I don't know the exact reasons why. I didn't complain about the shower formally as in the grand scheme of things, the bathroom being flooded was an inconvenience, it was a pest. There were bigger things to worry about at the time, or so you thought. I didn't realise the implications regarding the water at the time. You just trusted people and the hospital as it was new and state of the art.

INFECTIONS

39. [redacted] had a number of infections when [redacted] was at the RHC. [redacted] had quite a lot of temperature spikes.

40. Usual protocol if a child spikes a temperature is to admit them to hospital where they have blood tests carried out and start them on IV antibiotics. These admissions could be varying lengths of time but the minimum is 48 hours to allow for blood results to come back.

41. One particular time that stands out is in [redacted] 2015. [redacted] is the type of child that just carries on with things, even with the steroids, losing [redacted] hair and going through chemotherapy, [redacted] was still up and about doing things. That [redacted] though, [redacted] was really ill. [redacted] had been complaining of severe headaches, he'd been vomiting and was clammy. Even the way [redacted] was acting was different. [redacted] just wanted to go to [redacted] bed. [redacted] was really, really ill. We phoned the hospital and we were told to take [redacted] up. They carried out a lumbar puncture, where they took fluid out of [redacted] Central Nervous System ("CNS") and tested it. We thought [redacted] was having a relapse. Even the nurses thought [redacted] was relapsing as they said to me, "if it is leukaemia again, you'll get through it again". I was relieved when staff told me it was a virus. I wanted it to be anything but leukaemia again.

42. I found a letter relating to the [redacted] 2015 illness in [redacted] medical notes. The letter was dated [redacted] 2015 and it was from Professor Gibson to [redacted] GP. It stated that [redacted] had a recent viral infection which caused the CNS lymphocytosis. There was a reference made to cells being found during the lumbar puncture but they didn't look like Leukaemia blasts.

43. [redacted].

44. As I've previously said, [redacted] had a number of infections but we were never told what they were or how [redacted] caught them.

45. Even though [redacted] was poorly in [redacted] [redacted] was only ever told it was a virus. Nobody ever told me what the virus was or what had caused it. The letter I found gave me more information than I received at the hospital. I pushed for an answer at the time. I pushed and pushed for answers but when I was told by staff it wasn't a relapse, I was relieved. I moved on.

46. [redacted] was in source quite a lot but we were never told exactly why. A sign used to appear on your door or staff would maybe say to you that you're sourced but no explanation was given. You just accepted it was part of treatment. [redacted] had diarrhoea quite a lot and he'd be in source for that but that was one of the side effects of chemotherapy. It impacted [redacted] bowel but we'd still be placed in source.

47. [redacted] cough during [redacted] treatment. [redacted] would be given simple linctus for it and sometimes placed in source. They never told me what was causing the cough.

48. The communication about [redacted] treatment wasn't that great and I found this frustrating. [redacted]. Maybe staff had a reason for not telling you too much at the time but the communication was terrible. You didn't know what to expect. You didn't know what was coming and you didn't know what was normal and what was abnormal. It was a very frustrating and difficult time.

49. I recall a point where I'd booked a holiday [redacted]. I was told I was not allowed to take [redacted] as he had a port and that was an infection risk. If he was to spike a temperature [redacted], [redacted]. It may sound like nothing but at the time, it was a really big thing for me.

50. There was a complete lack of communication. [redacted]. Staff are very good at what they do but they forget that we're humans and parents and this is a very difficult time for us.

PREVENTATIVE ANTIBIOTICS

51. At the time, when [redacted] was undergoing treatment, he was on a number of antibiotics but I only found out [redacted] that [redacted] was on preventative ones. I'd given my solicitor some documents over the weekend and I was informed [redacted] had been on several, [redacted] when [redacted] was going through treatment at the RHC. I have no doubt that [redacted] would have been on the preventative antibiotics in [redacted] too.

OTHER ISSUES RELATING TO HOSPITAL CONSTRUCTION

Hospital build issues: impact of building issues

52. I do not remember much about building works going on at the hospital. I remember that the blinds on the windows didn't work and the rooms were very stuffy. There was no ventilation. We had fans in the rooms at one point to move the hot air around. I remember being able to use them and then not being able to use them. They had been supplied by the hospital but I remember them being taken away. Nobody explained why.

53. We did not have certainty about whether [redacted] would be admitted to Ward 2A if [redacted] had to come into the RHC, for example, with a temperature spike. The protocol at the beginning was that we would phone Day Care and they would tell us to come in and go to ward 2A. If [redacted] was admitted with a temperature spike, [redacted] was admitted for a minimum of 48 hours as that's how long it took to get the blood culture results back. However, they changed the protocol. I can't remember when the protocol changed. Nobody told me the protocol had changed or why. When I phoned after the protocol had changed, we would have to go in via Accident and Emergency then the Clinical Decision Unit. The department you were in would liaise with the Schiehallion Ward and tell you where you were going but sometimes this meant [redacted] was admitted on another ward as they said there were no rooms on the Schiehallion Ward. Sometimes we were not even told where you were going, you found out when you arrived at the ward you'd be in.

54. [redacted] could be placed in any ward where there was space. I noticed that there were rooms shut on ward 2A. All of the bone marrow transplant rooms were closed too with big yellow tape all over them. We were only told they were closed for cleaning. With these rooms being shut, there were less rooms on ward 2A, which is why [redacted] sometimes was admitted to other wards. This caused anxiety as you'd want to be on your own ward with your own team who knew [redacted] and knew what they were doing as they were all experts. However, the majority of time, you would be placed in another ward. It was horrendous.

55. Every ward was different too. In some, you could get a cup of tea or coffee but in the other wards, you couldn't. You would be isolated in a wee room waiting for your team to come and see you. That's another thing, if you weren't on ward 2A, you would be forgotten about. You had to phone the ward to remind them to send the doctor to you, so sometimes you wouldn't see the morning doctor until 6 PM. This was unsettling, frustrating and worrying. It caused a lot of anxiety.

56. When [redacted] was in a different ward the protocols didn't follow [redacted] Staff in the other wards didn't know how to deal with the grippers which are for the needles that go in and out of the port. Sometimes because it took so long for the staff in the Schiehallion Unit to come and see [redacted] treatment was delayed. This would have a big impact as you wouldn't know what was wrong but under protocol, [redacted] chemotherapy would have been stopped. If treatment was delayed, it meant a longer stay. It was very distressing and frustrating.

CLEANLINESS

57. The cleaner came in daily and cleaned the room. I was also cleaning the room on top of that with antibacterial wipes. We were never told to clean the room, we did it out of fear for our immunocompromised [redacted] and because we were observing the cleaners not deep cleaning the rooms. We were all ready for Covid long before it came as this is how lived before with having an immunocompromised child.

OVERALL EMOTIONAL IMPACT ON [redacted]

Overall emotional impact on [redacted]

58. [redacted] spent longer at the hospital due to infections or being in source and having [redacted] treatment delayed. [redacted] hated being stuck in that little room as [redacted] was so active and sociable. [redacted] had a lot of anger at that time and was lashing out. Its' difficult to tell whether it was normal, a side effect of the treatment or the situation. Normal kids have tantrums too but there was a period of time when [redacted] behaviour was more difficult than normal. [redacted] was angry, upset and lashing out. [redacted] was quite down too when [redacted] was usually quite cheerful.

59. [redacted] had a lot of anxiety. It [redacted]. We have a great community here so we had a lot of support. [redacted] just catching up now.

60. [redacted] was not offered any education while [redacted] was in hospital for the entire time [redacted] was treated there. By law they only have to arrange for a teacher to come and educate a child if they are an in-patient over a certain amount of time, I am unsure how long that was. But in [redacted] we did not see a single teacher.

Overall emotional impact on witness

61. [redacted].

62. Being in source was difficult. I was trying to entertain a [redacted] child who is active and very difficult to entertain due to [redacted] lack of concentration which was a side effect of [redacted] treatment. It was a very depressing, lonely and isolating time. It felt as if [redacted] was constantly put in source without explanation which was upsetting. There were no protocols in place to help support [redacted] during [redacted] time in isolation but I don't know what else they could have done. [redacted] wasn't into arts and crafts which is what [redacted] was offered by the play

leaders. If the communication had been better my anxiety could have been reduced with understanding [redacted] situation. If the TVs in the room had been working at least, then that would have given [redacted] something, but even they were broken.

Overall emotional impact on other family members

63. [redacted].

COMMUNICATION GENERAL

64. We were never told why the play park attached to the ward was never opened. I'd heard it was because of the pigeons and their droppings. There were plenty of pigeons at the hospital but we didn't know the impact pigeon droppings could have at the time when we were at the hospital. [redacted].

65. [redacted] we trusted what staff were telling us. Don't get me wrong, the nurses and doctors saved [redacted] life and they were amazing. They helped us at that time and I feel for them too as they weren't given the information about the issues either. They didn't have the information to give to us so they were working under difficult circumstances as well as trying to care for us, [redacted] and all the other children and parents. I don't feel it's the fault of the

staff that we didn't get answers. I think it's a culture thing. It's a need to know basis.

COMPLAINTS

66. [redacted]. [redacted] was my main concern at the time and some of the things seemed so insignificant at the time when [redacted] was going through treatment. [redacted].

OVERSIGHT BOARD / CASE NOTE REVIEW / REPRESENTATIVE GROUPS

67. I've heard about the Oversight Board but don't know much about what they've been doing. I've only really heard about it in passing.

68. [redacted].

69. [redacted]

[redacted].

70.[redacted].

71.[redacted].

CONCLUDING COMMENTS

72. The biggest impact for me overall is the lack of service, lack of community, being in source. By putting us in source constantly we were isolated from the parent community we had come to know. It made me feel they were trying to stop us speaking by isolating us all as well as trying to manage the constant infection outbreaks. While I was caring for [redacted], there were so many obstacles in my way. These things were not enabling me to care for [redacted] in the best possible way and give [redacted] the best possible care.

73. I have more trust in the staff than I do in the Health Board. I'm angry, disappointed and disgusted to be honest, that this has been allowed to happen at a Children's hospital. It should never have been built on sewerage

ground. I don't know why they moved it in the first place. They should have put money into Yorkhill and kept us there in my opinion. It's not the super state of the art hospital we were told it was going to be.

74. I don't know how faith is going to be restored in the hospital. The Public Inquiry is maybe the best way to do that and give us some answers as to what's happened, why it happened and how it was able to happen. Until we get these answers, I don't think any of us will feel reassured. I don't think the NHS standing up and saying, or lying again that's it's safe will help. That's all they've done is covered it up, passed it back. All they've done is lie.

75. I have received [redacted] medical records after requesting them. There is a huge pile of notes and none of them are in any order. I spent a weekend trying to sort them into some sort of order. [redacted]. I thought the books would be in order from [redacted] but they're not they're all over the place. I've tried to look at [redacted] admissions and infections to try and pull our certain dates but not all the notes are together. [redacted] I was expecting all the notes in the one place in some sort of order but no, there's bits about the same admission in all four books! There's no start, middle or end. It's a mess. I feel there's a lot missing too. The notes were sent to me like that from the records department at the hospital. Lots of us requested the notes for our children at the same time. It all comes back to the doubt we have now. I've lost trust in the hospital so I doubt [redacted] records will be right either. I don't know if everything will be here. I don't think they are. I know for a fact how many admissions [redacted]. You trusted them at the time and didn't get any answers so I doubt [redacted] medical notes will be right. It's a horrible feeling, doubting everything and questioning everything.

76. [redacted].

77. [redacted]. Everything worries me about it. The pigeons, the ventilation, the water. It fills me full of worry and dread. The people that we trust to look after our children and to give us the correct information which allows us to make informed choices, I don’t feel have done that. If I had all the information at the start, I could have made an informed choice and could have had [redacted] treated at another hospital, [redacted]. I could’ve decided whether I wanted [redacted] treated at a sick hospital a sick building because to me, that’s what it is, it’s a sick building. Why would I take my child somewhere sick?

78. The fact we weren’t able to make an informed choice annoys me. I, [redacted], kept taking [redacted] up there and putting [redacted] in a dangerous position but I didn’t know that. Nobody told us.

79. 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

Sharon Ferguson

WITNESS DETAILS

1. My name is Sharon Ferguson. I was born on [redacted]. I am [redacted] years old. I am [redacted].

2. I am the Mother of [redacted] [redacted]. [redacted]'s date of birth is [redacted]. He is 12 years old.

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

OVERVIEW

4. My son is [redacted]. [redacted] was diagnosed with Philadelphia Chromosome-Positive Acute Lymphoblastic Leukaemia (PH+ALL) in September 2017, when he was 8 years old. [redacted] was treated in the Royal Hospital for Children (RHC) and Queen Elizabeth University Hospital (QEUH) between September 2017 and March 2020, when he finished his treatment. He attended both hospitals as an in-patient and as an out-patient regularly for nearly three years. [redacted] still attends the QEUH for some appointments and hormone therapy.

5. [redacted] spent time in wards 2A and 2B of the RHC which are known as the Schiehallion Unit. The Schiehallion Unit is the children's cancer ward.

also spent time on other children's wards, being wards 3C, 2C and Paediatric Intensive Care (PICU).

6. Following the closure of the Schiehallion Unit in 2018, [redacted] was treated on ward 6A in the adult hospital which was where the Schiehallion Unit was moved to, and in ward 4B, which was the equivalent of Day Care (2B) in the RHC.

7. I stayed with [redacted] during most of his admissions to hospital as an in-patient and an out-patient. It was usually just the two of us however, my mum helped out when she could as I had another child at home at the time. I can speak to the experience which [redacted] and I had on these wards.

8. There are some specific events that I would like to mention. [redacted] lost the majority of his hearing as a result of being treated by certain antibiotics. He was on these as both a treatment method and as a preventative measure. In September 2017, he had itchy skin. He had been using the water since being admitted. This was diagnosed as scabies and numerous other skin conditions. This debate and [redacted]'s itchy skin carried on through-out his treatment at the hospital and I believe his itchy skin was caused by the water issues. contracted a number of hospital acquired infections while he was at the hospital including: Aspergillus in November 2017, Stenotrophomas in August 2019 and Acinetobacter in November 2019. I believe [redacted] had been prescribed preventative antibiotics in 2018 which may have been connected to issues with the water supply. There were a few issues with the building where rooms were out of use, which led to us being moved rooms a few times and a lack of facilities on the adult ward for patients and families which in my view, impacted his experience. The lack of communication impacted myself and the way in which staff didn't communicate with [redacted] when he lost his hearing, impacted him. There were issues with cleanliness in the rooms that

and I were staying in on ward 2A and Ward 6A. I attended meetings about this. I will come on to talk about these events in more detail.

FAMILY BACKGROUND

9. I live in [redacted] with my two sons, [redacted] who's the youngest and [redacted] who is [redacted].

10. [redacted] was in [redacted] when he was first diagnosed. He is an outside child. He loves being outside climbing trees, being on his bike, playing with his friends, raking the street as they do. We live in quite a quiet area so he's able to do that. There's a new park beside us, so all the kids go there to hang out, but it gets a bit busy for him. He struggles with noise so if the park is too busy for him, he just comes home.

11. [redacted] always used to have his headphones on; listening to You Tube or music. He liked Queen and AC/DC. [redacted] also loved his X-Box and his phone. Anything to do with technology; that was his thing. [redacted] loves cooking and his food. He loves talking to people. He's like a tube of Pringles, he takes a while to get to know you but once he does, that's it, you can't shut him up; he will just talk and talk. He has always been like that from a wee boy and he would talk to everybody he met.

12. He has struggled at school since he lost his hearing and struggles with social situations now. He was initially allowed to go back to school for the academic side of things but he wasn't allowed to be there for break time or fun time, which I raised with the school as he needs the social side to mix with his

friends and build up conversation skills. Eventually he was allowed in for full days but it was three weeks before the summer holidays so it didn't really help him.

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

Admission to hospital: September 2017

13. [redacted] was 8 years old when he was first diagnosed with PH+ALL (Philadelphia Chromosome-Positive Acute Lymphoblastic Leukaemia). Around 3 September 2017, he had developed a purple rash on his legs which became worse after a few days so, on 8 September 2017 I took him to the local pharmacy. The pharmacist advised me to take him to my GP immediately, which I did the same day. He then got transferred to Dumfries and Galloway Hospital where they did a blood test and he was diagnosed with cancer. [redacted] was then transferred to the Queen Elizabeth University Hospital and admitted to ward 2A in the RHC that same night.

[redacted]'s initial treatment: 8 September 2017 – 20 December 2017

14. We arrived at about 11.45pm on Friday, 8 September 2017. [redacted] was given IV fluids and, as it was the weekend we had to wait for tests and treatments to begin on the Monday. He needed a lumbar puncture and there were no staff available to carry this out at the weekend.

15. [redacted]'s consultant is Professor Gibson and he is still under her care. There were other doctors and nurses that attended [redacted] but I can't remember their names.

16. The Monday [redacted] was admitted, is a bit of a blur. I think he had tests done on the Monday.

17. On Tuesday 12 September 2017, [redacted] had his central line fitted and a lumbar puncture. We were initially told he had Acute Lymphoblastic Leukaemia (ALL) but a few days later doctors confirmed it was Philadelphia Positive, ALL that [redacted] had so he had to go on a high dose chemotherapy.

18. We were asked if we were happy for [redacted] to go on a trial for treatment. I said that I would be happy for him to go on a trial if he was accepted so he was put on to it. I can't remember the name of the trial as there's always different trials going on. He got a medicine like vincristine but he didn't get it as IV when he went on to the maintenance phase, he just got given oral chemotherapy. I did get a list of treatments that [redacted] was on but I had to chase for it. I was given a sheet that told us that [redacted] was on a six-week plan. It showed what days he would get IV chemotherapy and which days he would have oral chemo and steroids and other things.

19. The sheet of paper I was given detailing the six-week treatment plan for would maybe say that he was getting one week of IV chemotherapy and then depending on his counts, if they had crashed he would take a break from chemotherapy to build his counts back up but. Sometimes the chemotherapy would cause kids to have sickness or bowel problems. I didn't really question what they were doing regarding [redacted]'s treatment as I'm not qualified. I just trusted the doctors knew what they were doing.

20. On 11 October 2017, [redacted] was moved to ward 3C for four or five days and was then moved back to ward 2A around 14 or 15 October 2017 when there was a spare bed available. [redacted] remained on ward 2A until discharge on 20 December 2017.

21. On 23 October 2017, [redacted] had surgery to clean fungus out of his lungs. He had developed some lung problems and we were told it was chemo fungus. Staff did say that some children develop some issues with their lungs through chemo, because it's an aggressive course of chemo some of them have to get. When you read up on it, it did say they can have lung problems, so again I didn't question it.

22. I think it was October, after he had his lungs cleaned out that [redacted] was put on ambisome and caspofungin for a few months to stop the fungus in his lungs reactivating. I can't remember who told me that. Doctors were keeping an eye on his lungs and if he was getting bad again, they would increase the dose. He was sometimes getting it once a day and sometimes it would be twice a day depending on how he was doing. It was just the norm. It was part of his treatment. There was another one that he had to take as an IV. I can't remember what this was.

23. [redacted] had to stay as an in-patient for a number of weeks as he was on high dose chemotherapy. He was sick with the chemotherapy and had loose bowels sometimes so he would get a bit grumpy. It was when he lost his hair that he started to get really upset. He had long hair when he first went into hospital, his hair was his thing but it had started falling out in chunks over a couple of days.

Experience on ward 2A, 2C and 3C: 8 September 2017 – 20 December 2017

24. Between September and December 2017, [redacted] mainly stayed on Ward 2A. It was a lovely ward, which we described as shaped like a half moon, just because it has curved wards. We were always on the Teenage Cancer Trust side, so you didn't really get to see the bottom of the ward unless you were going down to the parents' kitchen or leaving the ward to go out the ward, but it always looked lovely. The playroom was there, the Teenage Cancer Trust

room was there, you had the classroom for the kids when they could go to school, but there was just nothing for the 7 to 12 year olds to do. [redacted]'s room was actually opposite the Teenage Cancer Trust games room and that used to annoy him as he wasn't allowed in. Everyone in that room seemed to be having fun.

25. I think there were 26 rooms in ward 2A. We were in room seven or eight when was first admitted. All the rooms were en-suite. Your bed was actually in a wardrobe so when you opened the doors, the bed would come out. It was just a camp bed which was fine, it was comfy, and it was better than a chair. You relied on the hospital providing your bedding. Sometimes you didn't get bedding because there wasn't enough, so I sometimes slept sitting on the chair with a dressing gown on.

26. There was a parent's kitchen there too that you could use when you weren't in source. I'd go down and make a coffee and sit down there for ten minutes just to clear my head, but sometimes you actually couldn't get into the parents' kitchen because there'd be families with their family members. They would overtake the kitchen and sometimes they would ask if you would mind leaving, because they wanted some private time. Ward 2A had a microwave and access to a fridge which was limited to three items. The food was terrible and uncooked in all the wards. I had to go shopping and had a bag full of food. If was late back from treatment, there was often no food when he got back.

27. [redacted] was put in 'source' quite a lot. Being in source meant that you had to stay in your room and weren't allowed access to the ward. Sometimes you would be told you were being put in source, other times staff would just put a sign up saying you were in source. This could be done if they thought you had an infection or something that could spread round the ward. If you were in source, you weren't allowed to use the parents' kitchen. You had to rely on staff or family members grabbing something of yours out the fridge for you.

Sometimes when you were in source, you just didn't use the stuff you had in the fridge as you would wait three hours for the nurses to bring you a yogurt, for example. By the time the nurses got round to it though, the notion had worn off and [redacted] didn't want it anymore. I felt I had to nip down to Marks and Spencer, sometimes ten times a day, just to get [redacted] what he needed, when he needed it.

28. The amenities on ward 2A were non-existent. There was nothing for the 7-12 year olds. There was a playroom for young children and older children but nothing for those in the middle. [redacted] told me that it was a lonely place. The hospital said they would allow 7-12 year olds into the playroom for an hour a day but that's not enough as they want and need somewhere they can go and speak to their friends. [redacted] doesn't want to glue and make things, he wants to play a games console and speak to people his own age.

29. The 7-12 year olds used to lock themselves away in their rooms but would sometimes be given an X-box or PlayStation to play with but there was never any Wi-Fi for them because the Wi-Fi didn't work properly in the hospital. lived off his phone and his iPad. I got a dongle with my provider with 50 gigabytes of data and I increased the data on his phone to 100 gigabytes. I was paying quite a bit every month just to keep him entertained. I didn't mind doing this as it kept him happy but he needed to be socialised too. The kids weren't allowed to stand and talk to other kids in the hall. You could go to your room but the kids didn't have anywhere else to go in that age group. It felt they were neglected and it's such an important age group; they've just made their friends at the school and they've been pulled away and not allowed to mix with other kids at the hospital.

30. [redacted] was too young to use the teenage cancer room, and we were often stuck in the room when he was in source. [redacted] would be stuck sitting in his bed as he couldn't get out to stretch his legs on the ward.

31. The hospital was a lonely experience for parents. You couldn't go down to the kitchen and have a natter with someone if your child was in source. Even when we weren't in source, the nurses weren't very forthcoming at keeping an eye on [redacted] for me. Even when I had to get a [redacted] but I couldn't get anyone to sit with [redacted]. My mum was eventually able to come up for him. At one point [redacted] hadn't left his room for two months in ward 2A. Nurses were blaming people coming on to the ward for bringing bugs with them so [redacted] said if he had no visitors, they couldn't blame us.

32. There were some nurses, an oncologist and some other doctors on the Schiehallion ward. I think there were two nurses for maybe six patients, depending what was going on in the ward. The Schiehallion ward was never empty, if that makes sense. A bed never got a chance to go cold; if someone was leaving, there was somebody coming in that bed straightaway, so we just used to say it was like going to the airport. It was just free flowing all the time, which wasn't nice to see, because it was like, God, is there never an empty room in this place?!

33. The nurses would walk in the room and do all the meds, the observations and whatever else they had to do then walk out again. [redacted] was old enough so sometimes I had to leave him on his own to go and do washing or to nip into Braehead to buy shopping. Maybe [redacted] had wasted his pyjamas because he'd been sick and I needed to buy him new things. When he was really sick though, you needed someone to keep an eye on him, and when you asked the nurses this, sometimes, you were told he was old enough to look after himself. He was attached to two drips bands. If he needed to get to the toilet, he would struggle. When I said this to the nurses they told me to give him the buzzer. If you did use the buzzer, the majority of times the nurses would respond, unless they were really busy or something was going on the ward. For example: another child needing help or people were on their tea break or

things like that. The joke between the parents was that you never rang the buzzer at eight o’clock at night, because you wouldn’t see anybody until at least quarter to nine, but that’s just because they’re doing medicines, their observations, they were tied up. You joked about these things because you noticed it, but they can’t be there 24/7 because they have got a lot of patients to see to.

34. The kids’ medicines were kept in a drawer in their bedroom which was locked and only the nurses had the keys, which was fine. But if I was downstairs getting a coffee or something for [redacted], nurses would come in, issue his medicines, and they’d leave them sitting out for me to give him. You’d go in the room and see the medications sitting. Luckily I was always clued in, but he could have been the typical child that really didn’t want to take their medicines and throw them down the sink. I didn’t like that fact that the medicines were issued but they’d just leave them sitting for me to come and make sure he takes them. I don’t know why the nurses didn’t sort out the medications, lock them in the drawer then say to [redacted] to tell me to go and get the nurses when I was back. The medicines were just chucked in a little pot so you had to trust that they’d put the right medicines out. You used to listen to the nurses discussing the medicines as they were putting them out and there was the odd time where you’d have to tell them that the dosage of a particular medicine had changed and then they would have to go and check as they weren’t given the update at the handover. I know the nurses are busy but I don’t think they should be issuing the medicine when there’s not a parent about if they’re expecting the parents to give the child the medicine.

35. I don’t know if all the nurses were specially trained cancer nurses but a lot of them had been doing it for quite a few years. You could tell the difference from a nurse that had been there a year and a half to a nurse that had been doing that job for ten years.

36. [redacted] liked ward 2A to begin with. When he could hear and he could have a bit of banter with the nurses. Some of them would come and have a bit of banter with him and they'd crack a joke. If the nurses had a spare five minutes, they'd come and pop their head round the door and say, "How's it going?", because they learned [redacted]'s life was his consoles and food. They knew they could strike up a conversation with him or have a laugh with him and that was fine, but his mood started to go down, and he needed to mix with other kids. Yes, he can go to the playroom but he doesn't want to go to the playroom, because nobody else wants to go to the playroom. [redacted] was so excited when they discharged us home 20 December 2017. He was glad to get home as it was like being in a padded cell at the hospital. You weren't even allowed to leave your door open. It had to be closed as part of infection control.

37. Ward 2A was fine to begin with but after I started asking questions around mid-January 2019 about the cleanliness of the room and what they were doing in the rooms regarding the water and infections, I found that [redacted] was put in 'source' more often. We were confined to the room in isolation and you can't open doors or windows and no fan is allowed. As [redacted] was having chemo his faeces and urine had to be monitored to see when his body was clear of it so he would soil in a pot and pee in a bottle. Usually I would take the stool samples or bedpans to the Sluice area in ward 2A where you would mark your name on it, drop it off in the room, wash your hands and come back out. The nurses would then go in and measure them. But when you're in source, you're not allowed to do this either so the bedpans would all have to stay in your bathroom until the nurses came to collect them and I often had to chase them to do this.

38. If I asked why [redacted] was being put in source, I was told by the staff that had picked up a bug in his bowel. They never told me what the bug was but they just told me that he kept getting a bug in his bowel and he had to be in source. I don't know how he was picking these bugs up in his room. When

he was in source for these bugs in his bowel we weren't allowed to go anywhere in the ward but I was allowed to take him down to the atrium. I don't know why that was allowed. I was told by the staff on the ward that it wasn't safe for him to walk round the ward as he could infect other kids, but it was okay for him to go down to the atrium where there were a couple of hundred people wandering past him. It didn't make sense.

39. The questions I was asking were about the cleanliness of the rooms and why there were always rooms locked up. There wasn't a day went by in ward 2A that a room hadn't been sealed off so I would ask why that was happening. I was always just told by staff that they didn't know or there was just something needing done to it. I would also be told that Infection Control were coming down, and they would send the Infection Control nurse, who was the head of infection control on the ward, to see me if I wasn't happy, which they never, ever did.

40. [redacted] was briefly moved to ward 3C, the children's renal ward, between 11 October 2017 and 14 or 15 October 2017. This was because his room in 2A was needed for a child who was sicker than he was. He was readmitted to ward 2A when another bed became available there.

41. In ward 3C, the staff couldn't have been nicer, they were lovely. [redacted] didn't want to go back to ward 2A. He didn't like the way staff on ward 2A looked at him and treated him. When he was diagnosed with scabies on ward 2A, some staff would wear gloves when they treated him, some would refuse to treat him altogether and some would talk about him on the ward, which [redacted] would sometimes overhear. They would dash in and treat him and dash out sometimes and that made him feel horrible. Ward 3C was a bit more relaxed. I found in ward 2A, everyone was on edge. I understand it's a busy ward and there is a lot of sick kids but you sometimes just felt as if the staff run in your room, do what they had to do, then run out your room again. There were other

nurses that would like a natter with you and a catch up which is needed when you're in there but in ward 3C, the staff were interested in [redacted]. They were asking him about his hobbies, school and how he was. It made a wee bit of a difference to [redacted].

Diagnosis of Scabies in ward 2A October 2017

42. On 23 October 2017, [redacted] developed itchy lumps on his legs. Scabies was mentioned and then eczema and chicken pox. The staff contacted dermatology and someone came up to look at him and initially said it was eczema. Then dermatologist then said it was definitely scabies and we'd all have to be treated, [redacted], my mum and myself. So I removed all the bedsheets and [redacted]'s clothes and pyjamas and went out and got new stuff. He was given all sorts of lotions and potions and he was crying because they were burning his skin. I knew it wasn't scabies. No one else was catching it.

43. I told the nurses that were on the ward that every time [redacted] used the water his skin was crawling and his hands got sore and he started to get nodules on his hands. He was just so uncomfortable after he used the water and the lumps on his legs, the rashes and the nodules would get worse. I know that if I ever had a shower I felt like something was crawling on my skin and some of the other parents had said the same. One of the nurses on the ward told me that because [redacted] was on chemo his skin would feel different because of the chemotherapy treatment, she did not mention the water as a possible cause of the problem. I wasn't on chemo and I felt it too, but I thought maybe it was because the water was harder in the city than what we were used to in the countryside. I was dismissed repeatedly by staff and the itchy lumps continued for months. If it was scabies, nobody else caught it and it's infectious. I don't think that they knew what it was but they wouldn't admit it. I would have had more respect for them if they had. I strongly dispute that it was scabies but it's noted in [redacted]'s medical notes that he had scabies.

44. On 22 November 2017 [redacted] had a chest infection. It was the same thing he had had in October 2017 which was the chemo fungus. His chemo was delayed for a couple of days; he was on IV antibiotics which made him sick so there was no point in giving him the chemo as that also made him sick. They held off with the chemo until he was fit enough.

45. On 27 November 2017, I was approached by a nurse who told me she was having to go home because she had itchy skin. She said, "I'm going home because my skin is itchy and other children in the ward have got what [redacted]'s got". I think she was blaming us and hinting that she had scabies but she hadn't been treating [redacted]. [redacted] had been in source on the ward so it was unlikely the nurses or children could have caught it from him.

46. At one point when my mum was there, another nurse, who I won't name because there is a chance in the future we may have to go back, said to my mum, "It's your fault this scabies is on this ward. You're going outside for a coffee; you're bringing all these bugs in here". [redacted] then stopped letting anybody visit him. He said if he didn't have visitors, the staff couldn't blame anyone. Certain nurses were refusing to come into his room to treat him because of the scabies.

47. I was asked by another parent if my son had scabies. I told her he didn't and she said that staff were talking about [redacted] at the desk. There was one point where the nurse in charge and another senior nurse were standing outside this other parent's room saying, "We need to get them off this ward because they are filthy. They're spreading this to everybody else". That was out in public where everyone else could hear them. I said to the parent, "He's got a problem with his skin because of the water. They think he has scabies but he doesn't. Not one of the staff puts a pinny on or gloves when they come in the room." I approached the staff and told them that they didn't have the evidence

that he has scabies and asked why they were discussing him. They apologised for discussing him and I just took it.

[redacted]'s treatment and other admissions between 20 December 2017 and 29 January 2018

48. [redacted] was discharged on 20 December 2017 as his treatment had ended and he was in remission and doing well. He was tested for enterobacter before the discharge, which was confirmed on 23 December after he'd gotten home. I only found out about this from his medical records. I knew [redacted] was being tested to see if he still had a stomach bug, but I was only ever told it was a bowel infection. Not once was I ever told that it was enterobacter or that it was an environmental bug.

49. When [redacted] was at home after being discharged, his skin didn't improve straight away but after a few days, you noticed it wasn't as inflamed. I was at home and he was bathing and using lotions and potions on him as his skin had gotten so dry after being in hospital. His skin hadn't fully recovered but you could see an improvement in it.

50. On 26 December 2017, [redacted] had a temperature spike so we returned to Day Care which was ward 2B in the RHC, for a lumbar puncture. Usually if children spike a temperature there is a protocol. You phone the Schiehallion ward and they tell you where to go. If we were at home when this happened, sometimes they would phone Dumfries hospital to let them know we were being sent there. If we were in Glasgow, staying at Marion House, [redacted] would be admitted to ward 2A. As the kids are having so many poisons in their system from the chemo, they can get sick quickly and this protocol was to get them checked out just in case they were unwell and it could be dealt with. Sometimes [redacted] was given antibiotics for 48 hours until his bloods had been checked for increased infection markers. That didn't happen on this occasion though as they rechecked [redacted]'s temperature and it had gone

back down. They did his bloods and his counts were too low so they sent us away. His counts needed to increase before they could give him a lumbar puncture.

51. On 27 December 2017, I received a call from the nurse in charge at Day Care, telling me that Professor Gibson wanted [redacted] to come back to the hospital straight away. [redacted] had to get a lumbar puncture which I thought they just needed before they could start the next round of chemo. The purpose of the lumbar puncture was so he could get some chemo blasted into his bone marrow, which was intrathecal methotrexate, and they also took a sample to test the fluid to check whether he was still in remission. We stay an hour and half away and I don't drive, so I asked if [redacted] could finish his breakfast then we'd head through. We went all the way back up and he had his lumbar puncture then we came home. There was no mention of the enterobacter at this time, or whether he was getting treatment for it, but [redacted] was on all different sorts of medications.

52. On 2 January 2018 we were at Day Care, ward 2B, collecting medicines but was re-admitted to ward 2A after having a temperature spike in Day Care. had the normal blood tests done and his infection markers must have come back higher than normal as he was given antibiotics straight away. [redacted] was also getting IV chemo while he was there. We were in ward 2A until 26 January 2018.

53. [redacted]'s skin started to get worse again after being admitted to the hospital. Every time he used the water, the itching started again. I would bring it up to the nurses and the doctors on the ward every time this happened. I told them that his skin recovered when he went home and that it only started to deteriorate when he came back to hospital and started using the water. Both the nurses and the doctors would dismiss the itching as potentially being scabies again.

54. During this stay we were moved rooms. We were in room 10 on 2A and we noticed that it was really cold. I am usually quite a hot person, as is [redacted], but I was putting my cardigans on and [redacted] had his pyjamas, his dressing gown, his socks, a hat and his bedcovers over him. We told the nurses and they got an engineer to come and look at the room. I was playing about with the temperature gauge and he told me not to bother as they control the temperature in the rooms. He had a look and said that it was fine. A couple of days later the doctors were saying the room was really cold and an engineer came back to look again. We had to leave the room while he looked at the air conditioning and he found that the pipes were frozen. We got moved out of room 10 into room 8 at that time. The temperature in room 8 was fine.

55. When [redacted] was discharged on 26 January 2018 we went to Marion House which is run by the CLIC Sargent charity. Marion House has ten bedrooms, three big kitchens and a games room. It's a home from home that families who live far away can use instead of having to travel back and forth. It became our own little fantasy. If [redacted] got out for a few hours, we could go to Marion House and make some fresh food, something nice to eat. You can get some peace and quiet in Marion House too. It was only a five-minute walk from the hospital so it was closer than home for [redacted] being able to get his treatment. It was booked through the receptionist at Schiehallion, Veronica, who asked if I'd like a room there. She explained what it was to me and I thought it would be great as I had previously been relying on people coming up once a week to take my washing away for me. Staying at Marion House meant I could get it done myself.

56. [redacted] was re-admitted to ward 2A on 29 January 2018 for more chemo. We went to Day Care that day and were told to return to the hospital at 9pm that night to be readmitted from Marion House to ward 2A for chemo the next day. He was admitted at that time of night because they needed to give [redacted] extra

fluids during the night to prepare him for the chemo the next day. It’s easier to give the fluids through the night than it is during the day. I am not sure how long this admission lasted for.

Aspergillus infection: February 2018

57. On 9 February 2018, [redacted] had an operation to remove fluid from his lungs. He got to the stage where he was getting more breathless. He was finding it hard just to walk the few steps from the bedroom to the en-suite bathroom. I was told by staff that [redacted]’s chest wasn’t sounding quite right and they sent him for a chest X-ray. After that the surgeons turned up, and they said that was going to theatre to get some fluid removed from his lungs under anaesthetic. We were shown the x-ray of [redacted]’s lungs and where the fluid was. They removed 330mls of fluid from his lungs which they said had been due to the chemo fungus rearing its ugly head again. I later found out from his medical records that he had aspergillus, but that wasn’t mentioned at the time. My friend, who is a nurse, told me that it’s from black mould spores in damp environments and people are more susceptible to it when they are in hospital. The doctors told me that some children do develop issues with their lungs when they have chemo and I just accepted that. I didn’t question it. [redacted] was on anti–fungal medication around this time. He was on ambisome before surgery, then after it, he was on gentamicin and lots of other antibiotics. I don’t know how long he was on the gentamicin for. He was really unwell and was spiking temperatures. I think it might have been round about this time the ambisome was changed to posaconazole, this was because posaconazole was an oral medication and it was thought that his central line could do with a break. At this time, [redacted] stayed on ward 2A and was put ‘on watch’ for a while where he had a W beside his name on his board. This is when, if the buzzer rings, the staff make sure they get there as soon as they can. They had to keep an eye him so staff would keep popping in and out of his room.

Recurrence of scabies: February 2018

58. On 25 February 2018, [redacted] was moved from ward 2A to 2C because the nurses in charge of the ward said he had scabies again. He had started itching his skin again and complaining. [redacted] hadn't been using the water on ward 2A. He had been using bottled water to wash his hands. We were told that we should not drink the tap water and should use bottled water, but we had been told that we could wash with it. I don't know exactly when we were told this, or who by, but it was at the start of 2018. [redacted] had to shower because he had theatre for another lumbar puncture and the nurses did a spot check to see if he'd had one. As soon as he started using the water again he told me that his skin was itchy. I was applying lotions and potions to keep it at bay, but [redacted] was scratching and this made it look worse. We were in one of the rooms on ward 2A that was just behind the nurses' desk. I heard the nurse in charge, another nurse and a doctor saying: "we need to get him out of here before he starts infecting everybody". I didn't open the door and shout at them as I didn't want to cause a scene in front of the kids in the ward. I just bit my tongue and we got told we were moving. We got moved really quickly to ward 2C but they didn't give us [redacted]'s medicines with us. A few hours later, I went back to get his medicines and there was another patient in [redacted]'s room that he had just been in on ward 2A. I went up to the desk and said, "If you're moving us out of that room because [redacted] has scabies, would the room not have to be deep cleaned?" I think the room had to be left empty for 24 hours too. We were made to feel really dirty. [redacted] didn't want to go back to ward 2A because of the way the staff made him feel.

59. The next day someone came from dermatology and said he thought it was chicken pox and not scabies. Every day they said he had something different and it got to the point where I asked dermatology to leave as they didn't have a Scooby doo what was going on. I was asking them to admit they didn't know. I asked how it could be scabies then eczema and now chickenpox. I told them

that [redacted] had already had chickenpox and it looked nothing like his rash, but the doctors told me chickenpox looks different when someone is on chemo. If it was scabies, they should have said it was scabies and not tell me at two o'clock that it was scabies and then at six o'clock that it's chickenpox. I wasn't getting any answers.

60. On 2 March 2018, [redacted] was transferred back to ward 2A. [redacted] was really upset about this as he didn't like the way he was treated on ward 2A and he wanted to stay in 2C where everyone was lovely to him. At that point we were told he had eczema, then on 5 March 2018, they said it was chickenpox. On 7 March 2018, [redacted] was allowed out on pass which meant we could leave the hospital for a few hours and go to Braehead if we wanted some lunch, or you go out for a walk for a few hours. You could have a bit of normality and be away for a couple of hours. On 8 March 2018, we were allowed to stay over at Marion House for the night. I didn't understand why, if had chickenpox, they were allowing him out on pass and into Marion House where there are other immunosuppressive children.

61. On 12 March 2018, we were put back into source because the doctors thought that it was scabies again. We were given more creams to put on. The next day, [redacted] was due to go for a lumbar puncture and we were asked to go to Marion House so that [redacted] could have a bath. [redacted] had made it clear to the nurses on the ward that he would not use the water on the ward. The Charge Nurse told us that his only option was to go across to Marion House and have a bath there ahead of theatre. If he had been diagnosed with scabies the day before, why were we allowed to go to Marion House the very next day so he could get a bath? It didn't make sense but we went. At this point, [redacted] wasn't using the water in the hospital. He was using big bottles of water to wash with. He hadn't been told to do that by the hospital, he was just sick of being labelled as having scabies. So he was quite happy to go to Marion House and use their clean water.

62. After he stopped using the hospital water, his skin did gradually start to feel better and he wasn't itching his skin.

63. On 16 March 2018, Professor Gibson came to our room and told us that the kids were going on Ciprofloxacin to stop them from getting ill. I did ask her why and she said it was just to protect them from issues with the water. Whenever you asked what was wrong with the environment and why our kids were the only kids who were on these drugs, we were told that it was because they had a weak immune system. It was the doctors and nurses who were telling us this, but I never felt that we got a straight answer.

64. On 25 March 2018, I was approached by a nurse who asked if I had leaked anything about the water in the hospital to the press. I think she thought it was me because I was very opinionated and telling people I was sick of their bullshit and just wanted the truth. The nurse told me there was stuff all over the news and asked if I had seen it. I hadn't seen the news but I had people messaging me about it. A week later a reporter contacted me for an opinion. I didn't speak to the press though.

65. [redacted] was discharged from the RHC on 5 April 2018 and he attended out-patient appointments from then until 10 May 2018. [redacted] struggled to hold his salt when he was going through chemo. Some days he could have three or four bags of potassium and one of magnesium and this took a long time to administer. The bags are 500mls so you knew it wouldn't be a quick appointment. We were staying at Marion House during this time and his appointments were in Day Care at the RHC.

Diagnosis for hearing loss and link to antibiotics: March - September 2018

66. The teacher [redacted] had at the hospital and I noticed there was something wrong with [redacted]'s hearing around the end of March 2018. We thought he was maybe pulling a fast one and just not wanting to do his school work. I was noticing silly things as well; for example, he was turning his headphones up to the point where you could actually hear what he was listening to and he wanted the TV turned up louder. He was missing things that I was saying to him. I started saying silly things to him such as, "[redacted], you know I'm going home this weekend, would you like me to go and get you some iTunes?". Normally, a child's ears would prick up but they didn't. Normally, if I opened a bag of crisps I would usually get, "Do you really need that bag of crisps, mum?" I'd get a bit of cheek from him but there was nothing at this point. I did wonder if there were any issues. Then the teacher said to me that [redacted] wasn't picking things up in class but that it had been a really hard lesson. So I asked a couple of different doctors to look at him but I was brushed away. I asked and he said he was struggling to hear people. I then asked Dr Albert, who was a junior doctor, if he would humour me and have a look in [redacted]'s ears. He did and he saw some little air bubbles in the fluid in [redacted]'s ears. He said it looked like he had maybe had an ear infection but they didn't pick up on it because he was on so many antibiotics. He arranged for [redacted] to have a hearing test on 3 April 2018 and I was told that he had lost some of his hearing. I wouldn't say I was annoyed, but I did wonder, "Why has he lost his hearing? Is it part of the chemo?" A few weeks later, in May/June we found out that he had lost 52% of his hearing. We were told that the antibiotics given to could cause hearing loss because they were ototoxic medicines and this is what they thought happened to [redacted]. I cannot recall who said this to me.

67. After that, there was another test done that I didn't know about and it was sent to Dundee and then they had to send it to Manchester. A few weeks later, I don't know when exactly, Professor Gibson told me that [redacted] had a dodgy gene from my mum's side of the family, so anything that was ototoxic was going to take his hearing. She said it was more than likely the gentamicin that

had caused it. I had asked if it could have been the chemo but she said he had been on that for months beforehand and his hearing was fine so they didn't think it was that. They put it down to the Gentamicin that he'd been given for the chemo fungus in his lungs in February 2018. So that was fine and he got fitted with hearing aids, but over time, I gradually noticed his hearing was still deteriorating, and I wondered why it was still declining, as he was not on gentamicin anymore. I felt that something wasn't right and I started to query it. [redacted] had been attending the Audiology clinic following his hearing loss in June 2018 and was receiving regular testing for his hearing there, which also allowed his hearing aids to be adjusted. During one of these appointments in August 2018 we were told that [redacted] was deaf as his hearing had deteriorated so much. Around that same time, one of the pharmacists at the hospital told me that any drug that has "azole" in it can cause permanent hearing loss with long term use. [redacted] was on cotrimoxazole and posaconazole and I knew it was the posaconazole as he had been on the cotrimoxazole from the first day he was admitted to hospital and it hadn't touched his hearing. By this point, [redacted] was an outpatient and I said to Dr Jacob (which was his first name), who was one of the doctors at the clinic, that I had concerns that the posaconazole might have affected his hearing and Dr Jacob said that he would take him off it as he didn't need it anymore as he was an outpatient. Dr Jacob did not say anything about posaconazole causing hearing loss. I think that, if he hadn't been on the posaconazole then [redacted]'s hearing might not have declined further, but I know it was the gentamicin that caused the permanent hearing loss in the first place.

Admission with Enterobacter: 14 May 2018

68. On 11 May, [redacted] hadn't been well in day care, and it was my mum that was with him. She was getting quite concerned, because [redacted] was just sleeping the whole time he was in day care. The doctor just said his blood was fine and

blamed the chemo. They always blame chemo when the kids are tired. My mum was trying to tell them he was not himself. All he was doing when he got back to Marion House was sleeping and he was complaining that his stomach was sore and he was having a lot of bowel movements. Before they left, a nurse said to my mum that she agreed that [redacted] shouldn't be going home and he should be getting his medication. She also told my mum and that if she was really worried about him, to phone 999. My mum spoke to me on the phone and I told her, as long as he's drinking, he should be fine. He's alright and breathing.

69. On the Monday morning, which was 14 May 2018, my mum took [redacted] into day care, and she phoned me about 12 o'clock, and told me I would have to go to the hospital as no one was listening to her. [redacted] was pasty and clammy and not well. I don't drive [redacted] , so I got a friend to rush me up to Glasgow. I took one look at [redacted] and walked into 2A and told them I needed someone to come and look at [redacted] as the "clowns" next door were not listening when we were trying to tell them there's something not right with him. Jane, one of the advanced nurse practitioners who was on the ward that day, came through and looked at him and agreed he was not right. She went to get Professor Gibson. When Professor Gibson arrived, she wanted observations done straight away and she wanted chest x-rays done. Within ten minutes of that, [redacted] started having rigors and that was him slipping into septic shock.

70. [redacted] was put on some antibiotics but he wasn't on them for that long. He perked up after a day or two, maybe after 48 hours he started getting back to normal. He was speaking to us, he was being a bit cheeky and demanding food, so we knew he was alright.

71. I think it was 48 hours later after he was admitted that one of the doctors who had been involved in his care, Dr Albert, came in and said, "Oh, [redacted] really

gave me a scare. That enterobacter has a lot to answer for." I asked if that was what he had and he said it was and that it was something to do with his bowels. I had suspected this because [redacted] had been moving his bowels so much. There was no explanation on how they thought he had got it. He spoke about it as if it was just another bowel infection.

72. [redacted] was in hospital for a few weeks, but it wasn't all to do with this infection. Whilst they had him there, the doctors just started the next round of chemo as an inpatient. I think it was during this stay that we found out the extent of his hearing loss and then a few weeks later we found out that it was a genetic problem linked to the antibiotics.

[redacted]'s treatment: July 2018 – April 2019

73. From July 2018, [redacted] was attending Day Care 5 days a week from Marion House as an out-patient. This then dropped to three days a week so we could go home at the weekends, and then it dropped to once a week so we moved home and just travelled up to Glasgow once a week. The out-patient treatment included regular blood checks and he attended clinic two in the RHC, every Tuesday. It wasn't part of Day Care but it was the Schiehallion clinic. He had a lumbar puncture every 12 weeks. [redacted] was on oral chemo as well but that was restricted to once a month so they could make sure all his blood counts were okay and he had no issues.

Closure of ward 2A and the move to the adult hospital: late 2018

74. When [redacted] was an outpatient we were not attending ward 2A/2B so we were not impacted by the move to ward 6A in the QEUH in September 2018. I was made aware of the move of the Schiehallion ward from the RHC to ward 6A. We were at home and I was getting messages on social media asking if I knew the ward was closed and that all these big investigations were going on. I knew there was something going on but I was at home so it was "out of sight out of mind". I was told by Professor Gibson and the Charge Nurse as I

was leaving the ward that the same protocol was in place if anything was wrong, for example, if [redacted] was to spike a temperature. I had all the telephone numbers and I was told that even though the ward had moved, the protocol was still the same. I wasn't given any guidance about the move but I didn't need it as [redacted] wasn't accessing Day Care or anything at this point.

ADMISSION TO QEUH FROM 23 APRIL 2019 – NOVEMBER 2019

75. On 23 April 2019, [redacted] attended an appointment for his routine lumbar puncture. He was on a high and was carrying on with Dr Storey and this was strange because they didn't usually get on. Jane and Wendy, who were the Advance Nurse Practitioners (ANP) doing the checks that day, noticed too. [redacted] went away to theatre to get his lumbar puncture and we went to Marion House afterwards. [redacted] had gone to bed and when he woke up he said to me he wasn't feeling great, which can sometimes happen after a lumbar puncture. I decided it would be best if we stayed another night as he didn't look right. He was eating and drinking, so I wasn't overly worried. On the Thursday morning, I flung open the curtains and [redacted] went absolutely mental. He was screaming at me to shut the curtains. He didn't like the light and he didn't want to move his head. [redacted] had a temperature so I phoned the ward and told them about it and that he didn't like the light and didn't want to move his head. I was told to bring him over straight away. I got him over but there were no beds on the ward so he was sitting upright in a chair. They were going to put us in ward 3C but I said I would take him back to Marion House if they didn't think he really needed to be there. I think they were going to let us go but when we were waiting on his Oramorph to take away the pain, spiked a temperature.

76. Professor Gibson was there by that point and said [redacted] wasn't going anywhere. She wanted a CT scan as his lumbar puncture from the Tuesday was abnormal. She wanted an emergency lumbar puncture done the next day. had the CT scan and we were put on ward 6A. They started to give him IV

steroids, once they actually got access to a vein; he hadn't really drunk anything all day so he was dry and they struggled to get a line in.

77. The next day, which was the Friday, he had his lumbar puncture. Later that night, Professor Gibson came to take me into the 'room of doom'. This is what we called the room you got taken to if there was bad news. She told me had relapsed with CNS disease which is cancer in the central nervous system so he had to start chemotherapy again and he was an inpatient in ward 6A.

78. [redacted]'s previous central line had been removed in November 2018 as he wasn't needing it for treatment anymore; he had taken unwell so when he was in theatre, Professor Gibson had decided just to remove it to stop any risk of infection. [redacted] had his new central line fitted on the Friday too, which was 29 April 2019. This was because he was starting a high dose chemo to treat the CNS.

79. [redacted] kept spiking temperatures from about 18 May 2019 to 24 May 2019. On 25 May 2019, we were told his liver was enlarged, which sometimes is a side effect of chemo. [redacted] got out on pass on 29 May and again on 31 May but he spiked a temperature when we were at Marion House. I phoned the ward so they started the protocols and took blood to check if there were any infections.

80. On 1 June 2019, [redacted] went downhill really quickly. He took really unwell and his belly was getting bigger and bigger. On 6 June 2019, he had a lumbar puncture and a bone marrow aspirate. This is when they told me [redacted] had Haemophagocytic Lymphohistiocytosis (HLH) due to chemotherapy. Basically, the immune system had started attacking his organs. Apparently this can happen if people have a rubbish immune system.

81. I had to go home to see my other son and my mum was with [redacted]. She phoned me on 9 June 2019, a Sunday, and said Professor Gibson was coming to speak to me. I was sure Professor Gibson was off that weekend but I got my friend to drive me up. Professor Gibson took us in to a room and said she would get someone to look after [redacted]. She sat us down and she said she was really worried about [redacted] and that the next 48 hours were critical and we could lose him. He was really, really unwell. He was on oxygen at this time and he looked nine months pregnant, that's how big his stomach was. It was really risky for him to be moved around the hospital, or from the QEUH to RHC and back, and if he had to go for an X-ray or an ultrasound, a team of people had to go with him in case something happened to him on the way. He had been so unwell at that time that when he sat up or walked, he would struggle to breathe. The team of people helped move him around the hospital in case he needed something like oxygen for his breathing during the journey. He was like this for a few days. On 11 June 2019, [redacted] had started spiking a temperature again and on 12 June 2019, he was sent for more scans. One of the doctors, Dr Shazi came in and said they were still really worried about him. Professor Gibson had had to go somewhere so Dr Shazi was in contact with her every day. This seemed to go on for days and he was still really unwell. I can't remember when he began to stabilise.

82. Between 18 June 2019 and 23 June 2019, he was spiking a temperature and he had developed a bug in his blood. I think this was enterobacter and stenotrophomonas but they didn't tell me that at the time. All I was told was that he had a bug in his blood that had gone in through his central line and he had to get his line removed. He was taken straight to theatre sometime around 26 June 2019 in an emergency slot and had the line removed. He was then moved back to ward 6A.

83. [redacted] had a new central line fitted on 9 July 2019. Throughout July he was an in-patient on the ward but they held his room and sent us out at night as

we had a room at Marion House. So he was effectively out on pass all the way through July 2019.

[redacted]'s admission to Intensive Care: August 2019

84. On 1 August 2019, his temperature was all over the place. We were still allowed to go out at this point but we didn't go. On 2 August 2019, we were allowed out on pass for the night and on 3 August 2019, [redacted] was his usual cheeky self. It was a Saturday and [redacted] had wheeled himself into the ward and shouted at Maxine, the nurse, "Right, Maxine. Get my injections and get my bloods done. I'm going back to Marion House for my steak and ale pie". Maxine came and did his injections and Marie, the phlebotomist came in and took his bloods. Marie had just left the room when [redacted] said to me he wasn't feeling well and was going to be sick. I opened the door and shouted, "Maxine, [redacted]'s rigoring". She came back in the room and hit the button. Everyone came flying in. At one point there must have been about 12 people in the room all trying to help him. They were pushing fluids into him and they were saying it was septic shock. [redacted] couldn't hold his blood pressure so he was taken down to intensive care to get medicine to help him.

85. [redacted] had his central line removed on 4 August 2019 in the middle of the night. He still wasn't holding his blood pressure, and the doctors had to intubate him to give him a rest so they thought it was better to take the line out too whilst he was under anaesthetic. As soon as they took his line out, everything just improved and his blood pressure came back.

86. The doctors told me they weren't sure what had caused him to become so unwell. They took cultures and they sent away the tip of the line to check it for bugs. I got told they were growing something. When we got back from intensive care, which was 6 August 2019, Professor Gibson and Theresa, who

used to be the microbiologist, took me aside and said it was an environmental bug and it was stenotrophomonas. They didn't say how he might have contracted it, but I did have some of the nurses and junior doctors say that they didn't think it had come from the hospital because [redacted] was out on pass at the time. I thought this was a lot of rubbish. No one had touched his line whilst he was in Marion House. And where would he have picked up the bug? He was only going from ward 6A to Marion House and back again. And Marion House was cleaned every day so I don't see how he could have got it there.

87. I think there had been a few infections on the ward at this time and there was a meeting on 7 August 2019 that was called for parents if they wanted to go to talk about the infections on the wards. I can't remember who was speaking at the meetings on behalf of the hospital. Even then, the staff were a bit blasé, it was almost as if it didn't matter. I'm lucky, my son wasn't in intensive care very long but I said to them that it was very upsetting to see your child get so ill so quickly, so they cannot tell us that it isn't important. They also seemed to be suggesting that the kids were picking up the bugs elsewhere and I said that was a lot of rubbish. A lot of the parents who were there were very upset and it felt as if we were just getting fobbed off.

88. [redacted] continued to get his treatment as an outpatient and was staying at Marion House. He was admitted to ward 6A to have a new central line fitted on 20 August and he was admitted again on 28 August for a temperature spike. I don't think this was due to an infection, I think this was just a reaction to his treatment.

Experience on ward 6A in QEUH adult hospital

89. Ward 6A was very different from ward 2A. There was nowhere in 6A to go, there wasn't a parents' kitchen, there was nothing. The food was tasteless

and the kids didn’t eat it. I spent a fortune in Marks & Spencer and WH Smith on food for us.

90. In ward 6A there was no kitchen, no playroom, nothing. If we wanted a coffee or a drink of water, we had to ask one of the nurses for it. Quite often you got forgotten about because the nurses were busy. You had to rely on other parents to get you something out of the fridge. We eventually got a parents’ kitchen fitted in July 2019 and the kids got a tiny playroom. I don’t think the kitchen made a difference. Not a lot of people used it. It would be open but people would be in source and not allowed to use it so you wondered what the point of it was.

91. I didn’t agree with the layout of 6A, because the inpatient ward was at the front of 6A and Day Care was at the back, which didn’t make sense. There’s a bigger turnover in Day Care with their patients, so they’re actually coming through the inpatient ward to get to Day Care. I didn’t like that part, but obviously I had no say in that decision. It was almost as if they didn’t want you to leave your room and they didn’t want you to go anywhere. You didn’t have the freedom to walk round the ward. If you tried to you would be asked by the staff where you were going.

92. The Schiehallion protocols followed you to ward 6A so you knew what to do but the communication issues with [redacted] still carried on here. [redacted] had said that if he didn’t speak English, they would have brought in an interpreter for him but because he’s deaf, the staff don’t give a shit. He has a meeting planned with Professor Gibson to discuss this because he’s still really angry that they didn’t talk to him. Could imaging lying in bed, not very well and nobody speaks to you?

93. It wasn’t the nicest experience as no-one was interested and speech and language couldn’t help us: nobody could help. This was supposed to be the

super hospital for the whole of Scotland, how could nobody help a deaf person? Even now we go and see them, and they keep their mask on. [redacted] struggles. He has got his cochlear implants now, but he struggles with people with masks on. They could wear a visor, so he could read their lips.

94. There were also HEPA filters in the room to purify the air. They were so noisy and so annoying. We were advised it was to keep the environment safer and the air clean as we were so high up in the hospital. They had to stay on all the time.

95. In ward 6A, [redacted] had several different central lines. They had to keep being removed because he kept getting line infections. I think they were all due to environmental bugs but the only one they told me anything about was the stenotrophomonas. I think I only got told about this one as [redacted] was admitted to intensive care with it. When he was in ward 2A, he had the same central line for 252 days without any issues.

[redacted]'s admission to ward 4B and ward 6A: September 2019 - November 2019

96. [redacted] was admitted to ward 4B on 8 September 2019 to start the protocol for his bone marrow transplant. 4B is an adult transplant ward but there were five rooms on the ward for kids who were getting transplants. As part of this protocol [redacted] had to undergo total body irradiation. The Beatson Clinic in Glasgow is the only place that does this, so between 9 and 12 September, attended there, twice a day for this treatment. He was taken there by taxi. I didn't understand why the hospital were shipping children and adults to the Beatson in a taxi. I thought they would have an ambulance specially designed. was neutropenic but he was having to get in a taxi that's used by 100 different people.

97. During this admission, [redacted] was in an isolation room. It's a normal room but everything had to stay outside the room. Anything that was in the room before had to be deep cleaned and washed down to make sure if it was clean. You tried to keep infections to a limit by limiting what you could actually take in the room.

98. On 16 September, I was upset with the way certain things were being done, the cleaning for example. As a result, I had a meeting with Jen Rogers the lead nurse for the children's hospital, and Gail Rolls, the lead nurse for the cancer ward. I didn't think the room was getting cleaned properly and the food wasn't great. Ward 4B didn't let you bring food onto the ward and you couldn't heat soup there either. Sometimes all [redacted] wanted was a bowl of tomato soup but there was nowhere I could get it for him so he would go without food. My mum sat with [redacted] on one occasion and she didn't eat all day as there was nowhere for her to get food from.

99. [redacted] couldn't get someone to come and help him with his sign language as the nurses wouldn't give us what we needed to facilitate this. No one would come in and sit in the room with [redacted] if I had to pop out and I felt like it was worse than 6A. 4B was like a prison.

100. [redacted] had his transplant on 19 September 2019 which was successful. He was moved back to ward 6A on 16 October 2019 and then discharged to Marion House on 23 October 2019 and was attending Day Care.

101. On 1 November 2017, [redacted] fractured his T7 spine. He was in the Marion House with my mum, when, all of a sudden, she heard him screaming after he had gone to the bathroom. He was rushed to hospital immediately and admitted to ward 6A where he went for a scan that revealed he had fractured his T7 spine. We were told by the nurse on the ward that this was likely caused

by the long-term use of steroids. [redacted] was given treatment to strengthen his bones as a result of the fracture.

102. [redacted] was admitted to ward 6A again on 15 November 2019 as he had a temperature spike. On 17 November 2019, [redacted] was allowed out on pass. We were told on 18 November that he had contracted acinetobacter. The doctors said that he must have picked it up from Marion House or from being outside and attending Day Care. I didn't know what it was because I'd never heard of it but I was told they needed to take his line out so that was done on 21 November 2019. They said it was another line infection. [redacted] was given antibiotics for it but he wasn't on them for very long. He just recovered quickly. He was discharged on 24 November to Marion House and then home a few days later but he was still attending Day Care to get medicine and to go to sign language classes. This continued until March 2020.

103. From March 2020 onwards [redacted] stayed at home and returned to hospital once for a lumbar puncture after six months and then clinic appointments in November/December 2020.

104. [redacted] doesn't get any active chemotherapy now, he's on a few basic medicines. We had a couple of appointments in December last year (2020) with a few people, to check [redacted]'s growth. He needs growth hormone therapy which had been supposed to start then but it's not happened yet. He needs a thyroid test and a puberty test but nothing's been done. [redacted]'s due another lumbar puncture in September 2021 in the Queen Elizabeth. After that we should be getting discharged from Glasgow and hopefully to Dumfries for yearly bloods.

WATER: EVENTS INVOLVING WATER SYSTEMS

Water incidents in RHC 2017 - 2018

105. There were issues with the water in all of the rooms we stayed in in ward 2A. There was the issue with [redacted] being itchy every time he used the water.

106. I was first aware of problems with the water in early 2018 I think. I did notice before, when [redacted] was admitted in 2017, that my skin felt different after using the shower and [redacted] developed itchy lumps but I had put it down to it maybe being harsher water in Glasgow compared to what we use at home. During his second admission, which was January 2018, there were signs being put up saying not to drink the water. I asked staff why but I never got an answer.

107. The flooding in the rooms was also a joke. If you had a shower, within five minutes the water would be running out the bathroom and through the bedroom, as the rooms were en-suite. It happened in a few of the rooms we were in, in ward 2A. One of the other mums has a video of this. You had to make sure you were in and out, the quickest shower possible as the water always used to flood. I had a stockpile of towels ready to mop it all up. I was told by the nurses and the cleaning staff that it was something to do with the drains, they can't handle the pressure, it's too quick. I'm not sure what causes the flooding but there's not much space between the holes in the shower drains as they're filled with black stuff.

108. Other parents had been talking about the drains. One had asked if I had ever shone my torch down the shower drain. She said hers was glowing because her daughter had had chemo and peed in the shower so it was bright red. I got my phone torch and shone it down the drain in the shower unit to see all the black slime and goo that was congregated. Other parents said to me that if they looked down their drain it was black slime too. I took the shower head apart to see what gunge was in the shower head. I have OCD and bleach my own shower head every week at home so I know how dirty they can get. Mine wasn't pretty but it became quite regular that they changed the shower heads.

They got changed at least once a month in [redacted]'s room. It didn't happen straight away; it was only when all the water issues started. I can't remember exactly when this was but it was the same time we were told not to use the water in 2018. I asked the maintenance guys changing the shower heads why they were doing it and they said it was to prevent a build-up of bacteria. This all seemed to happen in 2A, that's where I noticed it and I think it was maybe during [redacted]'s second admission which was early 2018. There was a sign up telling you to please run the water for two or three minutes before use.

109. The maintenance guys came and put filters on the taps, it was a big round thing that sat on the tap face. I think this was during March 2018 as they weren't there during [redacted]'s first admission. They got removed once a month and again this was in 2A. When we got moved to 3C the taps didn't have filters and I asked why they didn't have them there. The filters were on the taps in ward 2A at this point too but not in wards 2C or 3C. When I asked the nurses why they didn't have them, they said they hadn't got round to doing them yet but they were working their way round. They were meant to be getting filters fitted in Day Care too which was ward 2B at the time. Some of the nurses in ward 2C, were really open and said they wouldn't let immunosuppressive kids use the water. Nobody on any ward had ever said to us not to use the water for showering though. On ward 6A they had all the filters on the taps when [redacted] was first admitted to the ward. [redacted] didn't have the same issues with the water in 6A as he had in ward 2A so he was able to shower and this was one of the first things he commented on.

110. When we were in ward 2C, which is where you were put if you had chickenpox or scabies, in February 2018, the staff were giving out bottles of water and the parents were buying bottles of water too. We were also getting bottled water on 2A, although the water they gave us there had such a high salt content, I was worried about [redacted] having too much salt so I also kept going to Lidl or Marks & Spencer for water to make sure [redacted] had enough to keep him

going. This was happening at the start of 2018. None of this had been going on when we were in hospital in 2017. On ward 2A we got a piece of paper from infection control saying that we shouldn't drink the water or use it to brush our teeth. I've kept every piece of paper that the hospital handed out but this is the one that I've lost. It's the one that infection control handed out, undated, advising us not to brush our teeth with the water or drink the water. We got the piece of paper from infection control sometime in early 2018 telling us not to drink the water or use it to brush our teeth but we were never told why.

111. When we came back from ward 2C to 2A on 2 March 2018 it seemed that something was going on. All these "suits and boots" appeared, I don't know who they were but I think it was the top management people of the NHS. On the 3 and 4 March 2018 all these people appeared on the ward, checking things out and making sure everything was super clean. We were told they were there to inspect the wards but we weren't allowed to speak to them. I think it was because I had asked many times to speak to Jane Grant, the Chief Executive, but she would refuse to speak to me. I wanted the truth as I was sick of being lied to. I was sick of Infection Control blaming nurses, cleaners and parents for everything that was going on. They would come in and say that things weren't being done properly but the cleaners never had the right stuff to clean with and I just wanted the truth about what was going on with the water.

112. At one point in ward 2A, we had a portable sink and were handed a piece of paper telling you not to put tea and coffee down it as it was for hand washing only. I'm not 100% sure when this happened, but I know they appeared about two weeks after I had had a meeting on 13 March with Jamie Redfern, Professor Gibson and Melanie, the lead nurse and I had raised concerns about the water and several other issues. There was a little button on the sink that you pushed and the water would come out. I think there was a bottle inside the sink so staff would just come and change the bottle. These sinks

just turned up and we were told by the Charge Nurse and a member of management, though I cannot remember their names, not to use the water for any purpose but the hospital is denying they said this now. The other parents on the ward told me that when they raised the fact they had been told not to use the water on the ward, hospital management had denied ever saying this, even when there were portable sinks on the ward. We were told by the Charge Nurse and the person from hospital management that they'd found something in the water and they needed to make sure that it was gone. It was around this time that we were also told that the kids were to get antibiotics, which was 16 March 2018. I think we had the portable sinks for a couple of weeks. When they were taken away we weren't told anything other than we could use the water again.

113. When I had my meeting with Jamie Redfern, Professor Gibson and Melanie in March 2018 I raised the issue that the water was crap. I was told that there was nothing wrong with the water and it gets tested all the time, but then two weeks later we got the portable sinks and we were being told not to touch the water and we were drinking bottled water. We were told that there was something in the water, but we were not told what it was.

Water incidents in QEUH Adult Hospital

114. When we were in ward 6A, there were cleaners coming on to the ward and checking the drains and pouring this stuff down the drains. I did ask what they were doing and they said they were doing tests to make sure there was no bacteria in the drains. We were never told not to use the water in ward 6A. We never had any samples taken from our room, that I'm aware of, but we did have the stuff poured down them that the cleaners were using. I thought the issue with the water must be sorted and they were just worried it came back. I felt it wasn't normal, they were trying to fix up these rooms and my son was in the room next to the one being done. There was all this noise and clattering

going on and we would sometimes be moved rooms later at night so you couldn’t really settle.

HEALTHCARE ASSOCIATED INFECTIONS

115. At the time I was only aware of one Healthcare Associated Infection (HAI) that [redacted] had. This was the stenotrophomonas and I think I was told because he ended up in intensive care.

116. Throughout his treatment [redacted] was often “in source” due to things such as E-coli always coming back in his stool samples. I didn’t know that at the time and I only found out through his medical records and the Case Note Review that some of the infections he had were Healthcare Associated Infections. I am not sure if the E-coli was environmental, but [redacted] seemed to always have E-coli during his time in hospital. All I was told by doctors and nurses when I asked about it was that because he was immunosuppressive, he was likely to pick up these things.

117. On 23 October 2017, [redacted] had surgery for what I was told, was fungus in his lungs. He was breathless and I was told that it was down to the chemo. had surgery for this to clean out his lungs of the fungus. When I got [redacted]’s medical notes in 2020, the chemo fungus was recorded as aspergillus.

118. On 22 November 2017 [redacted] developed a chest infection. He was breathless and just wasn’t himself. I was told it was ‘chemo fungus’. I asked nurses, doctors and junior doctors what that was and was repeatedly told it was ‘chemo fungus’. I believed them but again this is recorded in [redacted]’s medical notes as aspergillus. In the Case Note Review they didn’t say if it was a healthcare acquired infection or not. They said you can get it anywhere as it’s airborne. My friend, who works for the NHS, told me it’s black mould spores

from damp environments but you're more prone to get it in hospitals for long stays. Hospitals don't like to mention it.

119. When [redacted] got discharged from ward 2A on 20 December 2017, he was tested for enterobacter that day. I knew [redacted] was getting checked for infections as E-coli came back a few times in his stool samples. [redacted] didn't get sick after he was discharged so I didn't know that it was confirmed as enterobacter on 23 December until I found it in the medical records in January 2020. I was only ever told it was a bowel infection he had. I also didn't realise had E-coli as many times until I saw that in his medical notes.

120. On 9 February 2018 he had surgery to drain 330 ml of fluid from his lungs. I was told by doctors that the fluid was a result of the chemo fungus which had reared its head again. Again, I didn't know it was aspergillus until I saw [redacted]'s medical records.

121. On 14 May 2018 [redacted] was admitted to ward 2A and diagnosed with enterobacter again. When [redacted] contracted the enterobacter for the second time, he was an out-patient but in day-care nine hours a day and only going to the CLIC to sleep. He was in the hospital environment all the time. It wasn't until I saw his medical records in January 2020 that I found out he had enterobacter three times but I was only ever told at the time it was a bowel infection. It was a junior doctor that told me the name of it, Dr Albert but even then, I wasn't told much about it. Staff at the time tried to tell me that it was the same infection as he'd had the first time and it just hadn't cleared up properly, but in [redacted]'s medical notes, it's down as a different strain of the infection. He had it on 9 July 2018 too.

122. [redacted] was in ward 6A on 6 August 2019 when Teresa, one of the microbiologists, and Professor Gibson told us that he had grown stenotrophomonas, an environmental bug, in his line. I asked them what they

meant by an environmental bug and they just said it was one of the environmental bugs found in ward 2A. I didn't think anything of it because they never really told you about the bugs they found. They said it could also have been picked up outside. [redacted] was an in-patient at the time but they were letting him out on pass quite a lot. I think I understood more about it being a hospital acquired infection when I got [redacted]'s medical notes and it wasn't made clear to me at the time that that is what it was.

123. I was told by someone from infection control that it wasn't a hospital bug because [redacted] was out on pass and that he more than likely picked it up leaving the hospital, or at Marion House.

124. We randomly got a letter on 9 August 2019 saying that there were two different infections at this stage affecting ward 6A and that there is nothing to link the infections to the ward, infection control practice or the environment. They were going to keep a part of the ward unoccupied for a short period and new admissions were going to be diverted. That letter was issued by the sister in charge of the ward and was addressed to those on the ward as opposed to specifically.

125. On 15 November 2019 [redacted] was admitted to ward 6A with a temperature spike. It was normal procedure to be admitted with a temperature spike. On 18 November 2019 a nurse told us that he had acinetobacter ursingii. He had to get his line out and was given antibiotics. I didn't realise at the time that this could be linked to the hospital environment until I got [redacted]'s Case Note Review (CNR).

HAIs: Physical Impact

126. On some occasions, these infections delayed [redacted] getting his chemo treatment. It was dependent on what medication he was getting to treat the infections. When he had the chest infections for example, the antibiotics he

was put on used to make him sick and so did the chemo so there was no point in giving him both medications at the same time. His chemo would get restarted when he felt better.

127. I'm not sure there are any long lasting physical impacts as a result of the infections. At the time it exhausted him and every time he got near to going home it would happen again and he end up with another infection.

128. I think because he was constantly cooped up in his room because he was in source so much there have been some physical impacts on [redacted], mainly that he has mobility issues and he gets tired easily. He's not my wee boy anymore, he's not got the same get up and go, he's quite different. He says that himself. He's not got the stamina anymore; he gets breathless easily.

PREVENTATIVE MEDICATION

129. [redacted] had been put on posaconazole the first time he was admitted to ward 2A in September 2017 through to August/September 2018 when he was taken off it. I was not told it was being given as a prophylactic specifically when first started to receive posaconazole, just that it was to protect his lungs from the environment. I just assumed it was part of his chemotherapy treatment. When he was admitted due to his relapse in January 2019, they tried to put him back on posaconazole straight away but I wouldn't let them as I thought it was linked to his hearing loss.

130. On 16 March 2018 Professor Gibson told me that all the kids were going to be started on a prophylactic antibiotic, ciprofloxacin (Cipro), to protect them from the environment and to stop them from getting ill. I just assumed it was every child on the ward that was getting put on them. I didn't ask her any questions about it. I just accepted it as normal. It's not rocket science

though, I think it was the air conditioning and the water that they were being protected from, although I wasn't told that by anyone. This is the only time I remember being told that something was given prophylactically. Doctors had wanted to put [redacted] back on posaconazole when he relapsed in 2019 to protect his lungs but I said no because I knew at that point it would affect his hearing. If the environment was clean, he shouldn't need it as a precaution, as it was suggested. [redacted] still had some hearing left at this stage and I wanted to protect it.

131. Whenever you did ask any questions you were told by Professor Gibson, the nurse in charge, other doctors and nurses that it was just because the kids were immunosuppressive and have weak immune systems. You would try and get a straight answer from them but nobody would give you one.

132. When [redacted] relapsed in 2019 the first thing they wanted to do was put back on posaconazole. That's when I asked why they were doing it again. I told them he wasn't having it and he didn't need it. I was told by Dr Anne-Marie Ewing, some called her Dr Anna Marie, that it was a precaution and part of the hospital protocol. She told me there was a risk that he could get sick if he didn't go on the posaconazole. This was a total contradiction as the hospital were saying that there was nothing wrong with the hospital environment but they wanted to stop him from getting sick at the same time. I told her they could give him the cipro but not the posaconazole because he still had a bit of hearing and I didn't want them taking that away from him. It was at some point in August 2019 I was told by the pharmacist that posaconazole and the long term use of it can cause hearing loss in children and adults which is why I didn't want [redacted] back on it. When [redacted] was first given the posaconazole in 2017 I was told by the doctors and nurses that it was to protect their lungs from the environment.

133. The only time, [redacted] got gentamicin was when he had a chest infection and surgery to remove chemo fungus in February 2018. When he got sick they took him off the posaconazole and were giving him IV antibiotics, which included gentamicin. When he started to improve, they took him off the gentamicin and put him back on to the posaconazole, which they gradually increased. He was also on ambisome for a while too. When we found out about the genetic issue and the link to certain antibiotics and hearing loss, I didn't want [redacted] being back on posaconazole in 2019 so they put him on Cipro. Gentamicin was added to a list of medication he could no longer take after the discovery of the hearing loss too.

134. The staff constantly added medication into [redacted]'s regime and never told me. They would be doing the ward rounds, and come in and examine [redacted]. They would tell you things were looking good and that they might introduce another medicine in a couple of days, but then you would realise that the medicine had actually been introduced straight away and I hadn't been told and I would have to ask what [redacted] was getting it for. This is just a general observation about his medication, it doesn't relate to any specific medicine that he was getting. I felt I had to be on top of it. [redacted] hasn't overdosed on anything but there was one day he was given an extra drug by accident. You felt you had to be listening all the time to find out what he was taking. You weren't allowed to look at the files for his medicines which sat outside his room door. Whenever you did try and look at it, you were asked, "What are you looking at that for?" by the nurses.

Preventative Medication: physical effects

135. The major issue is that [redacted] lost his hearing because of the gentamicin and then I think the posaconazole made it worse. I first noticed that there was something wrong with [redacted]'s hearing around the time that the dispute was going on about what was wrong with [redacted]'s skin, so, roughly 23 March

2018. He had a hearing test in April 2018 and we found out that he had lost some of his hearing. A few weeks later, maybe May/June time, we found out it was over 50% of his hearing and Professor Gibson came and spoke to me and said that [redacted] had some sort of dodgy gene. I asked what she meant and she told me that if [redacted] had been taking Ototoxic medicine it would affect his hearing if it's been used long term. The prolonged use of posaconazole started to cause the hearing loss, gentamicin then took the main bulk of his hearing. The final use of posaconazole took the rest of [redacted]'s hearing. I think this was round about August or September 2018 that we spoke about this. She said that he'd been born with it and then she said that Manchester University wanted him to be part of a trial because more and more children were getting this hearing loss. [redacted] is part of that trial. You don't really hear anything about it though unless they're looking for information from you. She basically said it was gentamicin that took his hearing. I asked her how she knew that it was the gentamicin and not the chemo and she told me that it couldn't have been the chemo because he'd been on it for months and that I'd have noticed his hearing loss months ago. I have a friend who's an oncology nurse in America. She told me gentamicin is a good drug but it's a nasty one. She said I had to question every drug they were putting him on because every Ototoxic drug would take his hearing.

136. [redacted]'s hearing continued to deteriorate and he is now deaf. I think the posaconazole took the rest of his hearing, but no doctors have actually confirmed that.

137. The fact that [redacted] lost his hearing had a big impact on how he could communicate and how others communicated with him, especially in the hospital. We had an agreement with the staff on ward 6A that, if they needed to do obs (observations) on [redacted], they would stroke his arm gently to wake him or get his attention. Some of them didn't bother to try and communicate with him or gently try and get his attention. How would you feel if you were

lying in bed and can’t hear people and someone grabs your arm? You’d thrash out, wouldn’t you? I ended up not sleeping during the night as I had to be awake and aware of people coming into the room. The doctors and nurses didn’t talk to him because of his deafness, they only spoke to me. I had to show them how to communicate with [redacted]. He had a sticker on his door and he put on it, “I’m deaf, not stupid”. He would love his hearing to come back, that’s for sure.

138. When [redacted] could hear, communication wasn’t a problem but when he lost it, that changed. For example, after he had lost his hearing I had to go over to the CLIC to do some washing. [redacted] was attached to two drip stands and I asked the nurses to keep an eye on him while I was away, in case he needed the toilet. They told me they were busy and had other things to do. It felt as if I was asking for the world. There was nothing put in place when he became deaf, he didn’t feel safe after that.

139. Nobody in the RHC or the adult hospital could help me with the hearing problems. Ann Cameron, who was the play worker, contacted the speech and language therapist in the hospital who told her there was nothing they could do. Schiehallion weren’t interested and it was a cardiac anaesthetist who put me in touch with speech and language and I also got the Deaf Society involved and they suggested sign language. [redacted] started sign language and the hospital charity agreed to pay £850 for it as a gesture of goodwill as audiology didn’t know we were back at the hospital. [redacted] was to get cochlear implants at the end of 2019 but he relapsed so they put it on hold and he got the surgery in August 2020.

OTHER ISSUES RELATING TO HOSPITAL CONSTRUCTION

Hospital build issues

140. I remember windows falling out in ward 2A. There was one day where I remember hearing a woman screaming from another room. I later found out that the window had fallen out of the windowpane in her room, and she was then moved to a different room whilst they fixed it. Door handles fell on the floor too so you would have to be moved as it wasn't safe for you to be in those rooms. There was always something wrong and there was always a maintenance man. I felt sorry for the man as there was always a shower, a TV or something else that had broken. The maintenance was shocking. My friend actually has a video of flip flops floating in ward 2A. I think this was due to a broken shower.

141. On ward 6A the toilet handles were always loose. One Friday afternoon I flushed the toilet and the handle came away in my hand. You couldn't access the cistern because it was all hidden behind panels. I told staff and they told me nothing would get fixed until Monday. [redacted] was okay because he was using bed pans but I was told that I would have to use the toilet downstairs. I asked to get moved into another room but it wasn't until the Sunday night that they moved us.

142. There's nothing worse than lying in bed at two in the morning and you can smell the sewage rifling through the place. There's not a place in the whole hospital where you can't smell it. No hospital is safe, every hospital has its bugs and I know people ask why it was built next to the sewage works but there's always been a hospital there. It's the fact that the older hospital was built better than the new one, it was built to last, and the new one is built of Lego bricks. I don't think they can stop the infections unless they rip it down and start again and build it differently.

143. We got moved rooms a lot in 2A and in 6A. It was a competition to see how many rooms were closed down each day. Every day another room was being shut down or closed off. At one point there were eight rooms sealed off on 6A.

There was plastic sheeting over the doors and workmen were coming in and out all the time. Staff would tell you it was because the rooms were getting deep cleaned on ward 2A but when you went back in the rooms, they were still filthy. In ward 6A, you were told by staff that it was because they had to clean the filters in the ceilings. We were told that they were doing some tests to make sure there was no bacteria in the drains and things like that. You never knew where you were going. Sometimes it could be eight o'clock at night that staff would come in and tell you you're moving rooms. Sometimes you had planned to have an early night as you'd been up all night the night before but then you'd get moved. You couldn't really get settled in a room. We learned not to keep a lot of stuff in the room as you'd have to pack it all up. I felt sorry for the people that had little boys or girls with lots of toys.

144. I'm not sure, but it was maybe around the same time that we were moved out of room 10 in ward 2A because of the frozen pipes, we were also moved rooms because there was black stuff coming out the air vents in the ceiling. It was like flakes of black dust that fell onto [redacted]'s bed. There were also occasional drips of water that came from the vent onto the bed. We were in room 7 on ward 2A when this happened. Other parents were also telling me that had happened to them too.

CLEANLINESS

145. I always cleaned after the cleaners had been in when we were in 2A and 6A as I don't think they were cleaned properly. I had been cleaning with Dettol spray but had been told not to by staff as it leaves a smell. I was then using the hospital wipes to clean [redacted]'s room with. I had two meetings with Pat who was the head of the domestic services team. I had the same argument with her in ward 2A that I had with her in ward 6A. I told her that the antichlor which they used to clean with doesn't actually clean, it coats. The cleaners

had a single mop head that never saw water. They brought the mop into the room, used one side for the bathroom and the other side for the bedroom. The mop was not rinsed out in-between. The floor didn't get swept so when they used the mop all they did was move the dirt about the floor. I got told off for using Dettol but the place was dirty and it wasn't clean after the cleaner had been in. I watched [redacted]'s feet after he'd washed. Within half an hour his feet were manky and that was just him walking from his bed to the bathroom, that's why I always cleaned the room after they'd been in. Put it this way, if you weren't one of the first three rooms to get cleaned, the water started smelling like sweaty socks. I asked why they didn't change the water more often but the cleaners told me they weren't allowed and they were restricted to what they had.

146. On ward 2A the staff knew when infection control were doing a spot check because they inform them when they're coming that day. The staff would run round the rooms and get a cleaner in some rooms. Some of the nurses would come and see me and ask if infection control could come and see my room because it was always clean and tidy. In every room I was in I would use their wipes to clean all the equipment. [redacted] was on TPN (Total Parenteral Nutrition) for a while and it would spill and it would be all down the drip stand. The nurses wouldn't clean it when I asked them to because it was all sticky. At one point a bag of blood burst and it was all over the bars on his bed and that didn't get cleaned. They just came in, wiped with some cloths and that was your room cleaned. I know it's not contaminated blood but I wanted them to clean things properly. Infection control were worried more about a bit of dust or if your shoes were sitting on the floor.

147. On 6A it was more general things, like the cleaning tick sheet on the door to each room. They were ticking things off that had been cleaned but hadn't been. I had to approach the nurse in charge and challenge her about it. I asked her not to tick the sheet when she didn't actually know if it had been done.

148. This happened when [redacted] was in the transplant ward (4B) as well because the whole time we were in there only one nurse cleaned the drip stand.

149. On 5 June 2018 I was handed a piece of paper on ward 2A, saying the hospital were using a new method of cleaning in ward 2A. A domestic cleaned the room as normal and then a mist was used, hydrogen peroxide vapour (HPV). At that time [redacted] was moved around more often, sometimes every day because they were constantly cleaning the rooms. I can't remember who was in charge of the ward that day, I hadn't met her before, but she knocked on the door and told me that they were just keeping me informed that they had decided to try this new cleaning method. She said they were advising families to pack up as much as they can because they could be moved at the drop of a hat. She explained about the rooms being cleaned with a mist so they would be thoroughly cleaned. The number of room moves due to this cleaning; I don't think was normal. Nobody said why this new cleaning method was being introduced but there were too many "boots and suits" on the ward clambering around so you knew something was going on.

150. On 7 June 2018 I was handed another piece of paper, a letter saying that drainage and chilled beams were getting cleaned and that your child would be getting antibiotics. The letter did not name the antibiotics. You couldn't get comfy in your room because there was so much cleaning going on. I couldn't keep track of the rooms we were getting moved to.

EMOTIONAL IMPACT

Overall emotional impact on [redacted].

151. [redacted]'s life was turned upside down when he became deaf. He doesn't want to go back to the hospital. He hates the way it makes him feel. The scabies

started it and losing his hearing made him angrier. It wasn't nice for him; the way he was made to feel at the hospital. His life has changed. They would talk to me over the bed and ignore him but he was able to tell them how he was feeling. Staff in ward 6A hadn't even told the Beatson Centre he was deaf, this was quite an important thing and they didn't communicate it. He can talk and he can say how he feels and what is wrong. It was his treatment, they could've spent a little more time with him and there's a "text to speech" app they could have used. I was angry. If someone can't speak English, they get a translator in. He can tell you how he feels but they just shrugged their shoulders. He was discriminated against. He wrote on his yellow sticker on the door, saying "I'm deaf, not stupid". It was like [redacted] didn't exist. It was heart breaking to watch it, they would come in the room and make a bee line for me. Sometimes I noticed the doctors wouldn't come in [redacted]'s room if he was there on his own, they would wait until I came back. He felt invisible and he would get upset and angry. He said "but they've caused this, they've made me the way I am and now they don't want anything to do with me".

152. [redacted] sometimes says he regrets getting the cochlear implant operation and that he may as well just be deaf. He has just been going through a bit of a rough time adapting to his hearing loss. He felt upset about having the operation for his implants and needing to retrain his hearing. It's hard for him and he needs some time to adapt to the whole thing. He does get upset and he's struggling.

153. He now has socialising issues because he spent such a long time with adults and not children whilst was in wards 2A and 6A. The nurses would spend time with the younger kids. They'd chase them up and down the ward and that was normal, they were playing. I don't think they were really meant to play with the younger children on the ward, but they did anyway. I had an 8-year-old locked in his room with no-one to talk to. They could've taken the time to even ask

what he was watching on his iPad. All the other kids his age were also in source so he couldn't talk to them either.

154. [redacted] hasn't really had any support to process what he's been through and what happened. I worry about the impact on him. He's never expressed it really. I found out from [redacted]'s medical notes that a referral had been made to psychology for him three weeks after he was diagnosed but because they hadn't discussed it with me, it didn't take place.

155. [redacted] loved getting treated by Professor Gibson, it was just the hospital he didn't trust because he doesn't feel safe in the environment. We're going for a check-up next week and he's already stressed about it. [redacted] gets stressed when he has to go to the hospital. It's a fight to get through the front door, never mind going to the appointment, because we don't get an appointment letter and they don't send us a text message. We have to argue with security to get through the door. If you don't have an appointment letter, you can't get in. The security guards have to go to the clinic to make sure you had an appointment. There was one day it was pouring with rain and we were stuck outside. Do they really think we would just turn up, 100 miles up the road, if we didn't have an appointment?

Overall emotional impact on witness

156. What was happening with the hospital building was hard on me emotionally because nobody was talking to me or telling me the truth. Even when the water guys were coming on ward 6A, to check the drains, you didn't get a straight answer. We weren't told who these men were or who they worked for. You were told it was just work that needed to be done, it kind of got wiped under the carpet. I felt it wasn't normal, they were trying to fix up these rooms and my son was in the room next to the room that was being done. There was all this noise and clattering going on yet they were not saying why.

157. I've been diagnosed with post-traumatic stress disorder now. I've held it together for too long now and this last year hasn't been a great year. I think having to relive this again over and over has had a big impact because of the lack of communication. If everybody had just been honest from day one, I'd have had more respect for them. We got our individual case note report and on it, it asks if you want your consultant to have a copy. I don't want [redacted]'s consultant to have a copy; she knows exactly what's wrong, and what was wrong with [redacted]. Why should I show her a piece of paper with what they already knew? I'm angry as they didn't tell me the majority of [redacted]'s bugs were from the environment. The same with the E-Coli. They kept telling me they didn't know why he kept getting it or they referred to the other infections as "Just another bowel infection". They should have just been honest with me.

158. I lost my marriage as a result of everything that went on. There was no support for us all.

COMMUNICATION: GENERAL

159. The overall communication from the hospital was rubbish when it came to [redacted]'s treatment. He had all these different protocols and they never told you what the plan was. I had to go and beg for a copy of what the plan was for the next month. You shouldn't have to beg for it, it should be the first thing they say to you; what medicines he's going to need, what chemo he's going to get.

160. When you got put in source, they sometimes didn't even tell you it was going to happen. The sign would just appear on the door. There was one time we were getting ready to go the cinema that they had at the hospital and [redacted] was really looking forward to it then the sign appeared on the door saying we were in source. I asked one of the nurses why we were in source

again and she said she would have to get someone to speak to me. They never explained to you why you were in source. Sometimes you would think you were out of source and then that sign would appear again.

161. The communication from the hospital has never changed at all, that's the sad part. When new parents came into Marion House and they were nervous or upset, I advised them to write everything down. [redacted] always went on about the water and told them not to let their kid wash themselves in the water because it was the water that made them sick. We explained we weren't scaremongering but we just told them to be very careful but to keep their eyes open and ask questions. I still feel sorry for parents to this day because I know exactly what's been going on.

162. [redacted] is due his last lumbar puncture but the hospital can't blame COVID for this one. He missed one last year because of COVID. We were at the hospital in December 2020 but he's supposed to be seen every six weeks. wasn't seen until about five weeks ago though. We've now moved to every six months, which is fine. He's doing really well but he should have had his growth hormone in January 2021 and I've had to push for this to be done. I feel like I'm having to force the doctors, the professionals to get [redacted]'s treatment finished. The communication is still awful, you have to get a COVID test the day before you go to the hospital and we don't know where to go for it. Nobody's told us the new protocol about how it's going to happen and we've been told nothing about any changes that have been put in place due to COVID. We feel that if [redacted]'s not in active chemo, they're not interested. I don't push it anymore, they should be chasing me, not me chasing them.

163. There was never any explanation as to why maintenance was happening on the wards. It was just "shut up and put up". Staff would just tell you things needed to get done but never told you why. You felt they just wanted you to be quiet and toe the lines. I think the doctors and nurses' hands were tied.

They'd been told to keep their mouth shut by the "powers that be" and it's not their fault. I wasn't causing problems, I just wanted to know what was going on. You were hearing all of these horror stories from other parents in clinic in day-care about their children contracting enterobacter again or another type of infection again and I was thinking, "My son has had all of these issues" but I was only told about the one infection he had and that was because he had been in intensive care.

COMPLAINTS/MEETINGS

164. I spoke to Professor Gibson about Day Care which was ward 2B, because my mum felt she hadn't been listened to for that whole week when [redacted] was really unwell in May 2018. My mum got upset so Professor Gibson told me that if I had something to say then I could submit a formal complaint. I said to her that if staff had acted when concerns were first raised, [redacted] might not have ended up in intensive care. I told her I've got to see these people every day as they care for my son. I didn't want to risk them not providing [redacted] with the treatment he needed, or risk them treating him differently so I didn't raise a complaint. Professor Gibson said I wouldn't be treated any differently but we were. Nobody came near us. The play worker didn't come near us. Some doctors didn't either when [redacted] was due examinations. He felt they were all looking at him and talking about him.

165. On 12 March 2018 we were in 'source' again on ward 2A with scabies and told nobody could come and speak to us. The next day we were told to go to Marion House for a bath because he was getting a lumbar puncture that afternoon. I didn't understand why [redacted] was in source seemingly because of scabies but he was allowed to go to Marion House, nobody ever explained it to me so I demanded to speak to someone. If it was scabies he had, he should have been kept in source and not allowed to Marion House.

166. On 13 March I got a meeting with Jamie Redfern, one of the hospital managers, Melanie the lead nurse and Professor Gibson, who agreed to meet with me. It took place in what we called ‘the room of doom’. That was the room you got taken to any time you were given bad news. I spoke to them about the scabies thing and getting put in source. They just said that it was one of these things. I told them that there was no support or help and they didn’t treat people well at all. They assured me that everything was okay and I asked about the water. They said they couldn’t comment on that and that there was nothing wrong with the water and it was perfect. They told me that the kids were getting bottled water as a precaution. I wasn’t getting any answers so I got up and left and I didn’t hear from them again.

167. On 7 August 2019 there was a general meeting with the parents about all the infections on ward 6A. I thought the meeting was sort of the culmination of all the questions that had been asked by parents on the ward. The meeting was with the nurse in charge and a doctor. I don’t know their names. It was a meeting for us to ask questions about the infections but not many of us knew what actual infections they were talking about. I asked why the kids were continually catching bugs and I pointed out about the dirt on the windows and blood on the floor. I asked for honest answers but I didn’t get any. They told us they were trying their best and that was the end of it.

168. On 16 September 2019 we were on ward 4B because [redacted] was getting his transplant. I asked for a meeting with Jen Rogers, the lead nurse for the children’s hospital, Gail Rolls, the lead nurse for the cancer ward, and Jennifer Haynes, the complaints manager, to complain about [redacted]’s care, the adult patient nurses, the noise they were making, the cleaning, the food and the conditions. The staff acted as if they didn’t want us there because they were too busy looking after babies or the younger kids. Their response was that they were doing everything they could for all the patients but nothing ever came of that meeting. They asked if I wanted another meeting but I didn’t see

the point as I didn't think that it would change anything. I had all of this written down and I've got a copy of it.

OVERSIGHT BOARD/CASE NOTE REVIEW/REPRESENTATIVE GROUPS

169. I know about the Case Note Review and I know that it's to see if they can link any of the infections to the hospital. [redacted] was one of the 84 cases that was looked into. I got an individual report for him.

170. The report says that the first episode of enterobacter cloacae was possibly related to the hospital environment and that the second episode occurred with the same organism although the type and results are not available. They said that a lot of the rooms weren't tested, only some of them were tested. They also said that the impact of the enterobacter infection was severe based on how long [redacted] had to stay in hospital.

171. I know they'll never say it has definitely come from the hospital but they have said it's a possibility the stenotrophomonas infection was related to the hospital and that the possibility was quite strong and that [redacted] had been an in-patient for the three months prior and that a couple of other kids were diagnosed with stenotrophomonas around about that same time.

172. I'm very happy with the Case Note Review. It's given me the answers I've needed and it's made me realise that I'm not paranoid anymore, I'm not going insane like the hospital made us out to be. I know some children's parents weren't happy with it but I'm fine with it.

173. I had some discussions with Professor White very early on. He was going over things with me: how we were made to feel, whether there was communication, what needs to change, stuff like that. I told him about the scabies and [redacted]'s hearing loss. Those were the two main things for me. We had one long

discussion for an hour and one ten minute discussion and the others were through email. It didn't improve anything with communication; I never heard anything else from Glasgow but the discussions and emails with him were useful. He used to be a psychologist so he understood why I was upset. I didn't say anything out of turn to him but we're trying to change what happens in the future. We can't change the past but there are issues with the hospital that are still there, people need to know, families need to know what is going on. I asked him about support for [redacted] and why nobody had sat down and explained to him that he couldn't hear any more. He couldn't answer that for me.

174. I'm a member of the closed Facebook group for the families. It was okay but I think it was very monitored by the hospital or Health Board, it was very restricted. I don't know who actually monitors it, whether it's the lead nurse or management but I know Gail Rolls puts a few things on it. If I had a rant on it, either the message would disappear or I'd get a private message saying it was maybe inappropriate. Parents are very reserved about what they say and do on it.

CONCLUDING COMMENTS

175. If I had to go back to the hospital tomorrow I would trust Professor Gibson with my son's treatment and the decisions she would make, and her team, but I would never, ever trust anyone that runs the hospital. They've done the damage. We were made to feel it was our fault that the kids were sick. For example, parents would be blamed for going downstairs to get supplies and bringing bugs on to the ward. That's how you were made to feel, as if it was your fault.

176. I think it's wrong that the doctors and nurses, should have to work in this environment that has this shadow over it.

177. I think the Chief Executive needs to go and I think some management need to go, to build up trust, not just with us but for the public who actually attend this hospital. Maybe a fresh set of eyes and ears is what it needs. I know of some people whose kids should have been having their transplant in Glasgow but had it in Newcastle because they didn't want to go after what they had seen on the news. They've got no faith.

178. I'll always be very, very wary of the hospital. The less time I can spend in there, the better.

179. I'm grateful I've still got my son, but I don't think you can treat anybody the way they've treated [redacted]. You wouldn't treat your pet dog the way they've treated [redacted], and it's disgusting, because they thought it was fine.

180. 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 Hospital Inquiry

Witness Statement of

Alfie Rawson

WITNESS DETAILS

1. My name is Alfie James Rawson. I was born on [redacted]. I am [redacted] years old. [redacted].

2. I am the father of [redacted]. [redacted] date of birth is [redacted]. She is 5 years old.

3. I live with my partner, Charmaine and our four children, [redacted], in [redacted].

4. I have a background in Health and Safety. I worked for 25 years in the Health and Social Care sector where I worked in a number of positions from Care Worker right through to being a Regional Manager. I then moved to Health and Safety within the Health and Social Care sector. Within my role in Health and Safety I worked in nursing homes, residential and leasehold properties where I would carry out inspections, fire risk assessments and deal with daily Health and Safety queries raised by staff members or management teams. I travelled all over the UK with this job.

OVERVIEW

5. My daughter is [redacted]. [redacted] was diagnosed with Acute Lymphoblastic Leukaemia ("ALL") in August 2018 when she was two and a half years old. [redacted] was treated in the Royal Hospital for Children ("RHC") and Queen Elizabeth University Hospital ("QEUH") between August 2018 and November

2019 when she finished her treatment. She attended both hospitals as an in-patient and an out-patient regularly for just over a year. At present, while [redacted] does have check-ups they are few and far between and often Charmaine has to chase them up for ongoing medical matters for [redacted].

6. I have provided the Inquiry with a timeline showing the dates on which [redacted] attended hospital and the wards where she was treated. Charmaine and Thompsons Solicitors prepared the timeline. The timeline is attached to this statement at appendix 1 (**AR/01**) and in so far as I am able, I confirm that it is accurate to the best of my recollection. Charmaine is better placed to speak to the detail of the timeline.

7. [redacted] spent time in ward 2A of the RHC which is known as the Schiehallion Unit. The Schiehallion Unit treats children with blood cancer. [redacted] also spent time in another children's ward, 3B of the RHC. Following the closure of the Schiehallion Unit in 2018, [redacted] was treated in ward 6A of the QEUH. [redacted]'s mother spent 100% of her time with [redacted] at the hospital while I was at home looking after our other children. I visited [redacted] and her mother in the hospital on a regular basis and stayed over-night with [redacted] on ward 2A at around the time she was first admitted. I can speak to the experience which [redacted] and I had on these wards.

8. There are some specific events that I would like to mention. [redacted] contracted a Staphylococcus Aureus Infection in September 2018 just before the move to the adult hospital. During her time at the hospital, she contracted other infections too. I believe that [redacted] was prescribed preventative antibiotics in August 2018 which may have been connected to issues with the water supply. There were all sorts of issues with the hospital through-out [redacted]'s time there which, in my view, impacted her experience. I will come on to talk about these in more detail.

FAMILY BACKGROUND

9. I live with my partner Charmaine and our four children in [redacted] . [redacted] is [redacted] years old, [redacted] is [redacted] years old, [redacted] is [redacted] years old and [redacted] is [redacted] years old.

10. [redacted] started nursery on [redacted] and is [redacted]. [redacted], out of all the girls, is the softest, most loving, thoughtful wee thing. As much as she's been through a hard time herself, she always made time to have her wee sister in bed with her. She would try and interact as much as she could with as she's her best friend. [redacted] is a loving, gentle wee girl.

11. As a family, we like to go to the park around the corner from us. We were there this morning feeding the swans and playing in the park. A lot of the time now is spent on holidays. We try and spend as much time as we can together whereas previously I just worked continuously in every job I had. Now, our focus has changed. It's not about having the money; the money means nothing if you can't share it with the people you want to.

12. Prior to [redacted]'s diagnosis, she was a healthy child and was never unwell.

13. [redacted] was only about [redacted] months old when [redacted] was diagnosed. was [redacted] years old and [redacted] was [redacted] years old. [redacted] was just about to [redacted] . Charmaine was with [redacted] 100% of the time during the whole treatment process. I brought [redacted] and the other girls to see them. Usually in the mornings, I would get them ready for school or nursery and drop them off. I would then go home to get clothing prepared and lunches made up to take to Charmaine and [redacted]. They were fleeting visits sometimes. Charmaine was still breast feeding so I was picking up milk from her at the

hospital and then I would go and pick the other kids up to take them home, feed them and go back up to the hospital afterwards. I was taking [redacted] in so Charmaine could see her and try to get a bond with her but sometimes that was too difficult with everything that was going on. [redacted] would be unwell and needed attention. Nurses were coming in and out of the room all the time so there was no privacy to chat to each other. There were days where I would choose not to visit because emotionally it was extremely difficult for everyone so I would try and spend more time with the kids at home and I would maybe go to the hospital at night.

14. The first two months, I was trying to be at the hospital every day and spend as much time as I could with [redacted] and Charmaine. My neighbour would sometimes pick [redacted] up from nursery and [redacted] could go to a neighbour's house so I could spend more time with [redacted] but also so that [redacted] could spend more time with Charmaine. During [redacted]'s first admission I was at the hospital most days.

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

Admission to hospital: April 2018 – October 2018

15. On 15 August 2018, Charmaine took [redacted] to the GP. She saw a locum GP who told Charmaine that [redacted] had a viral infection. Two days passed and Charmaine took her back to see the family doctor on 17 August 2018 who examined her and said her lymph nodes were raised. He told Charmaine that his son had a viral infection as well and to expect [redacted] to be a wee bit sicker over the weekend. On the Saturday, [redacted] was really uncomfortable and on the Sunday, she was screaming in pain. Charmaine took [redacted] to the out of hours at Gartnavel Hospital, around about 6pm, possibly later. Charmaine then sent me a text message to say that the doctor wanted her to go up to the Sick Kids (RHC). Charmaine took her there and again, they said it was viral. Charmaine wanted blood tests carried out and that took a while. She called me later in the

evening to say it was leukaemia and we were to meet Professor Gibson the next day.

16. We both attended the meeting with Professor Gibson but for me, it was all a blur. I sat in tears and Professor Gibson was rhyming off everything [redacted] would be going through. For me, that was the worst day of my life, ever. I couldn't take any of it in. Initially we were told they would see how the first week went and if she made it, they would start her on a list of treatments. For the first few days, it didn't really sink in with me. During the first week, Charmaine stayed with [redacted] and I looked after our other girls.

17. If I remember correctly, [redacted] had surgery on 24 August 2018 to fit her central line. She was given a Hickman line. [redacted] then started her chemotherapy on 25 August 2018.

18. Charmaine kept a diary for herself and [redacted], to record the experience. Initially, she was trying to monitor and understand the whole thing about cancer. When the doctors came in and spoke about white blood counts and haemoglobin, Charmaine tried to understand it. If [redacted] had a blood test, Charmaine would ask for the numbers to measure where [redacted] was sitting. She did a lot of research during [redacted]'s treatment to try and get an understanding of what she was going through, what medications she was getting, what side effects they would give her and what her blood counts meant.

Experience on ward 2A: August 2018 – late 2018

19. I stayed over on ward 2A for one night near the beginning of [redacted]'s treatment. I think it was a Saturday night. Charmaine was finding it too much. When she did get home, she was finding it even more intense. She was surrounded by [redacted]'s stuff and she couldn't bear to be away from her.

20. Ward 2A was a quiet ward, very quiet. Lots of kids were in isolation or ‘source’ as they call it. They had signs on their room doors. The play room was pretty much empty at times.

21. Nearly every kid in ward 2A had an infection or was in ‘source’. There would maybe be one or two children walking up and down the ward or in the playroom. Other than that, they were all in their rooms with signs on their doors saying you had to check with a member of staff before entering. There was heavy scrubbed alcohol wash on every door too.

22. [redacted] was in source on ward 2A because of the infection she had in her line. Her having diarrhoea too, meant that she was often in source. Sometimes she would be in source for ages, possibly weeks. I can’t remember what was causing the diarrhoea but Charmaine can tell you.

23. I only really had direct contact with the staff the night I stayed over. Most of the time I was at the hospital, the nurses would be in doing [redacted]’s observations, taking blood or giving her medication. The same happened during the night that I stayed. Nurses came in to change her nappy but I was awake so I told them I would do it. They did her bloods, checked her temperature and her heart rate. I found it really bizarre though that they wrote the results down on what I thought was a piece of kitchen roll and put it in their pockets. If nurses are in several rooms during their shift, how do they know who’s result belongs to who? I assumed they were being put into [redacted]’s notes.

24. In my view, the note keeping in her medical records was pathetic. I have looked back through [redacted]’s records. I saw a note from early on in which the staff nurse had taken it upon herself to write that I might need social work intervention for further support. Now, there’s two ways of looking at this. It could have been well-meaning which I dare say it was. They might have wanted to check to see if I needed any support. From my perspective, I do not think that should have been getting jotted down in [redacted]’s notes. The notes were there for my kid’s health and wellbeing so the next member of staff could

see how my daughter’s day had been, how her observations had been, what her temperament was, the medications she’s had, what her eating has been like, her fluid input and output, her bowel movements and urine levels, not “does dad need support?”. If I had needed support, I would have asked for it.

25. The ward protocols would differ depending upon who was on duty. Some of the nurses would adhere to them and some would happily turn a blind eye and get on with their shift.

Facilities on ward 2A

26. There was a playroom in ward 2A. [redacted]’s siblings came to visit but Infection Prevention Control wouldn’t allow [redacted]’s siblings into the playroom. Kids being kids, [redacted] would want to go into the playroom but how do you tell her that her siblings can’t go in with her? How do you say to her and her sisters, you can go in but you can’t? We’d remove our kids but on occasion, other families would be allowed to have their kids in the playroom including the siblings. It was inconsistent depending who was on duty.

27. There was a parent’s kitchen on ward 2A. If I was there, I would use it to make Charmaine and I a cup of coffee. It had microwaves, two fridges and a seating area where parents could go and have a seat and a coffee. One of the charities would bring in snacks for the kids and the adults.

Closure of ward 2A and the move to the adult hospital: Late 2018

28. I was not present during the move itself. I went up to visit Charmaine and [redacted] later on in the day and they were in ward 6A.

29. With the reports being in the media though and the hospital starting to move the kids to ward 6A, it became so obvious that they were moving because of infections. They were dousing the taps and the hand-wash basins. Looking

back in hindsight, I should have noticed all of this considering what I was doing for a living. It was all in plain sight.

Experience in the QEUH (adult hospital): late 2018 – September 2019

30. Ward 6A was split in two. If you come out the elevator there are two double doors then you would see four rooms then the nurses station. If you turned right, that would take you to another wing of 6A with maybe ten rooms there. At the top of that, there would be Day Care and the rooms in Day Care. The rest of the rooms would be after the nurses' station.

31. There was absolutely nothing for the kids in ward 6A. It wasn't fit for purpose. Kids would be in their rooms, in source, as they called it. The odd kid that wasn't in source, would sit in the corridor in a makeshift play area which consisted of a chair with a wee plastic table with a couple of bits of blank paper and maybe a couple of pens. That was to entertain them. That was what they classed as a play area. It was placed at the big entrance between Day Care and the nurses' station. You would have to walk past it to get to Day Care which did not make sense for infection control.

32. When [redacted] wasn't in source, our source of entertainment would be walking around the ward as it was split in two so we would walk up and down. would look into the rooms to see her friends and we'd maybe play hide and seek. During the day, they had the clown doctors for entertainment. Maybe one of the charities would come and do a bit of entertainment with the kids. Sometimes they would maybe get toys in but it was a pretty dark experience.

33. There were no facilities in ward 6A for making food or heating anything up either. Usually, if I was visiting, I would stop off downstairs and get a coffee or maybe soup and a sandwich for [redacted] and Charmaine. I often took them dinner in and I did this through-out. If [redacted] or Charmaine wanted anything heated up, I had to go downstairs to the main atrium where there was a microwave next to a vending machine. Anybody could use it; it was in a public area.

34. I was taking meals into Charmaine and [redacted]. I did this when they were in ward 2A and 6A. The food I was preparing at home was better than what they were getting in the hospital.

WATER: EVENTS INVOLVING WATER SYSTEMS

35. There were signs up in the parent’s kitchen above the sink saying ‘not drinking water’ and there were loads of bottles of water. Initially when we were in ward 2A, you had to ask staff to get you a bottle of water but you had to wait until they had time. We were not allowed to drink the water in the room and there were no jugs of water. I remember when you used to visit someone in hospital and there would be a jug of water in the room in the morning, it would get changed in the afternoon and again in the evening. There was nothing like that here. There were signs in the bedroom too telling you it wasn’t drinking water, it was for hand washing only.

36. I had a shower when I stayed over but [redacted] was always wiped down with baby wipes as after the two or three times she did have a shower she had an infection afterwards.

37. The situation was the same on 6A as it was on 2A. You were offered bottled water and there were signs up saying the water was not for drinking.

HEALTHCARE ASSOCIATED INFECTIONS

HAIs: events and physical impact

38. [redacted] had to have her line removed on 23 September 2018. I think she had a temperature and had taken unwell. Staff came in and took swabs of the site where her line was and they took blood samples from her line. I think the infection was a staph infection, Staphylococcus Aureus.

39. The impact of the staph infection on [redacted] was that her treatment was stopped. Staff had put a pause on it and they also had to revert back to cannulas. They removed her line under general anaesthetic in surgery and they reverted to cannulas. Staff couldn't always get the cannulas into [redacted]. On one occasion I was there and the staff tried 10 or 12 times to get the cannula in to [redacted]. We said no more, stop. It was so traumatic for Charmaine, me and of course [redacted]. Charmaine saw all of this. On occasion I would see this if I was visiting, but Charmaine saw most of this.

40. On another occasion, [redacted] developed marks on her legs. The dermatology specialist came to visit her and put circles round the marks and told us it was a fungal infection. Someone from microbiology came down to take samples. The next day or so, Professor Gibson arrived to say it wasn't a fungal infection. Before dermatology had visited, Professor Gibson said it was bruises from falls but [redacted] was pretty much bedbound so hadn't fallen. What she said didn't really make any sense. As far as I can remember, they said that someone from microbiology would come and speak to Charmaine but she was still waiting on the results and is still waiting on someone coming to speak to her to this day.

41. On 21 January 2019, [redacted] had a fever so was admitted again. She was placed on Ambisome and other medications. Charmaine is good at all this stuff. I only know a couple of the drugs, Methotrexate, antifungals and antibiotics, Charmaine was at the heart of this so knows it all.

42. I think the infections are related to the construction. It must have had an impact or they wouldn't have shut it and spent £14 million on water and ventilation systems. So yes, I think this has had a real impact on her.

HAIs: communication

43. I was not there when staff discussed the staph infection. Charmaine would be the best one to confirm this as she kept track of everything. She spoke to the staff about it.

PREVENTATIVE MEDICATION

44. I do not know if [redacted] was on preventative medication. Charmaine is the best one to answer this. I knew a couple of the names of medicine [redacted] was on but not them all. Charmaine did a lot of research to understand what medications our daughter was getting, why she was getting it and what it would do to her. I can't fault her for that. She looked after our daughter 100%.

CLEANLINESS

45. On one occasion when [redacted] was first admitted to ward 2A, she'd been there maybe a couple of days and I'd taken her a new doll up. It was in the usual packaging, cardboard and plastic. [redacted] was excited as she had lots of dolls and we took the new one out of the packaging for her. She wanted to go and play in one of the wee play areas that was set up so we were in there playing. [redacted]'s room was next to the nurse's station and we saw four nurses going into the room, stripping the bed and picking up all the packaging. When I say all the packaging, there was also a carrier bag as I had also bought new clothes for [redacted], new pyjamas and a couple of outfits. We went to speak to the nurses to ask what they were doing and we were told this wasn't allowed because of infection prevention control measures. I thought this was bizarre. There were two bins in the room, if they'd given me a moment, I'd have put the packaging in the bins but on that token, nurses go overboard with things like that but the same nurses would be happy to leave 14 bedpans in the room with faeces in them. It was really bizarre.

46. The incident with the 14 bedpans happened during the first couple of weeks when [redacted] was admitted. She had really bad diarrhoea and we were to take samples to monitor how many bowel movements she was having. I had visited and went into the bathroom and there were all these bed pans sitting. I asked Charmaine how she was managing to sit in the room with those being left. She had been waiting for staff to come and collect them. The bedpans had been

there two or three days. They were all you could smell, every time you opened the bathroom door. I spoke to a member of the nursing staff to ask if they could be removed and they said they would get round to it. Nursing staff said this quite a lot. If there was a trainee nurse or a student, they would come and collect them.

47. There was the odd occasion where getting a bed sheet was very difficult. It got to the point where I took [redacted]'s own. I bought [redacted] a new quilt cover, and bedding. The only thing that was supplied from the hospital was the bottom sheet. I used to take her bedding home, wash it and bring fresh bedding in for her. The hospital didn't provide the bedding quick enough. I was taking bedding home to wash daily, sometimes a couple of times a day if her nappy had leaked bearing in mind she had diarrhoea, or if nurses had taken blood as sometimes there would be blood on her bedsheets.

48. The cleaning process for the rooms on the ward was very sporadic. The task the cleaners were carrying out could be random. Rather than clean a whole room, one cleaner would come in, maybe about 11:00 AM and dust the room then maybe an hour or so later, another cleaner would come in and mop the floor. I did not see the purpose of the cleaning being done in this way.

49. On ward 2A there were people who I presumed were contractors, who came in to douse the drains. The kids would be moved from one room into another room and then plastic sheeting would go up to allow the contractors to do their work. I'm not too sure what they were dousing the drains with. The people doing this did not have any protective clothing on, just overalls which made me think they were contractors rather than in-house maintenance staff. They doused the drains in the bathroom, the bathroom sinks, the wash hand basins in the rooms and the showers too I think. The furniture was kept in the room and a cleaning team would go in and disinfect the mattress, the bedframe and the furniture. The room was cleaned from top to bottom.

OTHER ISSUES RELATING TO HOSPITAL CONSTRUCTION

50. I noticed in ward 2A, that there was a team of painters who would just go around painting. This surprised me for such a new building. It was not to just to keep up with the décor, it was to cover over cracks. When you saw one, you thought they were maybe just touching up paint work after builders had been in but the more you sit in that environment, the more you see. The rooms that had been in, there were cracks all over the walls.

51. On the outside of the building, they were taking off the cladding. This had me thinking, because of what I used to do in Health and Safety, about Grenfell. They were taking off the cladding and removing insulation to put in Rockwool. The difference being, one is flammable, and one is a fire stop. It had me thinking, was the hospital actually fit if there was to be a fire. Rockwool is an insulation but it buys you time should there be a fire. I think it was in 2019 that they were removing the cladding.

52. The temperature in the rooms was roasting, the same as the rest of the hospital. You were unable to open the windows and doors and there was nowhere to turn the heat down. I do not know if the temperature was controlled centrally.

53. I witnessed windows popping out when I was at the hospital. There was one which fell out at the Bute or Arran side of the QEUH, I can’t remember what that part is called. There were a few windows that popped out of there as well. I think at least four or five windows fell out.

54. There was a smell at the hospital, well more than a just a smell. Considering there’s a sewage plant 1000-2000 feet away, when that gets churned up, you’re not only smelling it, you can taste it and the smell is in the hospital.

55. I believe kitchen facilities have been put in ward 6A for parents now. I haven't seen them; they were getting installed as [redacted] was finishing her treatment. The kitchen was being put in at the entrance of ward 6A just through the door. They turned a storage room into the kitchen.

56. They've also changed the food on offer for the kids too and there's somewhere for them to go on that ward now I believe.

COMMUNICATION ABOUT BUILDING ISSUES

57. I was concerned that we were not being told what was going on with the building. I started looking into the construction of the hospital and the water supply. When I started looking in to it, I found out that before the hospital opened, people were aware that some places were not fit for purpose. I say that because there were transplant patients transferred to the hospital in, I think July 2015, but by the August 2015, they'd been sent back. This was due to the ventilation system but the hospital were well aware of the issues. I think that the issue with the ventilation system was that it was installed back to front. I found out information through reading reports online.

58. When it came out in the media that there were issues with the water, I wanted to see what the Dispatches water report said. I read some stories in the media and managed to find some news reports online. I have also asked for reports on the water samplings. I wanted to see for myself what had been going on at the hospital. I knew that there would be water reports because in my previous job working in Health and Safety at a nursing home we had staff working on a monthly rota. You would take one shower head off and replace it, disinfect the other one and swap it over every month. I wanted to see the hospital's record keeping.

59. I asked for the raw data on water sampling reports 18 months ago through Professor White. Initially I was told they were going to break it down to laymen's terms for me so I can read it but I am still waiting for it.

60. I recall attending a meeting at the hospital, when they said they had doused the water with chlorine dioxide while simultaneously maintaining the position that the water was meant to be wholesome. I do not know how water can be reported as being wholesome when they found 23 pathogens in it and some are growing fungus. This was on a slide at the meeting we attended. I've looked at the Healthcare Improvement Scotland reports online from 2018 and as far back as 2015 where it states water sampling was carried out before the hospital was open. That sampling was commissioned by the NHS GGC Health Board. That report has not seen the light of day. It was supposedly never reported to the head of the NHS or the Scottish Government. I have looked at the reports within Healthcare Improvement Scotland. The water issues were looked at and covered in 2018; there were also 11 patients with different types of infections. Those water samplings and the 23 pathogens in the water, ranging from staphylococcus to two different types of pseudomonas. In 2015, when the water sampling was carried out, and again in 2017 and 2018, actions that were required were not taken. In some of those reports, Legionella was mentioned.

61. Having seen these reports, I'm interested in finding out what the raw data shows. I would like to know if the sampling and testing was carried out in-house or if it was external. There is a main contractor I know of that the councils use. I want to know who was doing the sampling, and the microbiology testing. Why did they have to take steps to douse the water if the water coming into the hospital was wholesome? That would indicate that between the inlet and the outlet, there's an issue. Bacteria is growing somewhere.

62. Everything I've mentioned here is freely available information. It led me to ask my own questions to get answers for [redacted].

63. Throughout the whole process, we were asking questions, why can't we bath our kids, why can't they drink the water out of the tap and we were told nothing

was wrong. You asked the Health Board and they tell you nothing is wrong yet after a meeting with the Health Secretary three or four weeks later, you're invited to a meeting with the heads of the NHS.

64. There was a meeting with Jeane Freeman held in the Central Hotel in Glasgow. I went to that one. I thought it was lip service. We had a Health Minister who was trying to show she was empathetic and she tried to convey that she was unaware of what was going on but she's seen these documents that were released to the Scottish Press. I think she was aware of professional concerns and she chose to ignore them along with the Health Minister before her. The Scottish Government as a whole chose to turn a blind eye. She's the Health Minister, if she wasn't aware of all of this, then she isn't doing her job properly. If you have a Health Board that isn't passing critical data to the Health Minister then surely that Health Board shouldn't be in place.

65. What I have found during this process, even in Inquiries, these people are actually policing themselves. For example the report that Jane Grant commissioned before the hospital opened, never reached the Government. They state that they have never read the report, yet they commissioned it. I do have faith in this Inquiry that they will investigate things properly.

66. Three to four weeks after the meeting with Jeane Freeman, we were invited to attend another meeting with NHS GGC. I can't remember the exact date of this meeting but I do remember it being a Saturday morning at 10 am. A male nurse whose name I cannot recall, Jane Grant and the Head of Nursing were there. In total there were nine professionals from the hospital/Government that were in attendance. There were maybe six or seven of the bosses from NHS GGC who attended. They wanted to apologise for any distress caused by the lack of communication. There were maybe around 15 families there. They reiterated there was nothing wrong with the water. They kept using the word wholesome that was the word of the day. They said none of the infections were related to the water but they admitted they should have been better at communicating with us. They said they recognised this and were going to act

on it. I don’t know when they are going to act on it as they still do not interact with us or communicate with us very well.

67. I thought what was said at the meeting was just lip service and I felt it was backhanded. At no point were that set of people, unless told otherwise, getting out of their beds on a Saturday morning to hold a meeting at 10 am unless they were told to by the Scottish Government to make it happen. They didn’t hold the meeting of their own free will.

COMMUNICATION GENERAL

68. When I asked why they were dousing the drains, the nursing staff told me it was just part of the cleaning process. When [redacted] was being moved rooms due to this, we were only given about an hours’ notice.

69. I can’t remember exactly how many times she was moved but she was moved several times within ward 2A.

70. I found out about the closure of ward 2A via the media. I had a friend who sent me a text message asking if I had seen the news. The media were reporting that ward 2A was being closed and that the kids would all be getting moved. I went to the hospital and Charmaine told me there was a letter to say they would be moving. I can’t remember exactly what the letter said but it was on an A4 sheet of paper and it had been placed through the door. We were not told why ward 2A was closing and the kids were getting moved.

71. We attended a meeting where the facilities manager stated that everything would be moved back to ward 2A in spring 2020. To date, they have spent in excess of £14 million trying to fix ward 2A plumbing and ventilation. The same male nurse whose name I cannot recall said it was the Rolls Royce of ventilation that was being put in. If they were putting that in now, what were they taking out? Again regarding the plumbing, if they’re putting in the best

plumbing, what did they take out? All this yet we were told there weren't any issues in ward 2A.

72. I found out about the Cryptococcus that was related to the pigeon droppings, in the media. I think this was in the December of 2018. Like everything else regarding the hospital, everything is second or third hand. Parents were never told of this until it got so much exposure in the media that they released a statement. They said that two patients had caught Cryptococcus virus and this was through pigeon droppings. They didn't say where about in the hospital this had happened, only that it was an adult and child patient. There are only two places in the hospital that this could've been though and one of those places was ward 6A. There were adults on ward 6A and 6B as this was an adult ward too.

73. If it had not been for the media, we would not have known about the issues. Everything from the hospital has been relayed to us second hand. They couldn't tell us why our kids were moving rooms, they couldn't tell us why our kids were moving wards and when you ask a question, you get stonewalled by either staff, Professor Gibson or maybe hospital management. I don't expect a nurse to tell me what's going on; that is above their paygrade and I don't mean that in a derogatory way but that's not part of their job. It's the same for Professor Gibson, she's there to be the best doctor she can be. She doesn't get paid to carry the can for her bosses. Not for one minute will you hear any of the families criticise the way our kids have been looked after; they've saved our kids' lives. It's the environment and the management.

74. On 24 December 2018, Professor Gibson asked us to attend a meeting. I had posted on my own social media that [redacted] was now a guinea-pig regarding her cannula. Someone had been trying to insert a cannula into [redacted] but it took 7 attempts. I was sick fed up of the treatment. It's my Facebook page and it is for my personal views. There were a couple of times we were 'called in front of the head master' for doing this. The hospital don't understand people's frustration. People get frustrated when their kids are going through treatment and there is

only so much you can watch your kid go through before you have to tell someone to stop something they're doing. I don't mean the treatment but if you are going to dawdle, and take your time with the treatment then you do it properly. Staff should not need 7 attempts to put a needle in and if they do, then maybe you shouldn't be doing that. I was asked by Professor Gibson not to put stuff like that on Facebook.

75. There was a meeting on 27 December 2018 to discuss [redacted]'s treatment plan. I attended that however, [redacted] was admitted to hospital again on Hogmanay. She had a fever but Charmaine knows all the details about this.

OVERALL EMOTIONAL IMPACT ON [redacted] AND HER FAMILY

Overall emotional impact on [redacted].

76. [redacted] still sleeps with her Mum. She doesn't like being by herself. She's a scared little girl at times. I think the whole treatment she's had, people just coming in to her room at the hospital during the night, stabbing her with needles, pulling down her pyjama top to listen to her heart, rolling up her sleeves to take her blood pressure, all of this must have a horrible impact on her as a child. We are trying to teach her about her space and that it's her body. So yes, everything has had an impact on [redacted]. Even the water, she knows she can't use it. She's fine at home though and knows it's safe to take a bath there.

Overall emotional impact on witness

77. For me, every block of chemotherapy was difficult that was probably why Charmaine was better off being there 100% of the time. I can't watch things like that. I found it distressing even visiting. There was the odd day when [redacted] was really sick that I only lasted five minutes. She looked like a corpse. I walked in and walked out again. We didn't want her siblings seeing her like that. It's maybe selfish of me as Charmaine was sitting seeing [redacted] every day

like that but I just couldn't cope. There's times even now when she's unwell, even towards the end of her treatment, I always found it difficult. Nobody wants to see their child sick maybe to the extremity where I did visit [redacted] and she would be lying with blood coming out of her mouth or her backside was sore. That was just too much for me. Nurses not being able to get cannulas in, that became too much for me as well. On the times I was there when this happened, I'd tell them to stop. I know how it feels as an adult when the nurses can't get a needle in but for a kid, it must be so traumatising.

78. I think about how you can't protect your kids. Is there something more I could've done? I feel frustration, anger, a whole mix of feelings and baggage.

Overall emotional impact on family members

79. The whole experience has affected us as a family. It's had an impact on relationships. Our mental health has suffered.

80. The staff with Charmaine were intimidating. They would go into [redacted]'s room in twos, threes or sometimes fours when they spoke to her. It was overpowering and unnecessary. On one occasion when I was visiting, four nurses appeared in the room. Sometimes they would come in the room in twos, depending who was on duty.

OVERSIGHT BOARD / CASE NOTE REVIEW / REPRESENTATIVE GROUPS

81. I was involved with the Oversight Board. They were looking for other parents to take part. Myself and another parent were the only parents that came forward. The meetings for it were held every two to three months. I only went to one or two meetings. I had to come out of it due to my own mental health. I had lots going on and I didn't think I would've done any of the other parents any justice so I stood away from it.

82. I was involved in the communications and engagement elements of the Oversight Board. I understand why the Oversight Board was set up but surely as an organisation who are meant to be patient focused and have a person centred approach, they shouldn’t need outside people telling them how to engage with other people. Surely that should be at the forefront of person centred care delivery? They should know how to engage with the person receiving the treatment and how to engage with their family members. I’ve always thought, especially after having spent 25 years in Health and Social Care that the fundamental of care delivery is knowing how to engage with people.

83. I looked over the Oversight Board report but in my opinion, it’s probably the biggest waste of time and money. They shouldn’t have needed to do this if the people at the top of the organisation had filtered things down but I think the beast is too big. The hospital is too big to manage. The directive that’s coming from the above, isn’t being filtered down to those on the floor. It’s getting lost somewhere in translation and it doesn’t matter how many Oversight Boards you’re going to have, if there’s a break in the system, nothing will ever reach where it’s meant to get to.

84. I stated at the meeting, there’s too many bosses and not enough leaders. There’s a lot of people who have their own agenda who are power driven. Where you have a leader, people will follow a leader rather than a boss. If people are shown how person centred care should be and how to engage with people, that example should filter through. It’s like everything you do in life, everything is set by example and that’s where leadership comes in.

85. I don’t have anything else to say about the Oversight Board. I don’t think I’ve got any room to say anything further due to my limited attendance but that’s my view of it. There were three of these groups going on at the same time, one filtering into the other and it was all going up the chain. These groups are only as good as the person reading the end result and if there’s no action taken, then nothing changes.

86. [redacted] was included in the Case Note Review. I've had no interaction with it though. I think we can take a lot from the Case Note Review, it showed we weren't paranoid parents which is how we were viewed by some other people. We're not trouble makers. We were right in everything we said and we are still right in everything we said.

87. We have [redacted]'s report from the Case Note Review. One of the infections named in it is pseudomonas. The results are all broken down into different groups. You've got "possible", "maybe", "definitely", things like that and throughout the report you can see that there's a trend in all different types of infection. As parents, we knew our kids were sick and we knew they would pick up infections but we did not expect our kids to pick up an infection in the place that was treating them. Nobody expects to go into an environment to make them better and not be allowed to wash. You're in hospital to rest, recuperate and get better. Fight for your life but you can't have a bath or a shower and you can't drink the water. What kind of environment is that?!

88. The communication from the Health Board is still as bad as it was at the beginning. Half of the reports came back saying 'maybe the infections were related to the hospital environment'. Maybe I live in a different world but if I was Jane Grant and this was sitting on my desk, it would have been a priority. There weren't a lot of individual reports considering who was getting a reply so surely you would take time out of your day to write a letter and sign it. You don't just send out a bog standard letter if you want to show empathy and compassion as she stated she has.

89. At the end of the Case Note Review, we got a letter. It was a corporate nonsense letter just saying they were sorry about any distress caused and that they were trying to make it right. They can keep it. I believe it was sent out to all the families.

90. I was a member of the Facebook group for parents. I came off it though. It was set up for parents to support each other. People who are going through the experience, or have just finished the experience. It was supposed to offer support. It was a support mechanism, a blanket, whatever way you want to describe it but it seemed it was being monitored. There would be comments made on it, people venting. It wasn't for me though. Charmaine may have used it more than I did, I'm not too sure. I never really took anything away from it. If you raised concerns on it, the staff would always be aware. I left the group.

91. I joined the Facebook group set up by NHS Greater Glasgow and Clyde ("NHS GGC"). "Every day is a good day" was the impression you got from the page. If there was a story in the media, you would get a response on the Facebook page. I didn't think it was very good for communication.

92. I had some communication with Professor White. If you had a question, you would raise it through Professor White and he would then find the right person to answer you and you'd get an answer that way. It wasn't an immediate response you got, hence why I am still waiting 18 months later for water reports. If it was an easy response that was required, you'd get a response but if it was a wee bit harder, you would wait until someone spins you a story. I asked for water reports, a couple of Health and Safety reports and maintenance records. To date, I've none of these. I also wanted to see the structure of the Senior Management. I wanted to see how big this organisation was and who the top management tier was in the hospital and how many managers feed in to it. When you start a new job, you get a staff handbook with an organisation chart that shows you who your boss is, who their boss is and who their boss's boss is. I just wanted an idea of for myself, how big the beast was.

CONCLUDING COMMENTS

93. The whole thing could have been handled a lot better. If they had been open and transparent from the start and said right from the beginning that there were

issues then parents would not have been in this situation. I understand that it is hard to admit there are issues when you've just spent £842 million on the state of the art hospital to find there are big issues. If they'd said at the start about the issues, they could have had them fixed in 2015 when they were first highlighted. It could've been like the Edinburgh Sick Kids where they just delayed the opening but the reason they couldn't do that is because they had already closed every hospital in Glasgow so there was nowhere to go. They'd already shut down the Sick Kids, the Western Infirmary, and parts of the Victoria Infirmary. I can understand why they didn't say anything but surely if they did and had been open and honest we wouldn't be where we are today. That goes for the Cryptococcus incident too. If they just give people the answers then parents wouldn't find themselves in this position.

94. It's too late to say rip the hospital up and start again. That ship has sailed. In relation to the hospital itself, I think someone has to go in with an open mind and be allowed to restructure things because the way it is just now, it's not working.

95. I think the Health Board has let us down. What they are doing is also letting the nursing teams down too. If they had known how to engage with people and be transparent then this wouldn't be the situation we're all in now.

96. I still have concerns about the hospital. I've watched it. When you see windows falling out, workmen taking off the cladding, new insulation being put in and cracks inside the hospital, of course you still have concerns.

97. 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 – TIMELINE (AR/01)

- 17th August 2018– [redacted] became unwell and Charmaine took her to the GP. The GP said that this was likely a viral infection. They went home but remained unwell and was very pale.
- 19th August 2018 – Charmaine takes [redacted] to A & E for further investigations at QEUH. She was transferred to CDU and late in the evening after blood tests were completed, the family were told that she likely had leukaemia. She was moved to ward 2A to room 7.
- 24th August 2018 – [redacted] has surgery to fit a Hickman line.
- 25th August 2018 – [redacted] starts block one of chemotherapy, there were multiple room moves during this time. [redacted] remained in ward 2A till the ward closed around the 26th of September 2018.
- 23rd September 2018 –[redacted] has a line infection. The line is stopped.
- 24th September 2018 – [redacted] has emergency surgery to remove the Hickman line.
- 1st week in October 2018 – [redacted] is discharged home for 3 or 4 days and was then readmitted.
- 11th November 2018– [redacted] is admitted to hospital to start her 2nd block of chemotherapy to ward 6A
- 12th November 2018 – 2nd block of chemotherapy commences.
- 17th November 2018 – [redacted] is discharged home.
- 22nd November 2018 - [redacted] is admitted to hospital because she is throwing up blood. She is admitted to ward 3B in the Children's Hospital. ..
- 26th November 2018 – [redacted] starts 3rd block of chemotherapy.
- 24th December 2018 – Meeting with Professor Gibson. [redacted] is discharged home.
- 27th December 2018 – A meeting is conducted in the hospital to discuss [redacted]'s treatment plan.
- 31st December 2018 – [redacted] admitted to hospital to ward 6A.
- 3rd January 2019 – [redacted] is discharged home after a lumbar puncture
- 21st January 2019 – [redacted] has a fever and is admitted to hospital.

- 23rd January 2019 – Put on Ambisome – infusion – she was put on this infusion every 2 days
- 31st January 2019 – Charmaine reports to a nurse that [redacted] has been itchy. No rash evident. (this is a note from [redacted]'s medical records)
- 20th February 2019 – [redacted] develops a staph infection. The line is not removed.
- 25th February 2019 – [redacted] is discharged home.
- 15th March 2019 – [redacted] had a blood transfusion at clinic
- 19th March 2019 – [redacted]'s temperature spiked and she was admitted. Blood cultures were taken
- 21st March 2019 – confirmed Pseudomonas diagnosis. [redacted] receives antibiotics for this until she recovered.
- 24th March 2019 – [redacted] develops little round circles on her knees. They looked like bruises.
- 25th March 2019 – Dermatologist examines this and confirms it is "Candida (a fungal infection)
- 25th March 2019 – She starts medication for this infection. Ambisome infusions 4 times a day and Antifungal medicine posaconozol
- 29th March 2019 – [redacted] is discharged.
- 1st April 2019 – Maintenance round of chemotherapy commences.
- 26th September 2019 [redacted] was admitted to ward 6A room 11 for 48 hours for a cold That was her last hospital admission at the QEUH.

Scottish Hospitals Inquiry

Witness Statement of

Leann Young

WITNESS DETAILS

1. My name is Leann Young. I was born on [redacted]. I am [redacted] years old. I am [redacted].

2. I am the mother of [redacted] [redacted]. [redacted]s's date of birth is[redacted]. He is 9 years old.

3. I live with [redacted] in [redacted].

OVERVIEW

4. My son is [redacted] [redacted]. [redacted] was diagnosed Burkitt Lymphoma, Stage 4, in April 2018. [redacted] had just turned 6 years old a few days before he was diagnosed. He was admitted on 12 April 2018, and was an in-patient until October 2018. He had the odd day out but was an in-patient for the majority of this time. [redacted] was treated in the Royal Hospital for Children (RHC) and Queen Elizabeth University Hospital (QEUH) between April 2018 and February 2019 when he finished his treatment. He attended both hospitals as an in-patient and as an out-patient for nearly a year. [redacted] still attends appointments every 6 months to see his oncology consultant, Dr Chaudhury. At these appointments he gets a blood test to make sure everything is fine with his blood. He is also attending community physiotherapy every three to four weeks to try and increase the muscle strength in his legs. [redacted] also received care from Child and Adolescent Mental Health Services (CAMHS) although he has now been discharged.

5. [redacted] spent the majority of his time in wards 2A and 2B of the RHC which are known as the Schiehallion Unit. When we were first admitted, ward 2A was fine. Staff were really supportive but the longer we stayed, the more we noticed things that were going on. The nurses, for example, were having to take on more work, for example getting diluting juice for a patient and changing bedding. Following the closure of the Schiehallion Unit in 2018, was treated on wards 6A and 6B in the QEUH. This was supposed to be the 'new' Schiehallion Unit. I stayed with [redacted] for the duration of his admission. My mother helped out and came to the hospital with us. She had a room at the CLIC Sargent facility. I can speak to the experience which [redacted] and I had on these wards.

6. With the assistance of my solicitors, 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 as an appendix **(LY/01)** and I confirm that it is accurate to the best of my recollection.

7. There are some specific events that I would like to mention. [redacted] contracted aspergillus and other infections during his admission. Due to this, he was kept in 'source isolation', where he was not allowed out of the room. He was not able to play or speak with other children on the ward. He was prescribed prophylactic antibiotics in 2018 which I think may have been connected to the issues with the water supply. We were moved rooms quite a lot which had an impact on [redacted] and the treatment he received on other wards. There were ongoing construction works at the hospital during [redacted]s's time there, which in my view, may have impacted his experience. I will come on to talk about these events in more detail.

FAMILY BACKGROUND

8. I stay on my own with [redacted] in [redacted] .

9. [redacted] is in primary [redacted] and goes into primary [redacted] after the summer. He was in primary [redacted] when he was first admitted to hospital. [redacted] was quite a happy, healthy little boy before he went into hospital. He doesn't have any siblings so was pleased when his school friends came to visit him. His friends were prevented by the hospital from visiting him after the 18 May, which I discuss further below.

10. [redacted] is quite a popular little boy within his class although it tends to be mainly the girls that flock around him. He's quite a shy boy but is very talkative at home. He's not one for being the leader and prefers to take a step back. He loves his computer games, his IPad and his X-box, as many 9 year old kids do. He would rather sit in and play on his IPad than go outside. He is quite reluctant to go outside sometimes but I don't know if this because of everything he's been through. He has not really mixed with children his own age. He was only in primary [redacted] when he was diagnosed so he has not had a lot of time with children his own age and he's an only child. He does like to stay in the house with me. He has separation anxiety too. As a family, he loves going away in my mum and dad's motorhome. We try to go away in it as much as we can. He just loves being away and using the kayak my parents have or going out on his bike. I did not think we would get to see him out on his bike again because he has lost some strength in his legs but last summer he called me outside to see him riding his friend's bike which was really nice to see.

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

Admission to hospital: April 2018

11. [redacted] was diagnosed with Stage 4 Burkitt Lymphoma Leukaemia on 18 April 2018, when he was 6 years old. [redacted] had been complaining of a sore head and saying that things were upside down. He was also complaining about having a sore tooth, so on 9 April 2018, I took [redacted] to the dentist. He had an abscess which needed to be removed. On 10 April 2018, [redacted] still had a

temperature so I took him to the GP. I was told it was an ear infection and given antibiotics for him. By 12 April 2018, [redacted] was screaming in pain so we got an emergency appointment with the GP and I took a urine sample with me. Later that evening, I had to call NHS 24 and take [redacted] to the out of hours clinic in Paisley. They asked for him to be taken to QEUH Children's Hospital for further investigation. We attended the Accident and Emergency department initially, then [redacted] was given a bed in the Clinical Decision Unit (CDU) while more tests were carried out. He was then admitted to ward 2C (Acute Receiving Unit) while we waited for the results.

12. During this time, [redacted] had raised Lactate Dehydrogenase (LDH) levels in his blood. When we were told he had raised LDH levels, I questioned it with the doctors and they explained it to me using all sorts of medical terms I didn't understand as a parent. I googled it and the word cancer came up. At the time, I didn't understand what it was or what the implications could be. The Haematologist advised that a bone marrow biopsy would be carried out. Initially doctors were carrying out the biopsy as they thought [redacted] had an infection and they wanted to determine what kind of infection it was and what the right course of treatment would be but when the results came back they showed abnormal cells. Urgent blood tests were carried out and we were moved into ward 2A, room 16 on 17 April 2018.

13. The following day, 18 April 2018, [redacted] was given a formal diagnosis of stage 4 Burkitt Lymphoma Leukaemia. I was told that the cancer was around his brain and Central Nervous System (CNS).

14. During [redacted]'s overall admission, he had 6 rounds of chemotherapy which included two rounds of maintenance chemotherapy at the end. He also had multiple bone marrow biopsies carried out during his treatment to check his progress.

15. [redacted] was violently sick with the chemotherapy and was on anti-sickness medication. His chemotherapy wasn't delayed due to the sickness but it did

mean he had to have Total Parenteral Nutrition (TPN) which gave him all the vitamins and nutrients his body needed. It was given to him through his Hickman Line. He also had a number of infections during his admission.

Experience on Ward 2A: April 2018 – September 2018

16. [redacted] was admitted to ward 2A in April 2018. He had a Hickman Line fitted on 20 April 2018 under general anaesthetic. His line was fitted on his right side, just above his nipple via a cut in his neck. I believe the line goes into the main artery but I'm not entirely sure. He then had a bone marrow biopsy before he started his first block of chemotherapy.

17. I was given a copy of [redacted]'s treatment plan at the start of his treatment which included a list of all his chemotherapy drugs that he was to have. At the start of each block, the consultant would come in and go over that specific section of the treatment.

18. When [redacted] was first admitted, he was absolutely terrified of anyone coming in his room. It didn't matter if it was a doctor, a nurse, the kitchen lady or cleaners. It didn't matter who they were, as soon as anyone came in he would scream and cry. It got to the point where I had to put a note on his door saying, "When you come in the room, please say who you are and why you're coming in" so it gave him peace of mind. He was terrified as he'd been poked, prodded and had blood tests done and he was just scared as to what they would do next.

19. We started off in room 16 and there were no issues there. We were moved to room 9, I think because they had someone new coming into the ward.

20. On 15 May 2018, [redacted] was being sick. He had VRE which is vancomycin-resistant enterococcus. I understand this is an environmental bug. [redacted] often had VRE. When he had VRE, he was moved into source isolation.

21. On 18 May 2018, we were in room 9. I recall there were people in pouring chemicals down the drains. A nurse told me that they had to pour a chemical down the toilet and shower. No reason was given as to why this was.

22. On 1 June 2018, [redacted]'s infection markers were raised. I was told that he had a fungal infection but I was not told the name of it. [redacted] was put on medication to treat the infection. This delayed his chemotherapy treatment by 10 days. I have only recently discovered, after reviewing [redacted]'s medical records, that the infection was aspergillus fumigatus.

23. On 5 June 2018, we were moved from room 9 to a room with double door entry. I think this was a VAC room because it had double doors. We were only told about this move at the last minute. These were the rooms that children who had bone marrow transplants would go into. They had a sink just as you came in the double doors for the doctors and nurses before they came in the patient room. We were told that the room we had been in needed to be cleaned.

24. I think it was also on 5 June 2018 that we were told that all children who had central lines were going to receive Ciprofloxacin as a precautionary measure. I was not told why.

25. On around 6 June 2018, we were told we would be moving rooms again in the morning but we didn't move until 10 pm that night. We were only allowed to take toiletries, clothes and [redacted]'s cuddly toy that he slept with. We had to leave the rest of our belongings, gifts [redacted] had received and toys from the charities with no explanation other than being told we'll get the items back once they've all been through the cleaning regime. The room we had been in was sealed off with a plastic covering. A mist was blown into it which I was told was a cleaning agent. We were moved to a much smaller room. It may have been room 14 or 15.

26. I recall that around this time, we were told that the pipes behind the sinks in the rooms were to be changed because children were getting infections from

the water. I think we were told that bugs were sticking to plastic in the pipes. I cannot remember if we had to move rooms while this work took place or if we only had to leave the room for a short while.

27. [redacted] was put back into source isolation on 7 June 2018 because he had VRE again. [redacted] was put into source isolation quite a lot. There were occasions when they took stool samples from [redacted] to test and see what was going on. Around May 2018 there was a whole period of two weeks where the stool samples went missing. I cannot recall exactly when it was but I remember there was no sign of them being sent away and no sign of results. We don’t know what happened to them so for those two weeks, [redacted] could have been allowed out of source if we knew what it was he had but because those results had gone missing, he spent time in isolation which he might have avoided.

28. Being in source isolation is difficult. For example, I could not go to the parent kitchen myself to get [redacted] what he wanted to eat or drink. The hospital food was horrendous. It was all dry and not what you would want to give to a child who was fighting cancer. At one point, [redacted] had not eaten anything for the best part of two weeks due to being unwell. One day out of the blue he asked me for a drink of milk. I wasn’t able to get it myself in the parent’s kitchen due to us being in source so I had to ask the nurses. By the time we got it though, which was hours later, the notion had worn off. If a child hasn’t eaten and they take a notion for something, they should be able to get it when they need it.

29. On 10 June 2018, blisters appeared on [redacted]’s body. He was given acyclovir intravenously because doctors thought he had chicken pox. He’d already had chicken pox the year before. We were still on the ward at this time and they took a swab from one of the spots on [redacted]. I was told that if the swab was positive, [redacted] would have to be moved off the ward due to the infection risk to other patients. I was told the swab came back negative for chicken pox and [redacted] was taken off the medication.

30. A couple of days later, on 14 June 2018, Dr Chaudhury came to tell me that a mistake had been made and that [redacted] did have chicken pox. She said that the other doctor had looked at results on the same day but a different month. [redacted] wasn't started back on the medication as it was too late to put him back on it. He shouldn't have been kept on the ward. Dr Chaudhury apologised for this error.

31. On 17 June 2018, [redacted] started his third round of chemotherapy,

32. On 6 July 2018, [redacted] was given two doses of his anti-sickness medication. He had been given permission to attend a wedding that day. He had one at tea time and he was given an extra one later as the previous one hadn't been signed off in his notes. I think there had been a change from the night shift. He received too much anti-sickness medication. This meant that [redacted] could not have anti-sickness medication for a long time, as the levels of anti-sickness medication in his system were still too high. He was violently sick and could not have medication to help him. There are two nurses who come in to administer medication so one of them should have noted it or at least noticed it hadn't been recorded. My mother [redacted] put in a verbal complaint about this but I heard no more about it.

33. I learned how to administer his medication. The nurses taught me how to give [redacted] medication through his NG tube, which is the tube that ran from his nose into the gut. Sometimes this came out when he was sick and he had to be pinned down to have it reinserted if he wasn't due to go to theatre. This was quite traumatic for [redacted]. Me giving him his medication through his NG tube was easier and less stressful for [redacted] because he was quite terrified of people coming in his room at first. I was able to see the doses drawn up for him too. The nurses were there during the night and later on in the evening to give him his medication though.

34. On 11 July 2018, [redacted] had to have five teeth removed. The chemotherapy that the children are on can cause mucositis. This can cause a breakdown of their mouth, through their gut and out the other end. [redacted] had a couple of holes in his teeth which presented an infection risk. The best thing to do was to remove his teeth. This was because his neutrophils, a component in the blood, were so low. This meant he was at a higher risk of infection. If his neutrophils were below one then his immune system was at risk if he didn't have any protection to fight off infection. Usually his blood would recover itself in a few days or weeks but on the odd occasion, if quite a bit of time had gone past and his blood hadn't recovered, he would be given a medication that would help boost the neutrophils to bring them up to a suitable level. This was to help fight off infections. Neutrophils also had to be above a certain level for chemotherapy too.

35. [redacted] had his teeth removed under general anaesthetic in theatre. I think we moved rooms but can't remember exactly. I do remember we had been in a room with double doors before [redacted] had his teeth extracted, but I think we were in a room with a single door afterwards. I remember writing a note and sticking it to the door, which was a single door, after his teeth had been removed. [redacted] had been worrying the Tooth Fairy wouldn't know where he was. I wrote a letter and stuck it to outside of his room. The nurses wrote back to him which helped build his spirit a wee bit.

36. On 21 July 2018, [redacted] had a temperature spike of over 40 degrees. It took hours before he was given calpol to help bring it down. I think the nurses were too busy with other things to get to him. He was in ward 2C.

37. On 13 August 2018, workmen appeared first thing in the morning to remove cladding from the building. They were outside [redacted]'s bedroom window. I recall this work went on for weeks. During that time, there was scaffolding up around the children's hospital.

38. On 16 August 2018, [redacted] started his 5th round of chemotherapy. On 26 August 2018 he was put into source again with VRE.

39. On 31 August 2018, [redacted] was told that his cancer was in remission. He still had a further round of maintenance chemotherapy to go through in September. [redacted] had his final round of chemotherapy in ward 2A on 12 September 2018. He was discharged to the CLIC Sargent House to keep him close to the hospital because his blood counts would often crash after chemo. We lived too far away from the hospital to be able to get [redacted] there quickly. He needed to be near the hospital.

Closure of Ward 2A and the move to the adult hospital: late 2018

40. On 18 September 2018, we were at CLIC Sargent House and we saw on the news that the Schiehallion Ward was closing. I had been in the RHC the day before and there was no indication the move was happening. [redacted] was due to go back over to ward 2B in the RHC for a blood test the next day so I phoned the ward to make sure I knew where we were to go.

41. The nurse had not seen the news and knew nothing about the closure! You'd think the people working there would at least have had an idea.

42. On 20 September 2018, I was given a letter telling us the ward was closing and moving to ward 6A in the adult hospital. The letter did not say why. I do not have a copy of it now.

43. [redacted] was an inpatient on ward 2A on 25 September 2018, having spiked a temperature. This was the day before the move to the QEUH happened on 26 September 2018. It was organised chaos: there were no additional staff to help. Nurses were looking after everyone and everything. They were packing up everything in all the different rooms, all the equipment, medication and furniture. [redacted] had to wear a mask on his face. Once we moved over to 6A, they then had to unpack everything. This impacted how they were able to deliver care as you never really saw the nurses in the rooms at this point. Children are supposed to have their observations taken

every 4 hours but the nurses were just so busy with the unpacking and moving that the student nurses would get put in to do the observations.

44. If the observations weren't taken every four hours and he had a temperature, would have to go with-out calpol to help get his temperature down. If he was continuing to get temperatures when he was already on antibiotics then it might be a sign that another infection was growing. Staff were supposed to take blood cultures and send them off so if the antibiotics he was initially put on to fight the infection were the wrong ones, if the blood cultures weren't done, then time had been wasted on the wrong antibiotics.

Experience in the QEUH (adult hospital): late 2018 – 2020

45. In ward 6A, there was no playroom. When [redacted] wasn't in source on 2A, he was able to use the play room but there were no facilities like that on 6A. The play leaders tried to bring activities and toys in but they didn't have the storage for everything they had on ward 2A so they had to go back and forth for things, which meant taking them away from other patients if a child wanted something. There were no facilities for [redacted] to utilise on ward 6A.

46. We didn't have a parents' kitchen on ward 6A either. There was nowhere to store food, make a coffee or even sit and have a chat with other parents, get their support or even just have a cry.

47. [redacted] was allowed to go home to the CLIC Sargent house on 12 October 2018. On 19 October 2018, [redacted] had to go to ward 6A, from CLIC Sargent, to get his line cleaned and bloods checked. His line was cleaned weekly. The dressing is removed and they use a roller top type bottle with alcohol to clean round it. It was then dried off and a new dressing was put over it. There were a couple of times where it looked red and crusty round about it but it wasn't swabbed. They just used a foam pad that would go between the dressing and [redacted]'s skin to keep it clean.

48. To get to ward 6A, [redacted] had to use the lift in the adult hospital going up to the ward. They did not have a dedicated lift for the children at this time which was quite a concern for me. Previously, you could walk through a long corridor from the RHC and go up to the adult hospital that way but we were advised not to use the children’s entrance due to the cladding being replaced. We were asked to use the entrance at the adult side of the hospital where people would stand outside smoking. Our children were at a higher risk of infection and we didn’t know who had been in the lifts, what they were there for, why they were there. There were a lot of visitors using the lifts to visit other patients. Patients themselves were using the lifts after having been out to the shops. [redacted] would be sat in his wheelchair in the lift, which was jam packed with people who were leaning over the top of him or had their hands in his face. I was concerned that he had to do that initially to get up to the ward and then, once there, we had to go through ward 6A to get to Day Care. Not only that, [redacted] could have brought something in to ward 6A when he was trying to get to Day Care. It could put him and other children at risk.

49. [redacted]’s central line was removed on 14 November 2018. He’d finished his treatment but his blood counts hadn’t recovered. Even when he was able to ring the bell on 19 October 2018, when he’d finished his treatment, we still couldn’t go home due to his blood counts being so low. This is a bell that children with cancer ring to celebrate and mark the end of their treatment. We had to be within an hour of the hospital in case [redacted]’s bloods crashed but because we stayed an hour and half away, we were discharged to CLIC Sargent House.

50. Once [redacted]’s treatment had finished, he had to attend Day Care once a week to get the lines flushed to make sure they were still functional and didn’t clog up.

51. After [redacted]’s treatment had ended, there were a few times where he had to be admitted as an in-patient. Quite often, there would be no space on ward

6A, so he could be put elsewhere within the RHC. I don't know if this was because every room was full but we weren't told otherwise.

Other Admissions: End of 2018 – February 2019

52. On 10 December 2018, [redacted] had Respiratory Syncytial Virus (RSV). He was admitted for three or four days and put on antibiotics and fluids. I think it was ward 3 in the RHC this time as there was no room in ward 6A.

53. [redacted] was diagnosed with shingles on 6 January 2019 and was admitted to ward 2C in the RHC, which I believe is a general ward. He was put on acyclovir and was supposed to be in there for about 2 weeks.

54. On 18 January 2018, I saw the story about the pigeon droppings. As we were not on our "home ward", it took several hours for me to find a member of staff who could talk to me about it. When a nurse did come, I asked her if [redacted] was at higher risk because of it. The nurse's response was that [redacted] could go home that day. She did not answer the question.

55. [redacted] spiked a temperature on 10 February 2019. He was admitted to another ward in the RHC, ward 2C I think, as there was no room for him on 6A. He was diagnosed with flu and given fluids. He was discharged a few days later.

56. When he was on a different ward, it was difficult to get hold of staff from the Schiehallion ward as they see all their patients first then go round the wards where their other patients are.

57. [redacted] continues to have check-ups every six months.

WATER: EVENTS INVOLVING WATER SYSTEMS

Water Incidents in RHC 2018

58. There were filters on the taps and shower which were there during our admission. These would be changed every so often during our time there. The sink in the room was only for hand washing.

59. To my mind, the fact there were filters on the taps and the showers indicated there was a problem with the water which impacted on patient safety.

60. On around the 18 May 2018, I was told by the nurse that they had to pour a chemical down the shower and toilet of the room [redacted] was in. We weren't told why, just that we couldn't use the shower for a while to allow the chemical to go through the system.

61. On around about 6 June 2018, I was told by another parent that the hospital were going to change the pipes behind the sinks in the room because children were getting water infections from bugs that were sticking to the plastic in the pipes. I can't remember if we had to leave the room for a time or whether we moved rooms. Their child had an infection because of these bugs.

Water: communication

62. We were told the sink in the room was not for drinking water. It was only for hand washing but we were not told not to use the bathroom water for brushing our teeth. We were told by nurses it was fine to use.

63. I asked the nurses why there were filters on the taps but I was just told it was part of the hospital protocol and that they were always on the taps. I wasn't told the reason why.

HEALTHCARE ASSOCIATED INFECTIONS

HAIs: events and impact

64. [redacted] was put into source on 15 May 2018 because he was being sick and had VRE. Being placed in source was pretty constant during his duration at the hospital.

65. [redacted] would be in source isolation for 2 or 3 weeks then the VRE would clear for a few days but he'd be back in source isolation again. It continued like this during his stay.

66. Sickness can be a side effect of chemo but his diarrhoea, I'm not so sure. As far as I'm aware from looking up VRE, it's classed as a hospital super bug and is passed on by touch. [redacted] hadn't been allowed out of his ward or room and we weren't going anywhere so the infection had to have come from somewhere. I was quite on top of the cleaning including the touch points in his room, light switches, monitors with antibacterial wipes. I'd clean them, 3, 4 or 5 times a day to try to minimise the risk but the infection was coming in from somewhere.

67. On 1 June 2018, [redacted]'s infection markers were raised. Staff were quite baffled as to what the infection was and where it was so they carried out quite a lot of tests on [redacted] including a CT scan and ultrasound scan. He had his eyes examined too as they wanted to see if the infection was at the back of his eyes. They diagnosed a fungal infection.

68. [redacted] was already on antifungal antibiotics but when they diagnosed him with the fungal infection, his dosage was increased and he was given it daily. He was already being really sick because of the chemotherapy and the antibiotics added to this. The antibiotic he was on was called Ambisome.

69. [redacted] was back in source on 7 June 2018, once again with VRE. I can't remember how long for. All the occasions with VRE seem to merge together.

70. [redacted]'s chemotherapy was delayed by 10 days due to the fungal infection he contracted.

HAIs: communication

71. I asked the nurses who were coming in and out doing [redacted]'s observations, what [redacted] had. They would just keep saying, "Oh, we'll go and check his results" or "We'll check what's on the system", then they would disappear off. Eventually someone would come back, but it wasn't clear information they would come back with.

72. It was the nurse in charge who told me [redacted] had VRE. She handed me a wee slip just explaining what VRE was. [redacted] wasn't put on any treatment for it as it's resistant to antibiotics. It was just something he had to ride out until the symptoms cleared up.

73. We were never told he was clear of VRE. His symptoms would just clear slightly and they would allow him to come out of source isolation. We were never actually told it was gone only that when he developed further symptoms it was back again.

74. I wasn't told the name of the fungal infection he had in June 2018, I found out from his medical records that it was aspergillus fumigatus.

PREVENTATIVE MEDICATION

Preventative medication

75. [redacted] was put on prophylactic antibiotics three times a week as part of his treatment protocol. These were environmental antibiotics he was given them three times a week, Monday, Wednesday and Friday. At the time we believed it was part of his treatment plan. No one explained it as being anything otherwise. On 5 June 2018, I was told we were moving rooms. On

that day Dr Albert came in and told us that all the children on the ward with a central line were getting put on Ciprofloxacin. I wasn't told why though.

76. [redacted] was put on ciprofloxacin but it had to be changed as it made his sickness worse. He was violently sick every day due to his treatment but he was sick a lot more on the preventative antibiotics. I think he was given pozaconazole instead but I'd need to double check.

77. I wasn't asked for consent about the preventative antibiotics, the Cipro or any others. I was just told that it was happening.

OTHER ISSUES RELATING TO HOSPITAL CONSTRUCTION

Hospital build issues: impact of construction works

78. On 13 August 2018, I woke up to find them removing cladding from the side of the RHC. There was a blue film on the windows to protect the glass and scaffolding was getting put up. I was never told this would be happening.

79. While the cladding was getting removed, we were told that we weren't allowed to use the entrance to the RHC and we had to go through the entrance to the adult hospital. The entrance we were asked to use was where everyone goes to smoke. There were people coming and going through that entrance. Staff were happy for children to be going through smoke and goodness knows what else but not through the other doors because of dust. I wasn't happy about this. Adults were standing coughing and spluttering everywhere. It was not very nice.

80. The windows in the room couldn't be opened. There was no option to open them even if you'd been allowed to open them.

81. From about June 2018, we kept getting moved rooms due to cleaning. They had what looked like external people come in to do the cleaning. Once the

children had vacated the rooms, there was a plastic sheeting went over the door that would be taped off and there would be a machine on the outside that went through the plastic sheeting and it blew a fog or mist into the room. I think it was for 24 hours that the room would be locked off for until you were allowed back in.

82. [redacted] has been left with mobility issues since his stay in RHC/QEUH. He walks on his tip toes and he's had to have several serial castings done on his legs which means they put his legs in plaster cast for weeks at a time to try and bring his feet down. He now has to wear splints on both feet for 6 hours a day whilst he's at school to try and encourage his feet to stay flat. This is partly because of the medications he received to treat his cancer as it can break down the muscle in the legs. I think it is also due to him being bed bound. [redacted] was in source isolation a lot because he picked up infections. If he hadn't have picked up the infections and been in source, he would have been more mobile and able to walk up and down the ward to get exercise. He was a tip toe walker before he went into hospital but it wasn't as bad as it was when he left the hospital. I think the issues with the hospital mainly impacted [redacted]'s mental health.

83. I did not like the fact that you couldn't open the windows. The rooms were sometimes really hot so the temperature spikes could have just been down to that. Then there would've been no need to put him on the protocol and give him antibiotics he maybe didn't need. Even the nurses would come in and comment on the heat. The staff used to turn the ward lights off to try and cool the ward down. It was worse when you were in isolation as you weren't allowed to open the door due to infection control.

CLEANLINESS

84. Another point I want to raise is the cleanliness of ward 2C. I'd asked for bedding for myself for the parent's bed and I was handed a blood stained blanket. It was disgusting. I can't remember if it was a nurse or an auxiliary

that gave me the blanket but I told them they couldn't give me that and I handed it back. I asked why it hadn't been checked beforehand but they weren't interested.

85. Nurses just kept coming in and out of the room as normal; just washing their hands, no aprons and no masks until [redacted] was diagnosed with flu. [redacted] had already been in the hospital for two or three days with nurses being in and out so them spreading the flu was a worry for me.

86. [redacted] was violently sick multiple times every day and sometimes had diarrhoea where unfortunately, he didn't always make it to the toilet in time. We used to be able to change the bed ourselves but when everything started happening on the wards, when all the room moves were happening and the rooms were being cleaned with cleaning mist, we could strip the bed but had to ask the nurses to bring bedding for us. Sometimes they couldn't bring it straight away so we'd be there for an hour or two waiting for bedding and had nothing clean to lie on, just the mattress which wasn't comfortable for him. When you're sitting in the room, you can see the trolley with the clean bedding just two seconds down the corridor and you think "Why can't I just grab a clean sheet and put it on the bed for him".

87. The dirty bedding could be left sitting for a long time. It was the same with his stool and urine samples on ward 2A. Nurses wanted to check how much urine he was out-putting each day so they could measure his fluid intake and output. When [redacted] had the VRE he had to submit stool samples all the time. We weren't allowed to take to the samples to the sluice which was on ward 2A. The sluice was a room with two sinks it in, a couple of bins and the disposal for the samples. At first, we were allowed to take it down ourselves. We would just put the name on it and the nurses would deal with it but when that all stopped, we would be asking the nurses to come in and take the samples from the room. I think this practice changed towards the end of May 2018.

88. Sometimes the samples were left for hours and hours and you could have 6 or 7 sample pots sitting in the bathroom waiting to be collected. As you can imagine, sitting in a room that's warm, the smell was bad. I didn't think it was hygienic them being left to sit that long but again, it was down to the nurses' workload. They just had so many extra things they had to do that parents had been allowed to do before and now weren't allowed to do. It had all been put on to the nurses. Nurses had a lot more tasks to take on due to new protocols for infections on the ward.

89. When the nurses came in to do the observations, they would forget to take the sample pots away with them. It got to the point where I had to say to them if they're not going to collect samples, I'm not going to keep putting them out and I'm going to let [redacted] go to the toilet normally as it's not hygienic for them to be left sitting in the room.

90. There was a smell of sewage at the hospital when you were going outside to inside from the carpark into the hospital. It was disgusting. Not what you want to be smelling when you're going into a hospital. You could smell it on every ward.

91. We were aware of smells on the ward too. On one occasion, in ward 2A, it smelt like gas. It's hard to describe the exact smell, it was like a burning gas. One of the nurses came in and said she didn't know what it was. She got other nurses and the nurse in charge to come in to see if they could smell it too. The nurses were debating whether to pull the fire alarm or not but they decided it was in fact fine.

92. [redacted] had a fantastic relationship with one of the weekend cleaners. The rooms were cleaned daily but I would never put [redacted] on the floor. If you wiped the floor with a wipe after it had been cleaned, you would see that it was still dirty. It appeared the cleaners used the same water and same mop for every room but I really don't know if the water was changed or not. I never saw them change the water in between rooms.

93. There was a cloth over the mop which I'm not sure about. It looked like it went into a bucket of water, different to the stuff they dipped the mop into clean it but it was the same one for each room.

94. The cleaning was different when you were in isolation as the rooms were cleaned twice a day. I think it was once in the morning and once in the evening. Staff used to wear aprons when they came in to clean during isolation.

95. I saw on the news about the pigeon droppings at the hospital. I wasn't told by a staff member it was an issue. I asked the Nurse Practitioner a question about the news and asked if it would put [redacted] at extra risk being here. She said, no it's fine. She went away but then came back saying [redacted] was well enough to go home. It gave the impression that anyone who didn't need to be in the hospital was well enough to be managed at home. It looked as though you were better being managed at home rather than being in that environment.

OVERALL EMOTIONAL IMPACT ON [redacted] AND HIS FAMILY

Overall emotional impact on

96. [redacted] was affected mentally more than anything. The periods of source isolation when he wasn't allowed visitors were difficult. As a child, you want to be with other children. You want that sort of stimulation from doing normal activities and that was all taken away from him with the diagnosis, isolation and not having people there.

97. With [redacted] not being allowed visitors, it was just me and my mum that were there all the time. He now has really bad separation anxiety. Although he loves spending time with my mum, dad and family, if I say to him he's going

to be doing something at the weekend and he finds out I'm not going to be there, he won't go.

98. Even going to school sometimes, he's terrified about leaving me. It's not been helped by covid and being off school. We had gotten back into a routine then the lockdown happened and it's like being back in the hospital situation and he's got really bad separation anxiety from that.

99. [redacted] was under the care of CAMHS. He was on the waiting list for a year before he was seen. Even then, it was me they had video calls with. The psychologist at CAMHS said [redacted] needs tested for ADHD at school as he's displaying a couple of symptoms and they need investigated. Whether this was always going to be the case or whether it's been triggered by his time in hospital, we'll never know.

100. [redacted] can be very up and down. His behaviour can be very erratic at times. He can go from 0 – 100 in the space of a second. He can be sitting quietly and I'll ask him to do something and he can have an aggressive outburst. He's not aggressive but he has lashed out at me a couple of times. Whether this was triggered by the hospital and the situation, again, we'll never know.

Overall emotional impact on witness

101. You're already in a stressful situation when your child has cancer without having to worry about all the other things going on in the hospital or about your child getting an infection. I tried to stay cool, calm and collected in front of [redacted] and didn't discuss anything in front of him; he's got the personality type where he will stress and worry about things. I was stressing and panicking.

Overall emotional impact on family members

102. My mum was very angry and upset when the issues started to appear in the media. She had to watch her grandson getting treated at the hospital with all of the other issues going on.

103. My mum used the parents' kitchen in 2A quite a lot. She would get our daily food and drinks in the morning and prepare lunches with our names on before she came over to us. She would store these in the fridge for us and make us coffee. When the parents kitchen closed in ward 2A, that was taken away from her and she felt useless as she couldn't do anything else to help.

COMMUNICATION: GENERAL

104. When [redacted] was first admitted, his consultant, Dr Chaudhury, gave me a print out of the protocol [redacted] would be on. This had all the names of the different chemotherapies he would be on and the potential side effects which she explained he could get from them.

105. I felt I was well informed about his treatment. There was one time I asked the nurse if she could tell me the names of the medications and she wrote them down, which each one was for and why he was getting it so I had a physical copy of it.

106. I was told by a mixture of nurses and consultants about the possible side effects and things that can happen during treatment. They said that it won't be the treatment that causes him to be really ill, it could be an infection. I can't remember exactly who said this.

107. The communication about [redacted]'s treatment was like night and day compared to communication about other things. Why he was getting put on precautionary antibiotics wasn't explained. The room moves weren't clearly explained. The reasons why chemicals were being poured down the drains, why the ward was having to close and the situation with the pigeon droppings weren't explained either. These were just brushed over as if staff

didn’t want to answer them. We were just told, it’s precautionary, we have to do it. There have been infections and we have to get on top of it. Staff never went into details about anything. It was just brushed over.

108. We were not always given notice of room moves. They would come in and tell you that you’re moving but not why.

109. On 18 May 2018, [redacted]’s friend came to visit him, which they’d previously been allowed to do. We were told that day that it was only siblings that were allowed in. It was the day his friend came that staff told him they’re not allowed in. We were never told this was stopping.

110. [redacted] had a temperature spike of over 40 degrees on 21 July 2018. He was left for hours without any calpol. Nobody told me at the time that they’d actually suspected sepsis, which made his wait for the calpol worse. I found out about the suspected sepsis from his medical notes. They should’ve told me or my mum if that’s what they suspected.

111. On 4 September 2018, we were supposed to be getting discharged to back to the CLIC Sargent and were unaware [redacted] was going to be discharged home that day. I was completely unaware that [redacted] was being discharged that day. No one had mentioned it at all, even on the doctors’ rounds that morning nothing was said, as far as I was aware he was to continue being an inpatient for the remainder of his treatment. All of a sudden, we were told they needed the room and [redacted] was well enough to go over to CLIC Sargent House. I decided to take him home as we hadn’t been home for a long time. I took him home that night and took the opportunity to take some of our stuff home as we’d gathered quite a lot of things.

COMPLAINTS

112. My mum complained to the nurse in charge when [redacted] had been given an overdose of medication on 6 July 2018. The nurse in charge told my mum

that she would fill out a form that this had happened. We were never shown the form or asked to sign it. She informed my mum that on a monthly basis staff go through these forms and see what issues had occurred that month then they address it with the nurse.

113. We heard nothing back from this and personally, I think it should've been dealt with there and then, especially with an overdose.

114. There was an occasion when the First Minister and Health Secretary were at the hospital for a visit. I think it was maybe for Nurses Day. We'd been in a roasting hot room and my mum decided to speak to the First Minister or Health Secretary about the heat in the room. I think it was the Health Secretary that she spoke to and she said they'd get a member of the Management Team to investigate and have a look at it for us. A guy turned up wearing a suit and he had ladders with him. He put a probe up into the vents system and said everything was fine. That was the last we heard.

OVERSIGHT BOARD / CASE NOTE REVIEW / REPRESENTATIVE GROUPS

115. I have heard about the Oversight Board but I wasn't directly involved with it. I used to see the updates that were posted but had no direct involvement with them.

116. [redacted] was not included in the Case Note Review. I got a letter telling me he wasn't but I can't remember the exact wording. Maybe because his case wasn't "important enough", I don't know.

117. I'm not a member of any representative groups.

CONCLUDING COMMENTS

118. At the time, you're just trying to get from one day to the next and it wasn't until [redacted] was out of treatment that I've sat back and thought, "That was

actually horrific having to deal with that on top of everything else". You're already in a horrid situation and then having to deal with everything else on top.

119. There should have been more communication from the staff to the parents. That hospital was our home for 6 months. We were there day in and day out. There should have been more communication about what was going on. Yes, it wouldn't have been nice to hear and it would have been stressful but at least we would've been prepared and had knowledge instead of hearing it second hand from newsreaders, newspapers or news articles online.

120. If we knew exactly what was going on or what they suspected by cleaning the rooms, or cleaning the pipes, or pouring chemicals down drains, it would have made things easier to understand and deal with rather than just being left in the dark.

121. It was quite stressful hearing all the different things that have come out. In some sense you think, thank god it's not me in that situation but in the other sense, you think it quite easily could have been me. We were there at that time. We were in the hospital when everything was happening. It's not nice to see certain things in the press and things that have come out since.

122. To be told it's not the treatment that makes them ill, it's infections, then to find out children are getting infections, makes you more stressed. It shouldn't have been happening. [redacted] was there to get better, not worse.

123. 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 – LY/01 – TIMELINE

- 7th April 2018 – [redacted] showed signs of being unwell complaining of a sore head, that things were upside down. He also started complaining about a sore tooth.
- 9th April 2018 – Appointment at the local dentist. He had an abscess which needed to be removed.
- 10th April 2018 – [redacted] still had a temperature so Leann took him to the GP. Local GP was closed that day so he was taken to a GP in the next village. There he was told that he had an ear infection and was prescribed medication.
- 12th April 2018 – [redacted] was screaming in pain. He received an emergency GP appointment. He did a urine sample that day at home. Leann took this sample back to the GP and was told by the receptionist that the doctor had looked at it and everything was fine which Leann disputed. She phoned NHS 24 that evening and took [redacted] to an out of hours clinic in Paisley. They asked for him to be taken to QEUH children's hospital for further investigations. Leann and attended QEUH in the evening and remained there.
- 13th April 2018 – In the early hours, blood tests were done and Leann was told that [redacted] had raised LDH levels in his blood and more tests were carried out.
- 14th April 2018 – [redacted] was moved from CDU to ward 2C. Room number unknown. Haematologist said a bone marrow biopsy would be carried out.
- 16th April 2018 – Bone marrow biopsy carried out
- 17th April 2018 – Urgent blood tests conducted and Leann was told that abnormal cells had been identified. Leann was told that [redacted] had cancer but he was not formally diagnosed on this date. That day moved from ward 2C to ward 2A, room 16.
- 18th April 2018 – [redacted] given formal diagnosis of stage 4 burkitt lymphoma leukaemia. He went for an MRI that day and they were then told he had cancer around his brain and CNS.
- 20th April 2018 – [redacted] had a central line fitted.
- 21st April 2018 – [redacted] started chemotherapy. 1st round.

- 15th May 2018 – [redacted] put into Source because he had diarrhoea and was being sick. Moved from room 16 to room 9. He moved rooms because a new person came on the ward.
- Around this time [redacted] had VRE vancomycin-resistant enterococcus an environmental bug. Difficult to know how long he was ill with it as he had it so much. On this occasion or possibly at another point when [redacted] had VRE, stool samples were taken to see if he had any other bugs. Leann kept asking for the results and was not told anything. She came to find out later that there were two weeks' worth of stool sample results that had gone missing.
- 18th May 2018 – [redacted]'s friends from school came to see him and were denied entry to the ward on the basis that no children were allowed in, only siblings. This was extremely upsetting for [redacted] who is an only child and no one had communicated this to them.
- Around the 18th May 2018 or the surrounding days – Leann was told by the nurse that they had to pour a chemical down the shower and toilet of the room that [redacted] was in.
- 1st June 2018 – [redacted]'s infection markers were raised: he had a fungal infection. Leann was not told the name. Further tests were done to check if it had spread. These investigations included an eye examination, an ultrasound and CT scan. She was told that he had a ball of fungus on his liver. He was put on medication to treat this (a higher dose) and his chemotherapy was delayed by 10 days. Leann was given no further information but upon reviewing [redacted]'s records later on it states that he had Aspergillus fumigatus.
- 5th June 2018 – Moved from room 9 to a room that had a double door entry (Leann cannot recall the room number). They were told about this move last minute and were told he was moving because the room needed to be cleaned. On that day they were also advised by a doctor that all children who had central lines were going to receive a medication as a precautionary measure called Ciprofloxacin. Leann was not told why.
- 6th June 2018 – [redacted] was moved rooms from the room with the double doors. The family were told they were moving in the morning but did not move until 10pm that night. The family were not allowed to take any of their things with them. Stuffed toys, games, books, everything except the clothes on their back

had to stay for cleaning. The room was then sealed with a plastic covering and a mist was blown into the room which Leann was told was a cleaning agent. Leann thinks they were moved to either room 14 or 15. The room was very small is all she can remember about it.

- Around about the time they were in this room, Leann recalls being told that the hospital were going to change the pipes behind the sinks in the room because there were children getting water infections from bugs that were sticking to the plastic in the pipes. Leann can't remember if they had to leave the room for a little while, when this work took place or if they were moved rooms.
- 7th June 2018 – [redacted] was put back in source with VRE. Leann can't recall how long he was in isolation for.
- 10th June 2018 – Blisters appeared on [redacted]'s body on one side. He started receiving acyclovir by IV because the doctors thought he had chicken pox even though he had already had it the year before. A swab was taken and Leann was told that if the swab was positive he would be moved off the ward because of the risks it would pose to other patients/pregnant nurses.
- 12th June 2018 – Swab is negative for chicken pox and the medication is stopped.
- 14th June 2018 – A consultant advises that a mistake has been made and that the fungal infection was all clear and that [redacted] did have chicken pox.
- 17th June 2018 – [redacted] started his 3rd round of chemotherapy.
- 6th July 2018 – [redacted]'s blood counts had not recovered enough for him to complete the last part of cycle 3 of his chemotherapy. He was therefore given permission to attend a wedding that day. As part of this, too much anti sickness medication was signed off by the nurses due to a change in shift. The consequences of this were that [redacted] was not allowed the medication for a long time which made him very violently ill.
- 7th July 2018 – Leann's mother, [redacted] put in a verbal complaint to the nurses about it. A form was completed and the family heard no more about it.
- 11th July 2018 – [redacted] started the 2nd part of the 3rd cycle of chemotherapy. He had 5 teeth removed on this date which was a consequence of the

chemotherapy. The teeth had holes and this left him at higher risk of infection until they were removed.

- 11th July 2018 – 21st July 2018 – Leann thinks [redacted] may have moved rooms in this time period but she can't recall for certain. What she can recall is that from the day when he had his teeth removed to the events of the 21st July, she was in different sections of ward 2A.
- 21st July 2018 – [redacted]'s temp spikes to over 40 degrees, he was left for several hours before he was given calpol to help reduce his temp. The nurses were busy with other matters/too busy to get to [redacted]. Generally, there were many delays because the nurses were extremely busy.
- 13th August 2018 – 7:53am workmen appeared outside [redacted]'s bedroom window removing the cladding. This took place for weeks and weeks and there was a lot of scaffolding around the children's section.
- 16th August 2018 – [redacted] started his 5th round of chemotherapy/ his 1st maintenance round.
- 26th August 2018 – Put into source with VRE.
- 31st August 2018 – [redacted] was told that his last bone marrow biopsy was all clear and his cancer was in remission. He still had another round of maintenance therapy to go through in September.
- 4th September 2018 – Allowed home for a few days.
- 9th September 2018 – admitted back because he was sick at home and his NG tube came out. He returned to ward 2A. Room unknown.
- 12th September 2018- Final round of chemotherapy into ward 2A. Room unknown.
- 17th September 2018 – [redacted] received his last dose of chemotherapy and he was discharged over to the CLIC Sargent House. He was not allowed home because his blood counts would crash after chemo so he needed to be near the hospital.
- 18th September 2018 – Leann finds out on the news that 2A and 2B are closing and the wards are moving to the adults hospital. They had been in the day before and there was no indication that this was happening, nothing was mentioned. Leann was due to take [redacted] back that day so she phoned the

ward to find out what she should do and where she should take him. The staff knew nothing about the move. Leann was told to take [redacted] to Day care.

- 20th September 2018 – Leann took [redacted] to 2B to get his bloods checked. She was given a letter saying that the ward was closing and they were going to 6A in the adult hospital. They were not told why.
- 25th September 2018 – they were still staying at CLIC Sergeant House. He spiked a temperature and had to be admitted. He was therefore an inpatient during the move on the following day.
- 26th September 2018 – Leann described the move as being like “organised chaos”. The nurses were trying to look after everyone and move everything. was asked to wear a mask over his face. Mid-afternoon [redacted] was moved over to 6A. Room number unknown.
- 12th October 2018 – [redacted] was allowed to go home to the CLIC House
- 19th October 2018 – Went to Ward 6A to have his central line cleaned and bloods checked. He had to walk through the whole of ward 6A to get to day care.
- 14th November 2018 – The central line was removed
- 10th December 2018 – [redacted] had Respiratory syncytial virus RSV. He was in a different ward, possibly 3. It was not 6A. He was admitted for 3 or 4 days.
- 6th January 2019 – [redacted] is diagnosed with shingles and admitted. He was not allowed to ward 6A so he was put into ward 2C.
- 18th January 2019 – Leann saw on the news about the pigeon droppings story. [redacted] was in hospital when Leann read this. She asked if [redacted] was at a higher risk because of this and the nurse’s response was that he could go home that day. She did not answer the question, just that he could go home. He was discharged.
- 10th February 2019 – [redacted] spiked a temperature. There was no space on ward 6A to admit him so he was put in ward 2C. Tests were conducted and on the 12th February he was diagnosed with flu. He was discharged 3-4 days after this admission.

Aftercare

For 6 months after this he continued taking the prophylactic antibiotics and attended for check-ups. These were every 2-3 weeks to make sure he was ok, then this changed to once a month then after a year this changed to every 3 months. Now he sees the hospital every 6 months. First 6 months he attended day care for appointments, after this it was the clinic in the main atrium at the hospital.

Scottish Hospitals Inquiry

Witness Statement of

Charmaine Lacock

WITNESS DETAILS

1. My name is Charmaine Lynnette Lacock. I was born on [redacted] . I am [redacted] years old.

2. I am the mother of [redacted] . [redacted] 's date of birth is [redacted]. She is 5 years old.

3. I live with my partner, Alfie Rawson, and our four children, [redacted], [redacted], and [redacted], in [redacted].

4. I am a [redacted]. Alfie and I [redacted].

OVERVIEW

5. My daughter is [redacted] . [redacted] was diagnosed with Acute Lymphoblastic Leukaemia ("ALL") in August 2018. [redacted] was treated in the Royal Hospital for Children ("RHC") and Queen Elizabeth University Hospital ("QEUH") between August 2018 and December 2020, when she finished treatment. [redacted] attended both hospitals as an in-patient and an out-patient for over 2 years. [redacted] still attends for check-ups. I have prepared and provided the Inquiry with a timeline showing the dates on which attended hospital and the wards where she was treated. The timeline is attached to this statement at appendix 1 (**CL/01**) and I confirm that it is accurate to the best of my recollection.

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

also received treatment on other children's wards, being wards 1E, 3B and the Clinical Decisions Unit ("CDU") of the RHC. Following the closure of the Schiehallion Unit in 2018, [redacted] was treated on ward 6A of the QEUH which is the adult part of the hospital. I stayed with [redacted] during every in-patient admission with the exception of one night, and I attended all of her outpatient appointments. I can speak to the experience which [redacted] and I had on these wards.

7. My partner Alfie looked after our other children. At the time of [redacted]'s diagnosis, our youngest daughter [redacted] was only [redacted]months old, was [redacted]old and [redacted] was [redacted]old.

8. There are some specific events that I would like to mention. [redacted] contracted staphylococcus aureus infection in September 2018 when an in-patient in Ward 2A. She then contracted staphylococcus warneri infection in February 2019 when she was an out-patient during which time she was attending daycare at the hospital every couple of days for her chemotherapy treatment. In March 2019 she contracted a pseudomonas infection shortly after she received a blood transfusion in Ward 6A. She then developed a candida infection when being treated as an in-patient in Wards 3B of the RHC and 6A. During our contact with the hospital there were ongoing construction works at the hospital. I will come on to talk about these events in more detail.

FAMILY BACKGROUND

9. I live with my partner, Alfie and four children in [redacted]. [redacted] is [redacted]years old, [redacted] is years old, [redacted] is [redacted] years old and [redacted] is [redacted] years old.

10. [redacted] started nursery on [redacted] which was her birthday, and will begin[redacted]. She is a caring and loving child. She wants to be a princess, she loves all things pink, glittery and playing with her babies. She is very much "sugar and spice and all things nice". At nursery we have received reports that she is very

good at sharing and playing with others, that she is a very popular child. Everybody loves her.

11. She is very loving towards her sisters and is very close to the younger one, they are joined at the hip and do everything together. She has a good relationship with all her siblings. There is a bit of jealously sometimes because she had me to herself for so long. [redacted] wants to be the baby, the golden child and she got very used to having me to herself during her hospital stays and when she was going through treatment. It was just me and [redacted] for a lot of the time. She tries to share. The security blanket that I have to provide to comfort her is evident.

12. Following [redacted]'s diagnosis, our perspective as a family has changed. Before that we were very work orientated. Now our focus is on the family and spending time together as a family. We like to be outdoors whether it is playing in the garden or going away on trips, we want to make up for the time lost, for the childhood memories. We want to make memories together. It is all family orientated.

13. Prior to her diagnosis, [redacted] was a happy and healthy child. She hit all her targets and milestones and she never saw the GP. She had never even had a temperature, she was the easiest baby. When she was teething she just got on with it. Nothing was an issue for her.

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

Diagnosis: August 2018

14. I took [redacted] to the GP on Wednesday 15 August 2018. The night before we had been sitting on the sofa and I noticed that she had three lumps around her lymph nodes. I had been rubbing the back of her neck. They had appeared suddenly. She never had them before. Looking back now, there may have been other things that we might have missed but our youngest daughter,

was only [redacted] months old and she had been born two months premature. We thought that [redacted] was adapting to having a new little sister – that [redacted] was still trying to be the baby and she also loved babies. She went back to having a nap a couple of times a day when the baby was having a nap. She asked for milk out of a bottle, which was not like her and we thought that was to be like her baby sister. She would take her bottle of milk and lie down and fall asleep in the baby's rocker. She would play for short times with her sisters outside, then she would come in and sit at the window and watch them play.

15. There was one day that we had got the paddling pool out for the kids, was out playing then came inside and fell asleep halfway up the stairs. But we just thought she had tired herself out, that she was knackered from playing that day. We just put it down to her being tired and put her down for a nap. Her eating went down a bit and she was crying more. This was the day before we went to the GP.

16. The next day [redacted] was crying constantly, and I asked her why she was crying all the time, and she couldn't express why or what was wrong. We went to the GP on Wednesday 15 August and saw the locum GP. She looked her over, she had no fever, she felt her tummy and said that she thought it was viral. However she said that she would refer her to the hospital for blood tests, but that she was not overly concerned. I keep saying this to people when I describe this, that the GP had a mask that came over her face when she said that she was going to refer [redacted] for bloods. The GP also found that she had swollen lymph nodes in the groin area. I was told to give her paracetamol if she felt unwell but that she thought it would go away, it would pass.

17. On Friday 17 August [redacted] was falling when walking. It was unlike her as she was not a clumsy child. I said to Alfie that we had to take her back to the doctor. She would grab her head and scream, then calm down again. In between she would play but there were these moments where, this was not my child, that there was something wrong. Our neighbour was over at our house and she said that [redacted] looked pale, and I commented that it was hard to

notice when you see someone every day. All the concerns I had and coupled with the comment made about her being pale I felt I should take her back to the GP. We had looked at google and had identified worst case scenarios.

18. I took [redacted] to our own family GP on Friday 17 August 2018. [redacted] had swollen lymph nodes under her arms. He said all her lymph nodes were swollen. The GP said that he was not concerned, that it was probably viral and his own son was recovering from a virus and that two weeks later he was fine. He was not overly concerned and said that we already had the hospital referral for blood tests and to wait it out, but to come back if over the weekend something presented itself. Give her calpol, keep her comfortable and ride it out, that was the advice.

19. On the Saturday morning [redacted]'s lymph nodes were very swollen and it looked like she had the mumps, which was what we thought she had. We thought ok we can deal with the mumps. She didn't eat much that day. At that point we thought we knew what it was, that it was mumps and it was the "something" that might present over the weekend, as the doctor said.

20. On Sunday 19 August the swelling had gone down. She looked like the old [redacted]. I said to Alfie that I thought it was weird. I knew that it took a long time to recover from mumps and I felt that something was up with her. At 3pm that day she woke from her nap, her tummy was rock hard. [redacted] had not complained about her tummy. I called NHS 24. They thought that she might be constipated but given her age they referred her to Gartnavel Hospital to the out of hours doctor. I took her there immediately.

21. At Gartnavel Hospital [redacted] was seen by a nurse. She said that she looked a bit viral, at this point [redacted] was singing and dancing and she didn't look the part. We saw the doctor, and without even looking at her or touching her she said she had serious concerns. She told me to take her to A&E at the QEUH immediately. She was concerned about the swollen lump in her tummy. I said that she had been checked over by two GPs since Wednesday and that they

had checked her tummy and didn't feel anything. All I can tell you is that her tummy was never this hard. The doctor at Gartnavel told me to go immediately to A&E, not to go home and that if I didn't have a car they would call an ambulance.

22. I took [redacted] straight to A&E at the QEUH. Staff there said it was probably viral, that she was too happy and healthy and that she didn't look sick. But I am a mum and I had been on google. I asked the doctor to check her bloods and if her bloods came back all fine then we would go home but I said that until then "I am staying here". It was the fourth medical professional that we had seen since the previous Wednesday. I think it was a junior doctor who saw initially, she told me that they didn't normally take bloods from children who were so small, that they didn't want to hurt them and make them scared of the doctor. I refused to leave until they had carried out the blood tests. The junior doctor spoke to a more senior doctor, either the registrar or the consultant whoever was leading the department at the time, and they agreed to carry out the blood tests.

23. We were in the CDU. Forty minutes after the blood tests were taken, the doctor told me that the results showed that there were some irregularities. He said that [redacted] had a high white cell blood count. I said "I don't know what all of this means, are you telling me that my child has cancer?" and she said "yes" and that oncology was on their way to see us.

24. Fifteen/twenty minutes later Professor Gibson walked into the room. She told me it was leukaemia and that from the blood tests drawn from the line she could probably say what kind it was, as her count was so high. [redacted]'s white blood count was extremely high. For a normal person the white blood count sits under 10,000. The Professor said she had never seen a count so high in a child, and in a child playing. Maybe in a child on a stretcher or on life support. I am a planner and asked what the plan was, what was lying ahead. She said that if [redacted] made it through the night, and then made it to the following Friday that the hospital could insert a Hickman line and start chemotherapy.

They couldn't begin chemotherapy or a blood transfusion immediately, there were risks in giving her a transfusion then around clotting. Her platelets were very low, everything was low except the white blood count. I was in shock.

[redacted]'s initial treatment – Admission to Ward 2A: September 2018

25. [redacted] was admitted to Ward 2A of the RHC on the evening of Sunday 19 August 2018. Ward 2A in the RHC, is known as the Schiehallion ward. was in Room 7. She began to receive high dose steroids and high glucose water infusions to rinse the leukaemia out. The more you hydrate, the more it will come out. The aim was to lower her blood count.

26. Room 7 is behind the nurses' station and is for new patients with a new diagnosis. Within the room there was a small cabinet and a bed. As was so young the staff brought in a cot for her. There was a pull down bed for parents which could be brought down between the hours of 7pm and 9am. Outside of those hours the bed was to be folded away. There was a leather chair and a smaller plastic visitor chair. There was a side cabinet, the top drawer was locked as this was where staff stored individual patient medicines. There was an en-suite bathroom which had a shower, a toilet and a hand basin. Each of the rooms had a TV installed. Most of the TVs were broken and never worked. I was told by the nursing staff on the ward that the TVs had never worked and that it was due to the fault of contractor who built the hospital. We were told by the nursing staff that the TVs could not be fixed, that they had been done on the cheap.

27. On Monday 20 August, me and Alfie met with Professor Gibson to discuss [redacted]'s diagnosis and her treatment plan. [redacted] was diagnosed with Acute Lymphoblastic Leukaemia. We were told that she would begin Regimen B protocol. During that meeting the Professor told us that our children don't die from cancer, they die from infections. That is the big thing, the treatment meant she would be neutropenic a lot and could catch any sort of infection. Neutropenic is when [redacted] had no resistance, she had no neutrophils. This meant she was vulnerable to infections. That is imprinted on you from that

moment on, how vulnerable she is and how we have to protect her as a family and as parents. In order to minimise the infection risk during the initial Induction phase of [redacted]'s treatment we took the decision that there would be no visitors to see her. [redacted] was supposed to start nursery but we stopped that as you know how children are when they start nursery, they bring back bugs and that could have put [redacted] at risk. Alfie and I wanted to get out of front line treatment, which is the most dangerous treatment, and we were told that would be about 7 months. With the delays that occurred to her treatment that actually took 9 months for [redacted]. For the first five cycles of treatment, received very strong chemotherapy and then after that she moved onto the maintenance treatment which was not as strong and more spread out. We took the decision to shut down the business and Alfie stayed at home to look after the girls. I stayed with [redacted] in the hospital.

28. Professor Gibson was [redacted]'s consultant. There were a team of nurses and doctors who worked alongside her. There were random nurses and doctors all the time. Within the nursing staff there was some student nurses and some individuals who had worked on the Schiehallion ward for years, and they knew more than some of the doctors.

29. During that first week of treatment the medical staff used cannulas to draw blood from [redacted] and to administer medication. The cannulas didn't last long and would collapse, after one attempt of drawing the blood, the cannulas stopped working which meant that it had to be removed and a new one had to be inserted. There was one occasion during that first week when the staff were on their third attempt at inserting a cannula when I said to Alfie, I just can't do it, I can't hold her down to put the cannula in. She was screaming. I couldn't be there. Alfie went in to the room. He held her, they tried three times and she peed on herself and all over his clothes, she was petrified. Alfie came out of the room and he was crying. After that [redacted] would say things like "Mummy, protect me and hide me", "Make sure nobody gets me". She was frightened.

30. Following that first week of treatment, [redacted]'s white blood count lowered and she was able to begin treatment. On the 24 August 2018, [redacted] had surgery to insert her Hickman line. The line was inserted by a surgical procedure, under a general anaesthetic. [redacted] fasted from 2am the morning of surgery, which for a child who is on high dose steroids is evil, but you just have to get past it. Steroids make the child moody and hungry all the time, and that hunger is horrible. Towards the end of her treatment at the hospital she was allowed to have fluids up to an hour before any surgery so I gave her diluting juice to fill her up and take the edge off the hunger, but at that point it was a fast and it was hard. It was no one's fault, that is just part of the treatment.

31. [redacted]'s line was inserted on her right hand side, an incision was made near her neck, the line was inserted under her skin and came out in her chest between her shoulder and her breast. The end of the line was dressed. The surgery was about 1 hour and a half, maybe a wee bit longer. The Hickman line can be used to administer medication and draw blood. During the procedure to insert the Hickman line, [redacted] also underwent a lumbar puncture to check what was going on with the bone marrow, and she received the first dose of methotrexate to her spine which was her first chemotherapy dose.

32. On the 25 August 2018, [redacted] started block one of her chemotherapy. This was the Induction phase of her treatment. It was supposed to be a four week course of treatment of high dose steroids and high dose chemo. It actually lasted around 6 weeks. [redacted] caught an infection towards the end of the treatment so it was an 8 week stay overall. I speak about the infection later.

33. [redacted] was on Regimen B protocol. She received vincristine in her Hickman line, and oral chemo daily. I can't remember all of the medications but it was different medications that were to be repeated in cycles during the block. Parents are provided with a sheet at the beginning of each block of treatment so that you know what the treatment plan will be and what is coming, what the program is for her. She got a lumber puncture a week later and this was a

regular procedure, and with every lumbar puncture she got methotrexate in her spine at the same time.

34. She received PEG injections to her legs which was part of the chemo, attacking the cancer in her muscles. There were lots of different chemo infusions during that first block. It was hard for her.

35. In the second week she didn't want to go to the playroom. This was because when it was time to administer medication, the staff would administer it wherever the children were. The staff would come and find the children and administer it. So if the child was in the playroom, they would administer it there. [redacted] only wanted to walk about the hallways holding my hand. This was because the staff didn't administer medication in the hallways but took the child back to their room to do so. She knew they wouldn't do anything to her in the hall. She felt cornered in the playroom.

36. In regards to the rules and protocols on the ward, none of the staff on the ward told us what the rules were, we were not taught. It was more that we found out what they were. Communications were not clear. On our first day on the ward, I was told that we would be given a tour but it didn't happen. It was day 3 before I discovered there was a parent kitchen and that was because one of the other parents showed me.

37. On Monday 20 August a charity came to the ward. [redacted] had just been admitted and she didn't have any toys in with her, Alfie had brought her blanket. It was the nursing staff who said to keep toys to a minimum. There was a scribble pad that they had given her. We took the packaging and we put it on top of a bin, we were parents on the ward and we didn't know where the correct bins were. We put some other packaging on top of the cupboard in the room. Alfie had come to see us and bring some things in. [redacted] was still young and was drinking bottles of milk. [redacted] was [redacted] months old and I was expressing milk for Alfie to take home, so he had brought a breast pump into the hospital for me, there was a scribble pad and some clothes. He also

brought [redacted] a new toy doll. The cardboard box packaging and plastic was left sitting on top of the bin on the room. The suitcase that Alfie used to bring in the belongings to us was sitting on the floor and all belongings were inside it. We took [redacted] to the playroom. The auxiliaries burst in to the room and said, "you can't have the room in a mess like that, Infection Control will have a field day if they walk into this". They began to tidy up. One of the doctors came in to see us. We didn't know that something as basic as a suitcase could be seen as an obstacle to cleaning the room. No one told us. Again if communication of the rules had been clearer at the beginning then we would have known and would have ensured we followed them. They said they would get someone from Infection Control to come and speak to us. All the infection control did was to hand us a leaflet with basic rules.

38. The leaflet was related to the protocols when your kid had an infection and about being in-source: so you can't leave your room, you have to wash your hands, someone comes to remove your bins a number of times a day. The leaflet was more around what happens if your kid has an infection and not about the rules of preventing infection.

39. During the first week we took her to the playroom on the ward. No one told us what the protocols were on the ward. We let [redacted] go into the playroom with her sisters and we did not know that the room was only for patients of the Schiehallion ward. [redacted] was playing with her siblings in the playroom, staff burst into the playroom and said that siblings couldn't be in here, that it was a sterile environment and they were asked to leave. But we didn't know, no one told us. Over time we observed that the rules were not consistently applied as we saw other families in the playroom with patients and their siblings. We have no problem with adhering to rules and the protocols, but prior to that no one told us. We had not been informed, that the playroom was only for patients for infection prevention control reasons. It was a case of learning as you go.

40. [redacted] spent most of the first block of her treatment in Ward 2A. You never stayed in one room for a long period of time. They moved us a lot in Ward 2A.

The nursing staff would literally come in and say, pack up we are moving you out. Sometimes it was the auxiliaries who would tell us. Then a few hours later someone would move you to another room, then sometimes they would remove all the furniture and seal up the room. All the staff told us was that they were cleaning the rooms. You are living out of a suitcase so you throw everything in. We stayed for maybe two weeks in Room 7, then we moved about another 4 times before they closed the ward at the end of September 2018 and we moved to Ward 6A.

Line Infection - staphylococcus aureus: September 2018

41. In September 2018, towards the end of the initial treatment block, began to develop small blisters on her skin. She had a high temperature and began to spike. Swabs were taken of her skin and bloods were drawn for cultures. She was immediately started on antibiotics, gentamicin and tobramycin or something like that. It was four times a day and via infusion. On 23 September 2018, Professor Gibson told me it was a staphylococcus infection. She did tell me the full name at that time it was tazocin. I had been told by other parents on the ward that lives could be lost when a child developed an infection, that they pull the line and it would be taken out. For that could mean going back to cannulas and I wanted to avoid that. Professor Gibson told me that the infection lived on the skin and so it must have been something that crawled in, and she was going to speak to the doctors in microbiology to see what they thought and whether they could save the line and handle it with antibiotics. I wasn't told how [redacted] might have contracted the infection or what might have caused it.

42. By this point [redacted] had been spiking a temperature for two days. It takes 48 hours for blood cultures to come back. I took [redacted] out for a walk in the hall. Professor Gibson went away for a short time and then came back to our room and she said that [redacted] had to fast from 2am the following morning because microbiology wanted the line out and it would need to be removed. The plan was that [redacted] would be down first thing for emergency surgery. Then Professor Gibson left and I was not told anymore at that stage. Bless the

woman, she had done this for so many years that she knows what she means when she says things but as a parent I heard this for the first time. I didn’t know what was happening, and I was worried that [redacted] might die from the infection. Alfie left and I was on my own with [redacted]. I took her out for another walk in the hall and spoke to one of the nurses at the nurses station. Kimberley, one of the nurses asked me if Professor Gibson had been to see me. I said that she had and that [redacted] had a staphylococcus infection. All she replied was “hmm”. That was it and there was no reassurance or explanation.

43. I was worrying a bit more at that point. I am a research mum and I always want to know what we are facing. I did some research on Google that night, I wanted to know what it was and how bad it could get. I wanted to know the worse-case scenario as anything that is better than that is a bonus.

44. The next day I asked Prof what strain of staphylococcus infection [redacted] had contracted as I had been researching throughout the night. She wrote it down for me, it was staphylococcus aureus. Microbiology wanted her to take antibiotics for one week after the line removal. The line would be sent away for testing. The intention was that she would get another central line at some point but we were not sure whether that would be a port or another Hickman line. [redacted] underwent surgery that day under general anaesthetic to remove the Hickman line. When she was in theatre the surgical team inserted three cannulas, one for immediate use and two spares. I always preferred that we took the opportunity to have cannulas fitted when she was under if they were going to be required at a later point. The cannulas could be fitted anywhere, her feet, arms or the back of her hand. I was told that the line was sent for testing but I was not informed of the outcome of the tests.

45. Following the line removal [redacted] was prescribed antibiotics for a further week. She stayed on gentamicin, and tobramycin. That resulted in her being on antibiotics for nine days in total for this infection, as she started them two days before the surgery. Her IV chemotherapy was stopped for the nine days, and she took oral chemo. After she had her port placed they gave her the last

vincristine infusion to complete the first block of chemotherapy. I speak about the port surgery later on, it took place on 1 October 2018.

46. When a child in the Schiehallion Unit begins to spike a temperature, a protocol is followed as the concern is that the child has sepsis. A temperature spike is 38 degrees celcius or above. When a child has a temperature over 38 degrees they are given antibiotics: gentamicin if neutropenic and tobramycin. They are given the antibiotics intravenously four times a day. The nursing staff chart the temperature of the child every four hours. The equivalent of calpol is given to manage the high temperature. Blood cultures were taken and they took about 48 hours to come back. If an infection is identified then medication can be given to treat the infection. Generally when a child spikes a temperature the cancer treatment is stopped because children who are neutropenic are vulnerable to infection. If an infection is detected then chemotherapy treatment is immediately stopped to allow the infection to be treated. This is where delays in treatment arise, where your 7 months become 9 months.

47. If you are at home with your child and they begin to spike, during hospital hours you call Ward 2B daycare who call A&E and tell them you are coming in. When you arrive at A&E you are put into a room and then taken to the CDU who then to take bloods and, administer antibiotics. From there the child is admitted as an in-patient to wherever there is a bed and that might not be on the Schiehallion ward. It depended where there was a bed.

48. When we were on the wards, ten out of ten times I told the staff that [redacted] was spiking and asked the nursing staff to come and do a set of obs. You know your child and you are with them all the time. There was a charity called LoveOliver who handed out thermometers to parents on Ward 2A so I had my own thermometer. Sometimes you could wait up to two hours for paracetamol.

49. By way of example, there was an occasion when I had to push the nurses to get pain relief for [redacted]. [redacted] had an anal fissures at the end of the first

treatment block. Two nurses came in and started to change the dressing on the Hickman line and she was screaming out and every time she passed wind, she was in pain. It had been two hours since we asked for pain relief. She is not going to let you change the dressing when she is pain. I asked that they please go and get pain relief before they change the dressing. She was distressed. The nurses left and came back 10 minute later with paracetamol. The nurses told me that they needed to have two people sign off medication, but I said there were two of you here to change the dressing. It made sense in my book to do that first.

Move from Ward 2A RHC to Ward 6A QEUH: September 2018

50. On the 26 September 2018, Ward 2A in the RHC was closed and the children were moved to Ward 6A of the adults hospital in the QEUH. [redacted] was an in-patient in Ward 2A and had just had her Hickman line removed. We didn't find out about the move from the hospital. We found out about the move when one of our neighbours sent me a text saying that they had seen a news report on the TV that the ward was closing. They asked if we knew what they were going to do. We didn't know anything. When Alfie got the text, we asked one of the nurses about the news report and if the ward was closing. She was called Katrina. She said that she was not allowed to tell us anything about it and she ran out. One hour later the Charge nurse, Emma, came to [redacted]'s room and handed us a press release on a sheet of paper. She said that she knew we had heard about the ward closing and that we were to read the press release. There was no explanation as to the what and how.

51. All the press release said was that Ward 2A would be shutting due to a spike in the number of infections, it's why the ward would be closed. We were not told anymore. The only communications we had from the hospital was the press release, it was word for word what was all over the internet in news reports. There was nothing more and no reassurance was offered.

52. We didn't know where [redacted] would be moved to, if the children would go as a group or not, whether we would be moving with our medical teams or not.

Professor Gibson is god and she had got us this far. We didn't want to start over with a new medical team and build trust up. We had no information. The next day Professor Gibson told me that that we were going to move as a group with our medical teams but I was not told where [redacted] would be moving to. She said that the hospital would have to make a ward up for us somewhere and we would stay together. At that point it was enough for me to know what we were staying as a group and with our teams. At that point I was not as concerned about why we were moving. I was more concerned that we stayed together with the same care. It took about two weeks from the point we found out about the move to the point that we did actually move wards.

53. The TVs in Ward 2A weren't working so we couldn't even watch the news. Once we found out from our neighbour we looked up the press online and all it said was that Ward 2A would be shutting. During that period [redacted] had been in-source isolation for about 3 weeks, just me and her sitting along in the room with the blinds open. She had been on high dose steroids for seven weeks, it had been a hard time. It was like we were institutionalised and I thought [redacted] had depression. She would cry because she wanted her dad, then he would walk in and she would scream at him to leave. She had a sore head and so the lights were off, the blinds shut. Being in source was a lonely time, and if [redacted] saw kids outside in the corridor I would have to tell her that she couldn't leave the room. How do you explain that to a young kid?

54. I found out that [redacted] would be going to Ward 6A in the adult hospital the night before the move. The nursing staff told me. People spoke on the wards. The staff thought that we would remain in the children's hospital and would be put into the CDU. All the support services that our kids used were going to remain in the RHC. Those services included physiotherapy, dieticians, dentist, radiology and scanning rooms. Leaving the children's hospital to go the adults hospital meant that we would be further away from these teams and these services. For our children to get to those services they had to travel back from the adults hospital, through the corridors to get to the other departments in the

children's hospital. We had to use the shared lift, walk shared corridors with all sorts of people coughing around you. I felt this increased the risk of [redacted] catching an infection. Sometimes they would let you in the staff elevators or patient transport elevators to get back to the RHC. We felt at risk and dirty being in the adult hospital. We had avoided bringing the girls in to see [redacted] in order to reduce infection risks, and the move through to the adult hospital felt like an increased infection risk.

55. The move from Ward 2A RHC to Ward 6A QEUH happened around the 26 September 2018. We were told that the whole ward was moving which meant things like the furniture would be coming with us. In the days leading up to the move Ward 2A was a very busy place, the medical staff were trying to pack and also do their jobs on top of all that. There was a lot of pressure on the staff and it was their responsibility to pack everything up. Staff were counting supplies, some of the furniture was going to move over. Nobody on the ward knew exactly when we were moving. The staff did not know. It was maybe about two days before the move took place that we were told by staff that the move would happen on 26 September 2018.

56. The children were moved in order of vulnerability, with the most vulnerable being moved first. [redacted] was the second child moved and she was transferred early on in the morning at around 8/8:30am. [redacted] was neutropenic and she had to wear a facemask to stop her catching an infection as she was moved through the hospital. She had never worn a mask before. There was a team that moved each child, the porters, the parent and child, there was a doctor and a nurse walking with us too. The doctor was carrying an oxygen tank, which was quite scary when you don't know what you are facing. We went into the patient lift in the RHC and went down two floors. We then used the back corridors in the adult hospital to get to the lifts to travel up to the sixth floor in the QEUH. The move took place at early morning and late evening to avoid bumping into other people as we went through the hospital.

57. Ward 2A for in-patients and Ward 2B for outpatients were moved into Ward 6A. In Ward 6A there were roughly 27 rooms. Of those, roughly 16 were for in-patients. Ward 2A had around 18 in-patient rooms. So when you came in for an admission, 7 out of 10 times you didn't end up going into Ward 6A as it was full. Whilst we didn't experience it in Ward 2A, other parents told me lack of available rooms in Schiehallion was worse after the move to 6A.

58. The rest of the rooms on 6A were used for daycare patients, the old Schiehallion Ward 2B. In order to get to daycare people had to walk all the way through the ward, past all the in-patient rooms and to the end of the ward. There were no pressure rooms in Ward 6A like in Ward 2A. By pressure rooms I mean isolation rooms for transplant patients who need to be in a pressurised rooms. What that meant was that a normal room on 6A had to do the same job as a pressure room.

59. [redacted] was put into room 2 in Ward 6A. She was in-source as she had a tummy bug 3/4 days previously but hadn't had anything since then. Room 2 was so hot. It was the hottest place ever and you couldn't turn down the heating in the rooms. The nursing staff said they would call and have the heating turned down but then we later found out that it was not possible for the heating to be turned down by anyone. There was someone who came in and placed sticks up the vents to see why they were running so hot. It measured over 30 degrees.

60. The windows didn't open. We were in-source and the infection prevention control rules meant that we couldn't leave the room. I opened the door to let the room cool and I asked to move rooms. I didn't think it healthy. In any country this would be considered a heat wave and they wouldn't give us a fan to move the air about. I kept the door open and said we couldn't survive in this room with the door closed.

61. The next day [redacted] was still in-source isolation despite showing no symptoms for 3 to 4 days. We are not allowed to leave the room in line with the infection

protocol. No one had reviewed her or her notes and she had been fine and nothing else wrong with her tummy at that point. I spoke to Diane, one of the nursing staff on the ward. Diane was amazing, everyone said if you want to know something you ask her and she would go out of her way to get you out of source, run samples and call people. I said to her, you have to get us out of source, we cannot survive in this room. She reviewed [redacted]'s notes and said there was no reason for [redacted] to be in-source as she had no sickness or diarrhoea for a few days, she made a call to the doctors and finally [redacted] was allowed to come out of source. It meant we could leave the room and open the door.

62. Even if you could leave the room, you were stuck in a ward with no facilities. Ward 6A had no facilities for parents and children. There was no kitchen and no fridge to store food. I never left [redacted] to go to the shops or go anywhere so I relied on Alfie bringing food in for me. He had brought me meals in from the beginning but in 6A there was nowhere for me to store or heat up the food. The lack of kitchen resulted in more expense for parents. We had to buy food from M&S.

Description of Ward 6A

63. There was nothing for the kids in Ward 6A. There was no playroom. All they had was a couple of small tables, like a coffee table, in the hall with some chairs and some paper for the children to colour in, maybe some random toys if they felt like it. It was classed as a play area for the children. This was set up about a month after we moved. There was a lack of plugs around that area, [redacted] was often receiving medication via drip and was attached to machines. The machines had bad batteries and didn't last long when not plugged in to the mains. Around the small table there were few plugs. [redacted] could sit at the table drawing, across the opposite side of the corridor there was a plug. It meant that people passing through the corridor had to climb over the line, it was a trip risk and also increased the risk that a line is pulled out or a trip over the machine wires. All we could do was walk the hallways, but then we got into the way of the medical staff. People from all wards accessed Ward 6A to pick

up prescriptions from the hospital pharmacy and they would then have to walk all the way through the ward, so it was not ideal at all.

64. The parents asked if the hospital would consider emptying one room, not even for toys but somewhere for the kids to come together and interact. We asked for somewhere to congregate, for parents to meet to get support. There were a lot of parents of kids who were newly diagnosed and they lost out on that.

65. People spent a lot of the time in their rooms. Your morale becomes very low when stuck in a room like that. We, as parents lost the support of one another after the move to 6A. That support is such a vital part of this whole nightmare. If there was a parent of a child who was a month or so ahead of your own kid, you could ask about that and hear from them how it was. The lack of somewhere for us to meet meant we missed this. We didn't have the support. Some days the only people that we saw were the medical team and they were not always a friendly team as they were so stressed and overworked, I think that they were always worried that they would get the flack for everything else that might go wrong on the ward. Kids and parents were left isolated in the patient rooms due to lack of facilities. Ward 2A felt like a children's ward and 6A didn't; there was a noticeable difference.

66. There are a number of charities that came to visit Ward 2A. There was Les Hoey which provided toys and i-pads for the kids. There was Team Jack that offered music therapy classes and [redacted] went to those, they were really good. The hospital radio staff would come to Ward 2A to play games with the kids. There were some smaller charities what came to Ward 2A. One of these brought a snack trolley for the kids and [redacted] could get crisps or a fruit shoot. It was not about what the kids got, the charity staff and volunteers tended to be people who had been through what I was going through. It was so important to have that to hold on to. When you are told your child has cancer you think that they are going to die. These people had come through the other side, that interaction and support was so important. Even now I think the parents all walk away with some sort of PTSD about the situation you have been through with

your kid, whether they are going to die. You think that every moment might be your last one.

67. In Ward 6A there was none of this and no charities. We were made to stay in our rooms. When we were in Ward 6A it appeared that there were always a number of kids in-source more than in Ward 2A. There were maybe around 10/11 of the 20 odd rooms insource at one time. The parents joked on the ward, that if you are vocal and your kid is playing in the hallway then you go into source. We always use to joke “what is the outbreak this time?”, “why is everyone in source?”.

68. For example, just before Christmas 2018 I spoke to the staff as it did not feel like Christmas. There was no spirit, and I know that it is not their responsibility to create that but coming from a ward where there were a lot of things for kids to do, we had nothing.

69. The clown doctors still came to visit on Ward 6A. They were entertainment provided by the hospital I think, but they were for all children in the RHC. They would come round the wards blowing up balloons and making the children laugh doing silly things, but it was for a short time. Sometimes if [redacted] was in source and the clown doctors came up to the window of the room, it was worse as they waved and then moved on quickly. It was a big deal for the kids. The hospital radio staff came to Ward 2A to play games with the kids.

[redacted]’s treatment - Consolidation Phase, the second block of treatment: October 2018

70. On the 1 October 2018 which was seven days after the line removal, [redacted] returned to surgery to have a port fitted under a general anaesthetic but the doctors couldn’t really decide on what they were going to do for her central line. As parents we don’t really get much of a choice about the central line. Professor Gibson said that a port would be better for [redacted]. The skin goes over the port and there is no line coming out of her body. The Hickman line cannot go into water and there is a risk of the line coming out if it is pulled. We

were always so concerned about the Hickman lines being so fragile as they just dangle there. The port does not have the same risks. It was fitted to the same side, [redacted]'s right side. You don't see it, it is like a wee button that sits under the skin and there is an entry in the neck and it goes into the heart. The port is accessed using a needle that punches into the port under the skin, then into the line and medication can be administered that way.

71. A few days later in the first week in October 2018, [redacted] was discharged from Ward 6A and was able to go home. This was the first time since her initial admission in August 2018. She was only home for 3 to 4 days and then was re-admitted to Ward 6A in the QEUH again. What tends to happen between blocks of chemotherapy is that the children get a block of treatment and then one week off before beginning the next four week block. For [redacted] she did not get a break between the first and second blocks. This was because the medical team felt that we couldn't lose a week off and had lost too much time. It had taken us eight weeks to get out of the first block. By that point she had been off chemo for a few weeks so that the infection could be treated. That led to a delay in treatment overall.

72. At the beginning of October, [redacted] was admitted to ward 6A to start the second block of chemotherapy which is the Consolidation phase. She received a cocktail of drugs one of which was Cytarabine which she got twice a week, and every time she had that drug she spiked a temperature. With every spike we had 48 hours in hospital. We spent most of that block in hospital with [redacted] as an in-patient with temperature spikes, it was every couple of days she had a Cytarabine spike. Protocol requires that we had to go in and began antibiotics just in case it was sepsis. During this phase of treatment, [redacted] was admitted to Ward 6A for any temperature spikes.

73. The second block of chemotherapy lasted 6/7 weeks. It got to the point that the medical staff decided to push through the temperature spikes and carry on with her chemotherapy. I was told that the temperature spikes during this block were related to the Cytarabine.

[redacted]'s third block of chemotherapy: November 2018 to December 2018

74. On 12 November 2018, [redacted] commenced her third block of chemotherapy. This was a hard block, a nightmare. She was on high dose methotrexate. The high dose methotrexate was part of a clinical trial. She took oral chemo every day. Every 2 weeks she had to go in for in-patient treatment. On a Monday night she would go into the hospital for pre-theatre and for an intravenous pre-flush. On the Tuesday she would go to theatre for an intrathecal methotrexate injection into her spine and at the same time the staff performed a lumbar puncture. Then after that procedure they gave her a methotrexate intravenous infusion lasting 24 hours, along with a glucose flush to wash out the chemo. Then [redacted] was given another glucose flush to clean out and keep her at a safe level. After the first session [redacted] was discharged on 17 November 2018. As soon as the count is clear you can go home. For most kids it was five days in and then home.

75. On 22 November 2018, [redacted] was at home and began throwing up blood on the Wednesday night through to Thursday morning and she was throwing up with brown blood granules in it. She was always quite sicky from the treatment and this lasted all through her treatment. I called the ward and they told us to bring her in. On the way to the hospital in the car she threw up pure blood. We arrived at the hospital and [redacted] was admitted to Ward 3B in RHC, I think. Staff said she has mucositis and they began to administer antibiotics. She was given IV anti-sickness medication.

76. [redacted] was admitted to a double door isolation room on ward 3B. When [redacted] ended up on other wards, she was admitted to a double door isolation room if one was available. Only if there was a more vulnerable child would she go into a normal patient room.

77. Ward 3B was a renal ward I think, maybe also surgical. If you needed a doctor, you could call for a doctor but sometimes they would send one of the

Advanced Nurse Practitioners ("ANP"). The ANPs are amazing. You don't have the same access at the same times to the Schiehallion medical teams when you are on other wards. Sometimes we had to get one of the Schiehallion ANPs to come down and talk to the nurses on the other wards, they'd tell them to trust us to trust the parents as we know when our kids need something. There was one particular time that [redacted] was on oral morphine as and when needed for the anal fissure as it was the only thing that would numb the pain. The nurses on 3B refused to give it to me. As they said they didn't think she looked like she needed it. One of the ANPs from Schiehallion came down to talk to them and eventually she was given it. It was not to overdose her or sell it off on the black market, it was because she needed it.

78. Our kids get treated so different to other kids probably because of their vulnerabilities. I felt that when we were on the other wards that [redacted] was considered sick but not sick enough so we didn't get the attention. In their own ward the Schiehallion kids are treated so differently.

79. In Ward 3B we were confined to the room and we did not have access to the other facilities on the ward. This was due to [redacted] being vulnerable to infection. We were not allowed anywhere. The first time we were there they slipped up and said we could use the playroom so we did. We didn't know that we shouldn't. The toys in the playroom were disgusting, they were old and dirty. It showed me how much money people invest in the Schiehallion ward. It was a "posh" ward by comparison to the rest of the hospital; it was so different. Alfie and I did a toy drive for the playroom in Ward 3B when [redacted] was there, to get them some new toys for the kids as things were in such a state. We donated two huge bags of toys.

80. Occasionally on other wards we asked the ANP for a pass so we could go to the outdoor play park at the RHC. We did it very occasionally. The play park was quite modern as it was fairly new. We kept our distance from others. She knows about being neutropenic and she knows not to touch her mouth. Hand

hygiene is part of her history now, we would come back in and wash hand and change her clothes. The play park was amazing if you could get there.

81. It might sound horrible to say this but in a way I felt relief at not being on the ward with the Schiehallion staff. I felt that the staff attitude toward me was that I was not wanted on the ward and I didn't want to be somewhere I was not wanted. So in that sense I felt free. For [redacted], I was concerned as we were not where we needed to be in terms of her medical care, we weren't with her team. It could be hard managing her medication when were not on the wards with her team. It fell on the parent to keep checking it.

82. On Sunday 25 November 2018 I asked for a day pass as by this time she was well in herself once the sickness was under control. We went out of the hospital for a couple of hours. [redacted] was in Ward 3B for three days until the 25 November which was the day before she was due to begin chemotherapy. Later that day she was moved to Ward 6A as chemotherapy infusions can only be given on the Schiehallion ward.

83. On 26 November 2018 she began her next treatment in that treatment block. She started her pre-op cycle again, so received the pre-op fluids. Normally that is run at 70ml an hour. When this happened she peed all the time. She was still in nappies and I would change her overnight a couple of times. Sometime it was every two hours as she would pee so much. That began on the Monday night. On the Tuesday morning I said to the staff that [redacted] was not peeing. They told me it was fine and maybe she had been dehydrated. But I said she had been in hospital since Thursday and had been on fluids and was not excreting. They said they would keep an eye on it. [redacted] was taken in to theatre and given the lumbar puncture and the methotrexate injection, then the methotrexate flush and glucose infusion.

84. I raised a concern with three different nurses and a doctor. On the Wednesday morning around 9am I raised it with a doctor and said she had barely peed overnight. The doctor asked if she had maybe peed and I had not seen it. I

was changing her nappies and she had not done the toilet. The doctor decided to check her weight at a 12 noon and again at 6pm to see if she was retaining fluids. When she was checked at 6pm she was up to 800 grams. Then all of a sudden it was an emergency and they had to get her to pee. They gave her Lasix to make her pee. [redacted] began to pee and it was all blood. Because the methotrexate was stuck inside her for so long it had burned her insides and all of her soft cells her mouth, her gut, and her bum – everything was burned. She was lying there and blood was running from her mouth and her bum was sore. She was placed on gut rest and was started on a morphine driver and it made her sleep for 7 days straight. They stopped her chemotherapy and started her on the patient nutrition that goes into the central line.

85. The same day the nurse came in and tried to give her oral chemo. [redacted] had an NG (nasogastric) tube in and you have to aspirate before you put anything down to make sure it is in the right place. You normally get stomach fluids coming back up. I aspirated and it was blood that came out. I told the nurse that it was blood coming out of her tube. I said there is no chance I am putting oral chemo into her tummy when she is on gut rest. The nurse left and spoke to the doctor and told her I refused to give [redacted] her chemotherapy. The doctor came in to see me and I explained that if she was on gut rest that she should be on full gut rest as it didn't make sense to give her chemotherapy when she was like that. They agreed that she could come off oral chemo. This was now the beginning of December and she was an in-patient recovering from this until she was discharged on the 24 December 2018.

Social media posts: 24 December 2018

86. Alfie and I had some run ins with the staff about social media posts. Before [redacted] was discharged on the 24 December 2018, Alfie and I were called to a meeting with Professor Gibson. She said, "I am not on social media and I want to say that we are not treating your child as a guinea pig". This referred to a Facebook post that Alfie had posted on Facebook about [redacted] being treated like a guinea pig. We understood that the methotrexate that [redacted] was

receiving in this block was on a clinical trial. This showed me that the hospital staff were monitoring our social media posts. A couple of times they would refer to things that we posted on Facebook. It was always monitored and they would call us out on it. It was just another bit of what was going on. I was already speaking out about what was going on and I felt victimised. It didn't help the relationship between my family and the medical team.

87. Alfie put up a post saying that we were going to pull [redacted] off all high dose methotrexate. It was an unusual way to use that drug and was a trial. At the meeting on the 24 December 2018, Professor Gibson acknowledged we were upset. She said go home and cool down and we will have another meeting on the 27 December to discuss the treatment plan.

88. [redacted] was discharged and me and Alfie went home to discuss this. We didn't want her to continue with the high dose methotrexate. We didn't really want her to be on the trial in first place. The only reason we stuck to the trial was because it would have been easier for her during maintenance phase of treatment. She wouldn't require any IV medication as she had already had heavy front line treatment. At this point we decided to take her off the trial as she had a bad reaction on it. It got to the point that during that time in December 2018 that I sent Alfie a picture and she looked like she was dead, a corpse, she was grey. The first round was bad and it made her sick, the second one made her really ill and there were two more to go. Professor Gibson said that the next two rounds of methotrexate might be okay. But we decided to pull her off the trial. That meant that [redacted] went back to the standard protocol and she finished that block on vincristine and the other standard medications.

89. Professor Gibson was always the one who had to raise the social media things with me, or difficult things with me. When [redacted] had the pseudomonas infection she came in and said to me, “I am here to tell you that the line is coming out because everyone is too scared to come in and tell you”, and she

was referring to the other doctors. I speak about the pseudomonas event later on.

90. There was another incident relating to social media in September 2019. [redacted] was in with a fever. We got there at 11am in the morning and it was 8pm at night. They had nine attempts over hours to insert a cannula, it was long drawn out day for someone who is constantly spiking. We had been in since 11am that morning and she had been spiking all day. I asked that they give her oral antibiotics as it was better than nothing. As she was not neutropenic at the time they agreed to give her oral antibiotics. She was so tired and drained when the doctors left. All she wanted to do was to see her favourite nurse Susie. Susie was not on duty but there as another nurse who had very similar features to Susie, we fobbed her off that this was Susie. [redacted] had not been an in-patient for around 6 months at this point. [redacted] went to have a cuddle with the other nurse. The nurses head came down as she was cuddling [redacted] and you couldn't see her face. I took a picture of the nurse cuddling [redacted] and you couldn't see who the nurse was, and posted it on Facebook. I put up a comment that after everything that she has been through all she wants was a cuddle from her favourite nurse, and how important these relationships with the nurses were.

91. Two hours later one of the nurses came to see me and asked me to remove the photo from Facebook. I didn't take it down. I made it private. The next morning Emma Somerville, the charge nurse came to see me, she said you posted a photo of a nurse on Facebook and you can't do that. I showed her the photo and said it was a beautiful post and inspiring, and that frankly the NHS could do with anything positive coming their way at this moment in time. I told her it was private. She said it was nice and that I was to send it to her and she could send it on to the nurse but that I couldn't put it on Facebook.

92. There was another occasion a few days later when I was asked about social media posts. We are members of a parents group on Facebook and one weekend another parent must have posted a complaint on the group about the

service received from the ward. The Facebook group is set up by parents for parents of children of the Schiehallion ward. I hadn't even see this post. The Charge nurse, Emma came to my room and asked if I knew anything about it. She assumed it was me who made the post. I knew nothing about it. She must have heard something or saw something and automatically assumed it was me. I asked "isn't my Facebook a private account?" They told us that all social media is being monitored. A few weeks ago I was speaking to one of the parents. She was pulled up in daycare about posting updates about her kid, his treatment and situation and she was told not to post on Facebook. You are not even allowed to post any updates about your kid. We are being monitored.

The Cryptococcus outbreak in Ward 6A: December 2018 to January 2019

93. On 31 December 2018 [redacted] was admitted with another temperature spike. It was managed in the usual way in line with the protocol. We don't know what it was but could have been the common cold.

94. During the month of December 2018 there was the Cryptococcus outbreak in Ward 6A, although we didn't know about it at the time and we found out afterwards. During that time I saw rooms being blocked off in the ward, I think rooms 11-13 were closed. The rooms were being taped off, the doors were closed and you couldn't go in there. At the time, we heard about a death on the ward, but it was a cancer ward and these happened on the ward. At that point we were none the wiser about the outbreak; we knew nothing. During that whole month [redacted] was an in-patient in Ward 6A. She was neutropenic and was recovering from the methotrexate event.

95. The staff told us the rooms were closed due to building works, renovations or mould in the showers. No one really seemed to know, or maybe they knew but didn't want to tell us. When we were in Ward 6A they would say things like if you see any loose strips in the showers or anything that looks like it is coming apart, tell us as it increases risk of infection.

96. During December 2018 I did not personally ask what was going on in the ward at that time. [redacted] was ill during that time, she was my focus during that time and I hardly left the room. I didn't pay much attention and was not interested enough to ask. You run into other parents from time to time and they update you.

97. In January 2019, we learned in the press about the Cryptococcus infections. This was after [redacted] was discharged. It was the 21 January 2019 when we found out. We saw that there were rumours that a young boy had died and an older woman a couple of days later in ward 6A. The news mentioned that the ward was closing because of the deaths. The same day that the news broke, [redacted] was admitted to the hospital for a temperature spike. She was not admitted to ward 6A. Instead she was admitted to CDU which was Ward 1C next to A&E in the QEUH. She was one of the first patients there. Ward 6A was closed for about 6 weeks. She started antibiotics and blood cultures were taken, nothing came back. It was a random spike.

98. We knew from the news that Ward 6A was closed due to Cryptococcus and the hospital staff told us that the ward was closed when we arrived. Later, on the 21 January 2019, that day we had a meeting with Professor Gibson and the doctor who was the head of microbiology, or infection control. I can't remember her name. We had demanded a parents meeting with the medical team and we wanted this to be an open parents meeting for lots of parents of children on the ward, it was better to have this as a group so we could all ask questions. Sometime when you are in groups you can bounce off one another and it triggers memories so you can ask questions. They refused to hold an open meeting. So I met with Professor Gibson and the other doctor that day.

99. During that meeting I said to the doctor who was the microbiology or infections control doctor, "You knowingly put my kid at risk". She said she would have to be severely immune compromised to be at risk, and I said that she was neutropenic for that whole month. But the doctor said that was not long enough. I thought that was a load of rubbish.

Prophylactic Medication

100. When [redacted] started her initial treatment for ALL, she was given a prophylactic anti-fungal called pozaconazole. At the time we were told it was part of the treatment and all kids were on it. We were not told why she had to take it. Being a new parent through the door you really don’t care what medication you give your kid as long as they survive. During the meeting on 21 January 2019 I asked why [redacted] was on pozaconazale and Professor Gibson said it was because of all the building work going on in the hospital. I told her that I spoke to other parents in Dundee and Edinburgh and their kids don’t get it. Professor Gibson said that it was because there was always something going on in the Glasgow hospital and that the dust particles travel and it was to prevent anything happening to them. She said it was prophylactic due to hospital environment and the building work going on. The would do regular checks to see the levels in the kids bloods, they wanted the kids to have enough but not too much of the pozaconazole, if that makes sense. It was obviously a big deal for the medical staff to monitor this, they would lower the dose or up the dose. [redacted] took pozaconazole 4 times a day.

101. I am a member of a Facebook group called mumcology. It is an international leukaemia group. A mum in America posted that her child had the candida infection and that her child was being given posaconazole to treat it. I knew that fungal infections posed a real risk to our children. I thought about this and realised, if posaconazole is only being given to treat a confirmed fungal infection why is [redacted] on it? I then began to wonder why [redacted] had to take it 4 times a day if she didn’t have an infection. I asked about it. The nurses said that all the children in their care received this. The first time I asked Professor Gibson about it was on the 21 January 2019. By this point [redacted] had been on the medicine since August 2018.

102. I am not a hippy mum. If you have to need medicine you get it. If the hospital had sat us down and said these are the risks involved and these are the side effects then I would have felt informed enough to make an informed decision and live with the consequences, but we were we were never given that opportunity. [redacted] finished treatment in November 2020. She has ongoing tummy issues and has done through the whole treatment. We don't know if this is due to the treatment or the prophylactic medication. She has an ongoing tummy ache and other paediatricians are investigating it. She has been placed more at risk and we were not informed. The side effects of pozacoanzole hit your liver and your kidneys, but we just don't know the impacts yet. Oncology are not interested as she is not on treatment anymore.

103. I know the child cancer patients in Dundee and Edinburgh are not on pozaconazole because I am a member of a Facebook group and I asked a question about it. Some parents responded to say their kids didn't take that medication.

Delayed intensification: January 2019 to March 2019

104. In January 2019 [redacted] was in her fourth block of chemotherapy which was the delayed intensification phase. During that block they stopped her pozaconazole and she was given an ambisome infusion which was administered every 2 days. It was a prophylactic infusion. She took that medication for the whole block and tit lasted up to mid-March 2019. During that block they throw everything at the patient. It is an intense block of chemotherapy and [redacted] was given every drug that she had been give during the previous three blocks. Before the block her consultant said that she was worried as she didn't know how [redacted] would react.

105. Surprisingly [redacted] responded well. Some days she would receive four infusions and would be singing and dancing, we kept waiting for it to hit her but it didn't. She was fine. At the start of the block the Schiehallion daycare was

moved from Ward 6A to the ward that was next to the theatre recovery. Maybe it was ward 2C in the RHC.

106. On the 31 January 2019 [redacted] told me she was itchy. I couldn't see anything on her skin. I don't know what might have caused it, but it might have been a side effect of oral morphine. We were at home and I called the Ward, they told me to give her piriton. The response is very much wait and see and carry on. We never found out what the cause was and she was not admitted as an in-patient on this occasion.

107. [redacted] had one temperature spike during that treatment block and she was admitted to Ward 3B in the RHC. This was on 20 February 2019. They ran blood cultures and we were told that it was a staph infection, the nurses did not tell us the full name at the time. It is staphylococcus warneri and we only found out once we got [redacted]'s medical records. They just told us it was a gram positive infection and that it was something that lives off your skin. When [redacted] developed that infection she was an out-patient. Prior to that she had been in fairly regular contact with the daycare facilities for infusions every couple of days. She only had a temperature spike and she was off her food slightly. She was not that ill during this infection.

108. [redacted]'s chemotherapy was stopped to treat this infection. She had a week of antibiotics. She was on the same antibiotics as the previous infection. She didn't lose the port and central line on this occasion and I don't know why it was different this time round. They told me during the first infection in September 2018 that the infection would stick to the line and that every time you use the line it flushes the bacteria into the system and it makes them even more sick. They did not stop using the line and there was no requirement to remove her line. She was discharged on 25 February 2019.

109. On the 15 March 2019 [redacted] had a blood transfusion. This was her last day of front line treatment. She was well in herself. It was in the daycare centre at Ward 6A. She got it through her port using the needle. A blood transfusion can

take most of the day, five hours for the infusion and you have to cross match the blood. I can't remember what room [redacted] was where the waiting room is, the second to the right where the doctors desk are. I can't remember the room number.

Pseudomonas infection: March 2019

110. On 19 March 2019 [redacted] developed a temperature spike. She was admitted to Ward 6A. The medical team began to run the protocols. She was started on IV antibiotics and blood cultures were taken. On the 21 March 2019 the results of the cultures came back and Professor Gibson told me that [redacted] had pseudomonas. She said it was a life-threating infection and we would have to take one day at a time. The night before Professor Gibson confirmed it was pseudomonas one of the nurses had told me it was a gram-negative infection. So all that night I googled types of gram-negative infections and what they could be. When Professor Gibson told me it was pseudomonas, I said that I had read about it but Professor Gibson didn't say anything else. Just that it was a very serious infection and then she left.

111. Professor Gibson can be quite intimidating to a lot of parents. Anne-Marie, one of the more junior doctors came to the room, and I asked if pseudomonas was a hospital acquired infection? I told her I had read that it used to be a well-known hospital acquired infection and was associated with poor hand hygiene and contaminated equipment or things like that. She quickly washed her hands and left and said she would get Professor Gibson to speak to me. A short time later Professor Gibson came back into the room and she said something like, "in answer to your question, is this because of the hospital water, the answer is no". I said, "I didn't ask if it was about the water I asked if it was a hospital acquired infection". And she said no and that she would get microbiology to come and speak to me. Microbiology never came to speak to us. I was never told how [redacted] contracted the infection, other than it was not from the water.

112. [redacted] was already on two types of antibiotics and they added in a third antibiotic, once pseudomonas was confirmed. There was then emergency surgery to remove her port which was under a general anaesthetic. She was the first one out the door to surgery the following morning. The line was sent away for testing and I think that Prof told me that there was pseudomonas in it.

113. [redacted] was due to start maintenance the next week and she didn't need the port so it was going to come out anyway. There was a delay to her treatment block and she was neutropenic so they wouldn't have started it anyway. She didn't miss much chemotherapy at this time.

Candida Infection: March 2019

114. On the 24 March 2019 [redacted] began to develop little round circles on her knees, like bruises. It started off with just one, it looked like a pimple. It had a dark ring around it, like a pocket of pus. We keep an eye on her as we need to know where bruises come from, as it can be a sign of low platelets. She was still in Ward 6A receiving antibiotics for the pseudomonas. I asked the doctor about the thing on her knee. She had been in bed the whole time and hadn't fallen over. We were in source and she couldn't get out. At that point I was complaining about the general state of the hospital, how dirty the hospital was. When we were admitted on the 19 March 2019 there were hair all over the shower of the previous person who had been in the room, there were coffee stains all over the floor, there were bandages left in the drawer in the bathroom. I wouldn't let [redacted] on the floor as the floor was dirty; the ward was dirty.

115. I asked the doctor what these spots were. He said just to keep an eye on it. They drew lines around the mark, the next day they drew a mark around a second mark. Then the marks got bigger. Then they called in dermatology doctors who examined her and said it was candida, a fungal infection. He was convinced in what he saw. I showed him pictures from a few days before so he could see how it developed. She was already back on pozaconazole again

and they prescribed ambisome infusion too. She was on two anti-fungal treatments and it seemed to do the trick. Her neutrophils were very low at this point, they were 0.2. I saw on the Facebook group that if a child in neutropenic and the fungal infection can supress the neutrophils you have, and if they are zero there can be no coming back from that. I asked if they could give her a G-CSF infusion to artificially kick-start the bone marrow. I spoke to the doctor on the ward, they went away to consider it. They spoke to Professor Gibson who was not on the ward at the time. Professor Gibson considered this and agreed to give her a G-CSF infusion, she was given two infusions. Over the course of the two days the marks on her knees disappeared. I don't know what G-CSF stands for. I was told by the doctor in America that fungal infection is a biological war and that you want to try and quickly erase the count and kick start the bone marrow. He told me that 0.2 is better than 0. So the G-CSF infusion can kick-start something.

116. Professor Gibson was away at a conference when this was going on. She came in a couple of days later and the marks had disappeared. She said that it was not a fungal infection. I asked why she was on two sets of anti-fungals if it was not a fungal infection and said that had been confirmed by dermatology. Professor Gibson said we could go home and that was always the carrot on a stick, you could go home. We never had any confirmation of what it was. [redacted] began the ambisome on the 25 March and stopped it on the 29 March which was when Professor Gibson saw her.

117. She stopped taking pozaconazole as soon as she started maintenance and she had her port removed.

[redacted]'s treatment – the maintenance phase: April 2019 to November 2020

118. From 1 April 2019 to 13 November 2020, [redacted] was on maintenance chemotherapy treatment. That lasted for just over a year and a half. For [redacted] that was oral chemo medication every day. On a Tuesday she would have an oral methotrexate. Every 12 weeks she had to go in for a lumbar

puncture. She had an antibiotic called Ceptrin that she had to take every weekend, it was a prophylactic antibiotic. She would go in on a monthly basis. Every two weeks a nurse came out so see her to take bloods.

119. [redacted]'s last in-patient admission was to Ward 6A in September 2019. This was for a period of 48 hours with a common cold. We had another spike in December 2019 on Christmas eve, but she was taken to the hospital in Ayr. She didn't go to the Queen Elizabeth in Glasgow.

120. [redacted] is supposed to see the hospital every three months now. During treatment they told us we would never be away from the hospital, that it would be two weekly, then monthly then three monthly. [redacted]'s last chemo was in November 2019, and she had outpatient appointment two weeks after that in November 2019 and then another one two weeks after that just before Christmas. Then Professor Gibson said to me that they didn't know what to do with off-treatment kids and that they would write to me. I called the ward in second week of January 2021 and she said that it was only monthly that she needed to see us now. And then we received the appointment and it is now three monthly. So we have another year of three monthly appointments and then after that we are on our own. The hospital said that we would probably spot a relapse before they can pick this up in a blood test.

121. Now if I call about [redacted]'s tummy ache, they tell me to take it to the GP. They tell me that it is not an oncology problem.

September 2019: Meeting with Jeane Freeman

122. Annemarie Kirkpatrick and I contacted Jeane Freeman in approximately July 2019. We raised the issues with the hospital with her. We thought that the that the environment put our children at risk. We asked for a meeting with her on behalf of parents as we wanted answers.

123. A couple of meetings were set up with Jeane Freeman and the parents. They took place in September 2019 in the Central Hotel in Glasgow. In the meeting other parents were sharing their experiences. The stories were very similar to ours and I heard some stories from people I'd never even met before. Some children had suffered more infections, others fewer infections or not at all.

124. After that meeting I said to Alfie that the things we raised with Jeane Freeman at that meeting, it was nothing new to her. She was well aware of everything we told her. Jeane Freeman played the role during the meeting. She acted shocked and embarrassed and she apologised to the parents. She promised to look at things and promised we would get answers. She was put on the spot there, but this was not news to her. She knew about all of this already but she did a good job of acting surprised.

125. [redacted] spiked soon after that, so I was put in a difficult situation. We always found out what was going on with the hospital through the media and me and Anne-Marie Kirkpatrick were trying to raise the issues via the media. We tried to force the meeting with Jeane Freeman by using the media. I had to go back to the hospital with [redacted] soon after that meeting as she spiked on 26 September 2019.

126. Towards the end of [redacted]'s treatment there was a lot of hostility towards me, I was one of the initial two parents that went to Jeane Freeman and who spoke out about what was happening. I speak about that later on.

127. I was not there to make friends, I was there to get [redacted] healthy and for her wellbeing. If I had a question about her health I will ask it. There was some sombre feeling towards me and I wonder if that if why staff didn't pop in to see [redacted], because they didn't want to be there with me.

WATER

128. From the beginning of [redacted]'s diagnosis and from the date of her first admission in August 2018 in Ward 2A, there were contractors who would come into the patient rooms every week and put a bottle of crystals down the hand basin and the shower. They told us it was part of the cleaning routine. They never told us what and why, just that it was part of the cleaning regime to keep things nice and healthy.

129. There were grey filters on the taps. From the beginning we were told not to drink the water from the taps as it was not clean for drinking, we were to drink bottled water. If we needed water we were to ask to the staff on the ward who would bring us bottled water.

130. There were signs up in the parents kitchen in ward 2A saying not to fill the kettle up from the tap, we were to use bottled water in it. I have a photo from Ward 2A showing this sign in the parents kitchen.

131. This continued all the way through from Ward 2A to 6A, for [redacted]'s whole time in the hospital. It was bottled water for drinking the whole time for her.

132. Initially [redacted] did use the water to get washed. Early on in her treatment I had spoken to one of the other mums on Ward 2A, and she said to me that she had bathed her son twice and after each time he had developed a line infection. So we stopped bathing her in the water after that, we used wet wipes and alcohol rub. When [redacted] went in for her line removal in September 2018, one of the junior doctors came into see her before the surgery. I don't want to name him as he was amazing. He came in with a check list and one of the questions is "when was the last time [redacted] had a bath or shower?". I told him that she hadn't taken a bath or shower in around 4 weeks, and he asked me what I did

to clean her. I told him I used wet wipes and gave her a bed bath using bottled water, that we used alcohol rub. I told him that I had spoken to one of the other mums who told me about infections in her child, I said that I didn't want to take that risk. And he said, "if this was my kid I wouldn't put her in that water either". I said to him, "why say this to me now, why not tell every parent at the start who comes in that door?"

133. If we had been told from the start, that there were suspicions about the water then we would have known the risks from the start and could have been cautious. If they told us we would have been fine with it, we wouldn't have felt lied to or betrayed because what other option did we have? For the hospital to put our kids at risk, that was the unforgiving part for me. Knowing that there was something or that it was possibly something in the water and they just left it.

Other issues with the building

134. There was comments from staff that the hospital was not safe. One of them mentioned that it would be parents in hospital beds in 20 years-time as the hospital environment was not safe. That was based on general conversations with parents and staff. The consensus among everyone was that it was not safe. Staff were telling me that they were concerned about their own health, that they were healthy and were concerned for their own health never mind having a sick child in this environment. All these things make you scared of the hospital and the environment and who you could trust.

135. Alfie and I were in the RHC one day, around the start of [redacted]'s treatment when one of the windows fell out the hospital building. I can't remember what floor and where it occurred but I remember it happening, hearing the loud thud as it fell out.

136. During [redacted]'s treatment there has been constant construction work at the hospital. The cladding has been removed from outside the building and there is

a scaffolding around the building. They were doing something with green foam, taking it out and putting something else in. When that was going on the front entrance to QEUH was blocked off for a time. There was always something going on.

137. There are cracks everywhere in the walls, which for a new building I found surprising. One day Alfie and I were waiting for [redacted] to come out of surgery and we were sitting near the surgical wards in the RHC. We saw cracks all over the walls and remarked on it. I wondered if it was a sign of subsidence in the ground.

138. There are people constantly painting the interior of the building; again this surprised me for it being a new hospital.

139. The shower floors came up in Ward 6A. The edges of the wet floors came up. There were signs up asking you to report this if you saw it. There was an issue with the strips from the ceiling coming down when we were in Ward 2A. The shower room was built so it was wet walls with a lining over the concrete to make it water proof. Bits of the floor and skirting would come up.

PHYSICAL AND EMOTIONAL EFFECTS

Physical effects on [redacted]

140. I fear that there are possible long term side effects from the medication used to treat the pseudomonas infection. We don’t know the impacts of that medication. Did it contribute to her tummy issue that we are dealing with now? I worry her quality of life has been impacted due to the infections.

141. She likes to be in a dark room and listen to the iPad on her own. Everything with her is full volume and I wonder if she has suffered any hearing loss related to her treatment in the hospital. One side effect of pozaconazole is hearing loss. When we speak to her she can and does hear us though.

142. [redacted] always asks to wear sunglasses. And we have wondered if she has sensitivity to light. When we are outside she always asks for sunglasses as it is too bright and the light is hurting her eyes. I wonder if it could be linked to the treatment. I grew up in a hot and sunny country and our house is always cool and dark. When we go out she mentions her eyes.

Emotional effects on

143. [redacted] knows not to touch the water in the hospitals and knows there are bugs in the water. She has a fascination with going to the toilets there, so we arrive and she wants to go to the toilet and she says "don't worry, I know not to touch the water". At Crosshouse Hospital she was able to wash her hands, she was able to bath her toy baby in the hospital bath, something we never did to her or with her in the QEUH. I couldn't find any reports about the QEUH not being safe, so it is hard for her to understand why she can't use the water at her own hospital but she can at another hospital.

144. She has a lot of anxiety about her losing friends as that was the environment she was in, her friends would be there and then disappear from her life.

145. [redacted] has finished her treatment and every night she still needs to sleep in our bed. We have to make sure that "nobody gets her". I remind her she is at home and she is safe.

146. [redacted] is not scared of the dark, but she is scared of people touching her in the dark. We have had to mention to nursery that [redacted] does not have the realisation that "this is my body" and her "no-no" areas. We have to re-introduce it all, as much as she is cuddly with us she is scared of interaction with others but she just let's people do it to her. She was used to people coming in and take blood overnight, take obs and do whatever they wanted and she got used to it, so she needs to learn that again. The hospital just leave you.

147. I think it is cruel to give a family a terminal diagnosis of cancer and then put them in a room with no psychological support. We are not in treatment now and we are away from the hospital environment but our family is falling apart. We have a six year old with more issues that I can name. Me and Alfie, our relationship has suffered. [redacted]'s relationship with her siblings has suffered. She wants to be the golden child, but she can't be and she has to share me with her sisters. Maybe these are all things that are normal under the circumstances. There was no support and we were stuck in a room and that was it. There was no support.

148. We asked for a referral for counselling and it took a year for them to come back to us. They said it was just for me and Alfie but we need support for the girls too. [redacted] was really affected. She is worried that I leave her. She woke up one day and I was gone, [redacted] was gone. She didn't see us for months at a time. We were trying to shield the girls from seeing [redacted] like that, looking back now maybe we shouldn't have. Maybe it would have avoided a different kind of issue. It is hard.

Emotional effects on witness

149. In relation to the hospital, I don't trust anything that anybody says to me. We have been lied to our faces. We have doctors promise us that the hospital was safe and then you see things in the news, that a kid has died.

150. I put so much pressure on myself to keep [redacted] healthy and alive, that if anything happened to her it would be my fault that I would have failed her. If her cancer comes back I feel it would be my fault as I didn't spot it in time. I feel that we walk away from this with PTSD at a high level. [redacted] was in the hospital 2/3 weeks ago. I called NHS 24 as she had a sore tummy, they told me to give her medication. The next morning I called back as she was screaming out in pain and NHS 24 told me to take her in to A&E and we will check her over. I just burst in to tears at the thought of going back, the thought that there might be something wrong with her and then taking her into that environment. What we witnessed in the building and being in that environment,

I don't think I can go through it again - it is just too much. At the same time I know if we have to do it again that I have to push on with it.

151. I hate the hospital. As much as I am thankful that they saved her, I hate every part of it. It feels like a death trap, I feel that every time I go there I put my kid at risk. It is definitely not a place that I want to go back to. It doesn't help that I did not always have good relationship with the staff. There were a couple of bust ups and we fell out. It is hard when you are in that situation, you are on your own. I am not saying I was right all the time but I felt like I was making valid points. It didn't help and it is definitely not a place I want to go back to. It would be amazing if [redacted] could keep on getting better and stay away from there.

Complaints

152. I complained in March 2019 about the state of the room in Ward 6A. At that point the floor had not been cleaned in five days. The shower had hair in it and there were coffee spills and marks on the floor. The charge nurse came into my room and she had the head of housekeeping. I said to her that I had so many issues about the cleanliness in the hospital. They had one mop that they used to clean everything. The bedpans could sit in the rooms for twelve hours maybe more. If the child is in source they want to check the bedpans. But they could sit there for eight, ten, twelve hours.

153. I had a rant. I pointed out that they tell us that infection kills our kids, but that they should look at the state of the hospital. I said if you come to my house you would say this was not acceptable. Now we work in partnership and I am telling you this environment is not acceptable. The Charge nurse was very hostile towards me. The head of housekeeping said that the floors had been cleaned twice a day, every day. I told her I had photos and that the floors had not been cleaned. It was like they didn't believe me.

154. I also made a complaint about [redacted]'s nursing care. At the beginning of

[redacted]'s treatment the nurses were in to see [redacted] a lot in Ward 2A. Towards the end of [redacted]'s contact with the hospital, the regular nursing staff came in less and less and it was student nurse taking blood pressure and observations. The only time you saw a nurses was when they would administer medication. I did raise a complaint about this, if my kid is lying there and she is not well and you send random students in to take obs how can you monitor if she is getting better or worse. How can a nurse write a report if they were not there. We have her medical notes and from what was recorded there was not a lot about her medication condition, but more observations about me and the family, personal things. Everything on the parent, the point of having nurses is so that they perform the obs. I found that they wrote a lot of personal things in [redacted]'s medical notes, but didn't record medical information. The couldn't have written a report from the notes. This happened in Ward 6A.

155. Sometimes the wrong doses of medication were given. Half the incidents were not recorded in the case notes. They would give us half a dose of what [redacted] should have or more than she should have. I felt I had to look after her. I complained about that too. If you tell me that I need to give her medication at a certain time I stop what I am doing and give it to her. Sometimes her chemo could be two hours late when we were in hospital. The nurses came back and said they had a window to administer medication. I felt the hospital staff were dismissive of me when I raised this.

COMMUNICATION

Communication: general

156. In general communications from the hospital are really poor. The teams try their best. If you want something higher up you have to ask for it. I am still waiting to speak to microbiology about the pseudomonas infection, two years and a bit later.

157. Communication from the hospital might have changed during [redacted]'s treatment, but I am not sure if it has been for the better. Changes have been for face value and they have not been valuable.

158. NHS GGC set up a Facebook group. It contains information about the ward, but it is not in-depth information and is face-value and not much more. Things like "we are setting up a new deli trolley". It feels like this is a group they were told to set up to keep face value, it doesn't really mean much. There is a bit of feedback but not much.

159. Craig White was appointed as a parent liaison point. I asked Craig White and Marion Bain for the raw data of the water sampling. We found out that there was another child who got pseudomonas within a few days of [redacted]. We wanted to know if the water samples had been tested and if anything showed up in the water. We wanted to know if pseudomonas was in the water. We asked for the test results for the water for that period. They came back and said they would have to process the test results for us and put it into layman's terms. Alfie worked in health and Safety for years and he can read a water report, he can interpret the raw data. So we responded and said please just give us the raw data, then they wrote back and said there is so many thousands of results. We only wanted the data for that period, we didn't want it all. They were just stalling and were not going to give it to us anyway.

160. When the Case Note Review was published, the report said that they didn't have the water data we sought from the Board. There were always people coming on to the ward to sample the water and the air filters. So I was shocked when the Case Note Review said there was no sampling and the samples that did exist were unmarked and all over the place. It looked like they knew what they were doing when they were in our rooms taking those samples.

Case Note Review

161. [redacted] was one of the children included in the Case Note Review. We weren't invited however, [redacted]'s case was simply part of it. I received an email stating they didn't want them to be shocked by the letter but [redacted] is in the study for gram negatives infections. I was told initially we would hear by summer last year, then it was the Autumn then the spring of this year (2021).

162. I have received [redacted]'s individual report. The report said that her infection was possibly caused by the conditions in the hospital. The words "possibly/probably" sounds the same to me. In legal terms it probably means something different. There was another child who was diagnosed with pseudomonas 5 days after [redacted] was diagnosed. The report concluded that they couldn't understand why the hospital did not act on these triggers and investigate this, and take water samples. There was no investigation carried out.

163. The main report involved eighty-eight children and the majority of those infections seem to have some link to the hospital. As parents we thought it might be a whitewash like everything in the past. Up until then remember we had been told by the hospital that it was safe and there were no issues. To see it in black and white that the concerns we had as parents were not for nothing, it felt like a small win. It is sad to see how many kids has been affected and this review only looked as gram-negative infections; it didn't look at all other types of infections. We are now finally moving in the right direction, we might get answers and there might be change.

164. Some of those kids have died, when we parents first started speaking out there was a child [redacted]who's mum spoke out.[redacted]died. [redacted]mum said that [redacted]chemo had to be placed on hold to deal with the infections. [redacted]cancer grew too fast and[redacted]couldn't be treated. I always think, is that something that could this have been prevented? If someone is sitting with empty arms and the kid is in a grave because of the hospital hiding things. We are one step closer to getting answers. There is some comfort that there is a public Inquiry and that it will be open and transparent.

Communication: infections

165. There was no communication in relation to infections. For the second staph infection it wasn't even the doctor who told me what it was it was the nurse in Ward 3B who came to tell me what it was. She had to go away and look it up on the notes. She said it was the same one that she had before. It was only when the hospital sent us a letter which was meant for our GP that they sent it to us by mistake, I think there might be mix up with the envelopes. It was only when we got that letter that we found out the full name of the infection.

Press Coverage

166. Me and Alfie have worked closely with the BBC. They did a Panorama episode that we were involved in. It was through pure determination to get answers that we turned to the press. It is for nothing else, no other reason other than to get to the bottom of this. We read every bit of news about the hospital in the press, not from the hospital. We could literally be in the room with the hospital staff and they would turn their backs and something would hit the press. They knew that this was going on, that this was going to happen. The news coverage has been very valuable to us as parents as without it we might not know what was happening.

Oversight Board

167. I don't know a huge amount about the Oversight Board, this is more Alfie's area. I feel that things were put in place to change the hospital, but those from the hospital that are on it will not be honest and transparent.

168. I feel that there won't be change under that culture, under Jane Grant. What we want is for Jane Grant to leave her post, and this was something raised at the parent's meeting that we had with Jeane Freeman. Her response was "I can't just pull people out of a hat to run a hospital." I mean surely you can find someone who is not going to lie to parents. The focus has been very much on

oncology but there are other vulnerable people, for example neonatal is same boat they are vulnerable people.

169. By keeping her in post, keeping her here, she knows where the bodies are buried and we expect that when you, the public inquiry, are carrying out your investigations that they will tell you that they don't have the documents or information that you are looking for. That is our fear.

CONCLUDING REMARKS

170. If [redacted] relapses she will have to go back to that hospital. I say to parents, if your child has to go back to that hospital and they contract an infection how do you live with yourself if you didn't speak up? Not everyone is as thick skinned as I am and not everyone is comfortable to come forward. It is hard for some parents as they are scared that their relationships with their medical team will be compromised.

171. There were a few occasions that I raised matters with the Health Board and got a call from Professor Gibson in response. I said to her that this is not for you, it is for the Health Board or senior management. Professor Gibson's job was to look after [redacted], the questions were for others to answer. I didn't want to compromise my relationship with her, it should be one of mutual trust. I didn't want to put her in the position. The health boards said if you have any questions, ask your medical teams which was so unfair. It is not a healthy environment for her to work in. It is not a healthy environment for our kids to be in.

172. I went to the media to get answers. Kids were getting infections, patients were dying, and when our kids were getting infections they couldn't tell us where it was from. We didn't know if the water was safe. We didn't know if the ventilation in the hospital was up to scratch. A lot of it was to do with the handling of the psedenomous infection. We didn't know how [redacted] got it. I spoke to a doctor in the USA, who said that she could only have got that

infection in her port by medical access. We don’t access ports as parents that is something only the hospital does. The hospital turned around and said she was not an in-patient at the time she developed the infection but there is a 72 hours incubation period which aligns with the blood transfusion on the 15 March 2019.

173. It is the fear that drives you, I don’t want someone else to go through this. My friend’s daughter got psedenomous at the start of this year just after her port was accessed. It is still happening. If we don’t speak up nothing will change. If we don’t drive this forward the hospital will not change anything.

174. I hate the hospital. It makes me feel sick. I just don’t want to be near it. I feel the Health Board is the hospital. I don’t think for one moment that our team wanted to lie to us, but they were put in that position where they had to and couldn’t tell us the truth. The Health Board are at the root of this. I will forever be grateful to the medical team, it doesn’t matter how we feel about each other. Professor Gibson did everything she could for [redacted], not once do I look back and say she didn’t have [redacted]’s best interest at heart. It was the way things were gone about that make me sick.

175. Communications are still not adequate. What I want is honesty, parents only want honesty. Come and stand next to my kids bed, even if she is dying all I want is honesty. The hospital is not known for honesty. Jason Leitch was on the ward saying that the ward was safe, that there were no issues. He came round to daycare when we started kicking off about the prophylactic antibiotics in September 2019. He visited the ward and said it was fine, we could drink the water and wash our hands. They changed one of the rooms in Ward 6A into a parent kitchen. It is the same water supply in the whole ward, how can I drink the water in the kitchen when in 90% of the rest of the ward I am told not to drink the water?

176. The Health Board put everyone in danger. The Health Board is not the medical team. It was unfair of the hospital to put the medical teams in that

position. You shouldn't have to raised things like this with your team – they're medical. They're not management. We wanted to see Management.

177. I do have concerns about patient safety in that building. I feel that nothing has changed. When they closed the ward in September 2019 they closed the ward again and put all the kids who had lines on Cipro. This drug is only supposed to be for adults for 5-7 days and these kids were on it for months. The team could not tell them why or the reasons why the kids were on the medicine. [redacted] was never on this medicine as she didn't have her line in at that time. I know about it from discussions from other parents.

178. When they shut the wards they put HEPA filters in the rooms in ward 6A. Now the HEPA filters are gone but what has changed? What have they done to change the water supply? Nothing has changed. The issues that were there then are still there now.

179. 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 – Timeline (CL/01)

This timeline was prepared by Ms Charmaine Lacock. It was provided to the Inquiry and is referred to in her witness statement.

- 17th August 2018– [redacted] became unwell and Charmaine took her to the GP. The GP said that this was likely a viral infection. They went home but remained unwell and was very pale.
- 19th August 2018 – Charmaine takes [redacted] to A & E for further investigations at QEUH. She was transferred to CDU and late in the evening after blood tests were completed, the family were told that she likely had leukaemia. She was moved to ward 2A to room 7.
- 24th August 2018 – [redacted] has surgery to fit a Hickman line.
- 25th August 2018 – [redacted] starts block one of chemotherapy, there were multiple room moves during this time. [redacted] remained in ward 2A till the ward closed around the 26th of September 2018.
- 23rd September 2018 –[redacted] has a line infection. The line is stopped.
- 24th September 2018 – [redacted] has emergency surgery to remove the Hickman line.
- 1st week in October 2018 – [redacted] is discharged home for 3 or 4 days and was then readmitted.
- 11th November 2018– [redacted] is admitted to hospital to start her 2nd block of chemotherapy to ward 6A
- 12th November 2018 – 2nd block of chemotherapy commences.
- 17th November 2018 – [redacted] is discharged home.
- 22nd November 2018 - [redacted] is admitted to hospital because she is throwing up blood. She is admitted to ward 3B in the Children's Hospital. ..
- 26th November 2018 – [redacted] starts 3rd block of chemotherapy.
- 24th December 2018 – Meeting with Professor Gibson. [redacted] is discharged home.
- 27th December 2018 – A meeting is conducted in the hospital to discuss [redacted]'s treatment plan.

- 31st December 2018 – [redacted] admitted to hospital to ward 6A.
- 3rd January 2019 – [redacted] is discharged home after a lumbar puncture
- 21st January 2019 – [redacted] has a fever and is admitted to hospital.
- 23rd January 2019 – Put on Ambisome – infusion – she was put on this infusion every 2 days
- 31st January 2019 – Charmaine reports to a nurse that [redacted] has been itchy. No rash evident. (this is a note from [redacted]'s medical records)
- 20th February 2019 – [redacted] develops a staph infection. The line is not removed.
- 25th February 2019 – [redacted] is discharged home.
- 15th March 2019 – [redacted] had a blood transfusion at clinic
- 19th March 2019 – [redacted]'s temperature spiked and she was admitted. Blood cultures were taken
- 21st March 2019 – confirmed Pseudomonas diagnosis. [redacted] receives antibiotics for this until she recovered.
- 24th March 2019 – [redacted] develops little round circles on her knees. They looked like bruises.
- 25th March 2019 – Dermatologist examines this and confirms it is "Candida (a fungal infection)
- 25th March 2019 – She starts medication for this infection. Ambisome infusions 4 times a day and Antifungal medicine posaconozol
- 29th March 2019 – [redacted] is discharged.
- 1st April 2019 – Maintenance round of chemotherapy commences.
- 26th September 2019 [redacted] was admitted to ward 6A room 11 for 48 hours for a cold That was her last hospital admission at the QEUH.

SCOTTISH HOSPITALS INQUIRY

Hearing Commencing
20 September 2021
Bundle 4 –Witness Statements for Week commencing 27 September 2021