Scottish Hospitals Inquiry

Witness Statement of

Suzanne Brown

WITNESS DETAILS

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

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

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

OVERVIEW

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

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

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

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

FAMILY BACKGROUND

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

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

think that is because there is only [redacted] between them in age, they do get on when they need to.

9. As a family we like to go outside together. The kids love to go to the beach, it is one of their favourite places to play and they run about in the sand and in the sea. We can arrive first thing in the morning and be the first people there, then the last people to leave in the afternoon. We also like going for walks and to the local trampoline park.

10. Prior to [redacted]'s diagnosis, he was a healthy child and was very rarely unwell. The only time I can think of was when he had whooping cough at 14 weeks old and he was admitted to hospital then. Other than that he had kept well throughout his childhood.

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

Admission to hospital: December 2016

11. [redacted] was diagnosed with ALL in December 2016, when he was 6 years old. I first took him to the GP because he had been having trouble with his arms and legs. The GP told me to take him to Forth Valley Hospital. They did blood tests and suspected Leukaemia but we didn't have the diagnosis yet. We were told that [redacted] had to go to the RHC in Glasgow. I took [redacted] to the RHC on 30 December 2016 where he was diagnosed with ALL. He was admitted immediately as an inpatient to Ward 2A which is the inpatient ward of the Schiehallion Unit. Ward 2B is the out-patient unit.

[redacted]'s initial treatment: December 2016 to February 2017

12. The first week or so of [redacted]'s stay in the RHC was over the new year and was a blur. I remember that we were given a treatment plan which outlined all the protocols. There were different phases to [redacted]'s treatment. These included the Induction Phase, the Consolidation Phase, the Interim Maintenance Phase,

the Delayed Intensification Phase and the Maintenance Phase. Interim maintenance was around 4 weeks long, maintenance was the longest phase of treatment, being around 2 years long.

13. [redacted] was under the care of was Professor Gibson, his consultant. There were also nurses who administered the chemotherapy. There were other doctors too but he saw so many, I can't remember all the names. They changed every now and again and we got a load of new ones. They were maybe students or juniors. Professor Gibson is still [redacted]'s consultant even now he's in aftercare.

14. I remember some of the medications that [redacted] was on. Once a week he was to get Daunorubicin, a really strong chemotherapy drug with another one called Vincristine. There was also mercatopurine which is an oral drug. [redacted] was on Dexamethasone the whole time. Dexamethasone is a steroid. Unfortunately, had loads of side-effects from his treatment. His blood pressure was really high and he had to be medicated to bring it down, but it stayed high and he was on 2 different medicines just to reduce it.

15. The initial phase of [redacted]'s treatment should have lasted for four weeks according to the sheet we were given but it lasted much longer due to his side effects. [redacted] got very sick with the chemotherapy. He had really sore legs and he couldn't walk anymore. [redacted]'s kidneys were also affected due to the toxicity of the chemotherapy; his eyes were yellow. He was put on medicine to sort all those problems. [redacted] stopped eating and was put onto TPN (total patient nutrition); he had nothing orally then. The TPN provided him with all the vitamins and minerals that the body needs. All of that just set him back. In addition, he lost a lot of weight too when he got a sickness bug and he was only 6 years old at the time. The sickness bug made him very ill, he was sick a lot and lost his appetite. [redacted] was about 26kg when we he was first admitted

but he went down to 19kg. He was just really frail; really not well during those first few weeks of his treatment.

16. As a result of the side effects of his treatment, [redacted] was not discharged at the end of the Induction Phase. [redacted] was still an inpatient when the next phase of his treatment, the Consolidation Phase, started. The Consolidation Phase should last another four weeks. It is followed by the Interim Maintenance phase, Delayed Intensification Phase and the Maintenance Phase. We would be given a new sheet for each phase of treatment which explained what would happen.

17. [redacted] was discharged as an inpatient from ward 2A on 21 February 2017. He was part way through the Consolidation Phase of his treatment at that point. I think he was in ward 2A for about seven and a half weeks for the first inpatient admission from 30 December 2016 to 21 February 2017.

Experience on ward 2A: December 2016 to 21 February 2017

18. Ward 2A is specially set up for children with cancer and their parents to use. It has a playroom for the kids and we had a parent kitchen area with a wee couch. The parent kitchen was like a lifeline. I remember once when [redacted] had been admitted with a temperature and I met a lady when her wee boy had just been admitted and she was crying. It was her first time and I just helped her and consoled her a wee bit. I always remember my first night and I was panicking. There were all those other parents in there. When you spoke to other parents who can tell you their experiences it helps you greatly. I remember that when [redacted] was first admitted, it felt like a worse-case scenario, I was planning a funeral in my head. That’s the first thing you think about. When you speak to parents who are used to living that way it helps greatly. The parent kitchen is a lifeline. Its somewhere to go, to take a break, to speak to someone who has gone, is going through what you are, somewhere to

offload. The first night [redacted] was diagnosed I went to the parent kitchen in ward 2A, I was shell shocked to be told my child had cancer. Someone in there gave me a hug. People in that kitchen have been through it all before.

19. [redacted] was in a single room. They were all single rooms in Ward 2A. I think that there are about 26 rooms in total, around 3 of those rooms are Teenage Cancer Trust rooms and we could not use these due to [redacted]’s age at the time. Around 8 of those rooms were for transplant patients. That left approximately 15 rooms for the use of patients like [redacted].

20. Within those 15 rooms there was a bed for the patient, a small sink nearby the door of the room so that you could wash hands, there was an en-suite bathroom with toilet and shower. Within the bedroom area there was a bin, small chest of drawers and cupboard. There was a TV attached to the wall, most of the TVs did not work though. There was a pull-out bed for parents and that meant I could stay overnight in the room with [redacted].

21. Ward 2A also has a playroom which is set up for immunocompromised children. The playroom had board games, pencils and drawing materials. There were play specialists in the room and they would help the children play, set up activities, ask them what they would like to do and join in the play. The play room was for the use of the Ward 2A patients only, for example siblings were not able to access or use the playroom for infection prevention measures. [redacted] used the room, as he was often quite unwell when admitted to Ward 2A he was not really in the mood to use the facilities, he might go in for a short time then leave.

22. The playroom was for children up to 13 years old. Teenagers had their own facilities in the form of the Teenage Cancer Trust Room (“TCT”). [redacted] was in that in-between age in the 7-12 year old age group, and he didn’t really want to draw with the young children and he was too young to use the TCT room.

The TCT room had facilities that [redacted]'s age group were interested in. They wanted to be in the room that had X-boxes and a pool table but they were too young to be allowed access. The staff on ward 2A were really great and they always came in to see [redacted] when he was in.

23. Ward 2A has special protocols. For example, there is the Protocol that applies when a cancer patient spikes a temperature. If [redacted] spiked a temperature during the day we'd go to Ward 2B which is the daycare ward. From there he was admitted. The nurses draw blood and send the samples away to the lab for blood cultures and to check for infection. It takes 48 hours for blood cultures to come back with results. Antibiotics are started immediately on admission as during those 48 hours the staff don't know what the cause of the temperature spikes are, whether it is an infection or not. Once the blood cultures come back then decisions on treatment can be made. Patients are discharged when the blood cultures come back negative and as long as they do not have a temperature spike. If the patient continues to spike and cultures are negative, then the protocol is to continue testing blood cultures every 48 hours to keep checking for infection. So patients can be in for a few days working through this cycle of antibiotics, drawing blood and checking blood cultures. Best case scenario patients can go home after 48 hours, but it can take a few days, sometimes up to a week, of working through this protocol before the temperature is manageable.

24. In Ward 2A I think that the nurses have specialist training in administering chemo, there were times when [redacted] was not admitted to Ward 2A and was not looked after Ward 2A nurses. On some of those other wards staff could not administer chemo as they were not trained, that is what the staff on those other wards told me. The doctors on Ward 2A are specialists in oncology and haematology. There appeared to be a lot of doctors coming and going, I think that they were junior doctors and were on training rotations so I'd see them for a while then they moved on.

25. Day to day, [redacted] enjoyed being a patient in Ward 2A especially when compared to his experience in other wards in the hospital. It felt like it was a home, apart from times when you were in isolation. That could be difficult.

26. For [redacted] being in-source meant being in isolation. The types of things that could lead to a patient being in-source was if the child had sickness or diarrhoea; cold or flu; or a virus that could spread. Sometimes [redacted] was in-source to protect him, to stop him from getting an infection. Usually if [redacted] was admitted to another ward (not 2A), he would end up in-source to protect him.

27. If [redacted] was in-source in Ward 2A there was a yellow laminated sheet that was placed on the door. I think it said “Please ask a member of staff before entering”. I was allowed in to stay with [redacted] but I couldn’t access the kitchen on the ward when in-source. For visitors permission had to be given by the nursing staff. If granted visitors had to put on an apron and wash their hands, as did the nursing staff and domestic staff who came into the room.

28. In-source isolation is a different type of isolation to “strict isolation”, which is for patients who are waiting for or have received a STEM cell transplant. Those children stayed in the special isolation rooms that had the double doors, with a wash basin in between so hands could be washed before entering the room. [redacted] was never in strict isolation although he did use a special isolation room on one admission but I can’t remember the date.

[redacted]’s admission for staphylococcus infection: 22 February 2017

29. Although [redacted] was discharged from inpatient care on 21 February 2017, he was readmitted to the RHC one day later on 22 February 2017. We had only stayed one night back at home. [redacted] had a check-up visit to the clinic as an outpatient at ward 2B on 22 February 2017. [redacted] had day care first at 2B and

we had gone home. When we were at home, he spiked a high temperature and we called the hospital. We were told to take him in. He was not even home for 24 hours. For [redacted], that was the first of a number of inpatient admissions when his temperature spiked.

30. We went to the ward 2A where they took blood cultures and put him on antibiotics. I'm sure he was neutropenic because he was in the aggressive part of treatment. The cultures came back showing an infection in his line. had a central line at that time. The central line was used to administer treatments and to take blood. They said they were going to change to a different type of antibiotics for that kind of infection.

31. When this type of admission happens, they stop all other treatment to get rid of the infection first. Chemotherapy would only be re-started when [redacted] had finished the antibiotics and even that was only if the swabs showed that the infection had gone. I think it was the ANP (Advanced nursing practice) nurse who told us about the infection; they come round in the morning. We weren't really told much so I didn't think it was too serious. They just put the antibiotic in and that was it really. But [redacted] wasn't very good. He had a high temperature, was shaky and feeling not very well at all. It made [redacted] quite sluggish. I'm not too sure how long he had the staph infection for. Admissions for infections would usually be for up to a week but I think we were in for longer that time from 22 February 2017 until 5 March 2017.

32. [redacted]'s blood cultures came back within 24 to 48 hours of his admission and it was confirmed that he had the staphylococcus infection. Once the staff knew that he had this infection then [redacted] was given an antibiotic to treat that infection. The specific antibiotics prescribed was a course lasting a week and that prolonged the admission. [redacted] was not required to be in-source during this admission. Following this infection, he was weak and not able to walk. I think this was due to both the infection and the treatment he had received. His

chemotherapy was stopped and treatment delayed, it started again once he finished his course of antibiotics and once his neutrophils in his blood had increased. I can’t remember the exact date when he began chemotherapy again.

[redacted]’s treatment and other admissions during 2017

33. [redacted] moved on to the Interim Maintenance Phase of his treatment a few weeks after his second admission in February 2017. During 2017, [redacted] was going into hospital for his monthly chemotherapy as an out-patient, we attended clinic appointments in Ward 2B. Between clinic appointments, we’d be getting monthly supplies and treatment from the hospital pharmacy to take home. He’d get his Vincristine and so on to take home.

34. As an outpatient, [redacted] received his chemotherapy via a central line and then through a port-a-cath. He had a central line between January 2017 and July 2017. They were going to try and use cannulas but they just didn’t work for him unfortunately. This meant that [redacted] had to have a port-a-cath inserted in October 2017. A port-a-cath is inserted via a surgical procedure under a general anaesthetic, [redacted] attended day care early on the morning of his surgery. Following the procedure he stayed overnight for observation and he was allowed home the following day. [redacted]’s port-a-cath was inserted into his chest on his right side, some children had them fitted under their arms. It still had to be flushed every month, the lady came out to the house and did that.

35. When [redacted] moved onto the Maintenance Phase of his treatment, he attended ward 2B for outpatient treatment as he had before for Interim Maintenance. I think that this phase started in around July or August 2017. The outpatient chemotherapy was accessed through [redacted]’s port and that got the chemotherapy into his line. We were in for outpatient treatment to the clinic in ward 2B every fortnight or four weeks.

36. Throughout 2017 [redacted] had numerous inpatient admissions. Only one of [redacted]'s inpatient admissions was for pain management, he was in such a lot of pain. All the rest were for temperature spikes. That involved him being started on antibiotics straight away.

37. Temperature spikes always worry the hospital staff and parents, because they think it could be an infection, so [redacted] was always treated. They're always worried about sepsis so it's a sepsis protocol they do straight away. They need to cover the line and check it's not a line infection. It could just be a cold with kids but they just want to get antibiotics into them straight away. It could just be something simple like rhinovirus, just a cold. The protocol in Ward 2A was that, if there was a high temperature it would mean Calpol to bring the temperature down, and then it would be checked an hour later. In other wards it was only every four hours. They take bloods from the line and send them to the labs for cultures. That takes 48 hours so they would always have to admit until the results come back. If they come back negative you can go home as long there isn't another high temperature. They take throat swabs too to check for viruses. Often both of [redacted]'s would come back negative and it's just unexplained, nobody knows.

38. If the bloods came back with a particular infection, like when [redacted] he got the staphylococcus line infection in February 2017, we were re-admitted. As I have already said, these protocols had to be gone through every time.

39. When there was a temperature spike, depending on his blood counts, they'd look at his last count, and if he wasn't neutropenic (too few white blood cells), for example, if they were not below one, they'd start him on one antibiotic. If they were below one he'd be put on two antibiotics, both by IV. One was an IV bag and that takes an hour and the other is in a syringe and they would just push it through the line. Sometimes he'd be put on fluids as well.

40. Temperature spikes can lead to delays in treatment. If [redacted] had an infection or low level of neutrophils, a hold would be put on his chemotherapy. Sometimes his neutrophil levels were close to zero and he would not be given more chemotherapy then. They would wait for the counts to go up. That causes a lot of delay, sometimes 2 or 3 weeks. Nothing is set in stone. In an ideal world it would be week by week treatment for the ALL. In reality, the chemo holds delayed things.

[redacted]'s inpatient admission for Parvorvirus: March 2018

41. There is another particular admission that I would like to mention. [redacted] was admitted to the RHC in March 2018 when he contracted parvovirus. Parvovirus is the virus linked to slap cheek in children. Normally it gives children red cheeks, but for children who are immunocompromised and on chemotherapy, it can really mess up their platelets and haemoglobin. This can result in a requirement for blood transfusions to replace red blood cells.

42. At that time, [redacted] was attending ward 2B for his monthly chemotherapy. He was getting monthly supplies and treatment to take home.

43. [redacted] had a high temperature, he spiked at home and we took him to ward 2B daycare, Ward 2A was full so he was admitted as an in-patient to one of the wards on the 3rd floor, either 3A, 3B or 3C – I can't remember which one. Blood cultures came back negative after 48 hours and his temperature came down so we were sent home. The next day he spiked a temperature again and we went back to the hospital to Ward 2B for assessment, he was admitted again and to ward 3C in the RHC as an in-patient. Ward 3C is renal, dialysis and orthopaedics. [redacted] was admitted to ward 3C instead of ward 2A because of capacity issues, the nursing staff in ward 2B told me there were no rooms in Ward 2A. A lot of the rooms in ward 2A as well as the transplant and

strict isolation rooms were getting boarded up. I will come on to say more about that.

44. During the admission, [redacted] developed a red rash all over his body. He was scarlet red. He had a very high temperature, over 39 degrees. His platelets were low and when the nursing staff placed a cuff round his arm to take his blood pressure he bruised really easily. He had blood spots on his chest that began to burst. He received 4 blood transfusions during this admission. There was no other treatment to give other than to manage the symptoms, his temperature was managed using Calpol and ibuprofen. The staff took swabs from his throat a few times but they kept coming back negative. Eventually staff told me it was parvovirus. His chemo was stopped during the admission and treatment for the virus.

45. I did my own research on parvovirus. I am a member of a few Facebook pages set up about kids leukaemia. They are pages with members in the UK, America and there are some parents of children being treated in Schiehallion who are members too. They are for parents of kids with ALL. Through those pages I learned about parvovirus, I wasn’t really told much by the staff.

46. When [redacted] was admitted to Ward 3C for treatment for parvovirus, it was for 4/5 days in ward 3C and then he was moved to ward 2A when a bed became free. For the 3 weeks as an inpatient he was in insolation. When we were in isolation [redacted] goes into himself. He wasn’t allowed to leave the room for 3 weeks. It’s horrible in itself, let alone for 3 weeks. It’s mentally hard when you’re only 6. Nobody is allowed in [redacted] could only stare at the clown doctors going past his window. The clown doctors are entertainment for the children, and I think they are provided by the charity Hearts and Minds. They wore yellow coats, had big shoes and red noses and came around the wards and made the children laugh. He used to love them. But that was only for 5 minutes a day, it was hard for him.

47. The experience is just not the same when you're not in ward 2A. On ward 3C, we did not feel as safe. The Schiehallion staff and protocols are not there with you. I felt like I was the nurse and had to make sure things were right. A lot of times when [redacted] was not being treated in the Schiehallion ward and when he was admitted to other wards in the hospital, there would be overdose amounts in the syringes. Sometimes there were under-dose amounts. It was crazy amounts. I sometimes had to take some medication out before giving him it. I said I would give him it. I wanted to check myself. If I was going to the shops for food for [redacted], I would ask them not to give him it because I wanted to check the amounts. I knew what he was getting because I was used to giving his oral medications at home. That happened during this admission.

48. The protocols on ward 3C were not the same as on ward 2A. When children are admitted in all the wards and do not have high temperatures, it is standard practice for the nurses to carry out observations every 4 hours. During obs [redacted]'s temperature is checked and his blood pressure taken. In Ward 2A the protocol changes when a child cancer patient has a temperature spike. The frequency of observations increases, calpol is given initially and then after an hour the nurses check the child's temperature again to ensure it is coming down. If temperature does not decrease then ibuprofen can be given, that is not normally given when kids are on chemotherapy but sometimes they have to give it, to get a bad temperature down. This did not happen during this admission. It was scary. I was carrying out the hourly observation on my own, using my own thermometer. His temperature was over 39 degrees and did not decrease when given calpol. During the parvovirus admission, [redacted]'s temperature was so high, he was drifting in and out of consciousness. He was so, so ill. I'd never seen him like that. In ward 3C, during the night-time, later at night, I was pressing the buzzer. The auxiliary came and said they'd get somebody to come and see him. But they didn't come. So, I was buzzing again. That was from about 5pm. Eventually, I went down to Ward 2A and

asked for help. A doctor came up from Ward 2A at 11 pm, I can't remember his name. It was just Graeme and I there. I was trying to help. No one else was doing anything in ward 3C. [redacted] was given ibuprofen by the doctor from Ward 2A, he was also given IV paracetamol as it acts faster. His temperature began to decrease. There was a lack of understanding in the staff in Ward 3C, they had thought that they could not prescribe ibuprofen at all and so they didn't.

49. Another thing I noticed was the staff had a different approach to taking blood out of the line in Ward 3C. In Ward 2A when drawing blood from the line, the nursing staff would take a discard sample and dispose of it. Then they draw the blood sample required, then put the antibiotic into the line, then flush the line and then cover the line. In Ward 3C the took a discard sample and kept it, then drew a very large amount of blood, larger than that taken in 2A. Then they administered antibiotics then put the discard blood back in the line and then covered the line. When I went down to Ward 2A from 3C to ask for help with [redacted], I asked the Ward 2A nursing staff about the blood draw. The Ward 2A staff told me that they shouldn't take blood like this, that they shouldn't be doing this. I was worried about [redacted] getting an infection in his line. It was a different way of doing things, maybe because it was a renal unit and that was their approach. It was different from Ward 2A. I asked the nurses in Ward 3C to stop drawing blood in this way, but it didn't stop them.

50. There was a difference in the care provided, but I don't think it was the staff's fault. In Ward 2A there is a doctor available 24/7. If [redacted] was admitted to another ward then he only saw the Schiehallion doctor or an Advanced Nurse Practitioner during morning rounds. So I had 10 minutes each morning to ask all my questions. It was not the same as having the specialist doctors there all the time.

51. I was with [redacted] that whole time on ward 3C. At the time, I felt I just had to get on with it. But it's horrible. During the first week it was horrible; we didn't know

what it was, his whole body was shaking. He was going red. They didn't know what it was; he was spiking temperatures up at 40. I was crying, I didn't know what was happening. They were telling me he was fine but when it's your child you don't know if he is fine. His bloods were just tanking, he was getting blood transfusions every day. His platelets were really low so when they put the blood pressure cuff on him it was causing big red bruises on his arms. It's not easy, you just have to get on with at the time. It's later on when you think 'how did we get through that?'

52. The staff kept saying they'd move him to 2A to keep an eye on him but after I sought help from them, it was a full night during that stay until they moved him to 2A. We had to wait for a free bed.

53. During that admission in 3C, [redacted] was in-source and he was not allowed to use or access the Ward facilities.

Other admissions during 2018

54. [redacted] was admitted to the RHC as an inpatient on other occasions during 2018. These admissions usually related to temperature spikes. Often, [redacted] was admitted to other children's wards, not to ward 2A. Sometimes, we were put into TCT (Teenage Cancer Trust) wards, if that was the place a bed was available. They were supposed to just be for teenage patients though. They just had to give you any bed that became available. That started becoming more frequent in 2018; we just knew we weren't going to be in a ward where we felt a bit safer. Most of the time we knew this was going to happen. We knew that we wouldn't be admitted to 2A where we felt a bit safer.

55. We used to dread not going into our own ward. The admissions to other wards in 2018 were exactly the same, every single time. They didn't stick to the protocols we were used to on ward 2A. These wards aren't used to kids with

no immune system. I had to go down to 2A myself and beg the nurses there to get someone to come and look at him.

56. On the other children's wards, wards 3A, 3B and 3C, the only contact was when nurses came in to do [redacted]'s meds. We didn't have many visitors. We're from [redacted] and when you're two years down the line, visitors don't come so much. When [redacted] first went in he had visitors all the time but two years down the line it was different. They were allowed to come but they needed to wear an apron when we were in source. There was a lot that [redacted] lost.

57. In the other children's wards, such as ward 3C, there are playrooms and a parent kitchen but that is just for heating things up. The nurses use it as well. It's not the same as in Ward 2A. Also, even though there were playroom staff in children's ward, our immuno-compromised kids did not have access to them when we were put into source. When they were put into source in other wards, they lost that the access to playrooms and play staff. That was usually what happened with us, [redacted] wasn't allowed to use the playrooms. If [redacted] was in source to protect him, it was in case he caught something from somebody else.

58. There were a good few of those isolation periods, when he was in source. Most times when he came in, if he had diarrhoea or felt sick, you got put into source immediately. You had to tell them straight away to cut the risk to everyone else. They brought urine bottles, they had to check everything going in and out of him. People came in with aprons on. Everything would stay in the room, even the dishes, staff would take things away for you as you can't leave the room. You had to buzz and ask for things to be done. I would normally do that kind of thing but I wasn't allowed to or to go into the parent kitchen to get my dinner, I just had to get M&S microwaved meals which I had to ask the nurses to do.

59. We lost other things too when we were on other wards. You get friendly with the ward 2A nurses and they got to know [redacted], he knew them all. He could go and play with other kids on 2A too, like at home going out to play. In other wards it was just isolating. They didn't know us and we didn't know them.

60. Being on other wards, affected me too. It was hard, upsetting. I used to phone my mum and just cry because I just wanted to get out, it felt like prison and to see [redacted] like that. I just had to tell him that hopefully it wouldn't last. And you just hoped and hoped he wouldn't get another temperature and stay in much longer or have to be admitted. That was one of the worst things - where would he be put? The scariest thing about going back was he wondered where we'd be put. That was the first thing [redacted] thought about. If we were lucky, we'd be put on 2A but, even if we were, the chances we'd be moved so you never felt settled. It was unlikely we'd be put on 2A.

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

61. I remember that in 2018, wards 2A and 2B in the RHC closed. Wards 2A and 2B were moved to the adult hospital. [redacted] was in day-care as an outpatient at the time. I remember all the staff, auxiliaries and porters moving everything over. Big trollies were being moved.

62. I do not remember being told much about why the wards were closing. We were just told we were moving over to 6A in the adult hospital while work got done on 2A and 2B. I actually asked the receptionist lady what was happening. I think she called the registrar. I asked what was going on. She said 'we're moving for a few weeks 'til work gets done'. I think they're still there.

63. I was not given any detail about why the wards closed or what work was being carried out. I never actually questioned why it was getting done. Work

was always getting done so it seemed normal. As far as I know the parents were not told the reasons for the work. I do not know if the inpatient parents were told but outpatient parents were not told anything. I wondered how it would work in the adult ward. Would it be like a children's ward? We were led to believe it would just be a few weeks, we spoke to the member of staff that sits at the reception desk in ward 2B. We never really got communication other than it was to do with the water and that they were sorting the ventilation. The whole system was getting renewed. That's all I ever knew. The water issues were in the news at this point. I think the other parents spoke about that, it was what was thought. We were never told except when it would re-open. They initially said it would be 6 weeks and then more and more time was added on.

64. After the move to the adult hospital, things operated basically just the same but they split things into 2 parts. All of ward 6 in the adult hospital was used and half operated like in ward 2A, for inpatients, and the other half into day-care like in ward 2B in RHC. It was just in one big ward instead of two separate wards. It was all the same staff.

Experience in the QEUH (adult hospital): late 2018 – 2020

65. The experience on ward 6A was very different from ward 2A. In the adult ward there is nothing like the parent room. That's all taken away from you. You're in your room with the door shut and that's it.

66. In the adult ward, there was nothing at all for kids to do or even an adult kitchen for me. [redacted] is a fussy eater, I'd go to the hospital shop. Sometimes all he'd want was cereal or strawberries or tomato soup The food really wasn't nice, it wasn't nice looking. At one stage all he had to eat for 3 weeks was tomato soup. Also, there wasn't a fridge to keep stuff in or a playroom for the kids. There was nothing for kids to do. The TV was almost always

broken. The blinds were often broken and stuck shut. There was not even any daylight. the internet wasn't working and we were in isolation all the time. It was crazy. A couple of times he was in source in 6A. It was hard.

67. The loss of the facilities that he had in ward 2A and 2B had a big impact on [redacted]. It made him quiet. We would just play silly wee games. It makes me want to cry when I think of it. It was just me that he had. It's not the same as having the other kids. He lost a lot. There were no play support ladies to sing and dance. That was all gone. He was with me, in the room 24 hours a day playing whatever, snakes and ladders. He'd sometimes sleep just to pass the time. We'd watch TV if it was working; the picture was sometimes upside down or it wasn't working at all. You couldn't make it up in a new hospital.

Completion of [redacted]'s treatment: March 2020

68. [redacted] finished treatment in March 2020. He had his port-a-cath removed in September 2020. He had that until 30 September 2020; it was supposed to come out when he finished his treatment in March 2020. However, due to the pandemic it wasn't classed as emergency surgery and he had to wait. He still attends the adult hospital for check-ups.

WATER: EVENTS INVOLVING WATER SYSTEMS

69. I have been asked whether I have any recollection of specific incidents or concerns involving the water system at RHC or QEUH. I remember that there were issues with the water right from the start.

Water incidents in RHC: 2017 - 2018

70. During [redacted]'s first inpatient admission in early 2017 there was a time when I took a shower in room 9 in ward 2A. I don't know why I remember it. We'd just moved there from room 1 in ward 2A. Room 9 is en-suite. I was

washing my hair and heard Graeme, my partner, shouting ‘turn the water off!’. When I looked, the full room was covered in water. It ran under the door and was running into the ward. The drain was completely clogged and water was running right out of the room. It went into the patient bedroom where [redacted] was and into the ward. The nurses came in with loads of towels to soak up the water. We were told that maybe the drain had been blocked. Someone came and took it apart to try and fix it. I don’t know if that flooding happened anywhere else in the hospital.

71. I remember other issues with the water. At some point in 2017, there was a bathroom in ward 2A which was closed. There was a sign in the bathroom saying it was out of order and not to use it. It was away up at the other end of the ward. It was a wee room on its own. This was definitely in 2017, I’m not sure of the exact date; it was during one of [redacted]’s many admissions that year, I know that.

72. I cannot recall the exact dates but there were other things which happened relating to water. There was a water cooler that I always used to get a drink of water from but it was out of order so then we went up to day care and *that* water cooler was out of order as well. The next time we went up all the water coolers were gone too.

73. We started noticing that filters were getting put on all the taps. In 2018, during a clinic appointment in 2B, we were in one of the rooms with a nurse and all of a sudden a guy walked in and started fitting a filter to the tap so we asked what was going on. The person who was fitting the filter just said it was to try and get clean water or something.

74. At some point, when we were in ward 2A, we were told not to use any of the water for showers. There was an ‘out of order’ signs on the door of the room where the bath was. We were told not to use any of the water to wash our

hands, brush our teeth or shower. That's when we got the bottled water. When we were inpatients we were told not to use the showers and things like that. That is why we were given bottled water to wash [redacted]. They would drop off big two litre bottles of drinking water for us to wash him with and brush teeth and things like that.

75. I saw things in the building, like the water filters being added to taps. The workmen had to re-do the filters, I think about every 4 weeks.

76. Similar things also happened in wards 3A, 3B and 3C during all of the admissions in 2018. When we were inpatients in the other wards, 3A, 3B & 3C, the kids from our ward (ward 2A) weren't allowed to use the water but the kids who were the usual patients were still using the water then as normal. They have still got filters on their taps though.

77. [redacted] used the hydro-pool a good few times, in 2017 and 2018. I cannot remember all the times he used the pool but he definitely used it on 8 August 2017, 22 August 2017 and 27 February 2018. It is on the ground floor of the RHC, in the physiotherapy department. He used it due to his sore legs; he could barely stand, and couldn't walk for some of the time. He was in a wheelchair for a good while. The pool had heated water and [redacted] did his exercises. It was to get him moving again and build up his muscles. He had hardly any muscle in his legs as he just hadn't been weight-bearing or walking. When he used the pool the central line had just been removed. We stopped using the hydropool when all the issues with the water were coming to light in the news.

Water incidents in the QEUH (adult hospital)

78. The water in the adult part of the hospital was just the same. The only difference was that we could use the showers in ward 6A. Filters were on all

the taps and we were told not to use the water. It was the nurses that told us not to use any of the water but we were never told why. There were no signs up, it was just the nurses that told us.

Water: communication

79. I have been asked if I remember what we were told about the water issues.

80. At first, we were told nothing about the water. I was using the water, especially in ward 2A at start of [redacted]'s treatment. During the first inpatient admission at the start of 2017, we were using water as you would in any hospital. We never knew about any concerns at all with the water. We washed dishes, we washed our hands and we brushed our teeth. [redacted] was in a bath almost every night. We were told to try and give him a bath to ease his joints and the pain in his legs. This was when he had his central line in. We were never warned at all. At that point nothing indicated that we shouldn't use the water though. During those first months, there was nothing about us not using the water. It was after that we were told not to use it.

81. It was in 2018 when it all first started coming out on the news about the water. I'd say in maybe February/March 2018 it all started changing. Filters were being fitted on taps around the same time and that was also when the water coolers started to disappear in 2B and the foyer. When we were inpatients we were told not to use the showers and we were given bottled water.

82. I do not remember the hospital telling us anything about the water. We just were aware there was something in the water, a bug or germ, coming from the water, and the filters were there to stop it coming through the supply. This never came from them, it came from the news, not actually from *them*. They have never told us what it was; they've still never told us. They just

said ‘don’t use it…preventative…don’t use it’ but there’s never been a *why* we’ve not to use it. If you asked it was just said that it was preventative measure to do with what’s on the news, that’s what you’re told.

83. One day I was on daycare Ward 2B with [redacted] and I picked up a leaflet that was sitting out for people to take. It was from the hospital and it was about the water. It was along the lines of ‘you have probably heard on the news about the water’ and they reassured us not to worry. They told us, ‘well, you know what’s going on’ but we didn’t know *from* the hospital we were attending every week, it was crazy. I was mind-blown really. Still we weren’t being told anything, just what was already on the news. It was like they were scared to tell you. You get that feeling from the staff, they didn’t know and we were thinking, wow, really? It was scary, really scary.

84. I don’t think that the hospital staff always knew what was going on either. I was invited to a meeting with Professor Gibson in 2019, it was before [redacted] finished treatment and around about the time the water issues were in the news. I thought it was going to be a meeting to tell parents about the water issues, but it was actually about the proposal to lower the time that boys received treatment for ALL. Girls receive treatment for 2 years, boys receive treatment for 3 years and the meeting was about a study looking at reducing the time for boys. Professor Gibson began the meeting by stating that she was not going to tell us about the water as she didn’t know about it either.

85. We found out about concerns with the water from the news and other parents talking about it or saying their kids have got these infections. I thought the reason was because of the water and that was why these kids were getting sick and dying; I began to think that the water’s got something in it. I thought it was because it was built right next to a sewage works. Could it be something to do with that? When you got out in the carpark you

were just hit with this smell, it was horrible. In your mind it's all speculation because you don't know. You're just thinking you don't know what it is and nobody is really telling you. We were scared, absolutely terrified to go in the place. You felt angry that they weren't telling you about why were we getting put into a place where we were risking our child's life just by being there. You're dodging bullets the whole time.

86. The parents were using the water and washing with it as well. It was like a lottery, with the water, whether you caught something or not. Knowing what I know now, it was like a lottery with [redacted]'s life. We weren't told anything about the water.

87. In a way, I think [redacted] might be one of the lucky ones because he just had one infection; that we dodged that bullet. I've seen other kids who haven't been so lucky but we were all there at the same time. That will live with me forever. When I think of it like that it's scary. I was putting him in the bath every day, not knowing any of this was going on. So, I was putting him in danger just by putting him in the bath and by letting him brush his teeth. If I'd have known, he wouldn't have been anywhere near the water.

88. Overall, I would describe the communication about issues with the water system as extremely poor, really, really poor. It's made me feel that the hospital wasn't fit for purpose and that we should never had been there. We live in [redacted] and go to Forth Valley Royal Hospital normally, so we are pretty central between Glasgow and Edinburgh. I wished and wished and wished that we'd been put into Edinburgh. The distance between the two is hardly anything. Glasgow's supposed to be this *super-hospital* and at the time, we think, 'great', it's supposed to be fantastic. I've never seen any of that, *super-hospital*. I just wish we'd been put to the hospital Edinburgh.

89. The issues with the water and poor communication had an emotional impact on us. We were scared, absolutely terrified to go in the place. We felt angry that they weren't telling us about why we were getting put into a place where we were risking our child's life just being there. I say more about that below.

HEALTHCARE ASSOCIATED INFECTIONS

HAIs: events and physical impact

90. As far as I am aware, [redacted] had one healthcare associated infection. That was the staph infection he contracted in February 2017. I have described the circumstances of that infection in more detail above. The physical impact of the infection meant [redacted] was tired. He was in bed a lot and he had the shakes initially. He wasn't great. If there were other physical effects on [redacted] then I couldn't really say because we didn't really know much about it at that time.

HAIs: communication

91. I have been asked what we were told about the staphylococcus infection which [redacted] contracted in February 2017. I never knew much about the 'staph' infection. The hospital just told us one time that [redacted] had a 'staph' infection in his line. That is all we were told. I remember it was the nurse that told us about the infection but said the source had not been identified. The doctor does a round in the morning and you get swabs taken. The doctor didn't go into any detail about it. He said "we'll do this and that" and that was about it basically. [redacted] was put on antibiotics at that point but I don't know what kind.

92. We were never told of the likely source of the staph infection. I honestly don't know where it came from. It could have been anything. From what we've heard about all the things that went on in there, we're never going to be told. It's one of things we've accepted; that we'll never know.

93. When [redacted] caught the parvovirus in March 2018 it was the same, we were never told how he picked it up. [redacted] was ill, he got antibiotics. He was really ill then and that delayed his chemotherapy then too.

PREVENTATIVE MEDICATION

Preventative medication: events

94. I have been asked whether [redacted] was given any preventative medications. I think that [redacted] was given preventative antibiotics although we were not told much about it at the time.

95. All of the child cancer patients are usually started with Septrin. Septrin is to stop the growth of bacteria or fungus in the lungs and to prevent pneumonia. [redacted] got that the first day he started treatment. They said all the kids were the same. He got that on a Friday or Saturday, once a week. I think that was protocol that they were put on that but [redacted] took a reaction. The Septrin was keeping his blood count down. They had to stop his chemo when that happened. The Septrin stopped, I think in January/February 2018. They put him onto a new one, Dapsone. I think that's to stop pneumonia but [redacted] took a reaction to that too. It badly affects a very few cases, and [redacted] was one of them. It turned him blue, it affects blood/oxygen levels, they go really low. I think he was on that for 3 or 4 weeks. He got that when he had the parvovirus in March 2018. He was then put on Atovaquone right up until March 2020 when he finished treatment. I think Atovaquone was to prevent bad chest infections. I thought they were to stop pneumonia developing in the lungs. [redacted] was then put back on Septrin in March 2020. It didn't matter if his counts were lowered, because for the next 3 months he still had to take Septrin.

96. At some point [redacted] was put on another drug called Ciprofloxacin (Cipro). I was told that Cipro was to "cover his line". I am not sure when [redacted] was first given

Cipro. I know he was taking it in 2018. I'm sure it was at the time when they started putting filters on the taps in the wards. I never even thought to keep note of it because we were just told the new medicine was part of the treatment for ALL. We didn't think anything of it at the time. [redacted] was always getting different medicines so we didn't question it. We shouldn't have to question his treatment. One of the doctors, Professor Gibson, at the clinic told us that he was getting the Cipro. We'd go to the pharmacy to get his monthly supply and it was just added into that. We weren't told anything more about it. It was just a new medication, an antibiotic. I'm sure I remember it was 'to cover the line'. [redacted] had his port in then, so we were told it was only for children with a line who got it. We were told kids without a line didn't need it. We were not told exactly what it was for. Other parents were talking and were concerned about it, that it was linked to the water. They had researched it so I did too. I discovered that it had side effects, sickness, heartburn, stomach pains.

97. [redacted] was on and off the Cipro until he finished treatment in March 2020. I don't know why he would have been off it from time to time. I have no idea. We weren't told.

Preventative medication: physical effects

98. I think the Cipro affected [redacted] physically. All the side effects have really affected him in the long term. [redacted] stopped his cancer treatment in March 2020 but he still goes monthly to clinic as an outpatient and is waiting for a gastro referral. He still has problems with his tummy and his legs. He usually goes monthly for check-ups and bloods to be done. I think that usually, treatment goes down from once a month for 3 months, then every 3 months, then 6 and then yearly but [redacted] has continued to be seen monthly because of his tummy problems. It's not unusual for them to get side-effects. I didn't question it. He still goes to physio for his legs too. The

issues with his legs might be linked to a toe injury that he had but I don't know.

99. [redacted] experienced really bad side-effects from the Cipro. They include sickness, bad heartburn, indigestion, sore tummies. He still has these side effects and is waiting for a gastro referral. We've never been given a reason for the side-effects. There hasn't been any investigation into that yet, not for the gastro team or about his legs. We don't really know if it is related to the Cipro or if it is just side-effects of treatment. However [redacted] did not have any of these issues until he started taking Cipro, it all began after that.

Preventative medication: communication

100. I think that we were told about the Cipro by a doctor, I cannot remember their name, during one of [redacted]'s out-patient appointments It was just one of his check-ups. I think we were told that [redacted] was getting it to cover his line.

101. At the time, we didn't put two and two together. Nobody told us about possible side-effects. We heard some things from other parents. I started to Google it. It was crazy. I found it out it was a prophylactic which was to stop infection caused by contaminated water supplies. Alarm bells started ringing. We did what were told and we didn't ask questions. I was scared of him catching something so I didn't want him to come off it. I was probably quite naïve about it. The other parents were maybe more switched on and then I started to wonder about it all. I didn't raise concerns personally but I know others did.

102. There were news reports about the water at the hospital, about patients contracting infections, patients being admitted to ICU and some patients dying from these infections. Parents were up-in-arms about the news stories. We wondered, 'what is going on?' I think it's crazy we got all this from the

news. We had to rely on the news stories when it was the Hospital that should have been telling us.

103. I felt it was mind-blowing, we still weren't being told everything, they were changing medicines but didn't tell us why. We got the feeling from some staff that they didn't know what to say but they were being sent in to tell us. We didn't know what to feel, we just knew what we saw on the news and it was scary. It was like nobody really wanted to tell us what was going on. It was horrible, scary, really scary.

104. Eventually we found out the children were on the new antibiotics because of the problems with the water. I think one of the doctors, Professor Gibson, who told us why they were on the new antibiotic (Cipro). It was because of the problems and the things we'd seen on the news, not what *they* the hospital had told us about. I think it must have been Professor Gibson who told us what they did share. We saw her a lot at that time. Unfortunately, I can't remember exactly when we were told that.

OTHER ISSUES RELATING TO HOSPITAL CONSTRUCTION

Hospital build issues: impact of construction works

105. I have been asked if I remember anything about construction works going on at the hospital.

106. It felt as if there was always works going on in the hospital. It got to the point that you were told not to use certain entrances. They were cordoned off for work being done. Even now, there's work being done. There is always scaffolding up somewhere. We were never told about it except when we just got a sheet of paper saying come in using a different entrance. The kids' entrances were shut so we had to use the adult entrances. I remember after the Grenfell fire one of the other parents told me that the hospital had the

same sort of cladding. That had to be changed. He was in the buildings industry and we were stood looking out of the windows as the building was surrounded in scaffolding.

107. The biggest impact came from work on the wards. There was work always going on in the wards too. I think that impacted our experience at the hospital. I think that was the reason [redacted] was sometimes put on other wards, not on ward 2A. I think it was around the end of 2017 into 2018 when I saw works going on in ward 2A. They would cordon off rooms. There was a wooden box being built around the doors and the rooms were completely emptied. Windows were blanked off so you couldn't see what was going on. Guys with big white suits would be there in ward 2A. Sometimes we would be moved out of a room because there was work going on. There were big orange plastic sheets that get zipped up, going up around the room.

108. I also saw similar work happen in happen in ward 6A in the adult hospital but I didn't see it anywhere else in the RHC, apart from ward 2A. At the end of 2019, they were still cordoning off rooms.

109. I think that we were impacted by these works. Sometimes we had to change rooms within ward 2A. Sometimes we were moved out of ward 2A and other times we were not put on ward 2A in the first place.

110. Ward 2A is one of smallest wards There are only 26 beds. Some are for patients like [redacted] who are not in strict isolation rooms. Three are for teenagers so they can't be used for patients like [redacted]. About 8 are strict isolation rooms That means 11 out of 26 rooms that can't be used for patients like [redacted]. When some are blocked off there are even fewer rooms available. They were working with so many fewer beds which then meant you had more chance of being put into another ward. Some of the other wards had about 40 beds. It doesn't bear thinking about what it was like.

111. We were given hardly any notice if we had to move. We were just told there and then. We would maybe be told we had to move within the hour. The nurses would come in and tell us we were moving. When you're in a room for a while, you've got lots of stuff with you like toys and books. We would have to pile it all onto the bed beside [redacted] and push the bed out into another room.

112. When we were moved I didn't know what was actually going on. It was funny because you just grew to accept what was going on. You didn't even think this wouldn't be going on in other hospitals. It was just normal. Is this what goes on, is it normal? Probably not.

113. Moving wards impacted [redacted]. He knew what it would be like in other wards; he hated it there. He didn't know anybody, it was horrible for him having to go. He was getting older and knew he wasn't safe in another ward. He'd be crying. It was hard. But we just had to go, that was it. The nurses would come in and tell us we had to move. A lot of the time they knew the kids would be upset by the move, but they'd been told by someone further up than them that we were moving. It happened quite a lot, quite frequently. Sometimes to another room in 2A or to another ward. There was never a reason given, sometimes we thought someone else needed the room more than us, we just didn't know why.

Hospital build issues: physical effects

114. I do not think there was much direct impact on [redacted]'s physical health as a result of the build issues. That impact was mainly because of his treatment. His mental health has definitely been affected.

115. I should maybe say that there was an incident that might be relevant though. He injured his toe and it wasn't taken seriously. He had weak legs and his legs collapsed one day when he was in the bathroom, he fell and hit his head and his toe. On numerous occasions I asked staff to look at it but they wouldn't. I was worried about it but staff would say it was fine and shrug it off. After that, he never walked again for 9 months and ended up in a wheelchair. His muscles wasted and his bones got so brittle, his bone density reduced. He needed calcium drawn into his bones and that hurt. He ended up on different medication to tackle that. All because he fell and hurt his toe. I took pictures, I ask myself why nothing was ever done about that toe.

CLEANLINESS

116. I would like to make some observations about cleanliness in the hospital. As far as cleaning goes, personally, I would take my own cleaning stuff in clean things myself, especially the bathroom. We always kept cleaning wipes in the hospital bag and I used them wherever I needed to, that was in all wards in the hospital. I would clean the table that [redacted] ate off and all the handles. The cleaner's mop just looked like a dirty mop. It had a really thick bleach smell. They'd mop your room with it and put it in the bucket then move to the next room I assumed. They were cleaning the rooms but it wasn't clean, I would say. The cleaning was exactly the same after the move to the adult hospital. Things would not be cleaned up until the next time they were due in. So, for example, if [redacted] got a blood transfusion, there would be blood spilt all over the floor, next to the bed and it could be left until the next day. Some of the kids don't like to see the blood so they would cover it when the blood was being given by a transfusion, the bag was covered. I didn't want to touch it either because it's blood.

OVERALL EMOTIONAL IMPACT ON [redacted] AND HIS FAMILY

Overall emotional impact on [redacted].

117. I have been asked to comment on the impact which the issues I have described above had on [redacted]. When we were in wards 3A, 3B and 3C, the other children's wards, the loss of the facilities had a big impact on [redacted]. We'd watch TV if it was working but sometimes the picture was upside down or it wasn't working at all. Sometimes the blinds weren't working and you couldn't see any daylight. You couldn't make it up.

118. As [redacted] got older, he started noticing more about what was going on with the taps. The emotional impact got worse as he got older. He would ask why he couldn't have a bath and why he needed to be washed with bottled water or to brush his teeth and so on. At times he stopped interacting with the staff, he was inside himself. He wouldn't laugh or smile, he wasn't like himself. It was really hard on him. I don't know if he'd seen the news or maybe even someone at school had said, 'that's the hospital you go to'.

119. It was funny because he never once asked if he was going to die of the cancer but he started asking if he'd die if he drank the water. It was crazy. He just wasn't himself. He was always worrying about things. Even now, I'd say he's a worrier. If we are out and about, he won't even use a tap in [redacted] hospital. We never had a problem with their water but he's taken that with him to other places, maybe even to school.

Overall emotional impact on witness

120. The experience affected me too. I found it hard and upsetting. I used to phone my mum and just cry because I just wanted to get out. It felt like prison and to see [redacted] like that meant I had to try and make it seem like less of a problem than it was, for [redacted]'s sake

121. I suffered greatly from anxiety throughout the whole thing. I was afraid of taking [redacted] in there. When I saw things in the news and read online articles, I would worry that he'd have a temperature spike. It's absolutely shocking.

122. I also have a sense of guilt. I put him in that water not knowing it unsafe to do so. It's hard, even now. After all this time, I still have that guilt. It's something I don't think I'll ever get over. I feel like I unknowingly put his life in danger, giving him the bath, brushing his teeth. It makes me feel physically sick. I don't think it will ever go away.

123. I was affected by seeing these kids dying. I feel like we never should have been put in that hospital. You think having a child with cancer is the worst, well imagine having him in that hospital. You think that the cancer is going to kill him but to think that it could be the water, it's just crazy. It makes me really angry. I feel like these people should have been the good guys looking after him and they weren't telling us. There were kids not going home. My mind doesn't want to go there anymore, it was so dangerous without us even knowing, we never knew. Putting [redacted]'s life at risk every time he had a bath or brushed his teeth. It was like dodging bullets all the time.

Overall emotional impact on family members

124. My partner, Graeme, was diagnosed with depression, and is on medication still to this day. He saw me having anxiety about going in there and he was the one trying to stay strong for everyone. The man's got to be the strong person. It affected him as well. He tried to keep it together. It's men's mental health, it's not really spoken about. The mental health person at our GP practice diagnosed him with depression.

125. [redacted]'s brother and sister were not affected too much. They are younger than

[redacted] so not much impacted on them. They were with Graeme at the time. Obviously they saw us going through stress. They'd get passed around a lot, between my Mum and Graeme's Mum. I think they were young enough to be quite resilient to it all. My younger son, he wasn't even 1 year old then and my daughter was still able to go to school and keep her after school activities going.

COMMUNICATION: GENERAL

126. I think the communication about [redacted]'s treatment was actually okay. We knew what was going on and what was next on the protocols. We always knew what should be coming next so were quite happy with that aspect.

127. Communication about other things that were happening at the hospital was really just poor, non-existent. The communication about issues with the hospital and the water was really poor. Why were we even in that hospital?

128. During the time when there was a lot of news reports and when parents were speaking out about their concerns, I remember that there was a meeting hosted by Jeane Freeman, who was the Health Minister at the time. I didn't arrange the meeting personally, I think one of the other parents did and I was able to attend along with other parents. I think it was in 2019 in a big Glasgow hotel. I went to that meeting. She made out as if she was really shocked about what was happening but later we found out she already knew about all the problems. All the parents were there. It was like a big circle time with the parents. She said she didn't know about the issues. These things were all going on and we didn't know anything. Jeane Freeman came across as if she'd never known but we found out later that she already knew all about the problems. To be honest, we just came out of that meeting feeling even angrier, and the same with the meetings with people in the hospital.

129. Shortly after that I went to a meeting with the Labour MSP Anas Sarwar. It was a group of parents who were concerned about what was being reported in the news, and who had concerns about the hospital. The purpose of the meeting was so we could tell him about our concerns, and he said he would bring it up in Parliament for us. He did raise our concerns in Parliament, I saw it on the TV a few times, on the news.

130. We met higher up people in the hospital too. I think it was the Health Board. It was a panel of people and we could ask questions. [redacted] was an inpatient in ward 6A at the time. It was held in the university part of the hospital so we went down there. It would have been 2018. It could get quite heated and some parents got upset that their kids were on these preventative medicines. All they could say was 'we're sorry'.

131. At the meeting with the Health Board, it felt like they came armed with spreadsheets. They had a PowerPoint, to go through this and that. They couldn't really answer the question, not about *why* it had happened. It felt like it was just them just saying sorry, they can't really answer the questions. They told us *nothing* about *why* it happened. They told us things about the building of the hospital, water supply, ventilation and all that kind of stuff. I didn't understand a lot of the stuff about building's construction. It was well over my head. I think unless you were a builder you probably wouldn't have understood; some of the parents did though.

132. I feel that the communication about what was happening with the hospital should have been a lot better. When this was all in the news, I feel they should have spoken to us. Someone who knew what was going on should have told us about it. I feel that even the nurses didn't understand what was going on. They didn't know what to say. When it was going on those higher up in senior management in the hospital, or those on the health board should

have told us exactly what was going on instead of them lying about what was going on with water and ventilation and covering it up. We just never knew. That stress felt as stressful as your child having cancer. They made out that they didn't know; that there was nothing wrong and we were just not to use the water. I felt the medical staff didn't always know what was going on with the water and ventilation.

133. I do not feel communication has changed that much. The hospital have set up a Facebook page and a help board there. It goes directly to the hospital. One of the men whose daughter's in the Ward is good at going forward with anybody's concerns, John Cuddihy. If there's anything going on, he'll take it forward.

134. I'm a member of the Facebook group. You get a lot of information from it, especially as an outpatient. Like when they expect ward 2A to re-open. Parents can ask questions but I'm not sure who replies. To my knowledge it's from NHS GGC, Haematology. I've not asked any questions but have seen other people's questions and read the responses. The Facebook group is a positive thing, definitely. For example some complaints about the food have been taken on and they've introduced a lunch cart with wraps, snacks and things, so really helpful for things like that.

135. The hospital still hasn't really told us things about the building. They direct us to reports, to see the findings and things like that. Professor White has been involved. I haven't had direct contact with him but concerns are made like a collective group on email. He'll get back to them. I'm not sure if that's done through the Facebook page. I really don't know if that kind of contact has improved.

136. The press coverage affected me greatly. I would also see things on Facebook. I'm on the STV news link. It's scary hearing about kids dying.

Loads of people comment saying ‘this is all fake’. You could reply saying it isn’t fake but they’d just think we’re overprotective parents. If they were in the position we are, they’d be exactly the same. It felt like it was never off the news at one stage. It’s hard reading it and stuff on TV as well.

137. It can feel like there’s something new in the press all the time, like the pigeon droppings. It felt like we were living a joke and were getting no answers from anybody except from the news. I never heard anything from the hospital before it was in the news. The first I heard was on the news and then we started seeing things happening, like when we started seeing the water coolers disappearing and the tap filters.

138. I think communication in relation to the staph infection, the water issues and the move from ward 2A could all have been better. I think communication is better now that it was. Now we are not there as much, we are not in throes of the treatment and we don’t need as much communication with the hospital. What we’ve got is sufficient for us. I cannot speak for people that are going through treatment now.

COMPLAINTS

139. I did not make any complaints to the hospital. I was scared. These people were saving your child’s life. At the end of the day, you just take it and that’s it. I would not want to compromise care in any way. It was one of the hardest bits, not knowing what was going on. You didn’t want to feel like they were keeping things from you. These were people that we trusted with my child’s life, I didn’t want to think they were keeping things from you that they shouldn’t have been.

OVERSIGHT BOARD / CASE NOTE REVIEW / REPRESENTATIVE GROUPS

140. I have heard about the Oversight Board but haven't been part of it. I'm not part of any family representative groups either but I am a member of the Facebook group.

141. [redacted] was not included in the Case Note Review. I do not think we will ever know what caused the staph infection.

CONCLUDING COMMENTS

142. If someone asked me if I wanted to go to that hospital over any other one, I was say absolutely not. If we could be finished and done with that hospital forever and I never needed to step foot in it again that would be the best case scenario for me and for [redacted].

143. It is described as a "super hospital". I don't see any kind of resemblance to a super hospital there. The staff, you could not fault them in the slightest. But the problems that happened at the hospital, it doesn't bear thinking about. Even just talking about it, it is not nice opening up those memories and remembering what actually went on at the time and the fears you had. I don't think it is fit for purpose and it should never have been opened.

144. I feel that the Health Board and hospital management lied to us. They made things a million times worse when they didn't need to. They could have told us what was going on and just been honest. I would rather they were honest. I was shocked at what I heard, but I would have been better knowing that I had been told the truth rather than sitting there not knowing anything, and being told nothing. I would rather have had the truth and dealt with it, and not them covering things up and not telling anyone anything.

145. I have ongoing concerns about the safety in the hospital. In Ward 6A they are still zipping up and sealing off rooms. They still have filters on the taps. We are not in the hospital much anymore especially up in the ward, but if I am in there I still wouldn't use the water even if they told me it was safe. They told me it was safe in 2017.

146. I really don't know how they could make us feel any different about the concerns I still have. It may be different for new patients and families who have not gone through all this. They might believe them more. But I was there at the time and I don't think they can do anything to make me feel any better now. I don't believe anything that was said, so I still would not use the water. I would still be wiping [redacted] down to get him washed because I have absolutely no trust in that place at all. It is scary to think that is a children's hospital. It is somewhere that you are supposed to feel safe. It is somewhere you are supposed to go to get better.

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

APPENDIX 1 – SB/01 – Timeline

2016 /2017

30.12.16 - 21.2.17 - ward 2A inpatient

2017

14.03.17 outpatient ward 2B

21.02.17 outpatient ward 2B

22.02.17 - 05.03.17 - ward 2A inpatient

07.03.17 outpatient ward 2B

10.03.17 outpatient ward 2B

05.04.17 outpatient ward 2B

11.04.17 outpatient ward 2B

19.04.17 outpatient ward 2B

02.05.17 outpatient ward 2B

19.05.17 - 22.05.17 - Ward 3 A,B,C inpatient

21.03 17 outpatient ward 2B

28.03.17 outpatient ward 2B

09.04.17 outpatient ward 2B

25.04.17 outpatient ward 2B

15.05.17 outpatient ward 2B

25.05.17 outpatient ward 2B

31.05.17 outpatient ward 2B

07.06.17 outpatient ward 2B

12.06.17 - 13.06.17 ward 2A inpatient

20.06.17 outpatient 2B

22.06.17 - 28.06.17 ward 2A inpatient

03.07.17 outpatient 2B

11.07.17 outpatient 2B

18.07.17 outpatient 2B

27.07.17 outpatient 2B

08.08.17 - 10.08.17 Ward 1E/1A inpatient

08.08.17 outpatient 2B

22.08.17 hydropool

01.09.17 outpatient 2B

11.10.17 outpatient 2B

28.10.17 - 31.10.17 ward 2A inpatient

14.11.17 - outpatient ward 2B

14.11.17 - 15.11.17 ward 2A inpatient

16.11.17 - 18.11.17 ward 2A inpatient

20.11.17 - 24.11.17 ward 2A inpatient

06.12.17 - 09.12.17 Ward 1E/1A inpatient

11.12.17 - 13.12.17 CDU admission - inpatient

12.12.17 - 14.12.17 Ward 3 A,B,C inpatient

2018:

09.01.18 outpatient 2B

06.02.18 outpatient 2B

27.02.18 outpatient 2B

27.02 18 hydropool

17.03.18 outpatient 2B

18.03.18 - 20.03.18 Ward 3 A,B,C inpatient

21.03.18 - 24.03.18 - Ward 3 A,B,C inpatient

21.03.18 outpatient 2B

24.03.18 - 06.04.18 ward 2A inpatient

13.05.18 - 15.05.18 Ward 3 A,B,C inpatient

20.05.18 - 22.05.18 Ward 3 A,B,C inpatient

29.05.18 outpatient 2B

31.05.18 outpatient 2B

19.06.18 - 21.06.18 ward 2A inpatient

03.08.18 - 07.08.18 ward 2A inpatient

08.08.17 hydropool

31.08.18 - 04.09.18 ward 2A inpatient

31.08.18 outpatient 2B

02.10.18 outpatient 6A

10.10.18 outpatient 6A

30.10.18 - 05.11.18 Ward 6A inpatient

13.11.18 outpatient 6A

<u>2019</u>

26.03.19 outpatient ward 6A

27.03.19 outpatient ward 6A

03.04.19 outpatient ward 6A

23.04.19 - 25.04.19 Ward 6A inpatient

28.05.19 outpatient ward 6A

06.06.19 - 10.06.19 Ward 6A inpatient

18.09.20 outpatient ward 6A

01.11.19 - 04.11.19 Ward 6A inpatient

18.11.19 outpatient ward 6A

10.12.19 outpatient 6A

16.12.19 outpatient 6A

2020

08.01.20 outpatient ward 6A

20.02.20 outpatient ward 6A