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.