SCOTTISH HOSPITALS INQUIRY

Hearing Commencing
20 September 2021

Bundle 5 – Witness Statements for Week commencing 4 October 2021

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Scottish Hospitals Inquiry

Witness Statement of

Denise Gallagher

WITNESS DETAILS

1. My name is Denise Gallagher. I was born on [redacted]. I am [redacted] years old. I am employed as an Advanced Nurse Practitioner [redacted].

2. I am the mother of [redacted] who is 11 years old. He was born on [redacted]. I have a daughter, [redacted], who is [redacted] years old.

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

OVERVIEW

4. [redacted] was diagnosed with Chronic Myeloid Leukaemia (CML) in May 2018 when he was eight years old. There are three phases of CML. The initial phase is where leukaemia is present in the blood. The middle phase, or accelerated phase, is where the body doesn't make useful blood cells and there are more immature white blood cells, called blast cells, being developed than mature ones, so the leukaemia becomes more prominent. The third phase is called blast crisis, and this is where the body is in overdrive and is treated as an Acute Myeloid Leukaemia (AML). This is where there are more blast cells in the body and the myeloid sarcoma comes about when the bone marrow gets squashed out and the blast cells take over. The body is then just full of myeloid cells. That's what the tumour found on [redacted]'s leg was. I will talk about that later.

5. [redacted] was treated at the Royal Hospital for Children (RHC) and the Queen Elizabeth University Hospital (QEUH), Glasgow, between May 2018 and March 2020, when he finished his treatment. He attended at both hospitals as an in-patient and an out-patient between these times. I have been asked to provide details of issues that I encountered at both hospitals when [redacted] was treated. Since March 2020 [redacted] has attended reviews mainly over the phone and occasionally in person at the hospital.

6. [redacted] spent time in wards 2A and 2B of the RHC, which is known as the Schiehallion Unit, which treats children with blood cancer. [redacted] attended there between May 2018 and August 2018. During that time, he was briefly in ward 3A for his central line to get put in and ward 3B after his appendectomy. In October 2018 [redacted] also spent time on ward 4B of the adult hospital at the QEUH, where he had a stem cell transplant. Following the closure of the Schiehallion Unit later in 2018, [redacted] was treated on ward 6A of the QEUH which was where the Schiehallion Unit had moved to. In between [redacted]'s chemotherapy and transplant, and when he was discharged after his transplant, he went to day care as an out-patient, quite a lot. I stayed with [redacted] during most of his admissions at the QEUH, as an in-patient and an out-patient. My husband, James, stayed at home with our daughter [redacted] when [redacted] was in ward 4.

7. There are specific events and issues that I would like to mention. Some of these are in relation to domestic staff and the cleaning, frequent room moves related to drainage and ventilation, water, sewage smells and poor communication. [redacted]contracted a gram-negative infection, stenotrophomonas, in September 2018. This was just after he had undergone an appendectomy to remove his appendix. There were issues with the water when [redacted] attended both hospitals. He was also prescribed preventative antibiotics in 2018, which I was told was due to 'environmental

issues'. I will talk about these events in more detail later. I have provided the Inquiry with a timeline showing the dates on which [redacted] attended hospital and the wards where he was treated. The timeline is attached to this statement (DG/01 – appendix 1) and I confirm that it is accurate to the best of my recollection.

<u>FAMILY BACKGROUND</u>

8. [redacted] is in [redacted] at [redacted]. He was in [redacted] when he was first admitted to hospital. [redacted] loves school and he's happy when he can spend time with his friends. He also loves his food; he's actually been worse since his transplant. [redacted] eats me out of house and home. He's on the autistic spectrum and he has been assessed as being about two years in front of his peers. He was tested straight after his transplant and this had slowed down to one year but he's still in advanced classes for maths and reading. He likes to correct the teacher and that can lead to very interesting conversations. He likes to stand up for himself if he thinks something's wrong. Because of his autism, [redacted] thinks everybody is his friend. Sometimes he can be quite outgoing depending on his mood, but when he's anxious, he'll become quiet or he can become quite verbal, it just depends on the situation. [redacted]'s been seen a couple of times by a psychologist because of the transplant situation as he was suffering very badly from anxiety, but we don't know if that was related to lockdown or to the hospital treatment.

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

Admission to Royal Hospital for Children: May 2018

9. In late March 2018, [redacted] started to complain of having a sore left knee. He was kind of limping. Progressively, he started having difficulty walking. He had no visible injuries, so I gave him painkillers. I took [redacted] to the local Accident and Emergency Department at Forth Valley Hospital,[redacted]. The Consultant deemed that [redacted]'s knee was okay because he was partially walking on his leg. On 20 April 2018, I took [redacted] back to the hospital because he wasn't walking at all, he was non-weight bearing and his thigh was much bigger. One of[redacted] x-rayed him and found a sarcoma, which is a large tumour, at the base of his femur (thigh bone) on his left leg. [redacted] spoke directly with Mr Duncan in the Royal Hospital for Children, who is an orthopaedic specialist. At that time they thought it was a bone tumour. Mr Duncan agreed to see [redacted] on 23 April 2018 at the RHC, where [redacted] was given an MRI scan. The next day, [redacted] attended ward 1, day surgery unit, for a biopsy of his femur bone and some bloods.

10. From then until 13 May 2018, we waited on the results at home and then on 14 May 2018 [redacted] was admitted to ward 3A at the RHC for surgery to have his Hickman or central line placement, as part of his treatment plan for the bone tumour. He was only there overnight, but during that admittance we met with Dr Chaudhry, who became [redacted]'s consultant, who said they were struggling to find the type of cancer that he had. The results were not coming back classically as a sarcoma, as his bloods were off as well. Dr Chaudhry said they were wondering if [redacted] had some kind of haematological cancer rather than a bone cancer.

11. We then remained at home, just going in and out to day care on Ward 2B for bloods and assessments until 23 May 2018, when the hospital confirmed that [redacted] had Chronic Myeloid Leukaemia (CML) and he had a myeloid sarcoma

in his femur, which is why he had the growth. He was also in a ‘blast crisis’ with Acute Myeloid Leukaemia (AML) which meant he had rapidly deteriorated in a short space of time and that had to be treated.

Treatment and experience on ward 2A: May 2018 to August 2018

12. On 23 May 2018 [redacted] was admitted to ward 2A, the Schiehallion ward, where he started his chemotherapy on 25 May 2018. [redacted] received quite intense chemotherapy for five or six weeks. Because of the type of chemotherapy they gave [redacted], he had an extended period of neutropenia. The normal length of time for blood levels to return is three to four weeks but [redacted] was beyond day 40, which is considered a prolonged neutropenic episode. This was due to the kind of chemotherapy they gave [redacted], as the hospital wanted to hit the cancer hard to get him into remission very quickly. He stayed in ward 2A until mid-July 2018 when everything had settled down.

13. When [redacted] was admitted to ward 2A, he was put into room 1, behind the nurses’ station. That’s the room where kids who are getting inducted are put, so they are closer to the staff for observation. [redacted] stayed in that room for a week or so, during the first courses of his chemotherapy, then he got moved to room 15. He was there for a couple of days but Professor Gibson, the consultant, was quite unhappy because [redacted] was still in the general ward instead of being in strict isolation, so he got moved to room 20. [redacted] stayed in room 20 for four or five weeks and while he was there he had several temperature spikes. It’s quite normal for people when they have prolonged neutropenia to have spikes in temperature because their neutrophils are trying to return, but the one of note during that admission, was on 7 July 2018,[redacted].

14. This was one of the worst times I’d seen [redacted] during all of his treatment. He was already on four antibiotics at that time to protect him from all the temperature spikes. The antibiotics he was on were meropenem, gentamicin

and vancomycin. He was on another one, casprofungin which is an anti-fungal antibiotic used to prevent any fungal infections. The hospital gave that to [redacted] during his chemotherapy to protect him. The meropenem was the first antibiotic he was on for a fever while he was neutropenic. He then was given vancomycin because he had spiked a temperature and he was on gentamicin, which again was related to the neutropenic fevers. All these antibiotics were given to [redacted] through his Hickman line.

15. That afternoon [redacted] got shivery and cold and rigored and got a worsening red rash on his body. This started just after he had finished or had just started an antibiotic fluid through his line. [redacted] was getting quite stressed so I called for the nurse. She checked his temperature, and then the Advanced Nurse Practitioner (ANP) and the Doctor came in to see [redacted] as well.

16. Doctor Cousins, one of the doctors on ward 2A, wanted to give [redacted] more antibiotics through his line but I told him that I didn’t think it was in [redacted]’s best interests because he was already on four different antibiotics. I didn’t think adding anything else to the line would have made any difference. I wanted them to give the line a rest as I felt we should be treating what was happening to [redacted] and hold off and see what transpired. The nurse said this is what they would normally do and the ANP agreed that we shouldn’t put anything else into the line.

17. The Doctor was unhappy; however, he did accept the views of the nurse and the ANP to give the line a rest and things started to settle down. The next day Professor Gibson also agreed about giving the line a rest and cut back the antibiotics. Once they had given the line a rest and stopped using it for a time, [redacted] then recovered very quickly.

18. With the red rash that [redacted] had developed, the hospital staff wondered if he had ‘red man syndrome’ which is a side effect of the vancomycin antibiotic. At that point it was mentioned that [redacted] might possibly have measles so the

Charge Nurse decided to take [redacted] out the isolation room, which was a ventilated room, as they were worried that if it was measles, the ventilation system could pass the infection around the ward. They put him in room 10 but a dermatologist had a look at [redacted] and said it looked more like a drug reaction rather than measles as there were no active cases of measles in Scotland at that time.

19. [redacted] stayed in room 10 for about a week and then got moved back to room 15 again for a couple of days. That was just for supervision and recovery because sometimes we had to leave him alone, more at night, to look after my daughter, [redacted]. They also were making plans for his next course of chemotherapy. There had been no fixed date for his transplant but he had been supposed to get it around September time, but because of the prolonged recovery time after the first cycle, they assumed the second cycle might be long too so they changed the transplant date. They wanted to arrange it in such a way that he would come in for his chemotherapy and then once he went into remission they wanted to act fast to get his transplant done.

20. [redacted] was then discharged home for a few days and around the start of August 2018, I don’t know the exact date. He was admitted back to ward 2A for his next cycle of chemotherapy. He was put straight into isolation, in room 24. He wasn’t eating much at that point because he started to get a sore gut, so we were force feeding him fluids all the time. The staff were concerned about his weight loss and they agreed to put him on TPN which is total parenteral nutrition, to support him. TPN is where they give someone electrolytes and nutrients, such as salts and fats, through the central line, as opposed to feeding the person orally.

21. [redacted] stayed in room 24 for three to four weeks. During this period, there was a lot of deep cleaning of rooms in the ward and they were also doing drain

cleaning. That was when [redacted] was moved to room 23 for about four or five days before he moved back to room 24. [redacted] was still on the TPN and getting antibiotics for fevers.

22. That was around the time my mum stayed in the hospital with [redacted] to let me and my husband take our daughter to school, as she was starting primary 1. That was the only time someone else was allowed in to sit with [redacted] when he was in isolation.

Appendectomy and stenotrophomonas infection: wards 2A & 3A, August 2018 - September 2018

23. Towards the end of [redacted]'s second course of chemotherapy, at the end of August 2018, he started complaining more and more of a sore tummy and was having high temperatures again. They seemed to subside, so he was discharged home for a few days, but he started to develop more pains so we took him back to hospital and he was admitted back into ward 2A room 10 on the 6th or 7th of September 2018.

24. I had a feel of his stomach and thought it could be appendicitis. Professor Gibson thought that might be a possibility because of [redacted]'s temperatures and blood counts so she gave him growth stimulating hormones to boost his neutrophils. They then did an ultrasound and found slight evidence of appendicitis. I didn't know if the inflammation was related to the chemotherapy but Professor Gibson was keen to remove his appendix as she thought that [redacted] may have possibly had early stages of appendicitis.

25. [redacted] got moved to room 10 or 11 while they decided what they were going to do about his appendix or his stomach pain. [redacted] had recovered in terms of his blood counts but the hospital wanted to get to the bottom of his abdominal pain. He was still getting antibiotics and we were waiting for a plan

for him to get his transplant because it was all to do with the timings. We were preparing for [redacted] to get his transplant at some point in September 2018.

26. [redacted] still had his central line in situ and we didn't know what was going on. He was seen by Professor Gibson and his bloods showed that he had some kind of infection, but they were still waiting on culture results and Professor Gibson thought that he probably needed his appendix out. The surgeons were not keen as they didn't think it was a surgical issue but Professor Gibson had a chat with us about the risk of infection during the transplant so we wanted to get the appendix out so that it was one more thing off the list. I wanted [redacted] to have the appendectomy as we needed to put him in the best position to receive the transplant.

27. [redacted] got his appendix out on 8 September 2018 and he was transferred to ward 3A because the Schiehallion ward couldn't look after him as they were not surgically trained to look after [redacted] during the night post-surgery.

28. After [redacted] had his appendix surgery and was in ward 3A, his consultant, Doctor Pinto, advised me that [redacted] had a gram-negative infection in his blood cultures. I asked what that meant and he just explained that it was his appendicitis. That's how he put it to me. Looking back, I suppose you could expect that because appendicitis is a kind of bacterium.

29. It wasn't until [redacted] was moved back to room 1 in ward 2A, later on that day, that the Advanced Nurse Practitioner came in and told me that [redacted] had a stenotrophomonas blood infection and the likely source was the central line. [redacted]'s post-op surgeon also told me that [redacted]'s appendix looked perfectly normal to him. "Lily white" were his words. I was a little bit peeved to say the least, thinking that [redacted] had been to theatre to have his appendix removed unnecessarily and also that they had left the line in, which was the source of the infection.

30. [redacted] stayed in room 1 in ward 2A until 11 September 2018, when he had surgery to remove his central line. He then moved to room 14 or 15 because he wasn't too unwell by then. He didn't need any intensive treatment.

31. Bacteria can attach itself to the plastic tube and although [redacted]'s line had been taken out, he still had to get IV antibiotics to treat the infections in case there was any other break off or anything else in his body. Break off can happen if there is any bacteria on the tube itself and, when the tube is removed, this bacteria can be dislodged and get into the bloodstream.

32. [redacted] then had several days of cannulas to get IV antibiotics into him to cover him for the line removal. The staff tried several times to get the cannulas into him and there were several fails, which was quite traumatic for him. It got to a point that I asked if they couldn't get a line into him then could they not transfer him to oral antibiotics and I could look after him at home. They agreed and for a few days we could take [redacted] home during the day for a few hours in the afternoon but he had to go back at night time to get his antibiotics. There was a lot of to-ing and fro-ing because my daughter was at school then.

33. When the hospital agreed the plan of oral antibiotics and [redacted] was discharged in the afternoons, the consultant went through [redacted]'s checklist and he said that [redacted] didn't need to be on the posaconazole because he wasn't in the hospital environment. They kept him on the ciprofloxacin because of the fungal and line infections that were going about. [redacted] was also discharged on co-trimoxazole which was sensitive to stenotrophomonas.

34. [redacted] was fully discharged on 15 or 16 September 2018 and attended a day care appointment at ward 2B on 20 September 2018, to get his blood checked in preparation for his transplant. The hospital wanted to delay his transplant for three weeks in order to give his system a chance to recover from the chemotherapy and to let his appendectomy wound heal.

35. At the end of September 2018 [redacted] had a scan at the end of his chemotherapy. He had a PET scan to check the level of disease in his body. It's like a CT scan where you get radiated and it lets you see where active hot spots are located. Doctor Chaudhry did the scan to complete [redacted]'s treatment and it showed a hot spot, which came as a complete surprise. The hot spot was at the base of his tibia and he got a bone marrow biopsy. It was negative and Doctor Chaudhry said it was likely due to the trauma of the infection. This resulted in a two week delay to [redacted]'s transplant, which he was meant to get on 16 October 2018, but which was postponed until 29 October 2018.

Transplant in ward 4B and admission to ward 6A, Adult hospital: October 2018 to December 2018

36. On 29 October 2018, [redacted] was admitted to ward 4B in the adult hospital, to start conditioning for his transplant. He got his transplant on 8 November 2018 and he stayed there until 4 December 2018 when the hospital allowed us to take [redacted] to Marion House, which is the CLIC Sargent house across the road. It's a place to stay for children with cancer and their families. We had literally only just got there when [redacted] became unwell again. He was hot and shivery, which can be quite common post-transplant. We ended up back in the hospital that same night. We went to ward 4B but the ward had already used [redacted]'s bed.

37. There's such a high demand for transplant rooms because they can't do any treatments to a child until they know they have a secure place, but because [redacted] had recovered well enough he was put up to ward 6A. He got put into a day-care room because they had no ward rooms left. It was a side room but it was part of the day-care unit, they had just extended it and they put an air filter in his room. The staff deemed it was probably graft versus host

disease on his skin because he had bright red, scarlet rash and he had a fever, so they thought it was a reaction that's common after a transplant. [redacted] stayed in 6A for a week or so as he had to get weaned off the IV steroids and on to oral.

38. When [redacted] had the red rash across his body, an infectious diseases doctor and a dermatology consultant came to see him because they were so concerned. I don't remember their names but the infectious diseases doctor said that she was quite confident that it was a drug reaction rash, maybe secondary to the 'red man syndrome'. The dermatologist agreed and they started [redacted] on some topical steroids and creams to moisturise his skin and stop it peeling off.

39. [redacted] was discharged from 6A around 8 December 2018 and he attended a day care appointment back on ward 6A on 11 December 2018 and a bone marrow test on 18 December 2018. The day care on 6A is at the end of the ward so if you come in with a fever you have to go past everybody in the ward.

Re-admission to ward 6A: December 2018 – January 2019

40. [redacted] was re-admitted with a fever, to ward 6A, on 30 December 2018. That's when they found he had a line infection and a staphylococcus epidermidis, which is a skin infection. They gave him a course of oral antibiotics and removed the line in surgery. [redacted] stayed there until 6 January 2019

Admissions to ward 6 and ward 3B: January 2019 – February 2020

41. After [redacted] was discharged on 6 January 2019, he still attended day care on ward 6, two or three times a week. That continued for three months and he

was re-started on his oral chemotherapy for the remainder of the year. CML is very rare in children, it's more an adult's disease, so they were following the adults' protocol and guidelines. [redacted] also got immunoglobulin therapy (IGG) to support his immune system because he had an unrelated donor and they had to wipe out his whole viral memory and immune system. After that, it was changed to a monthly appointment system throughout the rest of the year.

42. [redacted] was admitted on three occasions during 2019 and the start of 2020, when he had temperature spikes. The last was in February 2020 when he had adenovirus. That was when he was admitted to ward 3B which was an orthopaedic ward that had a special ventilation room. This was because any time that [redacted] was admitted, he had to be in the Schiehallion or a ward with a special ventilation room. I don't have the other exact dates but I know he was admitted to ward 6A in May or June 2019 for five days or a week. It was always that length of time. Since then [redacted] has been at home and presently gets reviews mostly by phone and occasionally gets hospital appointments to attend in person.

Experience on wards 2A, 3A and 6A: May 2018 to January 2019

43. [redacted] was 8 years old when he was in ward 2A. He wasn't interested in playing with the kids toys in the playroom but he was too young to use the teenage room so he pretty much stayed in his room playing the x-box or the PlayStation because there was nowhere else for him to go. When his sister [redacted] came to see him, there was nowhere else for them to play with each other, apart from the room. The play team tried to facilitate as much as they

could, but they were also catering for the younger kids and the teenagers had their own environment. I would say [redacted]'s age group was neglected, there was nothing for them.

44. There are different types of rooms in ward 2A and [redacted] was in several of them. When we first went into ward 2A, [redacted] was in room 1, next to the nurses' station. They put all the kids close to the nurses' station when they first go on so they're closer to the staff for observation. This was just a normal room with the bed and an en-suite bathroom and shower. He was also in rooms 10 and 15 mainly when he was not in isolation. These again are just normal rooms.

45. [redacted] was also in rooms 20, 23 and 24. Rooms 23 and 24 are specialist transplant rooms and are for patients who are receiving transplants from someone they are related to. These kids they don't need quite as intensive chemotherapy as the kids who are receiving transplants from anonymous donors unrelated to them. Rooms 23 and 24 have a different ventilation system to room 20. Rooms 18, 19 and 20 are specialist bone marrow transplant rooms. This means they have different filters compared to all the other rooms. These rooms have to be super-clean environments because when these kids are in their neutropenic stage they are knocking everything out the kids' systems and anything could hurt them. That's why there is constant movement to make sure the right people are in the right rooms.

46. The normal rooms had a sink in the room with [redacted] and then there was a sink in the bathroom. If [redacted] was in a specialist isolation room, there would be the sink in the outside room, a sink in [redacted]'s room and a sink in the bathroom. All the taps had filters on them.

47. You had the parent's room to use but it was often used by the nursing staff and auxiliaries making their tea or having their tea break. It was quite good

having it there though and you had a fridge and a microwave to make yourself something to eat

48. There was a marked difference in the facilities between ward 2A and wards 6A and 4B. The facilities for the parents were better in 2A. You had a better general area to meet and chat and the kids had more space. [redacted] didn't have very many facilities in 2A, but there was more afforded to him there than 6A and 4B. I was grateful to have access to a kitchen to make something to eat and drink. I didn't like not having access to get a drink of milk for [redacted] because I like to get it myself rather than having to get someone to serve you. I think that would have loaded extra work onto the nursing staff because kids can be very fussy. If you gave [redacted] something he didn't like then you'd have to call the nurse to change what they're giving you, whereas if you know what your kid likes you can prepare it yourself. Having a lack of facilities just added to the workload.

49. In ward 2A, if you'd had a bad day, you had the luxury of coming out the room for a bit of fresh air or just a breather to get out. [redacted] was stuck in there for long periods of time and computer games became his escape. The fact that [redacted] is autistic and he had a computer game meant that he could disappear into that. Occasionally when the tellies broke down it was a bit of a problem. [redacted] used to like watching YouTube, but it was a problem trying to manage that when the tellies broke. We were in the fortunate position that [redacted] had a tablet so when something wasn't working we could give him that to take its place.

50. The TVs broke down most of the time in wards 2A and 6A. [redacted] was given a loan of a Play Station and he bought a couple of computer games as we had a computer system for him. We also bought a telly and a DVD player for when he went into transplant (ward 4) because I was aware that the tellies

there were also a bit dodgy. When you have a child who is autistic you have to have an arsenal to get through things.

51. I couldn't say what the facilities were like in ward 3A, when we were in there after [redacted]'s appendectomy, because I stayed with [redacted] all the time but we did have access to the kitchen which was shared with staff. There were no facilities on ward 4 because there were three rooms for kids getting a transplant so we had to live within the room. Occasionally when [redacted] was getting schooled, there was a quiet room at the end of the corridor, where I could sit for a short period of time. I could put food in the fridge for [redacted] and we were offered meals off the trolley but there were no other facilities there, nowhere else to go or anything to do.

52. In 6A we weren't allowed to leave the room and there were no parent facilities. I had to ask for water as I couldn't help myself because we were in isolation and you couldn't enter the kitchen as it was a ward kitchen which meant that it was for the patients but only the staff could enter it.

53. We began to love ward 2A because it became our home for so long. You know the staff, you know how the processes work and you know what you can get. It was a different environment for [redacted], going to ward 4B for his transplant, but they were very accommodating in letting him go down to see his room. He didn't know the ward but it was the same nursing staff, so that helped [redacted] settle down because every time there was a new member of staff it took him a long time to get to know them and he wouldn't talk to them or tell them if there was anything wrong. The fact that he had the same nursing staff that knew him made us very appreciative. The only thing was that it was very isolating because you were in your room and there was nowhere to go and speak to anybody. The ward seemed more organised and much calmer. The ward sister and all the staff were very approachable and

helpful. Wards 2 and 6 were always very busy with people running about so ward 4 was night and day in that respect.

WATER: EVENTS INVOLVING WATER SYSTEMS

54. From the outset of being in the Schiehallion unit in May 2018, we were advised to use bottled water for drinking. I knew not to drink water from the taps and only to use bottled water. I assumed it was for cleanliness and maybe because we were sharing cups. It was probably the auxiliaries or the carers that told us to use the bottled water that was provided on the ward. Sometimes there wasn't any water on the ward and I had to go down to the shop to buy some. I got into the habit of having a case of water in the car. A Doctor, probably Sarah, an American Doctor, once said to me to only use the taps with the filters but the taps in [redacted]'s rooms all had filters on them and the shower. The only place that didn't have filters was the actual bathroom. I just assumed that the taps had filters as part of the environment or to keep the place safe. We were quite ignorant to all the things that had happened in the previous years. We were focussing on the moment; we didn't know anything else about what was going on at the time.

55. In most of the rooms that [redacted] stayed in ward 2A, the water from the shower would spread out over the floor and sometimes you had to put towels down to stop the water from spilling out the room. In room 24, the shower used to fill up quite a lot to the point where [redacted] would be standing in the water, about an inch or so deep. The water took a while to dissipate. I mentioned the water problem to the carers but I think it was a general given because when the carers got you towels, they would give you an extra one just for the floor. [redacted] blocked the toilet once, which he found quite funny. But I think

that was more to do with the drainage of the hospital than [redacted] actually blocking it. He found that quite amusing for a wee while.

56. The showers in all the rooms were pretty much the same but room 24 was the worst. The other ones would fill up but not as deep and would eventually flow away. The only thing I can add is that you would assume that being a haematology ward, they would have filters on for protection, but they had no ventilation. The drains and toilets were open and there were no filters when you were flushing, so then you got the spread like an aerosol. Haematology is a ward where infection control has to be really tight. Haematology patients are quite susceptible to a wide variety of infections, fungi, and bacteria. This is why infection control is so important on a ward like this.

57. I showered [redacted] every day. He'll tell you I probably scrubbed him within an inch of his life but I had the thought of it's better to wash with soap, water and rub him dry rather than use baby wipes and things, just more for hygiene. I was obsessed by it. I didn't want him to get anything. I was never told to not use the tap water for washing [redacted] or told to use wipes to wash [redacted]. Myself and the other parents chose to do this because of the water problems on the ward, like the showers overflowing.

58. The hospital did provide soap and washcloths, but I used to take in liquid soap because [redacted]'s skin was quite delicate.

HAIs: events and physical impact

59. As far as I am aware, [redacted] had one healthcare associated infection. That was the stenotrophomonas blood infection he contracted in September 2018. I have described the circumstances of that infection in more detail above.

The physical impact of the infection meant that [redacted]'s transplant was delayed and we were really lucky that his donor, who was a ten out of ten perfect match for [redacted], was able to be accommodating and work with us to move the dates to enable [redacted] to get his transplant.

HAIs: communication

60. As I have said above, I was advised by Dr Pinto after [redacted]'s appendectomy that [redacted] had a gram-negative infection in his blood cultures. I asked what that meant and he just explained that it could have been caused by his appendicitis. That was how it was said. Later, the Advanced Nurse Practitioner told me that [redacted] had a stenotrophomonas blood infection and the likely source was the central line.

61. At some point after this a staff nurse came into the room. I don't know her name but she came in to check [redacted]'s observations and we were talking. I asked her if she had ever heard of stenotrophomonas and she replied, "What, steno, has [redacted] got steno?" I told her that he did and she hesitated and said "Okay" slowly.

62. I also asked her the question about [redacted] being in room 23, in ward 2A, previously because there had been a young boy in the ward roughly at the same time, who had sadly passed away. He had been in room 23 and had mostly resided there. I asked the staff nurse if [redacted]'s infection had something to do with that room as it was never really used and there always seemed to be senior staff and management around the room. I also asked if this room was a hotspot for steno. She replied, "You don't know how close you are" and she got quite upset and distressed. She said, "Nobody's listening, there's more kids becoming unwell on the ward and nobody's really paying attention." She said that the nurses were the ones that had been cross-examined and interrogated and told it was their fault when it had been something out with their control.

63. I found out that [redacted] had stenotrophomonas just before the news broke in the media about ward 2A being shut. I was livid. [redacted]'s consultant, Dr Shazi Chaudhry, came round the ward the next day and I asked her where the infection had come from because [redacted] had only made it home for a couple of days. The antibiotics had kept the infection at bay but it was already present. They had stopped his antibiotics and I asked if it had been in his line previously. Shazi couldn't answer that. I told her that I wanted to speak to someone about it. She didn't admit where the infection had come from but she told me that she would send an email to the infection control team. A day or two later I was informed by the ward charge nurse that there was going to be a meeting and that Professor Gibson was going to sit in for my support.

64. I was not told at that time what the source of [redacted]'s infection was. I received his medical records at the beginning of 2021. There was a report from the lab saying that the infection was probably not related to the environment. I also got [redacted]'s Case Note Review but it said they weren't testing anywhere for stenotrophomonas in the hospital so they couldn't say for definite that [redacted] caught the infection in the hospital or not, but that it was probable because of the amount of cases of stenotrophomonas in the ward at the time.

65. I attended at day-care with [redacted] on ward 2B on 20 September 2018, to get his blood checked before his transplant. That was the day I went with my dad and when we got there Jamie Redfern and Teresa Inkster met me to tell me what the new plans were for [redacted] and what was to happen to him. Teresa Inkster is microbiologist Doctor and Jamie Redfern is the deputy general manager of the Royal Hospital for Children.

66. Just before we met with Teresa Inkster and Jamie Redfern, Professor Gibson pulled me aside and explained that she was going to sit in on the meeting with me, to hear what was said. We had the meeting that afternoon in the parents room on the ward.

67. I informed them that I'm a nurse and gave a little bit of my background. I explained that [redacted] had only been home for a couple of days and that although I acknowledged he might have caught the stenotrophomonas at home, I thought that it was more likely that he had caught it in the hospital. I also told them that no one had answered that question.

68. At that point, Teresa Inkster apologised and said that it was most likely from the hospital environment. I told them that I knew they could do genetic testing to find out exactly where it had come from conclusively. Dr Inkster told me that they would send the samples off to the labs but it would take a number of weeks to properly identify the source. I explained to them that, from what I had read, this had been the third time that there had been an outbreak on the ward and asked what was going to happen if the antibiotics and the enhanced cleaning stopped working. I explained that I knew that once an area was colonised with bacteria it was very hard to get rid of unless you physically take out whatever it's attached to.

69. Professor Gibson told me that there had been ongoing issues on ward 2A with drainage. That was all she said. That was the first time someone had actually admitted there was something wrong with the drainage system or the drains on the wards. The others didn't really have an answer, they just said that they were working on it.

PREVENTATIVE MEDICATION

Preventative medication: events and communication

70. When [redacted] was first admitted to ward 2A he had to go onto a protocol. Dr Chaudhry said he needed to go onto posaconazole or casprofungin as a preventative measure for fungal infections. He was also on ciprofloxacin, an anti-bacterial antibiotic, as a preventative measure as well, to protect him

from the hospital or hospital acquired infections. Doctor Chaudhry said it was because of the environmental issues in the hospital ward but did not specifically say what those environmental issues were.

71. I was quite happy with that explanation at the time because the risk was too great of [redacted] catching an infection, so I had to balance it up. [redacted] needed the chemotherapy treatment, so there was nothing we could do about it.

72. When [redacted] was discharged, Dr Chaudhry went through his list of medications and said he didn't need posaconazole or ciprofloxacin because he wasn't going to be in the hospital any longer.

OTHER ISSUES RELATING TO HOSPITAL CONSTRUCTION

73. When [redacted] was first admitted to ward 2A, from 2B in May 2018, the day care Sister, Angela, I don't know her second name, was taking us through the general rules of the ward. She told us that the ward was under investigation for environmental issues and they were still not aware of the cause. It was like a passing comment and I got the feeling that it was along the lines that things were in hand and they were dealing with it.

74. I looked at her and laughed and told her it was probably to do with the ventilation because there were no open windows. She didn't say it was anything specific, it was more like friendly banter. That was the only time that anything was mentioned face to face about the ward. Nobody ever mentioned anything else about the ward.

75. It was dark, hot and humid in ward 2. It was quite a stark change going from one place to another within the ward. It was quite a hot, sweaty environment, even just walking down the corridor, going from one part of the ward to the other.

76. When we initially went in to [redacted]'s first room, which was room 1, there was a central vent in the ceiling and it looked like it had come down a bit. It had popped a bit and there was a small clear plastic tube sticking out the side. I thought they were doing the ventilation tests as part of the environmental investigation and the tube might have been a sampling thing.

77. All the wards in the kids' hospital were particularly hot and sweaty, not just ward 2A. There were no windows that opened and there was no ventilation. I don't recall seeing fans in the hospital but when [redacted] was in ward 2A fans weren't encouraged because of the risk of spread of infection but there was no way of getting any extra air if it was too hot or cold.

78. The rooms were either too hot and you were sweating, or they were too cold but I would probably say it was mostly too hot. There was no way of trying to control that or bring it down. One of the auxiliaries advised us to keep the toilet door open to help with ventilation, particularly in the isolation rooms.

79. There were temperature gauges in all the rooms. You could try to put the temperature down to 15 degrees but it didn't matter if you put it up or down the register always showed that you couldn't put it under 23 degrees. It was the really hot summer of 2018 and we were stuck with the really hot temperatures and the smell from outside, and there was no way to get cool air in. If I mentioned it to the nurses the reaction was along the lines of, "It is what it is" and there's nothing that could be done.

80. [redacted] was in room 20, which was the specialist isolation room, during that summer. The smell of the sewage from outside was quite rancid, you could smell it quite strongly. You could smell it when you were coming into the hospital and when you were coming over from Marion House, the CLIC Sargent respite house.

81. It was particularly strong and pungent in room 20, it was like the smell of faeces, excrement, like a fermented smell. It would come in waves, it wasn't constant. I don't know if it was the way the wind was blowing or something to do with the ventilation but it would be more apparent during the day. I did raise the issue with the staff on the ward but they didn't know if it was to do with the wind or whatever.

82. I did also mention it as part of the questions to Craig White when I spoke to the microbiologists. I said that, surely if you could smell it within the room, then the bacteria must be present within the room because smell and bacteria go together, but I was advised that the rooms were clean. That was what came back in the report by Craig White, as a result of the questions and answers paper where he had asked for parent's questions. It said that although the smell was present, the rooms were still adequately ventilated and there was no risk of bacterium.

83. I think ultimately the ventilation issues impacted on capacity, which then impacted on children acquiring these infections. Rooms are held up with people being in for longer and suffering side effects of catching infections. This then means that other children can't come in to get their treatment, which then leads essentially to a non-safe environment to carry out treatments because you're playing catch up with the kids you've had to delay.

84. Ward 2A also gave us a letter at the end of August 2018 telling us not to use the paediatric entrance of the Royal Hospital, including the side entrance. We had to go round to the discharge entrance at the Queen Elizabeth wing to enter the hospital that way. That was to avoid walking under the cladding at the front of the RHC.

85. There was also lots of pigeon excrement everywhere, in the car park next to the discharge lounge and in the other car parks. It was also in the dead spaces that you had to walk through to get access to the discharge lounge

entrance to get into the hospital. I was so obsessive that I used to take my shoes off before I went into [redacted]'s room. I was also conscious that people were walking and sharing the same entrance ways so potentially they could have picked up whatever was on the floor.

86. When [redacted] was admitted to ward 6 in January 2019, he looked out the window between the Queen Elizabeth and the Royal Hospital for Children. There's a children's play area and a stoned area at the front where the theatres are. There were lots of dead pigeons on the roof space there. I only ever saw that once but I can't remember the exact date of that.

CLEANLINESS

87. When [redacted] was in room 1, within ward 2A, the cleaning would get done late in the day. When he was in his isolation rooms, the cleaning would be done early morning. I talked to the domestics and there was only a team of two or three of them.

88. They would clean the source rooms first; those were the rooms that had patients who had diarrhoea or vomiting or some kind of infection. Then they would clean the isolation rooms, which had children who were protected from infection. Surely they would change the water but they were using the same poles, the same uniform and the same shoes. I wondered if they brought infections round by contact. The bulk of the work was the isolation rooms and most of the children were in isolation at some point because of diarrhoea, vomiting or a temperature.

89. I passed comment to one of the domestic staff about the cleaners using the same mop handle to wash my room and the next room but I was told they wiped the mop every time they did a room. It seemed illogical to me to clean the dirty rooms, then the clean rooms, then go back to the dirty rooms again

or the general ward after. It's the same staff they're using to clean the different rooms.

90. I spoke to another domestic about protocols and asked that surely there must be a team. She told me there were only two of them for the full ward. That was at the time when everyone was getting moved around rooms so they could do specialist cleans with the machines. The domestic explained that the source rooms were the priority to get cleaned and then the isolation rooms, so sometimes the normal rooms would be missed or not get cleaned until later on in the evening.

91. I also remember that in May 2018, during [redacted]'s first stay in ward 2A, just before he went into isolation, there were a number of machines brought into the hospital, to clean and vaporise the wards. The rooms were getting vaporised at that end of the ward. The machines looked like Daleks.

92. The leaflet we got said that they sprayed the environment with hydro peroxide in the air to kill off bacteria or viruses and sterilise the rooms. They had to do some of the rooms again because some of the domestic staff told me that they forgot to do something with the drains. They had six machines, doing six rooms at a time so there was a lot of movement between rooms.

93. That was around the time they gave us a letter to say they had identified an issue with the drains or there was some kind of bacterium in the environment, so they were going to do an ionic vaporisation cleaning of the rooms. The letter also told us not to pour any milk, fluids or food stuffs down the sink or the toilet. The letter was left in room 1 by the nurse in charge but I probably don't have it any more as anything I brought out the hospital was discarded in case of infection.

OVERALL EMOTIONAL IMPACT ON [redacted] AND HIS FAMILY

94. Through his autism, [redacted] has managed to block out a lot about his treatments, in his head. When he's going into hospital and going into a certain room with vents in the ceiling, and on the side of the wall, he gets panicked, he gets quite scared because he thinks he's getting kept in for weeks on end and will not see or speak to anybody.

95. Normally with cancer in kids, families do separate and there was a lot of to-ing and fro-ing with trying to make sure [redacted] was settled and to keep [redacted] separate. I think [redacted] has probably suffered more than [redacted] in that respect because she missed her mum as we decided as a family to split up to protect[redacted] from infection. We were obsessive to ensure we didn't bring any infections in, so she effectively lost her brother and her mum for periods of several weeks at a time. It's only now that she's getting back to a relatively normal way.

96. We stayed at Marion House on two or three occasions. During the second spell, following [redacted]'s admission in August 2018, we actually stayed at home because our daughter was meant to be going to school, so it was to balance looking after her and her going to primary school. During [redacted]'s first admission, we stayed for four to five weeks at Marion House. That would have been between May, June and the start of July 2018. When [redacted] was discharged we gave up the room and we got a room later on whenever we needed it. [redacted] stayed with us once or twice a week dependant on what was happening with[redacted]. We had to depend on extended family members to care for [redacted] while we were with [redacted]. There were times she couldn't see [redacted] because of his treatment and she got quite upset because she couldn't even cuddle him.

Overall emotional impact on [redacted].

97. [redacted]'s been seen a couple of times by the psychologist because of the transplant situation as he was suffering very badly with anxiety. But again, it could have been anxiety related to Covid lockdown, because the minute you mentioned anything about isolation or lockdown he would panic thinking he's getting locked in a room again with the ventilation and he was going to have to be closed in. But we explained to him that we have the house this time and he's got a garden. He used to get a bit worked up if he thought he was going back to hospital, he thought he was going to get locked up again. But he's now at the state that he knows he's only there for a day or two. He's only there for what he needs to be there for and he comes straight home again. That's kind of the only difficulty he has. The rest of the time he's actually okay.

Overall emotional impact on witness

98. I have a suspicious mind, it's anxiety. I felt early on that there was collusion and I didn't know who to trust with my son's life. They gave you the impression that it was safe because the staff said certain things were being investigated for environmental issues and were being dealt with, but you knew he was getting infections. They were trying to do things to make things better, but I just felt at the time that a lot of things were being done underhandedly. There wasn't an open channel or conversations and the staff's hands were tied because they couldn't speak to you.

99. We were all told to stay in our own rooms in the ward 6A, obviously for isolation purposes, so you couldn't meet up with other parents, other grandparents or anybody else to find out what was going on.

100. When I was staying in Marion House, I approached some of the other parents and family members and they were all in agreement that there was something going on in the ward and they had actually been in part of or affected by the investigations being carried out into the environmental issues and infections on the ward in March 2018. We all felt that if we collectively came together and asked or broached the subject of what was going on, what was going to happen, and what was going to change, then surely we should have been able to come forward.

101. The staff appeared to be approaching a level of burnout. We knew something was happening but they were the ones getting the brunt of the questions and the management seemed to have disappeared and left them to deal with the fallout. It was the clinical staff being left with the face-to-face stuff, the questions and answers, when it should have been the management that should have been open and honest at the time. When I spoke to some staff nurses asking them what was going on, they would say, “Are you going on about that again, there’s nothing going on” and I thought, is it just me, was I getting more paranoid being stuck in the ward, thinking what’s going on in here. You were just locked in your room in ward 6A with nobody to talk to.

102. I think we were ignorant at the start of the process. We weren’t fully aware or informed of the full issues that were going on in the hospital at the time. I think that there were probably big risks to [redacted] and I do think the medical staff themselves tried their hardest to offset those by the use of antibiotics, antifungals, trying to implement certain care pathways, to try and prevent either infection or cross-infection.

103. I do think this put [redacted]’s safety at risk. He was unlucky to catch the infection before his transplant, but if he had had issues during either his transplant or during his chemotherapy that caused a deterioration in his condition and his

body was already fighting a further infection, then I do think he was put at risk.

104. I also have a general criticism of the nursing approach of the team working in the Schiehallion Unit. I didn't see the sense in it, it was very task orientated. You would have several different visits from the nursing team. You would have one nurse coming in to do all the observations, another one to ask what [redacted] had to eat or drink that day, another nurse to do all the drugs and another one to do all the IVs. If you had sent one nurse in to do all of it, it would have lessened the risk to [redacted].

COMMUNICATION: GENERAL

105. In terms of the chemotherapy, the information was well communicated. We had the information sheets that reiterated a lot of things. Other situations like temperature changes were ad hoc. It did vary a lot depending on the time of day or how busy they were. Things did change and weren't always communicated by the team.

106. Quite often you would find things out later from the nursing staff. For example, if there was a change in the antibiotics or if [redacted]'s counts had gone up or down or if a specialist or a dietician came in to see him. You were often told afterwards. I'm sure if you asked the questions they would tell you but they weren't always the greatest at communicating.

107. After the meeting with Jamie Redfern and Teresa Inkster, we were discharged home and I was under the impression we were going for October 2018 for a transplant date. The news then broke in the media that ward 2A had shut with no further plans made. That caused immense distress because we didn't know what was happening. It hadn't been announced that the ward

was shut and, other than the media reports, we didn't know any information about it at all, nothing was communicated to us. My husband had tried to phone to find out what was happening because we were in limbo waiting to find out what was happening with [redacted]'s transplant. We got passed back and forward and eventually Angela, the ward Sister, spoke to us later on that evening and explained that the management had got back to them and the ward was just moving.

108. As far as we knew at the time [redacted] wouldn't be able to get his transplant in Scotland because the QEUH was the only place in Scotland that does it and if the ward was closing we were looking at having to prepare to go to Newcastle or Manchester for my son to get his transplant. Again, we had no answers.

109. I could appreciate the delay in moving a whole unit but I think there should have been some assurances or they could have got something out to the families that may have been affected, to tell them everything would be okay. At that point I was getting ready to go to Newcastle with the prospect of my daughter having just started school. We were on tenterhooks for a couple of days until we knew what was happening. I like to pre-plan so I was thinking we had to pull money together and possibly go to Newcastle and I didn't want any delay for [redacted]. I did have confidence in Professor Gibson and Dr Chaudhry that they wouldn't have left us in a situation because I knew they would probably move heaven and earth and something would be done.

110. The next day, Jamie Redfern apologised for the lack of communication but assured me [redacted] had a bed for his transplant, in Glasgow. He said there wouldn't be a delay but couldn't tell me when the transplant would be until they had informed everybody else involved in the situation.

111. We also got a letter when [redacted] was in ward 6, after his transplant, related to a fungal infection. I think it was to do with the pigeon dropping scenario

but I didn't deem it important because [redacted] was just about to get out. We also got the letter I previously mentioned when they were taking the cladding off the front of the hospital. It advised us not to use the paediatric entrance but to use the discharge entrance to the adult hospital. The letter said that the bacteria was maybe falling on our clothes or our shoes and that we were bringing it into the ward so to prevent that we had to come round from the adult unit. I've not kept any letters. Anything that came out the hospital paper wise I discarded in case of infection.

112. There were a couple of Facebook groups I was a member of. There's a parents' one and a closed group one. The closed group for parents and staff was called "NHS GGC Paediatric Haemato-Oncology Closed Facebook Group". The parents only group was called "Schiehallion Parents". I can't remember who set up the parents' group but I think it was a collective of a number of parents involved in trying to tie up with each other. As single individuals, there were parents asking questions that were getting poo pooed and swept under the carpet. We felt as a group that they couldn't ignore us if we were all asking the questions and doing the same things. That was aimed more at the management situation rather than the clinical staff and management couldn't access it.

113. I am also a member of the closed Facebook group, set up by one of the parents I think. From a mother's point of view, I could see a lot of people being angry and upset that their child was having to suffer. Looking at it pragmatically and professionally, cancer is not without its risks, there are some things you can't prepare for. The concern is that if someone, somewhere knew that the environment wasn't safe or had risks and patients had continued treatment in that environment, then that was not okay. Something had to be done.

114. There were a lot of people coming on the group and giving information. There were some families saying that their kid had this and that and there was one in particular who said she had something on her daughter's death certificate and it was never explained to them what it was. I was quite shocked that it was never explained in that way. There were quite a lot of harrowing stories and I eventually came off the group.

115. I did say to people on the Schiehallion Parents group, at the start, not to go public, not to go to the press, keep it in house and try and fight it in a professional, level headed manner. But the issues were again, being poo pooed by the management, they were not taking the questions seriously and that's probably why it ended up going up to the Health Secretary.

116. There was one incident in January 2019, when it was all kicking off on the parents Facebook group, we put things forward to the management and they asked Professor Gibson to come and speak to us individually and try and assure us that everything would be okay and that they had things in place and the kids' interests were at heart. We felt that we didn't need to hear the assurance from the Professor because we knew she had our back and that she had done her job and was looking after our kids. The assurances we were looking for were from the Health Board, to say the environment was safe, the children were safe and that the Board were going to do things about it.

117. I don't really know if the Facebook group was that effective a means of communication. I came off it once [redacted] was in the hospital less often but I think a lot of people were on telling their own story and having their own bit to say and having their own piece. It certainly brought the issues forward, as a collective parents group, to a wider audience, in making it more public.

118. After the meeting with the Health Minister, which I will talk about later, I was given Professor White's email contact details. I emailed him to ask about the

infections in the hospital and how they must be in the pipework and about the smell in the hospital. The Professor replied back that the Inquiry would look at that but even though there was a smell, there might not necessarily be any bacterial or infection risk with that. The replies from him were very minimal, I got two or three emails at the most.

119. I did find the communication with him effective though and we had John Cuddihy who was the direct access point to management. Professor Cuddihy coordinated the parents group and kept it all on an even keel and listened to everybody and put questions forward. You can imagine that everybody was angry and had their own points to say, so I think having one person as a buffer gave kudos to John Cuddihy for taking that role on. He did an amazing job and I think having that point of contact and with his background made it all the more worthwhile, made it more listenable and gave it all a more professional approach, rather than having twenty odd parents being emotional and shouting and screaming about their child.

120. The press coverage relating to the hospital made me feel sick. I felt sad for other families as well, who were suffering, and I know that a lot of kids got their treatment delayed. I'm obviously aware of [redacted] dying and [redacted] was at that kind of cusp, so it was very close to home. I was then thinking that I had to take him back into that environment again. I actually felt quite unwell over the whole thing, that's probably the most polite I can be. It was like a kick in the teeth because we had been in there and the hospital had never once indicated how serious it was. It did feel like we had been kept in the dark.

121. I don't know how the meeting with Jeane Freeman came about. We were invited to attend personally by Ms Freeman's office. The meeting was set up out with the hospital, in the Central Hotel in Glasgow. I think it was either in September 2019 or during the summer holidays that year. It was set up there

because there were access issues in the hospital and I think some people wanted the meeting at the Queen Elizabeth so more people could attend, rather than smaller groups. We were able to chat to Ms Freeman and have a frank discussion about what the concerns were. There were a number of parents there who were raising their own issues, some minor issues that weren't fully relevant to the actual hospital environment. Ms Freeman did seem to listen and take on board what we said.

122. One thing that annoyed me a little, was when Jeane Freeman spoke about the duty of candour by the medical and nursing staff. She said that they could have informed families about the risks of infection and the antibiotics they gave preventatively. She said that the Professor Gibson, the medical team, or the nursing team could have, at any point, told us about the issues ongoing in the ward or their worries and concerns, because it's part of our professional regulation.

123. I did raise the point that as a nurse myself, I felt embarrassed and ashamed for the nurses because they're having to be under so much scrutiny by the infection control board, all the external environments and agencies and being made to account for their practise, whereas it wouldn't have mattered what they did because the kids were still probably going to catch an infection. It's a shame for them and the professional embarrassment they were probably going to suffer.

124. In terms of duty of candour, it was a logical explanation, however, when you have two young kids at home you have to feed, you're between a rock and a hard place when you feel you're not getting the support for whistleblowing. I wasn't really agreeable to that because if it was me and my own children and I had to choose between my job and feeding them, it would essentially come down to that.

125. I think Jeane Freeman listened during that meeting. I don't know if she was being fully apologetic or sincere with the apologies. She can only answer so much, so we knew her hands were tied but she did seem to genuinely want to listen to our stories and our information. I suppose you could say she was sincere in that respect. The only correspondence we had from her after that was to inform us that Craig White was taking over as the infection control lead to do with the public, for the initial inquiry and things would develop from there. That was in an email which was followed up with a letter.

COMPLAINTS

126. I spoke earlier about the meeting I had with Jamie Redfern and Teresa Inkster. I was surprised about the level of seniority at the meeting. Normally in my line of work you would usually speak to the charge nurse and the consultant in charge of the care. Very rarely do you get the general manager and the head of microbiology to speak to unless it was a serious complaint. It's not like your first stopping point, it's usually a progression or levels going up.

127. As I mentioned previously, Teresa Inkster immediately apologised for [redacted]'s line infection and said it was probably related to the environment however, they couldn't confirm that. Jamie Redfern was very quiet and non-committal about it all. Even when I asked about what was going to happen next, there were no assurances or decisions, it was a case of "We're doing what we're doing". There was nothing confirmed in that meeting. I'm still waiting just now for them to tell me where [redacted] got his line infection from, it was only the Case Note Review that informed me of this.

OVERSIGHT BOARD / CASE NOTE REVIEW / REPRESENTATIVE GROUPS

128. I have heard of the Oversight Board, but I only know that they were overseeing the whole Health Board. I try to distance myself from it sometimes, I don't really want to go back to that place. As far as I know the Health Board themselves were being managed by another health management team.

129. [redacted] was part of the Case Note Review. I've not spoken to anybody from the Case Note Review, I have only read the notes and things are very clear. There are some issues that have been skipped over but it's probably because it's not relevant to [redacted] or what they are physically looking for in terms of the review. They're obviously just interested in what infection he had and what impact it had because it's been hard on [redacted]. I would say it's pretty much nailed what it has done because it said in the report that it had a significant impact on [redacted]'s treatment.

130. When we got the initial report back about the infections and the sampling, we felt a bit disheartened that there was no evidence to prove anything about stenotrophomonas in the hospital because of the sampling issues and errors that were made. The report said that the samples they had seen from the hospital were often incorrectly dated and a number of samples didn't record the location of where the sample was taken either. The report does go so far in saying it was probable and a lot of the kids were affected by the environment and the impact that caused, but because there is no evidence so you can only surmise. I was happy that they did recognise the limitations and that with the sheer number of kids affected, you can't argue and say it wasn't the environment. With the lack of evidence, the sheer numbers alone should indicate there was an issue.

131. From [redacted]'s point of view, the Case Note Review was upsetting because it puts down on paper what you have suffered or what you've seen and it brings back things you might have potentially forgotten or put behind you. I just feel

disheartened that I allowed my child to have to undergo extra things. If someone had stood up earlier, or argued the point earlier, who knows, it may not have come down to the sheer timescale. If action was taken properly and promptly in response to issues on the ward, [redacted] wouldn't have had so many delays to the care he needed to have.

132. The only thing I want to add is that I'm glad they are coming to the point and making someone accountable, but who do they make accountable, that's the issue. It's not a catalogue of errors, someone somewhere must have made a decision to either open the hospital or to accept the risk of what was coming, because I don't think that was a collective decision. Somebody somewhere must have made that decision to proceed.

133. I have not been involved in any of the representative groups. I have added my tuppence worth but that's not been for a long time. By that I mean, when people were asking for information, or asking what stenotrophomonas was or what should they do and I said that it wasn't the clinical staff we want to hear from, it's the actual Health Board management that are the ones that should be answering questions.

CONCLUDING COMMENTS

134. I hate the hospital; I don't want to go back but it's a love/hate relationship because they gave me my son back. Ideally, if I can avoid going, then I'll not go. It's had an impact on my work life in the sense of when I'm working, I don't like to be in a room where there's no window or anything that looks too clinical. I try and manage my work environment so I don't go back to that place where I was before, and the memories. I will say that my employer has been immensely supportive throughout this time.

135. In relation to the Health Board, I feel there are a few people in a position of responsibility that are incompetent or not trustworthy, or worthy of the job.

136. With the amount of infections they have, I think the hospital is too big on one big site. There are too few entrances in or out of the hospital, to allow for adequate personal space, cleaning and management of that. The infrastructure of the building itself is probably too close and confined and there's obviously issues with the plumbing already because there's infections in there already going about. The things they have put in place or are putting in place, I don't know if they have worked or will work.

137. Though I'm no longer a member of the parents' Facebook group, from what I see of the NHS GGC Paediatric Haemato-Oncology Closed Facebook Group that is run by the health board, it's got a suggestions board and they seem to have been listening about food and things, so I think things are turning round. We've also been contacted about the new room they're putting in for kids aged between 8 and 12, in 2A, so they're thinking about [redacted]'s age group which will hopefully help to ease the journey for other kids, so I think they're listening now. They're rebuilding the ward and I hope redoing the ventilation and the plumbing. They're putting things in for kids that they should have done from the start. I'm only surmising, but with Edinburgh, somebody must have listened there as I take it they must have had the same issues that were evident in Glasgow. They listened and acted on that so hopefully this won't happen again.

138. I think it's time that somebody answered for what was happening. I think Professor Gibson and her team have taken quite a lot of flak unnecessarily when all they have ever tried to do is their best for the kids, that's ultimately what they've ever tried to do. Even if they gave treatment that wasn't necessary in some parents' eyes, it was all about maintaining the kids' lives

and giving them the best chance, so hats off to Professor Gibson’s team for what they did try to do. It’s not a reflection on them.

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

DG/01 – Appendix 1

Timeline - [redacted].

March 2018 – April 2018

- 29th March 2018 – 18th April 2018 - [redacted] started to complain of having sore knees which became worse. This progressed for just over a week to a point where he was struggling to walk and was non- bearing on one leg.
- 19th April 2018 – Denise takes [redacted] to [redacted] Forth Valley Hospital to be examined. It was deemed that there was nothing wrong with him.
- 20th April 2018 – Denise took him back to Forth Valley Hospital. Further investigations were conducted and a tumour on his leg was discovered.
- 23rd April 2018 – [redacted] is seen by Mr Duncan at the RHC and receives an MRI scan.
- 24th April 2018 – [redacted] attends the day surgery unit on ward 1 RHC for a biopsy of his femur bone and to have bloods taken.

May 2018 – July 2018

- 14th May 2018 – [redacted] is admitted to ward 3A RHC for surgery to have a central line fitted.
- 15th May – 22nd May 2018 – Denise and [redacted] return to ward 2B over the next week for a number of blood tests and further assessments.
- 23rd May 2018 – RHC confirms that [redacted] had Chronic Myeloid Leukaemia, he had a myeloid sarcoma in his femur and was in a blast crisis with Acute Myeloid Leukaemia. [redacted] is admitted to ward 2A. Denise is advised at admission by one of the Care Sisters, Angela, that the ward was under investigation for environmental issues, and they were not aware of the cause.

- 25th May 2018 – [redacted] starts chemotherapy in ward 2A. He remains in room 1 for about a week and is then moved to room 15 for a few days.
- End of May 2018/June 2018 – A Day or so after he is moved to room 15, he is moved again to room 20 which is a specialist isolation room. This move occurred because his consultant was unhappy about [redacted] being placed in room 15 as he had neutropenia. [redacted] remained in room 20 in isolation for around 4 weeks. Shortly before [redacted] was moved to the isolation room, a number of machines were brought on to the ward to clean and vaporise the rooms.
- 7th July 2018 – [redacted], still in room 20 becomes, very unwell. He was having regular temperature spikes and was on four kinds of antibiotics. He became unwell developing Red-man syndrome. Red man syndrome is a known side effect of vancomycin, one of the antibiotics [redacted] was receiving. When he was examined, a doctor proposed that he receive more antibiotics. Denise refused this as [redacted] was already on four antibiotics and it was making no difference. The use of [redacted]'s central line was then stopped to give [redacted] a rest. [redacted] then recovers very quickly.
- 8th July 2018 – [redacted] is moved from room 20 to room 10 by the charge nurse. This was because they were concerned that he had measles. A consultant dermatologist had a look and she confirmed that it was not measles, it was more likely a reaction to the drugs he was on. He remained in room 10 for about a week. He was then moved to room 15 and was there until he was discharged home for a couple of days.
- August 2018 – around the start of August, [redacted] is discharged home for a few days.

August 2018 – January 2019

- August 2018 – later in early August, [redacted] is admitted to hospital to begin his next cycle of chemotherapy. He was put straight into isolation for his chemotherapy. He was in ward 2A room 24. He started losing weight and wouldn’t eat much at this point so he was put on total parenteral nutrition (TPN). [redacted] remains in room 24 for around 3 or 4 weeks.
- August 2018 – [redacted] is moved to room 23 for around 4 or 5 days. This was a room that had a lot of problems, it was not uncommon for people with red uniforms to come in and examine the taps while [redacted] was staying there. After this [redacted] was moved back to room 24 again.
- August 2018 - Towards the end of August [redacted] started to feel unwell and developed stomach pains. These seemed to subside, so he was discharged home for a couple of days where he started to develop more pains and spiked a fever after returning home.
- August 2018 – sometime at the end of August 2018, Denise received a letter from ward 2A asking them to not use the paediatric entrance of the Royal Hospital, including the side entrance. She was advised use the discharge entrance at the Queen Elizabeth wing to enter the hospital to avoid walking under the cladding at the front of the RHC.
- 6th/7th September 2018 – On either the 6th or 7th of September, [redacted] is admitted back into ward 2A. [redacted] receives an ultrasound, and some slight evidence of appendicitis is found. [redacted] was moved to either room 10 or 11 while decisions were made as to what to do about his stomach pains. During this time, [redacted] is found to have an infection and Professor Gibson explained that she wanted to have the appendix removed to reduce the risk of infection during [redacted]’s transplant.
- 8th September 2018 – [redacted] has his appendix removed and was transferred to ward 3A. On this same day, [redacted]’s consultant, Dr Pinto, advised that [redacted] had a gram- negative infection in his blood cultures. Dr Pinto said this could have been caused by his appendicitis. [redacted] was then moved back to room 1 in ward 2A later that day, where an Advanced

Nurse Practitioner told Denise that [redacted] had a stenotrophomonas blood infection and the likely source was the central line. [redacted]'s post-operation surgeon also spoke to Denise that afternoon and said that [redacted]'s appendix looked perfectly normal to him.

- 11th September 2018 – [redacted] has surgery to remove his central line. Following surgery, [redacted] is moved to room 14 or 15 because he no longer required intensive treatment. [redacted] continued to receive IV antibiotics for several days to cover potential infections related to his line removal. [redacted] was then switched to oral antibiotics after several failed attempts to put cannulas into [redacted], which he found quite traumatic.
- 15th/ 16th September 2018 – [redacted] is fully discharged on either the 15th or 16th September 2018.
- 20th September 2018 – [redacted] attends a day care appointment on ward 2B to have blood tests in preparation for his transplant. Jamie Redfern (Deputy General Manager RHC) and Teresa Inkster (microbiologist) met with Denise to discuss the new plans for [redacted]'s treatment.
- End of September 2018 – [redacted] has a PET scan and the end of his course of chemotherapy which showed a hot spot at the base of [redacted]'s tibia. [redacted] then had a bone marrow biopsy, which came back negative. Dr Chaudhry told Denise the hot spot was likely due to the trauma of the infection. This resulted in a 2-week delay to [redacted]'s transplant originally scheduled for 16th October 2018. The transplant was postponed until 29th October 2018.
- 29th October 2018 – [redacted] is admitted to ward 4B to start conditioning for his transplant.
- 8th November 2018 – [redacted] receives his transplant.
- 4th December 2018 – Denise is allowed to take [redacted] to Marion House, the CLIC Sargent House. [redacted] soon becomes unwell again with a high temperature and shivers. Later that night, [redacted] is admitted back into ward 4B. [redacted]'s condition improves, and he is moved to ward 6A where

he was put in a day-care room as there were no ward rooms left. Staff deemed [redacted] to likely have graft versus host disease on his skin as he had a bright red, scarlet rash and a fever. [redacted] was treated with IV steroids in response to this. [redacted] stayed in ward 6A for around a week so he could be weaned off IV steroids and start oral treatment.

- 8th December 2018 – [redacted] is discharged around the 8th December.
- 11th December 2018 – [redacted] attends a day care appointment on ward 6A.
- 18th December 2018 – [redacted] has a bone marrow test on ward 6A.
- 30th December 2018 – [redacted] is readmitted with a fever to ward 6A. [redacted] was found to have a line infection and a staphylococcus epidermidis skin infection. He is treated with oral antibiotics and his central line removed in surgery.
- 6th January 2019 – [redacted] is discharged. [redacted] then attended day care on Ward 6 two or three times a week for three months, he then restarted his oral chemotherapy for the remainder of the year. [redacted] also received immunoglobulin therapy during this time to assist with the recovery of his transplant.

<u>January 2019 – February 2020</u>

- January 2019 – February 2020 – [redacted] is admitted several times during this period due to temperature spikes.
- May/June 2019 – In either May or June 2019, [redacted] is admitted to ward 6A for one of these fevers for around 5 days to a week.
- February 2020 - The last of these admissions is in February 2020, when [redacted] is admitted to ward 3B after having contracted adenovirus.

Scottish Hospital Inquiry

Witness Statement of

James Gallagher

WITNESS DETAILS

1. My name is James Gallagher. I was born on [redacted]. I am [redacted] years old. During [redacted]'s time in hospital I was a mathematics teacher at [redacted]. Now I am a mathematics teacher at [redacted]. [redacted].

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

3. I live with my wife, Denise Gallagher and my two children, [redacted] and [redacted] in [redacted].

OVERVIEW

4. My Son is [redacted]. [redacted] was diagnosed with Chronic Myeloid Leukaemia (CML), in April 2018 when he was 8 years old. [redacted] was treated in the Royal Hospital for Children (RHC) and Queen Elizabeth University Hospital (QEUH) between May 2018 and December 2018 when he finished his treatment. He attended both hospitals as an in-patient and an out-patient for nearly six months. [redacted] still attends the QEUH for check-ups. A timeline has been provided to the Inquiry showing the dates [redacted] attended the hospital. This was prepared by my wife Denise, as whilst I am able to speak in regards to the experience [redacted] had at the hospital, I am

unable to recall exact dates. I believe, however, that the timeline is accurate to the best of my recollection.

5. [redacted] spent time on wards 2A and 2B of the RHC which was known as the Schiehallion Unit. [redacted] also spent time on ward 4 of the QEUH when he had his bone marrow transplant. Following the closure of the Schiehallion Unit in 2018, [redacted] was treated on ward 6A of the QEUH which was supposed to be the 'new' Schiehallion Unit. I stayed with [redacted] during some of his admissions to the hospital as an in-patient and an out-patient. My wife, Denise and I both cared for [redacted] until August 2018 when I had to go back to work and also look after our daughter. After this time I would visit on a regular basis and stay overnight when I could. I can speak to the experience which [redacted] and I had on these wards although my wife is better at explaining the medical side and giving the dates of procedures.

6. There are some specific events that I would like to mention. [redacted] contracted a healthcare acquired infection in August 2018 when he was in ward 2A of the RHC. His bone marrow transplant was postponed twice due to the infection and issues with the hospital. There were ongoing issues with the construction work and the water which in my view, impacted [redacted]'s experience. I will come on to talk about these in more detail.

FAMILY BACKGROUND

7. I live with my wife, Denise and two children in [redacted]. [redacted] is the oldest and [redacted] is [redacted] years old.

8. [redacted] is in [redacted] and will be going into [redacted] after the summer. [redacted] is a lovable young boy. He has high functioning autism but he is so engaging with you that you wouldn't know he has it. He's lots of fun to be around and can be social and outgoing. He's never allowed his autism to hold

him back and neither have we. [redacted] finds certain things more logical. He likes to engage and talk, in fact, I would say talking is one of his hobbies. He has a nice wee group of friends that he has had since nursey. His friends sometimes find him hard and challenging but they always look out for him. It's nice to see him with that strong friendship group.

9. [redacted] is close to his little sister, [redacted] who will be going into [redacted] after the summer. They both attend [redacted] in [redacted]. [redacted] and [redacted] can fight like cat and dog some days, like any brother and sister but they are very close.

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

Admission to hospital: May 2018

10. [redacted] was diagnosed with Chronic Myeloid Leukaemia in May 2018 when he was 8 years old. He had been complaining about a sore knee at his sister's birthday party. He had been playing on bouncy castles at the party, so we assumed it was that which had caused his sore knee. The first week back at school, [redacted] was struggling to walk and was suffering from pain in his leg. The Wednesday of that week, Denise took [redacted], she was training to be an Advanced Nurse Practitioner (ANP), so she had taken him to A and E [redacted]. The doctor there said there was nothing wrong with him. He didn't X-ray [redacted] before sending him home. On the Friday, [redacted] was struggling to walk the really short distance from the carpark to the car, it was taking him ten to fifteen minutes so we took him back to Forth Valley hospital and he was X-rayed.

11. The Doctor told us there was an abnormality showing behind the knee on the X-ray and we thought the worst. We were really lucky as the doctor that saw [redacted] that night, knew Mr Duncan at the RHC and called him about [redacted]. We were given an appointment for the Monday at the RHC. Staff

there thought it was bone cancer so a biopsy was organised for the next day. This was done in the general surgery ward and this is when the process started for [redacted]. Two weeks later we had to go back to see Mr Duncan at the RHC and he informed us that it wasn't bone cancer. He said it was something else as the blood work was off. [redacted] was given progressive blood tests and we were told by Mr Duncan that he suspected leukaemia. [redacted] had a few more tests carried out. He had a central line fitted on 14 May 2018 and on 23 May 2018, [redacted] was diagnosed as having CML. He was admitted to ward 2A at the RHC.

[redacted]'s initial treatment May 2018 – July 2018

12. We were initially told by Mr Duncan that [redacted]'s cancer was a slow progressive disease so I had returned to work however, on my first day back we had been given test results. I had to leave work as we were advised [redacted] needed to be admitted to hospital immediately.

13. [redacted] had been getting weekly blood tests at ward 2B, Day Care of the RHC. His CML had progressed and he needed to go for chemotherapy. We didn't actually realise the seriousness until after his chemotherapy.

Experience on ward 2A: May 2018 – July 2018

14. When [redacted] was first admitted on 23 May 2018 to ward 2A, the room we were in was at the right hand side of the nurses' station. [redacted] was in this room for about a week and a half, getting his chemotherapy then he was moved to room 15. I can't remember why he was moved but Professor Gibson got really angry that he wasn't placed in an isolation room. He was then moved to room 20. [redacted] was neutropenic. This is where his immune system is no longer functioning and any little bug can easily attack him so he should have been placed in one of the isolation rooms at the start and not room 15, which I think was a standard room.

15. There was a parent's kitchen where I could go to make a cup of tea for us or [redacted]. There was the option to store meals in here too but on many occasions it became a pseudo staff room, particularly for auxiliary staff. We felt particularly uncomfortable being in here when staff were talking about work or relationships. We felt weird going in when they were there. That was the main facility for parents to use initially until it got closed. When the parents' kitchen closed, there wasn't anything else for parents.

16. The parents' kitchen was closed before the ward. I think the nursing staff said this was to tackle infections and to stop people mingling and congregating in the kitchen. [redacted] had the opportunity to disappear in to a computer game but there wasn't much you could do as a parent. I don't think there was signage up saying the parents' kitchen was closed but I can't remember 100%.

17. [redacted] had to get his leg in plaster due to weakness. Because of this, he couldn't go to the toilet so we were using pee pots. We were allowed to go and empty them in the sludge or sluice, I can't remember what it was called. At some point we were stopped from doing this and you had to call someone to come and collect the pots. I can't remember exactly when this was or who told us.

18. There was originally a playroom on ward 2A but it was a bit juvenile for [redacted] to use. There was a teenage part of the ward and then the playroom for younger children. There was nothing for the children in the middle age group but at least the playroom had been somewhere [redacted] could have the option to go to for a different space and get out his room for a bit. When the Schiehallion ward finally opens in ward 2A again, it will have a new and better playroom for children his age. There will be a playroom for children that fall into the same age bracket that [redacted] was in. I have heard this from other parents. But it got to the stage, before we moved, that

everyone was stuck in their rooms and you couldn’t move around the ward anyway, so by then it didn’t really matter.

19. Occasionally there was a teacher that came round during school time but this stopped in July 2018 when the schools went on holiday. There was also a group that went round doing events but [redacted] didn’t like these. He preferred being given stuff to do. The nurses would bring him computer games for his switch, well it was his sister’s switch, but she let him use it. He was able to sit and play games which he was happy with. If we asked for materials for [redacted] he was given them so he was kept going and had stuff to do.

20. We took our own tablets in with us which worked occasionally when the internet worked. We ended up buying subscriptions with Vodafone as the hospitals internet just didn’t allow streaming. Their internet was fine if you were just in visiting someone but not for someone who was staying in there long term.

21. There was a television in the room too, when it worked. The television was vaguely okay when it worked but it didn’t work more often than it did so if you forgot to take a book with you, you’d be sitting staring at your phone or the walls all day. You had to wait for someone to fix your television. There were certain staff members that had the knack of fixing them but many didn’t. There was one auxiliary in particular that could fix them and you hoped he was working so you could get your television fixed. We did ask about getting the television fixed properly but were told by staff they could put a proper repair call in but they take ages to get answered. When the TV wasn’t working, it had an impact on [redacted] too; with the teacher not coming in and the television not working, there was nothing to break up his day.

22. During [redacted]'s first round of chemotherapy, he was initially in isolation and he was allowed home for a few days when he was deemed to be recovered. He would then be admitted for further rounds of treatment.

Further admission to ward 2A: August 2018

23. [redacted] had been allowed home for a few days and we went back up to CLIC Sargent in preparation for his next round of chemotherapy. [redacted] was admitted to ward 2A at the tail end of July 2018 for his next round of chemotherapy to be started at the start of August 2018.

24. I believe the room that was he was in this time was an isolation room. There seemed to be less issues with the isolation rooms in that there were less people coming in and out checking taps.

25. During this time, I had to go back to work. This admission is hazy for me as I wasn't there for all of it. I would still visit him and Denise as much as I could but during this time, we were like two separate families.

26. [redacted] was due to start primary 1 at this point. It's not the start of school we imagined for her. Her brother wasn't there for her and for her, that was scary.

27. [redacted] had been discharged home during this period but I can't remember the exact date however, he then had to be readmitted to ward 2A again. He had been complaining of a sore stomach and when we phoned the hospital, they told us to take him up. This time he was admitted to room 10. Oncology doctors thought it was his appendix that was causing the sore stomach. [redacted] was due to get a bone marrow transplant however, this had to be postponed twice due to the problems with his appendix and subsequent events.

Experience on ward 6A: late 2018 - December 2019

28. The Schiehallion Unit, ward 2A, was moved completely to ward 6A. We were told initially that it would be for a short time but it soon became clear it wasn't for a short time.

29. Initially when we went to ward 6A, I think there was a kitchen and a fridge you could use. The rooms were nicer than the standard rooms and they had paintings on the wall. I thought they would have been better set up though for children that were going to be staying long term. It's good that the rooms had the paintings on the wall but they weren't designed for a parent and a child or two parents and a child. There were not enough seats and it had a horrible push up bed that I think had been brought out of storage. When [redacted] was occasionally staying with her grandparents, Denise and I would both see [redacted]. There wasn't anywhere for us both to sit though. You had to get someone to fetch you a chair and it was one of those hard, plastic chairs.

30. It surprised me that the ward was for children who were going to be staying long term as I thought it would have been better set up for parents coming and going. You felt you were an attachment that had to come with the patient rather than being wanted there. It wasn't done to make you feel unwelcome, it was just the environment.

31. There was nothing on ward 6A for [redacted]. It was lacking for his age group. The play room was another space to go rather than being designed for an 8 year old child as he was at the time. That side of things was hard for him. The nurses and play leaders were great at getting him a game system and stuff for him to play with as that was his world. The teenage space would have suited him but he was too young for it. I'm glad to say I've heard they've created a better space for the groups of kids that age, the group just before being teenagers so that's good for the next ones unfortunate enough to be in there but for him, there wasn't a great deal.

WATER: EVENTS INVOLVING WATER SYSTEMS

32. It wasn’t uncommon for men in uniforms to be coming in to [redacted]’s room to examine the taps in ward 2A. I was never told why they were doing it but it happened quite a lot. It seemed to happen in the normal rooms and not the isolation ones.

33. The bathroom on ward 6 was closed off too. It was at the entrance to the ward and had a bath in it rather than the showers that were in the rooms. I remember there being a sign on it saying, “Do not use”.

34. There were filters on the taps. I knew they were there because they’d had previous issues with the water but I can’t remember who told me. I think it was maybe the charge nurse during our induction briefing about the wards.

35. There was the constant need to use bottled water on the wards. I found this really bizarre as one of the things you’ve not to use on the list given to you for transplant, is bottled water! When the ward was running okay and people remembered to bring up bottled water, you were given it but there were many occasions when they forgot and you had to go and buy your own usually from Marks and Spencer’s and it wasn’t cheap. I sometimes used to go to Braehead to get water there so we had enough to keep us going. You had to bring it in from home or buy it.

36. I remember seeing the usual water coolers in the open public areas but they were without water. There were signs up saying not to use any of the water in the clinical areas too.

37. Denise didn’t use wipes on [redacted], she would scrub [redacted] and shower him but this was before we knew about the issues with the water. She

believed he always had to be clean and this maybe came from her background as a nurse so she always kept [redacted] clean. We also made sure our own personal hygiene was as good as possible. We regularly used the water, whether this was a good thing or bad, I don't know now. It was the best solution at the time, to use the water and shower [redacted] to keep him clean. In the normal rooms, the ones that weren't used for isolation, the water used to back itself up in the shower room. When showering [redacted], Denise would make sure she didn't get too much water on his line. I wasn't there when Denise was doing this but she told me.

Water: communication

38. We were told not to drink the water but that it was fine for washing with. It was the charge nurse that told us this when we first went to ward 2A. It was a bit like a briefing. You were told what to expect on the ward when we were due to move from ward 2B to ward 2A. She said they'd had previous issues so not to drink the water and there would be bottled water provided. She then went on to tell us about the parents' kitchen and the play room so it was just like an induction she had given us. We were told the same in ward 6A but we were deciding whether to use it to wash with or not. I used it to wash my hands with it though. I can't comment on ward 4 as it was just [redacted] and Denise that were there when [redacted] had his transplant.

39. As much as you were told not to drink the water, you were told it was okay for boiling. It's bizarre now that I'm thinking about it, we were regularly drinking it through tea after boiling it.

40. I remember speaking to some of the other parents and they were using wipes on their children as they were afraid to use the water.

HEALTHCARE ASSOCIATED INFECTIONS

HAIs: events and physical impact

41. [redacted] was neutropenic. On 7 July 2018, [redacted], [redacted] had red man syndrome. His body was completely red and the tips of his fingers had started to go blue. This was his body shutting down to protect itself. Doctors were flinging every antibiotic at him. It was ridiculous, there was every known antibiotic getting used. It was getting to the stage where he was going to be given some of the most powerful antibiotics and if they didn't work, we'd have been up the creek without a paddle. He was going from being fine one minute to rigoring the next because his temperature kept peaking. Other times he would settle then his temperature would spike again. This went on through-out the day. When we thought he had settled and was going to be okay, Denise and I went out for an hour but when we got back, [redacted] had deteriorated back into that position.

42. I've never seen anything like it. To see your son going completely red and his fingers tips turning blue was scary, it's not a sight I want anyone to see of their child.

43. Through the window we could see the doctor that had been attending him and the Advanced Nurse Practitioner having an argument. We couldn't hear what was being said as we were in the isolation room but they were clearly arguing about what was happening with [redacted] and the fact they kept pushing antibiotics in his line and [redacted] was going from being fine to being really ill. The more drugs they pushed in the sicker he became and Denise had been going to ask them to stop giving [redacted] antibiotics as nothing was happening, he wasn't getting better. I think the Advanced Nurse Practitioner went and got Professor Gibson as she turned up and told them to stop pushing the antibiotics. They stopped the antibiotics in the evening and Denise stayed with [redacted] that night. I went into see him early the next

morning and he was back to normal and completely better. Professor Gibson had come in to see him around 7:00 AM which isn't a normal time you would expect to see someone so senior coming in to see a patient. Professor Gibson checked on him and said she had stopped the antibiotics to a level to allow his body to recover. He was back to playing computer games and eating, my son likes to eat as well.

44. We had assumed it was the red man syndrome that had made [redacted] so ill. Staff had been telling us he could have picked an infection up at home but he wasn't home long enough for that to happen so we challenged this with the staff. [redacted] took part in the Case Note Review. He was one of the 83 or 84 children that had caught an infection on the ward.

45. At the end of August 2018, [redacted] had been allowed home for a couple of days. He started feeling unwell and was complaining of stomach pains. I think he spiked a temperature too. The minute [redacted] spiked a temperature, he has to go straight back to hospital. We went to the hospital that night and [redacted] was admitted to ward 2A, room 10. They thought it was his appendix causing the issues so it was organised for him to have it removed. For most parents and kids, having the appendix removed is huge thing but for us, it was as minor as getting a cut in his hand, compared to what he had been through.

46. Due to the gram negative infection and having to get his appendix removed, [redacted]'s bone marrow transplant had to be postponed. It was planned for September. He had his appendix out on ward 3 then moved back to ward 2A. Two days later he had to get his central line removed due to the gram negative infection showing in his blood cultures.

47. The gram negative infection and the removal of his appendix meant that [redacted] had to get two lots of surgery in a short space of time. [redacted] doesn't like injections and would get himself really worked up. His autism

comes in to play here. A child without autism would get really worked up but for [redacted], he would get extremely anxious and you would have to use everything within your powers to get him to settle.

48. [redacted]'s transplant was postponed a second time so he eventually had it in October. We are so lucky the donor didn't pull out.

HAIs: communication

49. We weren't told much about the red man syndrome. It was suggested that it was an allergic reaction to vancomycin but it was never confirmed.

50. The day [redacted] had his appendix removed, Denise was told he had a gram negative infection. She asked where the infection came from and she was told it was possibly from his appendix but when Denise spoke to the surgeon later on, she was told there with nothing wrong with [redacted]'s appendix. Denise will tell you more. She doesn't understand why the line removal wasn't brought up earlier. She has an understanding of these things as she's a nurse. She was trying to explain to me that they would have had an indication about the infection first then the detail would have followed.

51. I wasn't told anything directly from medical staff. I only heard it second hand through Denise. It was after [redacted] had the gram negative infection, Professor Gibson had arranged a meeting for Denise, someone from microbiology and Jamie Redfern, who was General Manager for NHS Greater Glasgow and Clyde. My father-in-law attended this with Denise as I was working. I was told by Denise that hospital staff in the meeting had been challenging Denise and saying that [redacted] could have caught the infection at home and not within the hospital. I can't remember exactly when this was. [redacted] was getting sent home though and his consultant, Dr Chaudhry, gave the impression that she was happier with that than [redacted] being on the ward. Nothing was actually said but we got the distinct impression that

when she said she was happy he was going home, she meant that she was happy he then couldn’t be affected by what was happening on the ward.

OTHER ISSUES RELATING TO HOSPITAL CONSTRUCTION

52. There was a smell at the hospital. On some days it was bad enough that you would mention it. Depending on which way you went to the hospital, you could smell it long before you arrived. We came off the M8, we didn’t go through the Clyde tunnel but instead through a wee industrial estate and then there’s a junction that looks like a Philips light bulb. On a really bad day, you could smell the sewage at that junction bearing in mind you’re not at the hospital yet, only the junction. It progressively got worse the closer you got to the hospital even with the car windows closed. When you got to the car park, you were literally holding your breath until you got into the building. You would then smell it in the building too and in the ward, even in the isolation rooms. If you can smell sewage, there must be something in the air that’s not right. There must be bacteria in the air to cause the smell. It was a regular occurrence.

53. There were people constantly in looking at taps and the ventilation, especially in the upper rooms. They seemed to have the most problems so did the rooms at the nurses’ station.

54. Also on the very day we received the news of [redacted]’s diagnosis, right at the start, my wife Denise noticed that the ventilation hoods were popped open. She commented “they’ve got a problem with ventilation.” The wards were ridiculously warm and there was a smell. The isolation rooms had better ventilation but the smell was worse in these.

55. When we were in Ward 6 they eventually brought in big ventilation units.

CLEANLINESS

56. The staff were carrying out electrostatic cleaning on ward 2A. I can't remember exactly when this was but I think it was round about the time that [redacted] went into isolation. Possibly the end of May. I was told by Denise that when she had been speaking to one of the nurses just before I came back, that the nurse had told her they had problems on the ward in the past and this electrostatic cleaning had resolved the issues. Current issues weren't mentioned, just that they had issues in the past and this had fixed it.

57. My general impression of the cleaners were that there weren't enough of them. There were 2 at most for the whole ward. There was one cleaner for the source rooms and the other did the rest of the rooms. They spent as much time in [redacted]'s room as they do in my classroom at school. They used the same mops for cleaning the bathroom in the room as they did for the rest of the room. They also didn't lift anything and cleaned round things like board games that [redacted] had been given by the play team.

OVERALL EMOTIONAL IMPACT ON [redacted] AND HIS FAMILY

Overall emotional impact on [redacted]

58. I think in some ways, [redacted]'s autism has been a blessing but in other ways, it's not. His anxiety when he was ill and getting his appendix out and then his central line, was bad. Cancer treatment is bad enough to be going through as it is without everything else included. He didn't like being away from his friends and his sister for so long though.

Overall emotional impact on witness

59. I was angry. I was angry that all of this was going on and we weren't getting answers. I was angry that [redacted] had to get two lots of surgery as they

thought his appendix was causing an infection when it was a gram negative infection. His appendix, according to the surgeon was fine and it was a line infection.

60. I was disciplined at my work during all of this for the length of time I had to take off. Although not a direct link to the hospital, it was an added pressure on top of [redacted] being treated for CML then having the infection and his appendix removed. I was also trying to support [redacted] as best I could.

61. I think I bury a lot of it. I'm more emotional now though.

Overall emotional impact on family

62. Denise's work were great with her. She had a really supportive line manager which helped. They were fully aware of [redacted]'s situation with treatment, the infection and other stuff that was going on additional to the treatment. Denise suffered badly with it all. She still has nightmares as to what could have gone wrong and what did go wrong, what if there had been another outcome. She can't work without a breeze in the rooms at her work as there some things that remind her of the time in the hospital with [redacted].

63. [redacted] missed time with her brother and her mum. Although I was there, she was needing her mum. When [redacted] was neutropenic or ill, she couldn't see him or Denise for weeks. She was pushed from pillar to post so I could go to work and visit [redacted] and Denise. She had to get used to other family members looking after her when I couldn't. Her confidence was knocked and she was very insecure for a while. She knew later on that when [redacted] spiked a temperature, it would mean him and Denise going away for spells again.

64. We were lucky as [redacted]'s treatment had been relatively short compared to some of the families who've had to go through years of treatment but if

[redacted]'s bone marrow transplant hadn't been postponed twice, we would have been a family again a lot quicker and this would have had less of an overall impact on us as a family.

COMMUNICATION GENERAL

65. Denise also told me about a conversation she had with a nurse round about this time. Denise had noticed the room as [redacted] was in one of the isolation rooms near it. There was nothing in the room at all, even the furniture had been removed. She had been asking the nurse why one of the rooms was completely sealed off and the nurse broke down. She maybe felt she could speak to Denise, nurse to nurse. Denise asked "is it that room?" She said to Denise that she didn't know how close she was to the truth. She said the staff weren't allowed to talk about it. It was tears of frustration I think. She said they knew there was a problem on the ward but they couldn't do anything about it. I walked in on the end of the conversation and the nurse was saying that there were a lot of sick kids on this ward. I saw what a state the nurse was in. Denise understands the life the nurses have. She's not one to hold back with asking questions, especially where [redacted] was concerned and she has the knowledge to know what questions to ask. I think this conversation took place around about the time that a death had occurred. It was maybe due to pressure that the nurse broke down but there was definitely something not right at this point. You could feel it.

66. It was on STV news about ward 2A closing in the RHC. The news stated that there were 6 families where the child patient was suffering from an infection. We were one of those families. It all came out in the media that the ward was closing before the hospital had its act together and spoke to us. The fact we heard via the media before the ward gave us a statement was diabolical. I was extremely angry about this and asked to speak to a manager. The hospital Managers were hiding behind medical staff. There was a Microbiologist who came to speak to us. I explained to her I wasn't angry at

her but I was angry with her bosses. It was common decency to tell us what was happening before giving a press release. Any time the hospital told us anything after that, it was through a copy of the press release. The hospital Managers had no time for the families.

67. When [redacted] was on ward 6A with a temperature spike, I received a letter from Jamie Redfern. The letter stated that there was something going on with the Schiehallion ward. I can't remember the exact content but nobody came to speak to us about it.

COMPLAINTS

68. I didn't make any specific complaints to the hospital. I can't speak highly enough of the medical staff. They did their best in very trying circumstances and they gave my son the best of care but my impression was that the NHS management team would rather "throw the doctors under a bus" than speak to families or answer questions.

69. I did phone to try and speak to senior management once, but I was told they were busy in a meeting and gave me a microbiologist to speak to, which was not satisfactory.

OVERSIGHT BOARD / CASE NOTE REVIEW / REPRESENTATIVE GROUPS

70. [redacted] was part of the Case Note Review. His report said it was probable he caught stenotrophomonas in the ward. We were on ward 2A when all of this happened. We applied for [redacted]'s medical records. Some are missing but there's also notes clearly stating that [redacted] did not catch the infection on the ward so someone has lied on official documents as the Case Note Review think it's probable that [redacted] did catch the infection on the ward. Speaking as a Maths teacher, when you're speaking about probable, this means you're talking about 60% upwards. When you head into the higher

bracket of probable, in my view that is the likelihood of something happening or not then the explanation is that either someone has lied in official medical notes or they've gotten rid of a piece of paper that said [redacted] did get the infection in the hospital and that's worrying.

71. There's other stuff that has come out too. You heard about things to get looked at in the minutes but they never occur. As a school teacher, I'm not making life or death decisions but if I agree to do something in minutes from a meeting, it happens and there's a follow up too. If I don't do something from minutes, there's a follow up for that too. The hospital are dealing with life and death but there's no follow up to find out what's causing it. Maybe they did know what was causing it but they don't want official records to show what's caused it. Logically, that's where my brain would take me. People would not do something if they didn't want official records of it. This is where I am coming from regarding the hospital with infections.

72. We attended the meeting with the Cabinet Secretary at Central Station Hotel in Glasgow. It was arranged by one of the parents, and it was at that meeting the Health Minister was promising the public inquiry. We found out about it via one of the family groups on Facebook. She listened to us, but we didn't get many answers. She said that the doctors and nurses could be honest with us, but we knew they feared for their jobs and they had their contracts of employment with the NHS Boards and that complicates matters. She saw how angry we were.

73. Professor White was appointed as family liaison. We got some communications from him but they tailed off. We got updates about the CNR from the Closed Facebook group. We were also a member of the Schiehallion parents Facebook group.

74. John Cuddihy was the family representative on the Oversight Board sub-group and he passed on what he could, that was allowed by the Oversight Board.

CONCLUDING COMMENTS

75. When [redacted] had his red man syndrome, he was only ill when they kept pushing drugs through his central line so that told me straight away, and I think it told Denise as well, there was something in the central line. The same central line that we were told ages ago, there was a gram negative infection in it. That very same central line got taken out. That’s what drives me insane about the whole issue. It feels like someone is trying to hide something or is doing their best to try and hide something. If that’s not the case, then they’re doing a damn good job of making it look that way.

76. I would fight to my dying day for the NHS but I hate that hospital. I don’t trust that hospital and I don’t trust the management team.

77. Nothing is normal about this process, and we knew that the illness and the treatment took time. But there were delays and we always just felt something was wrong, not quite right with the hospital

78. I am angry at the dishonesty. At every turn management tried to hide the issues, if they had just been open and honest and acted immediately when there were issues, it might have been different. The minute something occurred, they should have been open, instead things were pushed to the extreme and people have died.

79. I am now just glad that I don’t live in Glasgow and come under a different Health Board which hopefully means I will never have to go back to that hospital.

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

In accordance with Restriction Order 2 , the Inquiry has provided excerpts of the witness statement for Witness 1. The Inquiry will only provide excerpts of the statement that do not contain information that is capable of leading to the identification of the Witnesses

Scottish Hospitals Inquiry

Witness Statement of

Witness 1

OVERVIEW

1. My [redacted]. [redacted] was born on [redacted]. [redacted] was diagnosed with Acute Lymphoblastic Leukaemia ("ALL") on [redacted]. [redacted] was treated in the Royal Hospital for Children ("RHC") and Queen Elizabeth University Hospital ("QEUH") between [redacted]. [redacted], [redacted].

2. [redacted] spent time in wards 2A and 2B in the RHC, these are known as the Schiehallion Unit. [redacted] She also received surgery in the theatres in the RHC and was admitted to the Paediatric Intensive Care Unit ("PICU") in the RHC.

3. There are some specific things that I would like to mention. [redacted] contracted a number of infections in her central line when in ward [redacted]. [redacted] included in the Independent Case Note Review [redacted]. She was prescribed preventative medication which I believe was connected to issues with the hospital environment. There were all sorts of issues with the hospital throughout our time there which, in my view, impacted on her treatment and on our family's experience. I will talk about these in more detail.

4. I think she was sick twice, and that maybe we saw bruises coming and we took her to the [redacted]. I can't remember when or even what was specifically wrong with her for us to take her to hospital. She just wasn't quite herself. [redacted]. [redacted] [redacted] .

5. She was diagnosed not long after that and it was just a massive downfall.

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

Diagnosis and admission to the RHC

6. When we got to the hospital. [redacted] had been admitted to the Intensive Care Unit in the children's hospital. The staff performed a lot of tests. After a few hours we met Professor Gibson who told us that she thought [redacted] had leukaemia, the children's leukaemia which is ALL.

7. [redacted]was moved onto ward 2A in the RHC which is Schiehallion ward.

[redacted]'s treatment: Ward 2A RHC – the Schiehallion ward

8. [redacted] to the Schiehallion ward to begin her chemotherapy treatment. I don't remember all the details of the amount of different chemotherapies and stages but it was intensive induction chemotherapy treatment.

9. We were settling into the ward. We'd met a couple of other parents by this point. We were getting the lowdown of the ward; the lowdown of our new world. Our world had crashed, absolutely crashed down in front of us. On the ward everybody's enthusiastic about everybody's chances and they're trying to will everybody on and all the rest of it. So you make friends. We made friends that are like family now.

10. [redacted] an induction style blast of chemo and within 5 weeks she was MRD negative. The hospital did a Minimal Residual Disease ("MRD") test to see whether or not she was MRD negative. Basically this means that she's got no leukaemia cancer cells in her body and her immune system's producing good cells.

11. At this point the doctors were quite happy with her and we were transferred to a VAC room in ward 2A.

12. VAC rooms are the transplant rooms. When you entered you had one room where you walked into and it had a sink. You had to take your shoes off, wash your hands, put on an apron, and then you were allowed to go in through the next set of doors and into the patient bedroom.

Event:

13. Every time [redacted] was unwell they had to put cannulas in to give them a line to feed the chemo or a line to feed antibiotics or a drip, anything that had to go through some sort of vein. The first time this happened was when she had an infection, the line had to stop being used and then staff used cannulas instead.

14. I was saying to the nurses, what do you think is wrong with her? Nobody would tell me. She'd picked up some sort of infection and it's obviously not agreeing with her. She needed to fight hard to get herself over the infection.

15. The nurses pass it onto the doctor, the doctor can't give you a serious answer, so they pass you onto the professor. Nobody could be honest with me at all when it came to anything like that.

16. Every time the staff tried to insert this cannula, [redacted] could feel the pain.

Hospital Acquired Infection

17. Staff were just passing it off as if it was an ordinary infection that was getting the better of her.

18. [redacted] This one you could see was different. The way it was eating into her body, eating into her blood stream. You could see it was totally different than the way that she was able to actually contain it.

19. When she had the infection [redacted], [redacted]'s chemo was delayed for about two weeks. Her chemo was only ever delayed due to infections. I am not aware of any other reasons for the delays. [redacted] was really unwell.

20. They cannot use the line in the chest when an infection is found because that would spread it. If the infection is not as serious and it can be eradicated without removing the line, they will do that, in order to avoid the distress of having to go to surgery to have the line removed. [redacted] would have to be fasted for 12-14 hours before surgery. On this occasion they had to wait until the infection cleared up before they fitted a new line. [redacted] had to be taken to theatre for a PICC line to be fitted to give her antibiotics to clear the infection. Once the infection was cleared up, she went to theatre for a new line to be fitted in her chest.

21. When I read her report from the Case Note Review, it confirms the date and timings of the infection she had.

Relapse - Admission to Ward 6A of the QUEH:

22. This was the first time we were ever in ward 6A in the QEUH. At this point wards 2A and 2B in the RHC were shut. We were told it was shut because of maintenance works being carried out in Ward 2. I think they might have

actually said that it was related to water or sewers or something, but I couldn't tell you for sure. It was the nurses on the ward who told us that.

23. Most of the time it was the nurses we were chatting to I actually felt sorry for them. They were in the firing line from the parents as we were asking questions, and then they were in the firing line from management, because they weren't allowed to tell you the truth.

24. In ward 2A, the cleaners weren't great, the floor was minging after they'd cleaned it and [redacted] was going round after they'd cleaned it with baby wipes. It wasn't even a proper mop. It was one of those mops with the Velcro pads. They had tablets in the mop bucket but the floor was never wet. Ward 6A was still dirty. It was the same staff, the same nurses, it was the same cleaners as on Ward 2A. The scenery was better because you were up high on the sixth floor.

25. Everyone seemed to be "in source" in ward 6A. When a patient is in source, they are in isolation. They are not allowed to leave their room. A patient was put in source when they had a gut infection. They did not want the infection to spread to other patients. When a patient is in source, you are not allowed on the ward other than to walk to their room. You are not allowed to stand and speak to other parents. You are not allowed to use the facilities like the kitchen. [redacted] got no support from the staff. We felt like we were shut away on our own in a room.

26. [redacted], we didn't want to use the water. [redacted] used water wipes. By this time, we were told not to use the water, letters were coming round and people were talking. The communal bath was blocked off. Nobody was allowed to use it. At that point, the next stage in her treatment plan was to try to get [redacted] back to being MRD negative.

HEALTHCARE ASSOCIATED INFECTIONS

HAIs: events and the physical impacts

27. [redacted] had a line in her chest which goes to the main artery, it was a Hickman line. There are six main arteries in the body that this line could go into. [redacted] [redacted]. When [redacted] was being fitted, the doctors came to talk to us about [redacted] going into theatre and to discuss what they were going to do in the theatre. The line is used to take blood and give medication and chemo.

28. [redacted] had a number of infections. The other line replacements were due to infection. She had a lot of line infections when she was in ward 2A. A number of times when she had to have her line removed and replaced, it was a surgical procedure under general anaesthetic with the fasting and waiting and all that going into surgery involved.

29. When [redacted] had to have the line removed because of infection two surgeries would be required. The infection had to be cleared up with antibiotics before a new line was fitted.

30. Lines were removed when the staff couldn't deal with the line infection using antibiotics. They had to remove [redacted] central line. There were other infections too, but they managed to catch these with antibiotics. [redacted]. On none of these occasions could they tell us exactly what was happening with [redacted]. [redacted] There were a couple of occasions when she was admitted to PICU in the RHC. They were keeping an eye on her when she was really poorly at those times.

31. [redacted] did not have one infection when she was out at home on maintenance treatment [redacted]. Not one infection. Every infection she had was when she was in hospital as an in-patient.

32. Another thing which I raised with the nurses all the time was the frequency of the changing of the dressing round the line. [redacted]'s dressing would start to peel away from the line site and it would get all scabby looking. I had to constantly ask for the dressing to be changed. At one point one of them said to me, we're not allowed to change them now for a week. I asked why and I asked that they show me how to change the dressing. They said they were not allowed to change the dressing for a week, no sooner. Their reason due to stock supply. They commented that we cannot waste stock. They would give us wet wipes and tell us to make them last us.

33. Not only that, water could actually get underneath it and get to the site. Why would you let it get infected for a week? If you've got any chance of getting infection because it's curling up or whatever and it's getting exposed to water, why would you leave it a week?

34. In terms of infection prevention, the position for every kid in that ward is that they're on chemo. Chemo's whole job is to rip your immune system to shreds, basically. It doesn't matter who gets chemo, me, you, anybody, the minute you get chemo it starts to work on your immune system which leaves you susceptible to infection. It doesn't matter what age you are.

HAIs: Impact on [redacted]'s treatment

35. Every infection [redacted] got delayed her chemo treatment, which in turn give us that chance the cancer is coming back because she was not getting her chemo treatment. That's the biggest fear. It is the fear for every single parent on that ward, that the cancer is it coming back. It is scary if you've got a kid that's fighting an infection for two weeks and the staff can't give them chemo and they're putting chemo treatment off.

HAIs: communication

36. In terms of the hospital staff communication with me and [redacted] about the infections that [redacted] contracted, if I was rating it out of ten I would say a two. That's telling us exactly what it is, telling us how we're going to get rid of it, telling us how she got it. I would give them a two out of ten for that.

37. When it comes to the nurses and the doctors finding out if [redacted]'s unwell and keeping her comfortable, I would probably rate them a wee bit higher in that. They were really good and really efficient that way.

38. For the big statements they were honest, but when it came to infections, they don't tell us much. All they said was that they were growing the blood cultures in the lab for two days and we'll let you know.

39. They didn't always tell us what the infections were. We might have been told about some of the fungal ones. I can't remember the names but it's basically a gut infection. Staff would tell us about that one. But they didn't tell us when it was the blood that was infected with sepsis.

40. [redacted] contracted sepsis when she was in hospital. I cannot confirm the date of this.

41. At one point she was on five antibiotics. Five antibiotics in the one go, different ones. The nurses were scared for her at this point. They were frightened for her and when you see that you know how bad she is.

42. [redacted] had high temperatures. We used to sit and watch these high temperatures, and wish they would come down. They were off the scale. The wards have a thing called a Tempadot which measures your temperature up to 40 odd degrees maybe 42 or 45. I can't remember the exact maximum of it. The temperatures she was having at this time were taking her off the scale.

With the gut infections, the high temperature would go down. She might still have the runniness of the tummy for two weeks, but the temperatures would stop. When she had sepsis, her temperature would not go down.

43. I know [redacted] [redacted], and she had one or maybe two infections that were included in the Case Note Review. She had at least one infection that the panel said was saying is connected to the water, but every infection in that place just causes heartache. I speak about the Case Note Review later on.

44. The timeline I have given the Inquiry is about two, three pages long, but it’s not half of what actually happened when you look at the medical notes, what went through in that place. The timeline is just the main points that stick in our minds. There’s loads of stuff under the surface that’s in the notes.

PREVENTATIVE MEDICATION

45. [redacted] was given preventative medication at some point. First of all there were issue with the water, and the bird issue with the pigeons and then the hospital gave every single kid on the ward the same antibiotic. [redacted] did receive it but I can’t remember the name of it. It was given to all of the kids, and at the time we were told it was to keep her safe from an infection. We weren’t told every kid on the ward was getting it.

46. [redacted]We found out the other kids were also given the medication because every parent talks to each other, so it soon gets about. “Oh so and so has started on this today”, “oh such and such has started on this today. So had [redacted]. Before we knew it, everybody seemed to be taking it. I think that must have continued after we left the hospital [redacted], because when we left there were still filters on the tap, the air purifier were in the room and the bottles of water were still there.

WATER

47. When we were on ward 2A, we noticed that signs started going up around the ward "stop using the water", "don't brush your teeth in the tap water". We got a letter from the hospital which told us not to brush our teeth in the tap water.

48. I asked "are you sure this water's actually safe, why is she getting so many infections?"

49. Obviously lies, lies, lies, as I know now. They tell you it's fine. The staff would try and walk over [redacted].

50. [redacted] started to wipe her down around about this time in ward 2A. [redacted]. They were giving us bottles of water to drink as we were not allowed to touch the tap water.

51. I watched plumbers come into [redacted]'s bedroom, bearing in mind nobody's been allowed in [redacted]'s room, to change the filters on the tap and shower heads, and I'm like why is all this happening?

52. The bottles of water were for drinking, brushing your teeth, washing your face, that sort of thing. I don't know if [redacted] used them for anything other than that. But this is what I didn't get, as the hospital are telling us to use bottled water do these things at the same time they're washing their hands using water out of the tap. Every time they're leaving the room, every time coming into the room.

53. The situation with the water was not much better when we moved to ward 6A in the QEUH. In fact, I had the same conversation with the head nurse on the ward there too. When we went into ward 6A, we were still given bottled water. You walked onto the ward and there were big piles of bottles of fresh still water to drink. So I asked the question[redacted] when we were up there as well. She told me the water was fine to be used and that all the

precautions had been taken. The kids were allowed to bath and use the tap water, and in fact they were allowed to drink it too even though there was bottled water there.

54. In my view the water in the hospital was not fit to be used. That is based on what I saw in both ward 2A RHC and 6A QEUH. How can tap water be fit to be used, even when it's got a filter on it? When I saw the filters, [redacted] alarm bells were ringing. The filters on the taps were filthy. Absolutely filthy. On one occasion I asked one of the plumbers who was in changing the filter if I could see it. He showed me and it was absolutely bogging. That filter was changed maybe once a week or once every two weeks; imagine the amount of water that runs through that.

OTHER OBSERVATIONS ABOUT THE HOSPITAL BUILDING

55. The water wasn't the only thing wrong with that hospital. Everything was wrong with the building. On one occasion one of the big panels had fallen off and crashed to the floor. The panel fell off overnight, so I didn't see it happen. It's lucky nobody was hurt to be honest, because if that had hit somebody they are dead.

56. The rooms in ward 2A were absolutely roasting. You couldn't do anything to control the temperature. The air conditioning didn't work. There was a dial in the room and I could turn whatever way I wanted; it doesn't do anything. The staff have got a dial out in the ward, they can turn it whatever way they want; it doesn't do anything. We were always told it was broken. On a really hot, sunny day the rooms were absolutely roasting. Imagine sitting in that heat, no windows to open. Not that you would open them right enough because the smell would have been worse.

57. There's certain rooms on that Schiehallion ward which are situated at the front of the building, which is the road that the buses drive up right in front of the main hospital and children's hospital. If you are in any of these rooms round

about that front edge of the building, the smell of sewer was absolutely overwhelming. In the summer when it was absolutely roasting, that smell of that sewer was absolutely stinking. The smell was so bad in the building too, and I don’t know whether it was coming out the drains or whether it was just filtering. The hospital’s actually built on a sewer or next to a sewer. I don’t know if that’s something to do with it, but something was causing that big, horrible smell.

58. In the [redacted] was on her maintenance treatment, we had to walk through the doors of the children’s hospital. When the panels fell off, workman started to strip the panels off the outside of the building. I’m sure when I asked somebody in the hospital about it that I was told that it was so workman could get to the water and it was to do something with the water. The cladding panels were stripped off and all the insulation inside the panels was deemed really bad for cancer kids. I think it was something to do with the fibres in the insulation and their immune system, because their immune system was suppressed it was deemed bad. We got these letters from the hospital and we were told not to use the doors at the front. We had been walking through these doors for two weeks whilst this had been going on. Why are these letters only coming now?

59. I can’t even remember the exact response from staff at the time. The answer was along the lines that we had the letter now. They were just doing anything to shrug you off the subject.

60. When I received communications like that it made me feel disgusted. When somebody doesn’t communicate with you properly, you feel like you’re being lied to. You feel like somebody’s holding something back.

61. I just got hiding under the carpet. I always felt like we were told on a need to know basis

PHYSICAL IMPACTS ON

62. In terms of the physical impacts on [redacted], she had to get her lines changed [redacted]. This was a surgical procedure that took place under general anaesthetic. Surgical procedures [redacted] took a long time in total. It is not a case of in and then out. [redacted] had to be starved for 14 hours before surgery. On more than one occasion we starved her for 14 hours, and we were waiting to go to surgery only to be told it was not happening today and she was going tomorrow. [redacted] We were allowed to give her water up to a certain point, then we had to stop the water a few hours before.

OVERALL IMPACT ON THE FAMILY

The emotional impact

63. Obviously the impact on our family is caused by [redacted] having cancer. But the impact of her having all these infections from a place that wasn't fit for purpose made her life harder than it had to be. [redacted] [redacted]. She spent 10 months in hospital and then 3 months out at home, [redacted] If she hadn't had so many central lines her life would have been better. [redacted] breezed every single chemo but all these infections made her unwell, she got better and then she got another infection.

64. Will my family ever be normal again? I don't think so. Will it ever be easier? I don't think so either. I might be able to put things to the back of my mind for a certain time.

COMMUNICATION

65. At the time [redacted] was in treatment I didn't see any reports in the media about issues at the hospital. [redacted] [redacted] [redacted]. There were reports in the press and online. I saw parents sharing certain news stories on social media.

66. I feel ashamed for the people that built and run that hospital. I feel gutted that they can't even tell the truth. I've been to places like hotels, where you walk in and you know this place is beautiful. They've put loads of effort, loads of money and loads of time into actually making this place lovely. But that's a hotel.

67. A hospital is a totally different ballgame. Why was it built on a sewer?

68. When you're walking in to the building and there's panels hanging down, there's leaks everywhere. We walked into the main foyer and there was leaks everywhere. The ceilings were collapsing. The sad bit is I actually know a couple of people who worked on it, and these people are good tradesmen. But there was no doubt there were corners cut on that hospital. No doubt about it.

69. Everything that I witnessed when I was in that building makes me say that corners were cut when it was being built. Take the issue with the pigeons. How did the pigeons manage to get into that loft space to do their droppings into the ventilation? There was a panel missing. We were actually told that by someone at the hospital. I can't actually remember who it was but it was probably somebody on ward 6A at the time.

70. I think that we found out about the pigeon droppings from one of the staff members at the hospital I think they told us that because of how they handled the communication with the water system. They didn't tell us the truth about

the water, then they got found out so I think we were told about the pigeon stuff by the staff.

71. We were given a letter from the hospital saying they had to fit some sort of filter in the rooms in ward 6A that would purify the air. The filters were put into every room in ward 6A. When I got that letter and when I saw them putting these filters out, it made me questions what we were doing in the hospital. would have been safer in the house.

72. We were getting handed letters by the auxiliaries telling us they were cleaning the pipes, refilltering the taps and we were told again and again that it was fine. They lied to us.

THE INDEPENDENT CASE NOTE REVIEW

73. [redacted] was included in the Independent Case Note Review. I have received [redacted]'s individual report which told me that [redacted] did get infection that was likely to come from the dodgy water in the hospital. It's there in black and white in the Case Note report.

74. I thought it was a bit vague at parts. I'm happy that the Case Note Review told me the truth. They confirmed that [redacted] had infection from the water in the hospital. But what I'm not happy about is how vague it is. I don't know whether to trust that that's everything that she had, that's there's nothing else which might be getting hidden.

CONCLUDING COMMENTS

75. In terms of my experience and [redacted]'s experience at the hospital, don't get me wrong, there were some good times. But my overall experience is that it was just a horrible place and I wouldn't want my worst enemy to share that experience.

76. The hospital management and those running it should come out and tell the truth. I don't mean for people to lose their jobs or anything like that. I don't want to see anybody losing their job, and I don't blame them personally because I know how it works. There's somebody higher up covering up for somebody below. I get all that. But I would love for a bit of the truth. I mentioned that I thought that [redacted]'s individual Case Note report was a bit vague. I think there could be more that we've not been told about. I don't think that report give us the whole story.

77. I don't know who to trust, to be perfectly honest with you. I don't know whether I can trust the NHS, I don't know whether I can trust the Scottish Government. The Scottish Government opened the hospital, the NHS covered everything up since 2015, so what's changed now? The hospital in Edinburgh, there's another big flag. That was not opened for the same reason as the hospital in Glasgow, the Edinburgh hospital was opened because it was deemed not fit. So why could they not do this to the Glasgow hospital? Why were our kids put in a hospital that wasn't fit for purpose? And why did everybody feel the need to tell lies to their parents?

78. I watched the documentary about the hospital on the BBC1. What I found out definitely impacted me. I was thinking to myself, how bad it is that you've got to take your kid who's got cancer to fight for her life in a place that isn't fit for purpose? The people running the hospital aren't fit to run it. The hospital has brilliant doctors, the brilliant professor who worked on the ward. She was god to everybody. But after watching the documentary, I felt dejected. How can all this go on? It was reported that management knew there were issues with the water in 2015.

79. And every single day is a fight for their lives. Every single kid in that ward: fight, fight, fight. They had to do it in a place with facilities that weren't fit for it. These are kids that have absolutely no immune system because it's been ripped away with chemo, radiotherapy, everything. They couldn't use the water. They couldn't even brush their teeth in it. They couldn't go for a

shower. They couldn't have a bath. Later people were being told they could drink the water, but would you dare to drink the water? Imagine if you had to drink that water. I feel as if the hospital led us right up the garden path, and they're a bunch of cowards because they couldn't even tell us the truth.

80. The higher up the management chain you go, those people knew what was happening. They knew what they were doing. They knew the kids that were in that hospital with the issues. This plays over and over in my mind and I just keep thinking: that water, the infections, look at the impact that actually had on [redacted]. We thought she was in a place where she only had to fight the cancer. Not fight infections given to her by the actual place that she was being treated. The cancer had to be fought. She wasn't there to fight illnesses given to her by the water.

81. If had to start this journey all over again right now with [redacted], I would be petrified. Petrified looking at all the write ups in the press; watching the documentary on the TV; watching all this stuff that you've got going on in there; all the inquiries: the lies. Imagine you're a parent starting out on that ward for the first time today with all that has gone on previously; and you had to trust that place, you had to trust the people that run the place. I'm sorry, but I couldn't. [redacted]. Totally affected by all these infections. [redacted]. Our life as well. We had to sit and watch her going for operation after operation to remove and replace lines; we watched her fasting; not getting any food; crying. [redacted] was the toughest kid I've ever seen in my life, but that was all she could do.

82. But the reason why I'm doing this is because I don't want any other kid or any other parent to go into that hospital and to be told lies ever again.

83. I want people to know that they are taking their kid to fight for their life in a place that's worthy of their kid being in there fighting for its life. That's why I'm doing this. The kids deserve it. The parents deserve it.

84. [redacted] other kids that are there now, and that continue to fight for their lives every day and who will fight for their lives in the future. Those kids and their parents deserve to know that their kid is in a place where there's no lies, no deceit, and that it is a place where they can actually drink the water and brush their teeth.

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

In accordance with Restriction Order 2 , the Inquiry has provided excerpts of the witness statement for Witness 2. The Inquiry will only provide excerpts of the statement that do not contain information that is capable of leading to the identification of the Witnesses

Scottish Hospitals Inquiry

Excerpts of the Witness Statement of

Witness 2

OVERVIEW

1. My [redacted] . [redacted] was diagnosed with Acute Lymphoblastic Leukaemia (ALL) . [redacted]. [redacted] [redacted] was treated in the Royal Hospital for Children (RHC) and Queen Elizabeth University Hospital (QEUH) between [redacted]. [redacted] [redacted] was an in-patient during this time, except for a period she spent at home from [redacted]. [redacted].

2. [redacted] spent time in wards 2A and 2B of the RHC which are known as the Schiehallion Unit. The Schiehallion Unit treats children with blood cancer. [redacted]. Following the closure of the Schiehallion Unit in 2018, [redacted] was also treated on ward 6A of the QEUH which was supposed to be the 'new' Schiehallion Unit. [redacted]. I can speak to the experience which I had with [redacted] on ward 2A, 6A [redacted].

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

Admission to hospital:[redacted].

3. They took [redacted] up to the Intensive Care Unit (ICU) in the children's hospital. I don't know what they did but later on that night we met Professor Gibson, who became [redacted]' s main consultant. She came down to basically confirm that [redacted] had leukaemia. It was about midnight.

[redacted] Ward 2A: [redacted].

4. [redacted] was transferred to ward 2A in the children's hospital on the [redacted]. This ward was where the cancer kids stayed for their treatment. [redacted] put up in the room straight across from the nurses' station [redacted].

5. [redacted] went down to surgery to get her Hickman line inserted under general anaesthetic. This line went into her chest. It had two lines off it, one was used to take bloods and the other was used to give her, her treatment.

6. [redacted] had lots of Hickman lines inserted. Her lines were changed because of infections. [redacted]. She had to go to surgery each time one was put in or taken out.

7. Every time [redacted] got a Hickman line inserted, she got unwell. She always got a really high temperature and I think most of the time, she was put on an antibiotic after it just in case there was an infection there.

8. [redacted] kept getting infections in her line. There was always a plaster over it to keep it in place, but the plaster kept coming off and we used to always have to ask to get the plaster changed. [redacted]. So we didn't know at the time if the infections were coming from the water, because we were told it was safe to bath her in the water, or because the plaster kept coming off.

9. [redacted] started her chemotherapy on [redacted].

10. [redacted] was in isolation the majority of the time she was in ward 2A [redacted]. When [redacted] was in isolation, she had to stay in a room within a room. In the outer room, you would take off your shoes, and your jacket and leave your bag there. There was a sink in the outer room where you would wash your hands before going into the room [redacted] was in. You would wipe clean anything you had brought in for [redacted] in the outer room before taking it to her. We were confined to the room when [redacted] was in isolation.

Experience on ward 2A: [redacted].

11. Ward 2A is set up for children with cancer. [redacted] had lots of rooms in ward 2A. We were constantly getting moved. We started at the nurse station and then we were moved along because she got a wee bit better and the nurses didn't really need to be that close, so she was then moved down towards the door just as you come in. I can't remember what room it was. She was moved at least three times in ward 2A, that I can remember. I think one of the times she was moved was to allow the room she was in to be deep cleaned.

12. The rooms were fine but they weren't really that clean to be honest. The floor was never cleaned properly. They would only really mop in the middle of the room. They did not clean the entire floor. We had to use antibacterial wipes to clean the floors even after the cleaners had been in. [redacted] there was a bed for whoever was staying over. [redacted]. The rooms had their own en-suite bathroom with a shower [redacted].

13. [redacted] got her obs, like temperature checks and things, done a few times during the day, more if she was unwell, and once during the night. When the nurses came in at night I generally pretended I was sleeping, as I know [redacted] did too, when we heard

them coming. We would then see that the gloves weren’t used, hands weren’t washed, all the stuff that was meant to be happening when the kids were in isolation wasn’t happening. It seemed to be that the general hygiene slipped because they thought that we were sleeping. [redacted]

14. We had a kitchen in ward 2A. There was food in the fridge. Everyone had their own wee section in the fridge where you could put your own food. There were things on the tables like crisps, snacks and things for the kids, just in the middle table that anybody could go in and take. There were tea and coffee facilities, so it was quite good. The kitchen set up was pretty good.

15. There were other things there but [redacted] was never really allowed out of her room. She was allowed out a couple of times [redacted] for a wee walk around the ward but she was never really allowed to be out in amongst people.

16. [redacted] was admitted that day into ward 6A.

Experience in the QEUH (adult hospital): [redacted].

17. Ward 6A was different from 2A. In ward 2A [redacted] had almost like 2 rooms. You would walk in, take off your trainers, jackets and wash your hands in the outer room before you opened another door to go into hers, but in 6A you just walked straight into her room from the corridor.

18. There were no facilities in ward 6A. There was a kind of an uproar about it because it wasn’t just as easy for kids to be left while you went down to get a sandwich or a drink or anything like that. If you were there on your own you would have to ask somebody to come in and sit while you went for a drink. [redacted] . There had been water bottles and things like that where you could get cups of water in ward 2A, but there was none of that up on 6A.

19. There were filters on the taps in 6A. I can't remember if they were there when we got there but we were using bottled water. We were still allowed to shower in the water though [redacted].

20. We were moved a lot in ward 6A as well. I couldn't tell you how many times but we always seemed to be moving. We were told a few times it was for a deep clean and when we were in ward 6A they put big fans in the room for the air.

21. There was also one room that we were moved to in ward 6A where the smell was really, really putrid. We asked to be moved but there weren't any spare rooms to be moved to. I can't remember what room number that was, but the smell was really, really, really bad.

WATER: EVENTS INVOLVING WATER SYSTEMS

Water incidents in RHC: [redacted].

22. When we first went into ward 2A, we didn't know anything about water issues so that was fine and we just kind of got on with. Then we were told, maybe after [redacted] we couldn't use the water to bath [redacted]. I don't think that that went on for a long time though then we were told it was safe to use the water.

23. I can't remember when but after that people were coming in and putting filters on taps. We were told that we could bath her again with the water but then there was one day that [redacted] had asked a staff nurse if it was still ok to bath her in that water, we were brushing her teeth with it as well. She told us that we could use it and she said, absolutely we could, it was safe to do so.

24. [redacted] did question the workmen about why the filters were going on the taps but they said they were just doing as they were told. We didn’t really think it was a big deal then, we just thought they were testing the water.

25. At some point after that, I can’t remember when, we were told to use bottled water to brush [redacted]’s teeth.

HEALTHCARE ASSOCIATED INFECTIONS

HAIs: events and physical impact

26. [redacted] had lots of infections during the time she was an in-patient. I can’t remember specific details of all of them, just that she had lots of them. It was traumatic for her to be put under anaesthetic all the time because she was always having to get new lines. [redacted].

27. The first time I remember [redacted] taking a really bad infection [redacted]. She was put on oxygen and was really poorly. I don’t know the name of the infection but she got a new line in then. Her breathing was really bad and her eyes were all puffy. She was breathless because she was struggling to breathe. Her temperature spiked, maybe to 39 or 40 degrees and they put her on antibiotics. I don’t know the name of the antibiotic. [redacted].

28. At the start it was all kind of new to us so we just trusted in the people that were there to give her the treatment [redacted] we started to question why she was always so unwell, because she was never really unwell with her chemo but she seemed to be unwell at other times. We just trusted in the medical people to do what they had to do to make her better.

29. The PICC line just looks like a bit of thread, it’s really, really fine and really delicate so as soon as [redacted] moved in the wrong direction or if anybody touched it, it just came out. They tried to put the PICC line into her wrist and into her foot but no

sooner had they done that, it just came out. Later on the PICC line came out again and the only option then was to take [redacted] to theatre and put her to sleep. [redacted].

30. I don't remember anyone telling us how or why she had it, but her chemo was delayed that time because of the infection in her line. I don't remember dates but her chemo was delayed on more than one occasion because she had an infection. She couldn't have chemo when she had an infection.

31. She was really poorly that day. She was put on oxygen as well. That was probably one of the worst days that we had there with her because, again, we had to go through the stress of holding her down and she was upset and she was sore. It was really traumatic.

32. It was always really traumatic before she went to theatre. She always had to be fasted and she couldn't understand why we couldn't give her anything to eat. There were a couple of occasions that she was fasted, I can't remember the dates, but I know that she was fasted to go down to get new lines but then she wasn't taken that day. [redacted] .

33. I don't really remember if or what we were told about the infections. I think we were just told it was part of getting a new line in, that it was just part and parcel that after you got a new line, you had to get an antibiotic due to infection.

Cleanliness

34. I would like to make some observations about the cleanliness in the hospital.

35. When the infection control people were coming in, the nurses would come in and put [redacted] or whoever was there out so that they could clean the rooms and

everybody always seemed to be scurrying about when they knew that infection control were coming in. They would come in tidy everything up [redacted].

36. The rooms were cleaned every day to an extent but even after the rooms were cleaned we would have to go round and clean again. [redacted] We had wipes [redacted], so we always cleaned down everything. We took our shoes off at the door, jackets, bags, nothing was allowed in her room. Everything had to be taken off outside.

OVERSIGHT BOARD / CASE NOTE REVIEW / REPRESENTATIVE GROUPS/HEALTH BOARD

37. I don't really know about the Oversight Board.

38. I feel disappointed in the Health Board. I'm disappointed in the whole thing that's happened, with the water and that they were allowing the kids to get bathed in it and use it to brush their teeth. I mean, it potentially was serious for some of them, [redacted].

CONCLUDING COMMENTS

39. When we first went to the hospital, we thought it was this amazing place and the nurses were great. Then cracks started to appear when we found that they weren't washing their hands at night time.

40. I don't know how I feel about the hospital now. I don't think I would ever want to go there or have anybody treated there. If somebody says to me that they're going to the Queen Elizabeth, my first thoughts are "Oh no!". I know that hospitals are not very nice places but it does give me the fear. [redacted] it's just not a place we really want to go back or really want to be around because

even when you drive past, you just think of all the times that you were in there with and I just feel there’s no trust there anymore because we had to fight for her and they weren’t truthful about what was wrong with her unless we actually asked the proper questions. I just feel like it’s not really somewhere I want to be, there’s too many memories there for me.

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

Scottish Hospital Inquiry

Witness Statement of

Karen Stirrat

WITNESS DETAILS

1. My name is Karen Stirrat. I was born on [redacted]. I am [redacted] years old. I am [redacted].

2. I am the mother of [redacted]. [redacted]'s date of birth is [redacted] and he is 5 years old.

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

OVERVIEW

4. My son is [redacted]. [redacted] was diagnosed with Atypical Teratoid Rhabdoid Tumour (ATRT) in February 2019 when he was 3 years old. was treated at the Royal Hospital for Children (RHC) and Queen Elizabeth University Hospital (QEUH) from February 2019 and is still undergoing treatment presently. He attended both hospitals as an in-patient and an out-patient regularly for over two years. [redacted] is still under the care of Oncology and attends the QEUH for treatment.

5. I have provided the Inquiry with a timeline which my solicitor helped me to create, showing the dates in which [redacted] attended hospital and the wards where he was treated. The timeline is attached to this statement at appendix 1 **(KS/01)** and I confirm it is accurate to the best of my recollection.

6. [redacted] spent time in wards 3A which is the Neurology ward, and 3C of the RHC, and wards 1C, which is the surgical ward and 1A of the RHC. also spent time wards 6A and 4B of the QEUH. Ward 6A is classed as the Schiehallion Unit where kids with cancer are treated. We never got to visit the Schiehallion Unit when it was in the RHC as it was closed when [redacted] was going through his treatment. Andrew and I took turns in staying with as we had our other two children to look after too. I can speak to the experience which [redacted] and I had on these wards.

7. There are some specific events that I would like to mention. [redacted] relapsed in June 2020 and we had to fight to get him treatment otherwise he was just going to get palliative care. There were issues with the water supply throughout [redacted]'s time at the QEUH. I found out that was prescribed preventative antibiotics in March 2019 which were because of the water supply. There were other issues with the construction of the hospital and the communication around these, when [redacted] was in the hospital which, in my view, impacted his experience. I will come on to talk about these events in more detail. My family has had an earlier experience with the neonatal unit at this hospital in January 2016.

FAMILY BACKGROUND

8. I live with my husband Andrew and our three children in [redacted]. [redacted] is one of triplets which includes his two sisters, and [redacted]. They are all 5 years old.

9. [redacted] is really close with his family. He had a close bond with before he was ill and they used to gang up on [redacted]. Those two are very much alike, more like twins. When they all attended the nursery, the staff suggested splitting [redacted] away from them. They were

all kept in the same bubble but [redacted] wasn't with them all the time so he has a really good bond with [redacted] now. [redacted] and [redacted] have been [redacted]'s crutch. They help him and he helps them when he can. [redacted] and his sisters are due to start [redacted]school in [redacted] on 17 August this year. As they already attend the nursery there, some of the school staff already know them which is good.

10. [redacted] doesn't have many friends out-with his family because with illnesses going around and [redacted] going through treatment, we've had to keep him away from a lot of that. The situation with Covid hasn't helped. He has his cousins that he plays with. The older ones have been showing him how to use a play station and an X-box but I still think he's too young for that. There's [redacted]kids, including our three, [redacted] so they're all really close together. He enjoys going out and seeing his cousins and playing with them, so he's going to have no trouble making friends. [redacted] has been brought up in the house with mainly girls so it's good to see him doing boy things instead of just sitting with his sisters playing with dolls.

11. [redacted] loves playing games and is very competitive. He doesn't like to lose at anything. Every night I come in from work and I'll sit and play board games with him. [redacted] loves the outdoors and he's learning how to ride a bike now which is great to see because when he was going through his treatment, he couldn't do anything like that. He loves the trampoline too and it's been really good watching him build up those skills. [redacted] would rather be outdoors than indoors. We're quite an outdoor family and try to get out every day.

12. [redacted] has always been a happy wee boy. He loves to run around and just be a normal child. He doesn't let anything defy him at all. Nothing defines him with his illness, he's just on the go all the time. He's just had so much

strength and courage throughout. Looking at him, you would never think he was ill. It's amazing to see how incredible he actually is.

FAMILY'S EXPERIENCE IN THE NEONATAL WARD AT QEUH: 2016

13. [redacted], [redacted] and [redacted] were born at 27 weeks so they were 13 weeks early. Due to this, we had to stay in the hospital with them for 13 weeks.

14. There was a lot of miscommunication with the nurses in Neonatal. There would be times when a new nurse would take over the triplets' care and she wouldn't know the other nurse's shift so you would have to update her.

15. At one point, when [redacted] was just a couple of weeks old, she was overfed after staff had missed her feed. Instead of owning up, the staff member decided just to feed her subsequent food so [redacted] ended up with quite a lot of food in her tummy. [redacted] was really ill after this and had to be put back on the ventilator. Before this incident, she had been doing really well. It was only because we picked up on it that staff apologised and explained they missed the feed and had tried to spread it out and give her more. They should have just told us they missed the feed. To this day, [redacted] still doesn't eat very well. We don't know if it's down to that or not but the fact she had been doing really well then a of sudden went back the way, we wonder if it's been down to that. If I've asked anyone later on about it, I've just been told it's due to her prematurity.

16. One day when we popped in, [redacted] had an antibiotic in her arm. When we asked staff why she was on the antibiotic. They would just tell you that [redacted]'s infection markers were up so we think she's got something. They would never clarify what she actually had. Having three

premature babies, you were busy enough so you just go the stage where you started accepting everything staff were telling you.

17. There were also a lot of times where things were missed or they wouldn't listen to you as the parents. Staff would bring you bottles for feeding your babies and then requested that you purchased some. They would then change the bottles to the cheaper ones and tell you it was because they worked better as they were faster flowing but the babies would be choking and vomiting the feed back up. If you raised this, the nurses would just blame the babies' age. From personal experience and through speaking to other parents though, it was said quite a lot to parents. Nurses would say it was tried and tested methods they were using. They never wanted to do anything new to see if it would help.

18. One day when we walked into the ward, we saw that [redacted] had poo in her incubator. Rather than clean the incubator and put it away for it to be properly cleaned, staff just wiped it down with a wipe which wasn't even antibacterial and then just put [redacted] back in the same incubator. I was sat there thinking to myself, why have I just accepted that? I was sitting with a baby on me at the time so I wasn't going to be arguing about anything. I was really upset about that though. I went home that night and phoned the Charge Nurse. I told her I wasn't happy about what had happened. She told me that there had been numerous complaints about that same staff member from other parents. I had already heard from other parents that the staff member had been leaving their babies in nappies for over twelve hours at a time and their babies were soaking. We didn't see that staff member after that so we don't know what happened to her.

19. On another occasion, we came in and if I remember correctly it was [redacted]'s incubator this time where there was a dirty poo nappy left in with her. All her clothes had been put in the same bag and popped into her drawer rather than separating them out. If the clothes were soiled and had to go in the bin then fair enough but they put them all together in

[redacted]'s incubator. That was really upsetting to see. Things should be clean, especially around premature babies.

Water: Neonatal ward – 2016 to 2017

20. I noticed signs in the Neonatal ward stating not to drink the water but as it was the first time we'd ever had anything to do with a hospital, I thought it was normal so didn't take much notice of it.

21. When we were in the Neonatal Unit, we had been using the water. It wasn't until all the issues with the water came to light in 2019, when [redacted] was being treated for ATRT, that we found out that Neonatal staff should have been washing the babies in bottled water because there were septic tanks there already. We carried out our own research and found out from Anas Sarwar, MSP, that there was paper work stating that because there were septic tanks there, bottled water was to be used on babies. We didn't know this had been going on when we were in Neonatal in 2016.

22. A year after the kids had been patients, I started working for BLISS, the premature children's charity, in the Neonatal ward. Not once did I see any of the kids being washed in bottled water at that stage either. This should have been happening though. These kids could have picked up an infection because they weren't using bottled water.

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

Admission to hospital: February 2019

23. [redacted] had been violently sick over 12 hours and he just wasn't himself. Every half hour he was just being sick and I didn't think it was right. Being premature and not having a strong immune system, he hadn't actually been to any kind of preschool things previously and he had just started

playgroup. I thought he had maybe just caught a bug but I was alert; I'm aware of children being sick, but not like that. We left him overnight and hoped that things would be better in the morning. The next morning though, was quite lethargic and I thought it was just because he'd been sick so much. We left him until that evening and my mum came to visit. She had a look at him and said that he doesn't look right so get him checked at the GP. Andrew and my mum took [redacted] to the GP. The GP thought it was viral and that he was also dehydrated due to being sick so much. The GP gave us a letter in case we had to take [redacted] to A&E over the weekend if he deteriorated or didn't eat or drink anything.

24. Later that evening, [redacted] started complaining of a sore head. My mum and dad said to me that headaches shouldn't really be happening at that age as he's too young. I had been trying not to go back to the GP as they did tell me it was viral and I was hoping that was all it was. The next day though, which I think was Friday 22 February 2019, I thought something still wasn't right with and that we needed to get him checked. Andrew took him up to A&E with the letter from the GP. A&E were very busy that night so [redacted] was assessed in the plaster room. The doctor that assessed him said it was viral and sent them home with calpol. [redacted] doesn't like taking calpol though and just spits it out so the fact he wasn't getting any better, I thought it was maybe because he hadn't had enough calpol. At this point though, I thought it was strange the other two children hadn't been showing any symptoms. Usually when you have children and one of them catches something, they all get it.

25. On the Saturday afternoon, [redacted] still wasn't any better so I called A&E again. I told them my husband had been in the night before with but that [redacted] was still complaining of a sore head and I was worried. The staff member I spoke to just asked if I had given him Nurofen as that's for headaches. I told her we had only been prescribed calpol and she said to give Nurofen and he should be fine with that. I took [redacted] out in his buggy

later on, hoping the fresh air would help but he was just lying there, not himself at all.

26. During the Saturday night, [redacted] was writhing in bed shouting, “My head, my head”. I let him sleep for a couple of hours to see how he was. Early Sunday morning, I dropped the girls off at my mums and took [redacted] back to A&E in the RHC. I just knew something wasn’t right with him. The consultant at A&E was able to fast track us as [redacted] had been in before. She didn’t think it was viral and [redacted] had no other symptoms bar the headache from the Thursday night now. I told the consultant I wasn’t moving until something was done with [redacted]. She said she supposed she could call Neurology. We were moved down to Neurology in the RHC so could get a scan.

27. The on-call surgeon, Roddy O’Kane, was called in to treat [redacted]. I was told by Roddy at this point that they didn’t know what they were dealing with so he wanted to do an emergency CAT scan and MRI on [redacted] but they didn’t have time to sedate him as it had to be done very quickly. I was asked to go into the machine with him. [redacted] was delirious at this point. Staff had started pumping fluids through him so when he got in to the machine, he was starting to be a wee bit more awake than he was previously. He knew something wasn’t right but he was just a wee baby. I heard someone saying they’ll have to bring the crash team in because they didn’t know if anything would happen to [redacted] in the MRI machine. As it was a Sunday, all the staff were leaving to go home. I was saying to them, “You have to stay, we have to get this scan done, you have to come back”, and thankfully the staff did come back. In the space of half an hour, they had [redacted] in a room and were telling me that he had large mass on his brain which was beginning to bleed and that they had to get him into theatre as soon as possible.

[redacted]’s initial treatment: February 2019

28. Roddy took [redacted] into theatre and he was in there for eight hours. Thankfully he didn't need the crash team. He managed to get the scan done then too. [redacted] was in the theatre for the 8 hours and then he was put in to intensive care in the RHC for three days I think. They brought round after surgery and were happy with his progress in ICU at that point. He was going to be admitted to the Neurology unit, ward 3A until we found out further information as a biopsy had been taken.

29. Roddy was very forthcoming with information. I think it was Andrew he had spoken to initially as I had to go home for the girls. Andrew was better at understanding things as at this point, I had been awake for 36 hours. Roddy spoke to Andrew within a few hours of [redacted]'s surgery. He told Andrew that things had gone well but he would discuss it in more detail with us both later on. I went back up to the hospital with our parents a few hours later and Roddy spoke to us all. He showed us the X-rays and what he'd seen. He said that we were lucky we didn't go home that evening. If I hadn't have stood my ground and refused to leave until something was done for [redacted], then wouldn't have been here in the morning. At that point, the mass had started to haemorrhage and bleed. If we'd gone home, it would have been a full blown haemorrhage and he wouldn't have made it.

30. We were told it could be up to ten days before the result of the biopsy were back. Roddy had said the mass was very significant in size for such a wee person but that he wasn't sure what it was.

31. For the three days that [redacted] was in ICU, he was on pain relief. I think it was maybe morphine to begin with then I think he came off that and was given paracetamol. Within a couple of days, [redacted] was back to wanting food and being his normal self again, which was so nice to see. Staff couldn't believe how well he was doing considering he had just had major surgery. We were told that [redacted] might get bruising on his face over the next few days but this didn't happen until we moved to the Neurology ward.

32. I'm very fortunate in that I stood my ground the night [redacted] was first operated on. The doctor we initially saw was very nice but she was willing to send us home without doing anything further for [redacted]. Once it was realised that [redacted]'s situation was serious, she promised to come up and see how [redacted] was doing after his operation. She never did though. It felt as if some of the staff that night were over compensating with promising to visit him because they knew they had messed up. If they had done their jobs correctly in the first instance, I wouldn't have had to fight to get his scan. If I had just gone home, I dread to think what the alternative would be.

Experience on Neurology ward RHC; February 2019

33. After spending three days in ICU of the RHC, [redacted] was moved to the Neurology ward. I think this was ward 3A.

34. The ward was so accommodating and it looked like a children's ward. It had nice things on the walls, there was a playroom for the kids to play in and there was even a sensory room. In the sensory room, there were three balls and a soft slide that was to help children get back on their feet after operations. It was this room that got [redacted] back on his feet. He was only three years old and he had been in his bed for a week with being ill so when he saw the sensory room, that was him, he would go and play in it which was so nice to see. The playroom was good too, there was always someone around that you could speak to or another child that [redacted] could play with. Apart from the facial disfigurement from the surgery, [redacted] was back to his normal self.

35. Physios would come in and they were very good in the way they worked; each of them knew what the other one was doing. They were really helpful and they were checking how [redacted]'s legs and things were doing after the surgery.

36. The Neurology ward was such a good place. It had parent facilities and a staff room. There was as much there for staff as there was for the kids and their families. You could put things in the fridge on the ward, you could store things and take food in. You could go and help yourself to things too, before Covid, and if you wanted to make toast for the kids or anything like that, you could. There was also a microwave outside the ward and a seating area so families could go and sit there. We had the girls up a couple of times so they could sit down with [redacted] and have a meal. It was good that we could sit down as a family and do that. I think this also helped [redacted] recover as he was able to do normal things. You were able to do all the general things that you should be able to do.

37. I would say that the Neurology ward was a nice ward. All the staff know all the children and because a lot of them are on the ward long term, the staff take the time to get to know the children and take an interest in them. Everything was really on the ball in that ward, there were no big issues and I trusted all the staff in there 100%. The ward was a sort of circle shape. There were quite a few small nursing stations through-out it and there was a larger one in the central part of the ward which was just across from the big bathroom. At that point in time, they had the big baths that you could use. The only slight issue I had in this ward was that I never saw anyone cleaning the bathroom.

38. I can't remember which room we were in on the Neurology ward but it was just past one of the nurses' stations. There was a TV in the room, I can't remember if it worked or not but there was nothing about the layout of the room that looked off to me. The only thing that I would say was that it was just basic chairs in the room, not the fold back ones. There was also a bathroom adjacent to your room with a shower in it. I think there was also a small wardrobe and a unit too.

39. [redacted] had been on the Neurology ward for ten days when he was discharged on 6 March 2019. It was on this day that we first met Dr Sastry, who would be [redacted]'s oncology consultant going forward.

[redacted]'s discharge from neurology: 6 March 2019

40. We had been waiting on [redacted]'s biopsy results and knew we would get them on the Wednesday that [redacted] was discharged which was 6 March 2019. The results didn't arrive until the afternoon. The surgeon, Roddy came in with another doctor, who was Dr Sastry. Roddy introduced Dr Sastry as [redacted]'s oncologist. At this point, I didn't need to know any results as he had virtually just told me by introducing an oncologist. They sat us down and told us that they'd found a really aggressive brain tumour and that it was quite severe. I asked Dr Sastry what the outcome would be but he didn't want to say. I told him I'm direct and prefer straight to the point answers so I know what we were dealing with. Dr Sastry said less than 50%. I was floored. I didn't expect him to say that. I was thinking it would maybe be 70-80%. He said he didn't want us to dwell on that fact as [redacted] is in the higher bracket of the 50%. He said that some kids have complex needs that don't go in their favour but that [redacted] had nothing like that and he was a well, healthy boy. I asked if it was because he was an IVF baby or if it was because he was premature and he said no. It was just bad luck. I thought, how much bad luck can one family get. It took us so long to have the triplets. They were originally quadruplets but I lost one early on and now this.

41. When we went in to get [redacted]'s results on 6 March 2019 and Roddy had introduced his oncologist, I picked Roddy up on this later in the day. I can't fault Roddy but at the time I said to him, when you introduced Dr Sastry, I knew before you said anything else what we were up against. He said he was going to change the way he introduced the oncology doctors in future.

42. Andrew sat and took everything in. I was sitting trembling. I was trying to hold it together for my son who was still there sitting listening to all of this. He was only 3 years old but he knew something wasn't right when he saw our reaction.

43. We were given a timetable of the treatment plan for [redacted] by Dr Sastry and Roddy but I couldn't take it in at that point. Andrew was really good here as he knew what we were up against. They asked us if we had any questions but I just wanted to get out of that room and go home. They told us they had been on the phone to all the UK hospitals and America too about [redacted]'s tumour as it was so rare and treatment options. America were more advanced so they'd already given Dr Sastry and Roddy information and advice but they were still waiting on other bits and pieces being confirmed. Dr Sastry and Roddy said they would tell us in due course and keep us updated.

44. [redacted] had been himself over the previous ten days. I remember being on the phone to my mum the day before that telling her we could get devastating news and be told [redacted] had cancer but at the time, I didn't think it was that. We were asked if we had any questions and I asked if we could go home. I just wanted out of that room. We left and were told that [redacted] would have to come back to the hospital for chemotherapy but we thought we would have a couple of weeks before that started. A couple of weeks as a family where we could do things together.

[redacted]'s admission to ward 6A: March 2019

45. Initially we were told by Dr Sastry that [redacted] would have to come back to the hospital within the week to get his Hickman line fitted with the plan to start chemotherapy in the next couple of weeks. We had only been home for a couple of days and then received a phone call from the hospital to take back up to the QEUH the next day. This was possibly 8 March 2019. I was told to go to ward 6A on arrival. I did think it was strange telling me to go to ward 6A but I didn't know the Schiehallion ward had been moved. I think it was a male

nurse that called us. I remember as there was only one male nurse and he introduced himself when I entered ward 6A as the person who had called me. We had previously been told by Dr Sastry and Roddy O'Kane on 6 March 2019, that [redacted] would be getting treated in the Schiehallion ward. We were told it has a nice new play area, like a nursery facility. I was told would have good fun there.

46. I was quite glad when I heard about everything they had in the Schiehallion ward as it meant [redacted] wouldn't be missing out. [redacted], and [redacted] had only started play group six weeks before this all happened as they were premature and the girls had been on oxygen so we weren't allowed them at playgroups and things until they had built up their immune systems. We were told by the hospital staff that we would need to take and [redacted] out of playgroup due to risk of infection to [redacted]. had only just started to settle at play group too so I thought at least he was getting something on the ward that he could do.

47. There was confusion when we first arrived on ward 6A; it was as if they didn't know what to do with [redacted]. We thought with the way things were explained in the phone call, that [redacted] would be starting treatment that day as staff at the QEUH had been told by doctors at other hospitals that [redacted]'s condition was too serious to be left. However, it wasn't until the next day that things were put in place for him. Nobody seemed to know what was happening and I was just told I would need to speak to my doctor. I didn't see the point of us going in that day and we could have had another day at home. I don't think the staff knew what they were doing. We were getting bombarded with things at this point but we weren't really taking anything in. The communication at this stage wasn't that good. Nobody knew what the other one was doing.

48. We were asked some basic questions about [redacted]'s medical history by a nurse. I had a discussion with the nurse about [redacted] being fitted

with an NG tube as we weren't told about that. I asked why [redacted] was getting it and what it was for. The nurse said that kids don't eat when they're having treatment. I asked if we could give [redacted] the benefit of the doubt and see if he wanted to eat first and then give him the tube if he didn't but they were hesitant and kept saying that they thought I just needed to let get the tube fitted. I was thinking, this is going to get forced in him when he's awake, which I was against, and I told them they can't do that to him as he's only a child. The staff said they could put notes in to say, "Mum wasn't happy", but it wasn't about being happy. It was the fact that they had only just told me all of this and I was upset. I think in the end, staff said [redacted] could get the NG tube fitted when he was in surgery getting his line fitted which I thought was better than trying to insert it when he was awake. I was told afterwards what the feeding tube was for and how it would help [redacted] but only because I was asking questions. I was worried that [redacted] would pull the NG tube out as he didn't like the feeling of certain things on his skin. The staff just kept saying it would be okay. Staff do this every day and it's just a job to them. I think they forgot that as parents, it was all new to us and not something we were used to seeing.

Experience on ward 6A: March 2019 - April 2019

49. The day after we were admitted to ward 6A, which was maybe 9 March 2019, had his Hickman line and NG tube fitted in surgery under a general anaesthetic. Staff didn't go into detail about the Hickman line. All they said was that it was for giving him chemo. Staff said they could give us a booklet that would tell us a bit more about what it's like. I don't recall staff giving me any other information about the Hickman line just that when they put the chemo in, they said they were pushing it through the line. I think the day [redacted] got the Hickman line in, someone came down and said how they were going to do it but no further details were given. To this day, my knowledge of the Hickman line is still the same. It was at this point that the nurse said they were going to get the dietician in to speak to us about the NG tube and [redacted]'s milk. I asked what an

NG tube was. Obviously I had a rough idea what they were because the kids had them when they were babies in neonatal. The nurse said all the kids get fitted with an NG tube when they start treatment. I’m not 100% sure but I think had chemotherapy in his spine at this time. He would have had a lumbar puncture carried out too at this point. Staff do try and do everything like this at the same time so they don’t have to take kids into surgery more than they have to.

50. I gave [redacted] a bath a day to two after his Hickman line was fitted. The nurse was changing the plaster and putting a clean one on over his dressing and the Hickman line. My sister was with me at this point and she has previous experience at the hospital so she pulled the nurse up for putting the plaster on ’s wet skin. She asked the nurse if she was trying to cause an infection as she had just put the plaster over wet skin. The nurse was quite startled so rather than peel the plaster off [redacted], she just yanked it off him. [redacted] was crying horrifically at this point and after that, he was very, very fearful of his Hickman line and would have to be pinned down to get it cleaned. I’d been too scared to say anything that time as it was all new to me and we hadn’t been in the hospital that long so I was glad my sister was there.

51. The room he was in at first was right up the back end of the ward, nearer Day Care. I think the room number was in the twenties. I found out the area they were using as the Schiehallion Ward is the adult unit that used to be the cancer ward. Initially both wards 6A and 6B were adult cancer wards but they had amalgamated into one as the new children’s ward. Nobody ever told us that though, they just told us where the cancer ward was. It was only when we spoke to other parents that we realised this wasn’t the original Scheihallion ward.

52. I had been telling [redacted] about the playroom, even on the way into the ward, I had been talking to him about it but when we walked in the ward, it was just grey. There were no bright colours or friendliness and it was very narrow. It looked boring. Once we were settled in, I asked one of the staff where the

playroom was and she looked at me like I was a clown. She asked me what playroom and I explained I had been told there was a playroom that could go and play in. She turned around and said, “Oh, that’s the playroom there”, pointing to a plastic table with two little plastic chairs and a packet of crayons. The thought of it was hurtful. Out of everything, even now, that was really, really upsetting for me; I remember having to go back and tell there was no playroom. How are you supposed to sit there and tell a child that everything you had previously been told was wrong and therefore you had told him about stuff that wasn’t there? Looking back, I realise that when they were first telling me about the playroom, they were describing what the Schiehallion used to have. [redacted] was crying when I told him there was no playroom. As we were going to be in there for so long, I was wondering what I was going to do with him. At that point, I decided I needed to make it fun for and bring our own stuff in. People started rallying round and buying him gifts and things to take in to the hospital. Coming from neurology where it was so fun and friendly, he was expecting the same where he went. To go from that into nothing, where it was like a jail, was disappointing.

53. I mentioned to staff that I had some food to put in the fridge. They told me they didn’t have a fridge and that there were no parent facilities on the ward. They didn’t even have anything for making a cup of tea. They said they would make me cups of tea and bring them to me. There was also nowhere to sit so you couldn’t speak to other families.

54. I was overwhelmed at what we had walked in to. Within the space of an hour of us being in the building, we had found out there were no children’s facilities, no parents facilities, nowhere to sit. We couldn’t even look out the window as the blind was broken.

55. [redacted] was stuck in his bed attached to a chemotherapy machine for three of four days as the battery pack didn’t work. He was still in a cot at this point and he was stuck there. At one point, they had him hooked on to a

machine for 12 hours because there was nobody there to detach it even though he was finished his treatment. One of the nurses came in and joked that it was like a wee jail. I thought she can't be serious, she was actually joking about this; had been hooked up to that machine for so long but I couldn't say anything to her as I wouldn't be able to stop and it was early days in the hospital. [redacted] was in his cot for so long a physiotherapist had to visit him.

56. During [redacted]'s admission, he kept spiking a temperature so he was put in an isolation room which was a normal room but extra measures were taken; staff would gown up and there would be a sign on the door saying to contact staff before entering. In general terms, if you've got a bug you might be put in there depending on how serious it is. Staff put a note on the door about the isolation and staff are supposed to wear gowns when they come in. I'm sure at one point we were told he had an infection. There was a note put on the room door saying that nobody was allowed in. We were in there for three or four days as they were waiting on blood cultures coming back. Usually you get put in to isolation if your child has caught a bug so that they don't spread it to other children. [redacted] would get put on antibiotics but we were never told what they were or what infection they were treating. If you asked any of the nurses, you were sometimes just told it was because of the chemotherapy. It didn't make sense to isolate [redacted] if it was that.

57. Sometimes, if the children have a temperature they're put into isolation and the there's a protocol that's followed. Whenever [redacted] was put into isolation, there was a sign that got put on our door saying nobody was allowed in the room and we assumed that when isolation was over, someone would come and tell us. On one occasion, after being in isolation for three or four days, was allowed to go out and play on the ward. The nurse that had originally put us in isolation was off and it was another nurse that told us [redacted] could leave his room. However, when the other nurse came back on duty, she said had to go back into isolation and shouldn't have been allowed out. I asked why he was put in isolation in the first place but I never got any answer. They always

said they would go and get someone else to speak to you then they disappeared. Nobody would come and speak to you.

58. [redacted] was given fluids after his chemotherapy and the doctor had said to the nurse for him to be taken off them. He was connected to chemo and fluids but he had the fluids for an extra 24 hours. The nurse hadn't taken them off when the doctor had told them to. I think it was Dr Sastry that asked the nurses why [redacted] was still on them as he told them to take it off [redacted] the day before. The nurses told me to watch for swelling as he shouldn't have had so much fluid. They said they would investigate why this happened but nobody ever came back to me about it. There was no apology either.

59. It would sometimes be different staff that dealt with [redacted]. There were student nurses there too but they weren't allowed to administer anything so you would be going back and forward with things and sometimes miscommunication became an issue. Some of the nurses gave you the impression they didn't even want to be there as they took no interest in [redacted] and a lot of the nurses were leaving too. I think there was a lot of bank staff there which didn't help and I think some of the nurses were leaving due to the stress they were under due to everything that was happening. Around Christmas time 2020 when was at the hospital with the meningitis, one of the nurses that had originally dealt with [redacted] when he was first diagnosed asked me why we were back at the hospital. I told her what had happened to [redacted] and she said that nobody had told her anything and that things have been kept from her. She said half the nurses had left because of the stress; it had been one things after the other then the water situation and the lies and now with Covid, everything was being blamed on that. There was also a lot of scare mongering about the Inquiry. Sometimes you would hear things but the they didn't want to discuss it any further. I had also noticed the changeover in staff. There were a few familiar faces but a lot of the staff were new. Medications were sometimes missed, or under-dosed or overdosed as [redacted]'s records weren't filled in correctly so you had to be on the ball with his medication. The records not

being filled in correctly meant that the next person to come in and see had no idea what had been given by the last person.

60. There was nothing really for [redacted] to do when he was in the ward so I managed to get one of the blue play mats for him to play on. You were able to attach the medicine for the chemotherapy drivers and there would be just enough room for him to sit on the floor on one of those mats, which was better than sitting in his bed all the time. When we first came into the ward though, staff would often tell us that there were no mats available or they didn't know where they were. One day when I was walking through the ward, I noticed that the mats were being stored in a make shift bathroom at the front of the main entrance to the ward. There were quite a few mats in there. The nurses knew that every time Andrew and I came in the ward that we would ask for one of those mats so [redacted] could play with building bricks and just be a normal child for a while.

[redacted]'s Proton Beam Therapy and readmission to QEUH on return to Glasgow from Florida

April 2017 – October 2019

61. [redacted] had been in ward 6A at the QEUH for about six weeks as his blood counts weren't at acceptable levels for him travelling to Florida. was getting blood and platelet transfusions as this point until his blood counts came up to an acceptable level. Proton Beam Therapy was thought to be the better of the two radiotherapies. It has more of a direct hit rather than shooting everywhere, was how it as described to us. Proton Beam Therapy would hit less cells so wouldn't impact [redacted] as much with his development so it would be better for him. We were told that his case had to go in front of a panel who made the decision as to whether he would get the treatment.

62. Earlier in April 2019, there had been talk of [redacted] going to Florida for Proton Beam Therapy. We were told by one of the outreach nurses that the Board had agreed to him going but that it would be at least a six week wait for him. The outreach nurse however, then told us that we were going that week. She said she had told them in the meeting to make sure they spoke to us about going but nobody had. Bearing in mind, we had another two children to try and sort childcare out for too, telling us last minute wasn't ideal. There was miscommunication round [redacted]'s trip to Florida; at first we were told that [redacted] would be going with one parent then we were told it would be with two parents. They then told us that all three of our children should go due to them being so young but that they wouldn't pay for them. Initially it was one parent they paid for and we were to raise funds for the rest of the family. I was then told to take [redacted]'s grandparents to help with the other kids when we were over there. All of this was miscommunicated to us. The communication around Florida wasn't good at all neither was the duty of care carried out before we were sent over.

63. On 22 April 2019, [redacted] was discharged from the QEUH and sent to Florida for Proton Beam Therapy straight from the hospital. [redacted] was just out of hospital and was seriously ill. We had to triple dose his medication to get him to Florida. The journey out there was an absolute nightmare. We had to liaise with three different airports that hadn't been informed that there was an immune-compromised child on the flights and as [redacted] had an NG tube fitted, we had to cart two massive trunks of milk with us which was a nightmare. We had to take the milk with us as staff at the QEUH didn't know if they had the same suppliers in Florida and if the milk connectors would fit [redacted]'s NG tube. I can't remember if [redacted]'s NG tube fell out or not but the doctors in Florida decided that as he was able to eat and drink, they didn't need it put back in for the milk feeds. They had facilities at this hospital that enabled [redacted] to eat and drink easily. [redacted] used the NG tube for some of the medications but because he was doing so well with his eating and drinking, he didn't need it for that. We were originally meant to

be in Florida for 12 weeks but ended up only staying for eight; there was a mask that was designed for kids and that took two weeks to make but as was sedated, he didn't need the mask. That and the combination of him eating and drinking meant we could leave after the eight weeks as he finished his treatment quicker.

64. There were a few things that happened en route to Florida and when we first arrived there that I know aren't part of the Inquiry but I'd like to mention them. We had to get three connecting flights and the airlines hadn't been told that was immunocompromised. The accommodation in Florida was dirty and builders had only just left before we arrived. We had paid extra to upgrade and it wasn't how it was described to us. Florida hadn't received [redacted]'s notes from the QEUH either. We were told by staff in ward 6A that all of [redacted]'s notes would be sent over before we arrived. There was also an issue with the positioning of [redacted]'s NG tube as they didn't scan him to see if it was in the right place. We didn't have much time as the trip was brought forward and we had to organise things last minute and still fundraise.

65. We had to do a lot of the organising for the trip to Florida ourselves. We were given a list of approved hotels from the Florida Hospital that we could book and we had a contact, Coral Brady, from the hospital finance team in Glasgow. Coral was organising the flights and everything for us but I had to chase up things. We had to organise all the insurance and I had to tell the company [redacted]'s circumstances which I think I shouldn't have had to do, I think this should have been the hospital that did this. Things were bedlam on the ward and I was having to phone insurance companies and the hospitals. I was told I would have to pay the insurance out of my own pocket and they would pay it back to me. I had to organise the car and the house we were staying in too. Everything was left to the last minute. I think they also could have flown us out a few hours later; it was Easter Monday and the cost of flights had sky rocketed. I know that [redacted] had to go but a few hours wouldn't have made much difference. We had to find more money to pay for the flights. We

were also told to get our faces in the paper to raise the money as we had to go now so that was quite hard too. We were told we would have special assistance on the flights but when we got there, there was nothing in place for us. We had to organise transport from the hospital too. I think we phoned the taxi and the hospital paid for it. We shouldn't have had to deal with all of that, we should have had it all organised for us so we could just focus on going with [redacted].

66. We got home on the Wednesday which I think was maybe 19 June 2019. It was a long flight and as [redacted] wasn't due his next batch of chemotherapy straight away, I asked the staff in Glasgow if we could spend a couple of days at home and they agreed. We went back to ward 6A on the Friday of that week and [redacted] started his chemotherapy again. When he was in Florida, couldn't get the stronger doses of chemotherapy so the two lots that he missed, were administered back to back. It's the chemo which I think was called DOX. was really sick when he had that before. I don't know if he wasn't given it at the same time as the Proton Beam Therapy because they didn't mix but he couldn't miss them as they were the most serious ones in treating him. They had to give him them every two instead of every three days.

67. At this point, [redacted] was an in-patient for his chemotherapy. He would have five or six days at a time in the hospital then he would have two or three days off. As time went on, the more time he spent as an in-patient. It got to the stage that although he was only meant to be in as a day patient, he ended up being an in-patient or he would get to the stage where the day that he was off he would come would have to go back in because he was so sick and he needed so many blood and platelet transfusions. I said to staff jokingly one day that I would have been as well bringing my bed to the hospital as we were going home very late in the evening and coming back very early the next morning. It was cruel on [redacted] as he wasn't getting any time at home.

68. As there were no parents' facilities on ward 6A for me storing food for

[redacted], the nurse put [redacted] back on the bolus feeds, which are milk feeds. I was angry at this and burst out crying so I had to walk out but I had to stand in the corridor and cry as there was nowhere else for me to go. had been doing really well with his eating and drinking in Florida and had been progressing because of that. It was like being in a jail. I don't think he should have had to go without proper food because the hospital had nowhere for me to store it.

69. [redacted]'s admissions continued in this pattern from June 2019 to October 2019. I think it was the middle of October that [redacted] finished his treatment. He still had his Hickman line in at this point as he was due a scan so many weeks after his treatment ended. He was due to get his line removed the week before Christmas but it was brought forward a few weeks for several reasons, including me asking questions about the medications he was on. We were originally told there was a waiting list to get the lines out and Dr Sastry had said it would likely be Christmas time it was removed. When I was asking more questions, we were then told [redacted] could have his line out. I knew other families who had kids that had finished treatment but had to wait until after Christmas to get their lines out.

SEQUENCE OF EVENTS FROM MAY 2020 UNTIL PRESENT DAY (2021)

70. [redacted] had a scan in March 2020 which was clear. However, in May 2020 his behaviour had started to change. He became aggressive, eating constantly and just wasn't himself. I called the Schiehallion Unit and spoke to one of the nurses. I explained the changes in [redacted]'s behaviour and that I was worried. Previously, Roddy, the surgeon who initially operated on [redacted], had said if we noticed any changes in [redacted] like this, to phone the Schiehallion Unit. The nurse told me she would get someone to call me back. It was the on-call doctor that phoned me back. He asked how was and I explained the situation to him. He said that he would speak to Dr

Sastry but as [redacted] had a scan due, just to monitor him until then. The scan however, was delayed due to Covid so [redacted] got his scan four and a half weeks after that call.

71. On the day of the scan, we were called in by the staff. Due to Covid protocols, we were told that children could no longer have family members with them when they were put to sleep for the scan. But the day before, someone had shared a post on Facebook stating that wasn't the case and the families who were part of the Schiehallion Unit were allowed into the scan with them as the children had been through so much already. [redacted] had already had between 40 and 50 anaesthetics by this point so he knew the process but he needed someone there with him for reassurance. I knew he wouldn't sit still for the staff if one of us wasn't there with him. As the scan was being performed in another ward, 1C I think, we weren't treated as Schiehallion patients at all. I was told by staff that they would give [redacted] a mild sedative before they took him away. At about 9am the doctor said to the nurse that [redacted] would be going down for his scan at about 9:30am so to give him the sedative now. The nurse disappeared though and didn't come back until 9:20am. She gave me something which I had to force [redacted] to take then informed me it was ketamine. She didn't tell me the impact this would have on [redacted] and he started swaying. I had to hold him up. It was horrible. I couldn't believe what I was seeing. It was as if [redacted] was paralysed from the mouth down and he was making this horrible gargling noise. When one of the other staff members asked if [redacted] was okay, that nurse said he was fine and had just had his sedative. Staff took [redacted] down for his scan and I was allowed down with him but not into the scan room. When they brought back up, one of the staff said after he had come round he was feisty and was fighting against them. He's never usually like that. He couldn't get out the bed when he was given back to me so I was confused as to how he could've been feisty during the scan.

72. After a while, [redacted] had started to come round and staff told me to feed him something. I gave him some food and [redacted] started choking. One minute he would be with you then the next he would be away on another planet. It was as if the sedative hadn't worn off. I told staff I was worried as usually he comes round very quickly and is on his feet and out the door within half an hour.

73. I believe [redacted] shouldn't have been given the ketamine and had that nurse done her job properly, he could have had his usual sedative. Nobody had told me about any of the side effects with this one. We took him home after about an hour but he still wasn't right at home. I had to call the Schiehallion Unit and explain what had happened to them. They said to put [redacted] to bed and see how he is when he wakes up. Thankfully when he did wake up, he was fine.

74. On the morning of 1 June 2020, Andrew took a call from the Schiehallion Unit. We were told to take [redacted] straight up to the hospital as staff were reviewing the scans at 12:00pm. I knew something was wrong as before had that scan, they asked if we were okay for them to phone us with any results. Once we were at the hospital, we were met with Roddy and Dr Sastry who told us that [redacted] had relapsed.

75. When we were initially told on 1 June 2020 that [redacted] had relapsed, we were told by Roddy, Dr Sastry and the charge nurse, Angela, that had a mass again in an adjacent area from his previous mass and that there were three other spots. I asked what the plan would be and they said they were sorry, but it would just be palliative care, there was nothing else they could do. I argued the point as I'd done research and I was on a Facebook page for other ATRT families so I knew there were other treatments available. None of the three of them were very forthcoming with information. They offered to get the scans to show me but I found it very odd that they had all just come out of a meeting where they were discussing the scans, yet none of them had any

paperwork on them. I asked about Alisertib, which was a drug I had found out about from a Facebook group I'm a member of, and Dr Sastry told me it was something they couldn't afford on the NHS. I was shocked at this. He shouldn't have been saying these things. I begged if there was anything they could do. Roddy was sitting with his back against the chair at this point as if he didn't want to be in the room with us. He had always been forthcoming with us so this wasn't like him at all. I asked him outright what his opinion as a surgeon was and he replied that he could operate. Dr Sastry glared at Roddy, it was as if he thought Roddy was undermining him.

76. After we had spoken to Dr Sastry and Roddy, we were sent home. Dr Sastry had dropped this bomb shell then we were told there was no palliative care team or follow up in place at the moment. We were told that [redacted] would get a weakness down his side and he would have seizures and when it got to this point, we were to email the hospital and let them know. There was no support for us at all and no real explanation. I said I wanted a second opinion and Dr Sastry replied to say that everyone in the room had agreed, even the Beatson Team had agreed that nothing else could be done. I was devastated. We went home and tried to get our heads round what we had been told.

77. On the Friday of that week, which I think was 7 June 2020, after what we had been told on the Monday, Andrew said he thought there was something up with Roddy and that I should phone him. I did phone Roddy and his secretary got him to call me back. I said to Roddy that he once said if we had any questions, we were to contact him and I wanted to know what the hell was going on. I said to him, "You told us you could operate and the rest of them are telling me they're not going to do a thing, it doesn't make sense to me." He replied that if it was his child, he would fight tooth and nail for him and if we could get him the medication, he would operate on [redacted]. He gave me his secretary's email address and phone number and had told his secretary to let our calls through.

78. After I had the chat with Roddy on the Friday, we were trying to find medications that could help. I had put a request up on Facebook asking if anyone else was in a similar position and a parent replied on the Saturday telling me about a drug called tazemetostat. She said her child was on it and they were based in the UK, Manchester. I managed to get hold of the oncologist, Dr Kilday at Manchester hospital for children on the following Wednesday. Dr Kilday had then started to email Dr Sastry and was waiting for him to return paperwork. Dr Kilday even offered to fill in all the paper work for Dr Sastry just to sign it but Dr Kilday had nothing back from Dr Sastry and asked me what was going on. I was really surprised at Doctor Sastry not helping as he sat on the Board that dealt with trials. I let Roddy know what had been going on and it was decided that he would liaise with Dr Kilday as he had previously trained with him. Roddy took it out of Dr Sastry's hands and sent the scans to Dr Kilday. Roddy wasn't bothered about the consequences for himself at this point. I don't know if he could have gotten into trouble by doing all of this for us.

79. Round about 9 or 10 June 2020, [redacted] was at home and his headaches were being treated by morphine but the dosage was only half of what it should have been. He was on this for two or three days when he had to be readmitted to ward 6A. No member of staff ever apologised or explained this.

80. [redacted] was back in hospital due to headaches and he was still on morphine for them. Dr Sastry was in the room and he said that should be allowed to make memories and I thought, memories? I said to Dr Sastry, "Are you for real? He's lying in a hospital bed not even able to speak. Is this his memories?" Dr Sastry never really said anything after that. I think he knew how I felt about it. He said that he had been in touch with the trial company and hopefully they would come back to him. Hopefully. The word hopefully wasn't helping me. He knows with ATRTs you only have days, not months or even weeks. You have days before that haemorrhage and that's it. I was asking him to get me the answers but he was dragging his feet on it. [redacted] was initially admitted to ward 6A then was transferred to ward 3A shortly after being

admitted as he was going to be Roddy's patient and the nurses there were more trained than the oncology nurses as it was the brain they were dealing with. It was decided [redacted] would stay on that ward until after his surgery.

81. The outreach team hadn't been in touch with us either. There was no other direct communication with the hospital. I think it was me that made contact with outreach team first and told them what was going on. They weren't even aware of the situation. They knew we were getting bad news but they didn't know where we were with the situation. The outreach nurse said to me that we needed to get the ball rolling now and I explained I was trying to do that but nobody was listening to me.

82. Coincidentally, Florida phoned at that time to see how [redacted] was doing. They said that they never hear how the patients are doing as Glasgow send them over then never update them but they needed information about patients' progress for their research. I explained to them what we'd just been told by Roddy and Dr Sastry. Florida said they would be on board with us too.

83. I later asked Roddy what had happened at the meeting on 7 June 2020 that he attended before speaking to us. We had a call to bring [redacted] to the hospital with us but to then be told in front of your child there was nothing that could be done didn't make sense. Roddy told me off the record that he had looked at the scans on the Thursday and Friday of week before and had the plan in place for what he felt he could do so he knew he could treat at that point. He knew he could take away the mass but he didn't know the oncology side of it. He was under the impression he was going to be operating on [redacted] that day which is why we were asked to bring him with us. He knew oncology would have to give [redacted] some form of treatment but Dr Satry had said there wasn't any. The Board then unanimously agreed with Dr Sastry. The Beatson Centre had advised the Board that as had been given Proton Beam Therapy, it was too soon to do more treatment on him so they felt from their side, they couldn't do anything either. Roddy was

annoyed as the Board had blocked him doing his job. He apologised for his body language when he later spoke to us. I said in reply to Roddy, “Don’t you dare apologise because if it hadn’t been for your body language, and the way you reacted in the meeting with us, and then telling us you could operate, I would never have known anything was wrong. I would have just gone with what was said about the palliative care. You effectively saved my son”.

84. We were told that there were three shadows on the scan and Roddy told us that one of the spots was crossing a certain ventricle which was a risk. The first time Roddy operated on [redacted] in 2019 when he was first diagnosed, he went in not knowing what he was dealing with at all as it was all so sudden so potentially [redacted] could have died at that point. There was no time to think and discuss what to do the previous time, Roddy just had to act so this time round, it was pretty much the same thing but there was slightly more time to think about it. Dr Sastry however, was thinking along the lines of the team could operate but it risked leaving [redacted] in a vegetative state. He didn’t say this but that was impression I was getting from him. The team could operate on [redacted] and still lose him. I wasn’t happy with that. Roddy then informed us all that the other shadows in the scan could just be scarring from [redacted]’s initial operation so they might not be anything to worry about. I was annoyed at this as we were originally told the three spots were cancerous and now we were being told they were shadows that might not be. Was this to throw us off the scent and make things look worse than they actually were? This is how I was feeling at that point. I’d lost all trust in Dr Sastry now too. I didn’t want him to be with us. He should have been fighting my corner.

85. At some point when we were in Florida, the Christie, a new centre had opened in Manchester. The Christie did the Proton Beam Therapy like they did in Florida so we could liaise with them now instead of Florida. We had actually been the last family to fly to Florida for [redacted]’s treatment. There was a meeting set up with the Christie and various London Doctors. They all unanimously agreed that [redacted] should be given the option of

tazemetostat, which was the trial drug, after having the option of surgery. That was the treatment plan that was agreed on at that meeting. Florida had also been keeping in touch at this point and they were chasing things up at their side. They thought because the second tumour was so near the original one that [redacted] had removed, that it sat just outside the area that the Proton Beam Therapy was concentrated on. They thought that's why relapsed as the Proton Beam therapy wasn't strong enough to hit the other cells. Proton Beam Therapy is more direct than radiotherapy. Radiotherapy would have hit off outside areas too. It wasn't the QEUH that told us all of this, it was Florida and the Christie.

86. Due to the situation with [redacted] being so serious in case of haemorrhage and Roddy wanting an electrode team in so they wouldn't hit a certain part of [redacted]'s brain that would profoundly affect him. The electrode team pin point how far away from the nerves the surgeon is going. [redacted] had a wall and within this there was a vessel that they didn't know if it was debris or the tumour that was pressing against the wall. If they hit the vessel, could have bled out so to minimise the risk, the electrode team would tell Roddy how far down he could go. The operation couldn't be carried out until the Monday, which I think was 15 June 2020, when this team were available. From the Thursday to the Monday, [redacted] was kept under close observation and a theatre was kept free in case he deteriorated and the operation had to be done in an emergency. [redacted] managed to make it to the Monday though and he had his operation.

87. [redacted] was in ICU for a couple of days in the RHC then he was transferred to the Neurology ward which was ward 3A I think, for about six days. I think it was the Saturday that we asked one of the on-call doctors if we could take [redacted] home. Roddy was off that weekend so we hadn't had the chance to catch up with him and neither had the on-call doctor. However, the on-call doctor reluctantly agreed to let us take [redacted] home due to them all being happy with his progress.

88. We had been home for about two weeks when the outreach team called us to tell us the Beatson Centre wanted to see us. The outreach team, are a team of nurses that act as your point of contact if you're an in-patient or an out-patient and they can take bloods at your home so you don't have to go into the hospital. We already knew that [redacted]'s medication from the trial had been approved at this point and we were just waiting on [redacted]'s surgery healing so he could start on it. I asked why the Beatson wanted to see us but the outreach nurse said she wasn't 100% sure but thought the Beatson might be offering treatment. We went to see them with the outreach nurse and they said they wanted to offer [redacted] six weeks of radiotherapy. I couldn't get my head around this as they had earlier stated they couldn't give anything. They were now telling us that due to how well [redacted]'s surgery had gone, they didn't want to give him the trial drugs, they wanted him to have the radiotherapy first.

89. I'm a member of a Facebook page for ATRT so I knew about the trial drug already. There was a wee girl diagnosed with the same thing as [redacted] and she relapsed. She had been put on the drug round about the time was going to be getting palliative care. The trial drug was also a big thing in America so we knew that we could ask for it if [redacted] relapsed. We didn't know if the drug was available over here though as the wee girl was in Ireland and they're slightly different to us. A parent from Manchester got in touch with me to let me know her child was on it so we then knew the drug was available in Manchester. This is why I was so angry at getting told would just be getting palliative care. I was told by Dr Sastry when he told me about [redacted]'s relapse that we couldn't get the drug on the NHS yet I found it was already in Manchester through my own research.

90. [redacted] started the radiotherapy at the end of June 2020, possibly the beginning of July and it lasted for six weeks. He was attending the Beatson every day, five days a week for these six weeks and then he was to be seen

over at the QEUH, Ward 6A every Thursday so they could check his bloods and make sure everything was fine with him.

91. I think that three months after [redacted]'s surgery, there was another scan performed on him but I can't remember. He started his trial drug on 1 October 2020 and has been on that since. He takes the drug every day, twice a day. Every second Thursday, he has to attend the QEUH to get his bloods checked to make sure he's still on the right path. [redacted] gets a scan every eight weeks which the hospital had tried to move to every 12 weeks without consulting with me and this is when I had it out with Dr Sastry regarding the communication and his lack of support when [redacted] relapsed.

92. In December 2020, [redacted] had been complaining about a sore ear which the GP and ourselves had initially thought was maybe congestion as did have a touch of the cold. After a few days, he started complaining a wee bit more so I called outreach and they told me to take him in. Andrew took him in to ward 6A and when they arrived, staff checked [redacted]'s ear and there was illuminous green stuff in it which staff said they had never seen before. was sent down to Ear, Nose and Throat (ENT). ENT had a look at [redacted]'s ear and told Andrew they also hadn't seen anything like that before either. They said it was maybe contrast dye from his last scan and it was weeping or it could be the start of an ear infection but they didn't give [redacted] any treatment for it. ENT had also mentioned to Andrew that it could be a wee section in his head where the bone had moved to his ear so they were half blaming the surgery [redacted] had. Andrew was told that [redacted] might possibly get a temperature and if there was any fluid leaking in his ear, it was CSF fluid and to get [redacted] straight to A&E. ENT had wanted to do a scan but as this was mid-December and [redacted] was already due a scan at the end of January 2021 for his head, it was decided to wait until then and do the scans at the same time.

93. Two days later, which was a Thursday, [redacted] was back at ward 6A for his routine bloods and Andrew had asked if there was any information from ENT. The Schiehallion team didn't know anything about what had been said by ENT so they tried to chase it up. Over the weekend, [redacted] took a turn for the worst and was getting temperature spikes. I took him to A&E on the Monday and his temperature was 39.8 degrees. Staff in A&E knew was a Schiehallion patient so they put him in a designated room but he wasn't given any medication at that point either. [redacted] had spat his NG tube out at home earlier that morning and didn't take medication very well in his mouth so the staff were trying to get a tube or a cannula into him but they didn't have anything to get the cannula in with and they didn't have any tubes the size needed. This went on for two hours during which time [redacted] was becoming lifeless. One of the Schiehallion nurses came down and told the staff they needed to get medicine into [redacted] immediately through his mouth. couldn't even get up at that point so there was no way I could shove medicine in his mouth so I told staff they needed to get a cannula into him now. They did get a cannula into him after this and gave him medicine. [redacted] was then admitted to ward 3C but staff kept telling me it was viral. Andrew stayed the night with him and I went home. I got a call from Wendy, the oncologist saying I had to go straight back up to the hospital as there was a crash team around [redacted]. She told me [redacted]'s heart rate was through the roof and they didn't know what was wrong with him. I asked if they thought it was sepsis and Wendy replied yes.

94. When I arrived at the hospital, [redacted] had lines in everywhere and staff were all rushing around looking for packs of medication that were missing and trying to get scans organised. It was hell. We were told they were going to intubate [redacted] and take him down to intensive care. When staff had tried to intubate [redacted], he responded a little so they kept him awake for the scan whilst another staff member was on the phone to ENT to find out what was going on with him. Due to [redacted] being on the trial drug, nobody knew how to deal with him so they suggested calling the trial company.

was pumped full of antibiotics for the next two days and then it was decided by staff that they were going to do a lumbar puncture as they were now thinking it could be meningitis. I was told by the consultant in intensive care that it was meningitis but not the viral type. It was the bacterial one and it had come from an ear infection that was mistreated. The Schiehallion staff had assumed had been sent home from ENT with antibiotics for his ear infection. They didn't know he wasn't given any treatment and he should have been. As he wasn't given anything to treat the ear infection, it had turned into meningitis. Once again, I had to do their job for them. If I had done the usual stuff you were told to do, take him home, give him calpol and take him back if it got any worse, it would have been too late for [redacted] again. He was mistreated yet again. I've no trust in them now. Every time the doctors get it wrong. The next day, the ENT doctor came to see me. He was trying to blame [redacted]'s surgery but we had already been told it was meningitis. I feel the ENT doctor was trying to cover up the fact he had got it wrong. I told him I already knew it was meningitis caused by the ear infection not being treated. [redacted] had already been on antibiotics as part of the safety protocol when he was admitted. He had a lumbar puncture done and it came back with the meningitis and he was already on the right antibiotics to treat it so I think they just upped the dosage. [redacted] was meant to stay on the antibiotics for another ten days which would have been over Christmas. We asked if we could take him home and give him the antibiotics there and staff agreed. At home we had to give [redacted] and injection of the antibiotics straight into his leg. I think he was on the antibiotics from 16 December 2020 to 31 December 2020. is still attending ENT and had an appointment in February 2021. They still don't know what the green stuff was that was in his ear but he's due back in six months for another check-up.

95. [redacted] still attends the hospital. He takes the trial drug twice a day. Every two weeks, he'll go to the hospital, every second Thursday, to get his bloods checked to make sure that he's still on the same path. [redacted] also gets scans every 12 weeks.

WATER: EVENTS INVOLVING WATER SYSTEMS

Water incidents in QEUH:

96. I noticed filters on the taps in ward 6A during [redacted]’s admissions in 2019, but I can’t remember if this was during his first admission in March 2019, and in 2020. They had filters in the bathroom and on the wee hand-wash basin outside, there was a filter on that too. As you came into the room, there was a basin on the right or left hand side depending on which way the room was facing. They had filters over the taps on those basins. I don’t remember them being on the taps the first time we were in though.

97. In the bathroom, there was a sign telling you to run the shower for ten to fifteen minutes before using it. You had to watch that the showers didn’t flood too. The floor didn’t seem to be far enough down. Usually there’s a dip for showers like that. Some of the floors weren’t level enough the way they should be that’s why the water would overflow. My nephew had been in this hospital quite a lot so I had a rough idea of what the rooms were like in the RHC but my sister was telling me about there being sewage coming up through the floor and leaking in to their room when they were in. They had flooding too when they were there so she told me early on I needed to watch the floors as they can be dangerous.

98. I remember we would sometimes get people coming in the room in ward 6A, lifting the drain in the bathroom and putting something down it. It was a bottle of fluid of some sort. I think it was maintenance guys that were coming on as they were in their normal overalls. Thinking back though, from an infection perspective, should they just have been coming in the rooms like that? We didn’t ask them.

99. There were signs up saying not to drink the water. I think the signs maybe also said not to put anything down the sinks too but I’m not 100% sure about that.

Staff would give you bottled water, you could just ask for it and they would provide it. They would offer it to you too when you were having a tea or coffee and your dinner. There was bottled water in the fridge in ward 3A of the RHC that you could help yourself to but I didn't think anything of it at the time. The Schiehallion Unit staff in ward 6A were more proactive in offering it to you; even the diluting juice would be made up using the bottled water. I thought it was strange that everything was done with bottled water. We started bringing in our own bottled water though; [redacted] liked diluting juice but sometimes you had to wait ages on the nurses getting you some so we brought our own in so we always had it for [redacted].

Water: communication

100. Andrew asked one of the cleaners who was responsible for running the shower for the fifteen minutes and he told a staff member would come in every day to do it. We rarely saw anyone though so we ended up doing it ourselves. We knew there must have been a reason for doing this but nobody told us what it was.

101. When you asked the maintenance guys what they were doing with the drains in the bathroom, they just used to tell you they were in checking them even though you'd just seen them pouring fluid down the drains.

102. It was Dr Sastry who told us about the water situation when we were given the certain antibiotic. I think this was round about the August-October 2019, possibly. It was round about the time we had meetings with the Health Secretary. He phoned me and I said to him, "I am not going to sit here and be lied to again. I'm sick of it and I've just had enough now". He then told me that the reason the Health Board were saying the water was fine according to their reports, was that they knew the water in the taps was fine but they weren't sure about the moisture in the air or the cracks in the walls. [redacted] was still on the medication because they didn't know the impact this could have on

patients. At that point, it wasn't public knowledge. I asked him what I was supposed to do with this information because these families are in this situation and they don't know that because nobody wants to tell them. When he spoke about it, he told me I can do what I wanted with the information. I asked him what he expected me to do with the information he had given me. He said to me, "You do what you see fit with that information." So it was myself that told all of the families why we were still getting treated with that medicine. Things had started coming out in the media at this point too so I spoke out.

HEALTHCARE ASSOCIATED INFECTIONS

HAIs: communication

103. We knew there was some sort of bug in the hospital. It had started appearing in the media. One of the parents in the parents' group had shared it on the group page. She said it was possible that the hospital were treating the children for an infection but she didn't disclose what the infection was even though she said her child had it. Eventually the stuff about the infection came out in the media and what they were treating this child for so we found out what we were up against. I can't remember the name of the infection though.

PREVENTATIVE MEDICATION

104. [redacted] was on posaconazole which we found out when he went for treatment in Florida on 22 April 2019. This wasn't actually part of his chemotherapy treatment which we had originally been told about.

105. He was later put on ciprofloxacin in the August 2019, once again as part of the chemotherapy regime.

106. It was Dr Sastry that originally explained to us about the posaconazole and it being part of [redacted]'s treatment to protect against infections but the way it was explained, it was as if it was to help if [redacted] got a cold or anything that could go into the lungs. We didn't think anything of it at the time.

107. [redacted] had to go to Florida for Proton Beam treatment in April 2019. When we arrived at the hospital there, the doctors wanted a list of all his medication. I read them all out but when I got to posaconazole, the two doctors just looked at each other. One then asked why [redacted] was on that and I told him it was part of this chemotherapy regime. We had been told this at the start of his initial treatment by the doctors at the QEUH.

108. One of the doctors told me it wasn't part of chemotherapy treatment and he said he was going to call the UK to find out why [redacted] was on it. We met Lacey, one of the nurses who was looking after [redacted] in America the next day and spoke to her about the posaconazole. She told us that the doctors from the QEUH told her the reason [redacted] was on posaconazole wasn't anything to do with his chemotherapy treatment and that he was on it because of the hospital. I asked her what she meant and she told us it's the dirty hospital. It's the dirty water and the building in Glasgow.

109. I didn't understand what they were talking about regarding the dirty hospital. The staff in Florida then told me that UK doctors had advised to take off the posacanazole straight away but the minute we step foot off the plane back in the UK, [redacted] would have to start taking the medication again. I phoned my mum to tell her and she said I should phone Glasgow to find out what the hell they were giving [redacted]. I had enough to deal with and I decided to deal with it when we got home.

110. When we got home and attended ward 6A, this would have been approximately 21 June 2019. I was met by a nurse who we knew from Day Care and have dealt with quite a lot, who asked me straight away if [redacted] was back

on the posaconazole. I asked why he was back on it as I found out in Florida, it's not part of [redacted]'s chemotherapy treatment. The nurse seemed a bit startled and said it was because of the building. I said that didn't make any sense and the nurse said she would get someone to speak to me about it. Nobody did come to speak to me though. I asked another nurse, maybe a couple of weeks later why [redacted] was on posaconazole as I still wasn't getting answers. I was told this time that it was due to the climate we live in. I told the staff that I had been doing my own research and had found that other hospitals in Scotland weren't using pozaconazole. I had spoken to other parents and my cousin who's an NHS nurse and she did some digging.

111. I was now starting to wonder what other parents had been told. I was a bit fearful of asking other parents as I didn't want to upset the apple cart. If they didn't know already why their child was on this, I may set off fireworks but at the same time, I wanted to know what was going on. I asked a couple of the parents if their children were on the medication and was told yes, it's part of their chemotherapy. I knew this wasn't the case but what was I supposed to do with the information I had?

112. I spoke to one of the other parents about what I had found out and she was trying to get me to talk to the media. I didn't want to be put in that situation though as [redacted] was still going through treatment. There was an auxiliary nurse asking me to go to the media too but the final push was when dropped his dummy on the floor and the nurse told me not to wash it in the water yet the hospital deemed the water safe. I'd had enough of the lies at this point. Something clicked and I decided I was going to talk to the media. One of the other Mums was already going on the TV to speak out and when she asked me again if I'd be willing to speak out, I agreed. We spoke to BBC and STV. This was after a lot of too-ing and fro-ing with the hospital and never getting any answers about the water or the medication. We had previously had media involvement when [redacted] was due to go to Florida as we had to fundraise for it so he had quite a big following on his face book page. It had

turned from us needing help to send [redacted] to Florida to us needing help to get answers that the hospital weren't giving us. If I remember correctly, I think it was July 2019 that we spoke to the media.

113. In August 2019 I received a call from one of the outreach nurses, asking me to go up the hospital immediately. She said that everyone was being asked to go to the hospital but didn't tell me why. [redacted] had the posaconazole stopped and was put on Ciproflaxin. It was Dr Storey that put him on it and it was the first time I had met her. We were sat in a room with her and she was reading off a pamphlet which we were given a copy of. I asked what it was that they were giving [redacted]. She said it was Ciproflaxin but didn't say why was being put on it. Obviously I asked what she meant by that and she replied that she only wished she could tell me but the Board weren't letting her tell anyone because it wasn't good for their reputation given that so much stuff had already been in the media about previous infections. I think Doctor Storey had been given the horrible job of giving all the families the news. She was very upset herself that day and quite teary. I think this was maybe because she had been getting it in the neck from families all day. I just wanted to know the truth about what [redacted] was being given. We were just told that he was to take this medicine so many times a day. No other explanation was given. It was also round about this time that we found through the parent who had mentioned on Facebook that their child had contracted an infection, that this is what they were treating. Everything about the infections was now coming out in the media. The hospital apologised and said it wouldn't happen again but it kept happening.

114. Doctor Storey also said that [redacted] or ourselves were not allowed to use the toilet downstairs. The reason for that was if there was any spray off the sinks or the toilet itself. Andrew can give more details about this.

OTHER ISSUES RELATED TO HOSPITAL CONSTRUCTION

Hospital build issues: impact of construction works

115. I don't think the blinds were fully working and were broken. They never allowed proper daylight in. We raised this with them and asked how we got them fixed. We were told staff had sent a report in and were waiting on it coming back. I asked how long the report would take and I was told that they didn't know, just whenever they get to it, so we were sitting in darkness. I think [redacted] ended up with an eye issue from sitting in the dark all the time for three weeks.

116. The rooms were a hit or a miss too. One minute it was really warm, the next minute it was really cold. In the summer months you couldn't breathe as they were so stuffy. We asked staff numerous times if we could have fan but we were told no because it wasn't good enough in the environment the kids were in and therefore it wasn't good to have a fan so you would be left sitting in the heat. This came from infection control. They said we weren't allowed to use the fans. They didn't go into detail but from what was said I think it was to do with the air circulation in the room if we were to use a fan it wouldn't be good for the immune system. They never clarified what they meant by this. They had air filters in the room but not all of them worked, to purify the air but if you used a fan, it wouldn't work. Nurses would complain too as they were sweating working in that environment. There was never a happy medium. You could try and control the heating with the thermostat in the room but it only went down to 17 degrees but 17 degrees didn't feel like 17 degrees. The kids would then spike a temperature but they were just roasting due to the heat in the room. When we were in America I asked how they could tell if it's a temperature spike or just hot because of the room. The staff there told me that they if a child spikes a temperature over there and it was particularly warm, they would leave them for a few hours but still check their temperature. If the child's temperature had come down, they would know it wasn't a spike, they didn't just assume it was a temperature spike due to something else. I tried telling the staff that at QEUH as even the parents were hot and would likely show a temperature but the

response I got was that it’s protocol so then your child would be put on antibiotics when they maybe weren’t needed.

117. The televisions in the rooms didn’t all work either and the battery packs they had for the chemotherapy drivers didn’t last long. [redacted] would be hooked up to a machine that would drive the medication in to him and the battery pack would go in the back of the machine. This meant that would be able to hold the pole on his machine and walk up and down the ward. But nine times out of ten, those battery packs wouldn’t work or they would run out of charge after twenty minutes, so by the time I would have [redacted] out of his bed and doing whatever we needed to do, the battery would have run out. There was also a shortage of the battery packs and not enough to go round the children who were needing them. Some of the packs were obviously older too as they still had the old Yorkhill stickers on them.

118. I remember the windows falling out which was a big thing at the time. The hospital put these railings up and told us that the windows were safe but they had scaffolding round it for numerous months. How can the windows be safe if they’ve still got scaffolding round them? That makes no sense. Nobody’s ever picked up on that either. The windows in Day Care go round in a circle and there’s a ledge some of the kids stand on. Our kids can go in to Day Care and lean against the windows and could fall out of them, God forbid.

119. Ward 6A was not set up for long term use. When we came back from America in June 2019 and [redacted] had been eating proper food, to come back to ward 6A and not have anywhere to store the foods he was eating was devastating. I was told by the nurses that Infection Control wouldn’t allow a fridge. The food the hospital gave you wasn’t good. They didn’t have any salad or cold meats. It was all things like fish fingers and chicken nuggets that you could stot and bounce off a wall, soggy, freezing chips or congealed macaroni. It wasn’t pleasant.

CLEANLINESS

120. There was a lot of dust. For example, on the top of the overhead TV stuff, you never really saw anyone coming round cleaning them. You could have thick layers of dust on them as well. There was dust on the floors too. Sometimes you didn't know when the floor in your room had last been mopped, it looked as though it could have been weeks. The cleaners were very nice though and the majority of them tried to speak to the children but there were a few that just didn't want to be there. Their mops were dirty and yet they were still washing the floors with them and then going to the next room and using the same mop. You wondered how many rooms they were doing with that one mop. I thought they should have at least be changing the water. Considering this was supposed to be the 'new' Schiehallion and supposed to be clean, it wasn't.

121. The floor always felt grainy too with dust so I wouldn't let [redacted] play on the floor. I asked the nurses if I could have one if the mats for [redacted] but they said there weren't any so I informed them they were in the bathroom so they went to get us one. One of them said she would give it a wipe down but it was just a quick skim she gave it. I wasn't happy with this as they had been stored in a bathroom. I got the wipes out and cleaned it myself.

122. Due to the fact there was no parents' kitchen, we had to use the microwave which is down in the main foyer. There was once an infestation of flies that would circle round the microwave, literally. We were told that was where we should cook any meals that we brought in. We weren't supposed to bring meals in however, if parents wanted to, they could cook down there. Then you would have to walk through the main foyer full of people, in to a communal lift and up to your room with this food. It made no sense to me but that's what staff told us to do.

OVERALL EMOTIONAL IMPACT ON [redacted] AND HIS FAMILY

123. [redacted] couldn't wash his hands in bathroom at the hospital so he was obsessed with hand sanitiser, even more so now with Covid. He was behaving that way because of the way I was reacting.

124. I shouldn't have had to go to the media. I had been asked in July 2019 to speak to the media but didn't speak with them as [redacted] was in treatment but it got to the point that I was fed up being lied to and I wanted answers. Everybody now knows everything about me and my family now because I've spoken out. Don't get me wrong, I'm grateful to the media for their help when was ill and all the help I received through it but at the same time, it has a detrimental effect in your day-to-day experience. I was known as the bad woman on the ward for speaking out or at least, that's how I felt.

125. When you take your child to a hospital, you expect them to be safe and to be treated properly. To have to be constantly on your guard and fighting every day while you're going through treatment at the time too, it had a knock on effect. It wasn't good.

126. The thought of having to go back there, leaves us on tender-hooks. It will feel like, here we go again, the cleaning process and bringing you own stuff in to clean with. Bring your own plates and cutlery in for your child because he feels he can't get his hands dirty. That was constantly worrying that you felt things were going to happen in there.

COMMUNICATION: GENERAL

127. When the media had started reporting about the hospital, there was a meeting with Jeane Freeman organised. I think this was in the September of 2019. I don't know who organised the meeting but I was told by another parent in a group chat I'm a member of that this meeting was taking place in the Grand Central Hotel in Glasgow. At this meeting, I was one of the more forthcoming parents as a lot of the other parents were shying away. I was really angry with

being lied to about the posaconazole so I raised concerns about this, the treatment, blinds not working, the food that we were getting at the hospital and the miscommunication. I raised the issue of the battery packs not holding charge too and there not being enough of them. I told her that [redacted] had physio for his legs as he was stuck in his bed all the time because of this. Jeane Freeman apologised and said she would rectify the situation but it was never rectified. They still didn't have enough battery packs and the ones they did have, still run out of charge.

128. There was a note taker at the meeting who was writing everything down and if I remember correctly, we were given minutes of the meeting at a later date. A lot of the points were included in the minutes and we were told by the people holding the meeting that they would come back with answers. Once again, they never did come back to us. Jeane Freeman during the meeting appeared to be really shocked and appalled about what she was getting told by the parents and I thought at that time she was genuine. The parents felt that maybe something would be done now but looking back, I think I was maybe naïve to believe that. The one positive thing that did come out of that meeting though was we did get a parents kitchen in ward 6A. It was built in a room where there had been a bathroom before but you weren't allowed to use the tap but when it became the kitchen, the tap was fine to use. That didn't make sense to me.

129. There was a second meeting held in the November of 2019 I think and this was with the Health Board. Once again, I think this meeting was organised because of everything that was being reported in the media about the hospital and the Health Board had been forced in to it. The Facilities Manager from the hospital was there and he spoke about the building works, what was going on with wards 2A and 2B and what the progress was. He was trying to reassure us by telling us that works were in place to fix the issues and that they had to get a part for the ventilation system but there was a delay. He said that they were still on target for next year but initially it had supposed to be opened that January but it was postponed to the May 2020. He said we would all be kept informed.

Jennifer Haynes, who I think was one of the Heads of Patient Care, and Fiona McQueen, the Chief Nursing Officer, were at this meeting. Fiona McQueen had been at the first meeting too. There were also various other people at the meeting from the Board. They all said they were focussed on patient centred care and had a communication board set up. I think this is also when I first met Professor White. We were told he was there for us and they were trying to make us feel part of what they were doing to try and resolve things. I did have some contact with Professor White but he was only a point of contact. You could send him questions but he was never going to answer them or if he did, it was in an indirect way. This sounds really bad but if you weren't educated enough, you wouldn't realise that Professor White was answering your questions with another question so he never actually gave a direct response or confirmation to anything. In my opinion, he was just someone that the hospital could say to the media, they have someone in place so the parents had a point of contact and that they were doing their best. They weren't though as I still had questions further down the line.

130. The Chairman from the Board was there too at the meeting in November 2019 and he had been trying to speak to us before the meeting to try to get to know us which I think was a bit twisted as he should have said who he was. He was first to speak at the meeting and appeared quite overcome with emotion until we started asking him questions that he didn't want to answer. Those holding the meeting had started discussing the water reports that the hospital had received and telling us that the initial one was showing that the water was fine but they were awaiting another report. I asked the Chair to confirm if the water was fine and every child was deemed to be fine and he said yes to both. I then asked, "If the water was fine, why was my son still on the preventative medication?" The Chair then tried to blame the doctors saying it was miscommunication stating that the doctors hadn't spoken yet to the people involved. I told him that was rubbish as I had just spoken to [redacted]'s doctor and he had confirmed why the children were still on this medication and that it was to do with the cracks and moisture in the walls. I knew the answer

but I wanted the Chair to admit it but he wouldn't tell me the truth. He didn't want to answer me and just told me to take it up with [redacted]'s doctor then he changed the subject to something else. They had report after report so if everything was fine, why were they double and triple checking everything? The reports should've been gospel. They shouldn't have needed anyone to check again and get someone else to clarify it.

131. The other parents said to me that I had shot the Chair down as I knew the answers and he knew he was lying to my face. He was trying to blame it on the doctors then wait for the second water report. Two weeks after that meeting where I had questioned the Chair, I received a phone call to advise that would have his central line removed two weeks earlier than planned. I think this was the hospitals way of shooting me down so I couldn't ask any more questions; [redacted]'s line was removed so he was no longer on the preventative medication so I would have no need to keep asking questions about it.

132. I found out at these meetings that other parents hadn't been told the same information I was by Dr Storey about keeping away from the downstairs toilets. The other families were still using them because they were going to clinics downstairs. I thought that because they were out-patients at the clinics and we were in-patients, they weren't getting told the same information. Those families had still been using the downstairs toilets but I later found out we were warned about using them because [redacted] had a central line in and it was a line issue with the infections and the other kids didn't have a line.

133. Other parents had been told the same information we got at the start about the preventative antibiotics. They were told it was part of the chemotherapy protocol. I found this out after speaking to some of the other parents at these meetings. The only difference was that instead of it being posaconazole, it was a weekly injection into the central line rather than a daily one. I think this was because children aren't meant to be on that type of antibiotic for so long. Some

of these parents had seen me in the media when I spoke out and they asked me what was going on as they were new to this and wanted to know what to expect. I had to tell them to speak to their own doctor as their child had leukaemia which was different to what [redacted] had and the protocols may be different. It sounded like they had been fed the exact same script we'd had though. I never wanted to be put in that position. It wasn't my place.

134. I spoke to Jennifer Haynes and told her I had sent emails to Professor White and I that I had asked him what was happening after the previous meeting we had with Jeane Freeman. She said she would chase up the answers for me but she never did. I raised an issue regarding the positioning of [redacted]'s feeding tube when he was in America too and it took her months to come back to me about that.

135. I think it was in between these meetings that the parents met and spoke with Monica Lennon and Anas Sawar. I think this was organised by one of the other parents who had initially spoken to them. The BBC were involved and they had contacted us too.

136. I still don't think communication is adequate at the hospital. I'm thankfully not in frontline treatment with [redacted] any more so I don't know how adequate the communication is for the people that are in there just now but there are still no follow ups done. [redacted] can get his bloods done and staff just send you home after they've done them. You never get any results back. You have to phone the hospital for them. The same happens if you need to ask staff a question. You wait about four or five days for an answer that should be given on the same day. I don't think the communication issues are the staff's fault though. I think they're understaffed and they're not 100% focussed on their job and that's not their fault. I think it could maybe get better if I think the hospital employed reliable staff who are there all the time, not bank staff. They should not rely on students to do their job because there are more students than there

are staff. I’m not saying students shouldn’t be there but they should have someone with them that can do the job.

137. Dr Sastry was sent to see us the night before [redacted]’s surgery as the outreach nurse knew there was a lot of animosity between us and with him being [redacted]’s doctor, he was made to come and talk to us. I had been telling the outreach nurse about the way [redacted] had been treated and she said that they can allocate another doctor but that Dr Sastry was the best one for dealing with [redacted]’s type of tumour as it’s so rare. He didn’t know what to say initially. I said to him, “Will we just talk about the elephant in the room?” That’s when it all came out about why he acted the way he did. He told me about another family he had organised a trial for but the Board voted against it last minute and that’s why he’s not keen on trials now. At the time of ’s relapse, Dr Sastry didn’t respond to Dr Kilday in Manchester who had offered to help when [redacted] relapsed and I felt he wasn’t supportive of us at the time. He also told me about the issues he was having and he was quite heated. He said staff were complaining about not having a staff room and the phone didn’t work half the time and there was no reception so if they were across the other side of the building, they were having to get back over if something happened. I think he was venting about how he felt about the hospital at this point and I felt bad for him but at the same time, I’m a parent and I’m there for my child.

138. I had an argument with Dr Sastry in March 2021 as I felt he wasn’t helping us and the communication was awful. He didn’t come to check on [redacted] after his surgery and never commented on how well he was doing. Since we had the argument though, things have been a little bit better regarding communication from him. He will now email and if there’s ever a time where he can’t make a meeting with us, he will let us know and apologise. We got a treatment plan from him too but I worry if [redacted] was ever to relapse again and we have to go against the Board, will Dr Sastry stand up for us? I don’t feel the right outcome for [redacted] would be there if that was to happen again.

gets scans done and I always have to chase the hospital to get the results but I feel due to the way [redacted]'s tumour is, they should be calling me with results. I shouldn't have to chase for results. Dr Sastry will ask me now what information I have. He knows I'm on a Facebook group so he checks with me to see what information I've found out from Facebook. It's better than it was before but it's hard to get trust back once something like that happens.

139. I said way back at the beginning, if the hospital had just told us the truth, we wouldn't have liked it, but we would have taken it on the chin and went with it because we didn't have any other option. To blatantly lie consistently to your face, that's just morally wrong. I feel if they just were upfront about anything that was to happen and not have us finding out through a third party. Communication as I said, is key and that's what they need to get it right.

COMPLAINTS

140. I made a few verbal complaints to staff members that were never really resolved. They would always tell me they'll get someone to come and speak to me but nobody ever did. The complaints I'd made would be about things like the fact we couldn't store food for [redacted] on ward 6A or that I wasn't told the right information at times. It felt like it was a case of, well that's just how it is.

141. When [redacted] was given the ketamine at his scan appointment in May 2020, I complained about it to Dr Sastry. I told him what had happened and that I wasn't happy about it. I had sent an email about it to the doctor who was part of the anaesthetic team that day and to be fair, he did phone me about it. The anaesthetic team tried to call me again two weeks later but [redacted] was going in for surgery that day. They also sent me an email saying that they knew it was a bad day to try and speak to me, yet they were still trying to anyway. They said in the email that they didn't know what had happened. I never

followed this up though as we go the results from [redacted]'s scan back and we had to concentrate on him.

142. I complained to Dr Sastry in May 2020 about the delay in [redacted]'s scan. This was when Covid had hit. Dr Sastry told me he initially had 100 patients he was allowed to scan. That then got dropped to five people then two. He had always put [redacted] at the top of his list due to the aggressiveness of his tumour and what he had been through but he found it difficult to choose. It was the Board that made the decision due to Covid. It's awful for a doctor to be told that but I feel Covid has been used an as excuse for so many things. If had been scanned when he was meant to have been instead of it being delayed, his relapse would have been picked up sooner. I told Dr Sastry I didn't think [redacted] was very well and he didn't do anything about it. That angers me as [redacted] is a child at the end of the day. I understand we've to protect the NHS but it's these families in the same situation as us that are being compensated. Those children are meant to be our future. I felt at the time they were saving the older generation, which sounds awful but I felt we had been let down. There were already these misconceptions with the department and no clarification and then no communication. Then this on top of what was already a disastrous ward. Nobody knew what was going on or what they were doing ad we just slipped through the net. I know of another family who's passed away during this. She relapsed at the same time as [redacted] and was told she could get the same treatment, radiotherapy. The family came to me asking what they should do as the doctors wanted to stop her treatment and I told them they had to take it up with the doctors. She just didn't have the strength at that time so waited two weeks and when she came back they told her the child was too sick for the treatment so they stopped it then they came back again and said they should have continued the treatment but by this tie, four weeks had passed and it was too late. How many other families have been in this situation? Getting the citation for the Inquiry, it's nerve wracking but when you see the other families and what they're going through, they can't continue

the way they are so I have to do it. I hope it will get better when we're back in our own ward again although I have heard it's delayed again.

143. I sent Jen, the Head of Care, a list of questions about Florida and what had happened around that, especially with [redacted]'s NG tube not being positioned correctly. I never got a response from her so I then emailed Professor White who I think passed my email to Jennifer Haynes. After a while I eventually got a response and she answered my questions with another question. She said it wasn't protocol for [redacted]'s NG to be checked but I know it was as it's to make sure the tube goes into the right place and doesn't cause an infection. I wrote back to every point she made in the letter but I never received a response from her and to be honest, I didn't chase it after that.

144. On 19 November 2020, I sent a list of questions to Professor White about the water and the medication. By 25 November 2020, there was no reply from Professor White so I tried to contact Lara, Professor White's contact and Jennifer Haynes. I can't remember if it was the minutes from the meeting with the Health Secretary that I received on 7 December 2019 or whether that was the date of the meeting with her but there was still no reply from Professor White or Jennifer Haynes. I sent another email to Jennifer Haynes on 9 December 2019 and received a letter about [redacted] on 3 January 2020 from Jennifer Haynes. I think the information about the anti-fungal medication was in this letter. I replied to Jennifer Haynes stating that they had written to me with lies. I called them out on what they had said to me. I got a reply on 31 March 2020 so it took them three months to come back with a reply but by that point, I had caught on to what they were saying. There was no constructive response from them, no answers just lies. I did get the offer to go and meet them if I wished but I was advised by other people, MPs I think, to have everything in written form. I'd been told that if I don't have written communication to take with me to any meetings, they'll just try to bully me and if it's only me and them in the meeting, there's no witnesses. I wasn't interested in having a meeting with them though as they weren't giving me any answers anyway. I knew if I went to

a meeting with them, I was just going to get told a load of crap again so there really wasn't any point.

OVERSIGHT BOARD / CASE NOTE REVIEW / REPRESENTATIVE GROUPS

145. I know that a couple of the parents were on the Oversight Board but I just feel like a lot of that was just, information to cover the Oversight Board's own tracks. As much as they were trying to look like they were doing stuff, they weren't giving any answers. Every week you had the same. It got to the stage where after three or four weeks I just thought, what am I reading? All I'm reading is a whole load of flack that is of no relevance to us. You're just making yourself look important. And you put two parents on the page and in this meeting to make it look like we're involved. We're not any further forwards. We're not getting any answers. So is there actually any point to this oversight board? No.

146. That's my opinion on Oversight Board. Other people might have different opinions. Anything that I did get, any correspondence, I was sharing it with Andrew. I didn't even feel like I had to update him because I didn't feel there was anything there to update him with. A whole load of medical jargon and stuff that they would try and make them look important was my opinion.

147. [redacted] wasn't part of the Case Note Review. I understand why they were doing it in regards to infections but I don't know obviously infection-wise whether there's anything there for him. [redacted] may not have acquired an infection but we're part of this because we were given all these medications because of these infections. Families have been affected because they got an infection but, from our perspective, we've been affected because was given treatments and we'd been lied to and all the rest of it that goes with that. I think [redacted] should have been part of that Case Note Review.

It shouldn't just have been deemed on acquired infections. It should have been on the whole thing, like the Public Inquiry, the relevance of it. It shouldn't have just been on infections but the measures taken to prevent the infections too.

148. I know that the Case Note Review was partly done through the hospital, and although they say it's independent, I feel it wasn't fully independent. I feel it was pretty much one sided. I did read parts of it. I can't remember 100% but I think it came out possibly around the time that [redacted] was admitted with his relapse. The relevant pages for [redacted] were maybe one or two pages of that report. I felt again it was another cover up. I didn't feel that it was truthful. I felt the people who did the review were trying to make out that the parents were lying. They tried to cover up a lot of things in it like the death of a child They were saying things like, hospital acquired infections possibly have come from other environments. I think that's complete lies. Some of those kids weren't even out of hospital. I don't feel there was any relevance in it.

149. If I remember correctly, there were two reports. The Case Note Review one that was done last year and then the one that came out with the findings this year. Basically the conclusion of that one was that, yes, the parents were telling the truth. Overall what we had been saying previously, they were trying to say was wrong but it was actually true. It's now shown that they did give people medicine and there was a sort of cover up going on, and the lies and things. In some ways you felt relief that you were you weren't these paranoid parents, although as much as they were trying to help, there's people out there who aren't in this situation who would say, oh they just want five minutes of fame. They forget we were living it. We don't need our five minutes of fame. But just to have the clarification there that, you know, what we were saying was true and we weren't idiots that they were trying to make us out to be. At the end of that, much as this has all affected the families, it's those little individuals, those little human beings who are only children who were affected most.

150. I’ve been involved in a group just this year with Stephanie, from Thompsons. This is all the parents that are on the WhatsApp chat that are represented by Thompsons. I’m also in a Facebook group with some of the families. This group is quite informative. I’m in the WhatsApp group as well and we chat through that so it’s good, in terms of communication, because we obviously don’t trust the hospital. If anybody does find anything out, they always put in on there. You know that you're going to the answers from them before the answers come from anywhere else.

151. I think some of the parents have been too scared to come forward. Some of the parents that have been affected haven't spoken out, with scaremongering amongst staff and just being treated differently. I certainly felt like that at the beginning when I spoke out, that I was treated differently by some members of staff. They were on their guard with you or would leave you to your own devices because they didn't want to be involved with you. As time has gone on, I’ve been more public and I think more staff are on your side than not now but I feel a lot of the people on these Facebook pages, including staff, don’t want to speak out because they’re fearful, which is horrible. I know it’s a horrible situation to be in, especially for families who are still going through treatment. I think a lot of the families fear that if their child was to relapse, they worry about how they would be treated. We are one of those families who has been put in that situation. When [redacted] relapsed, Andrew straight away said that the Board had gone against us because we spoke out. I understood how Andrew felt as I had my doubts too at that point because of the way we were treated by the doctors and the board when [redacted] relapsed and the lack of help they gave us. I can’t sit and think about that though because at the end of the day, for my own family’s sake and for the sake of the children who died, you would just sit and cry. Some of the other families have asked me how I was treated after speaking out. I was honest with them and said it was hard but it doesn’t mean the same thing will happen to them as it’s different situations we’re all in and different treatments so there’s nothing to say the same will happen to their family that happened to mine with [redacted].

CONCLUDING COMMENTS

152. I have no trust in the hospital at all. The only person I trust is Roddy. Roddy is the only person who would tell you the truth. From an oncology perspective in the Schiehallion, I go in because I have to. If I had another option I'd use it. I hate going in to the hospital to be fair. But I hate going in in case they give me any answers I don't want to hear. At the same time it's not the relapsing side of it, it's the whole lack of back up, nobody in my corner. That's the way I feel. I feel like everyone's against me rather than with me. As much as I had the argument in March 2021 with the oncologist which has cleared the air a bit, I still wouldn't trust him as far as I can throw him. When you've broken somebody's trust like that, you can't get it back. That goes for the whole hospital to be fair.

153. If I had to pick a ward to be in, it would be the Neurology ward. Everything was really on the ball there and there weren't any major issues. As I've said, I only trust Roddy and that's his ward. There were a couple of little things that happened to us down the line in that ward but staff couldn't have done anything about them.

154. The issues are still there in Glasgow. Why is it allowed to operate? If those things happened in any other job, they wouldn't be allowed to operate. Look at Edinburgh, it was shut for similar issues but Glasgow was deemed fit for purpose. I'm still anxious about the water and the building works going on but I do feel a wee bit safer because [redacted] doesn't have a central line in now.

155. Regarding the Health Board, they should get rid of it. They always came out with an answer for everything but it was never the truth. How can you regain trust in somebody who's lied so many times? You just can't so I would never trust anything they said. They haven't been doing their job properly which leads

to the rest of the hospital not doing its job properly either. It's not the fault of the staff, it's the Health Board.

156. I requested [redacted]'s medical notes but the woman on the phone who I spoke to about them told me I should request the notes for all three children from birth. I was alarmed at this but I did request them all and I've only read the neonatal notes so far. There's a note in [redacted]'s when she was getting her tonsils out implying that Daddy was there but he wasn't really there, if that makes sense? [redacted] was getting his first round of chemotherapy on the same day [redacted] was having her tonsils out and the staff knew that but they wrote stuff in [redacted]'s notes about Andrew rather than medical facts.

157. When we had to take [redacted] to Florida, we were initially raising funds. The hospital told us that they would initially pay for the flights then we would reimburse them. They did pay for the flights and we had approximately two thousand pounds to pay them. We kept asking them if we could pay the bill. This went on for months. We were begging them to take the money from us and chasing them up about it. It wasn't for the lack of trying on our side that it hasn't been paid. In the September of 2019 though, it all went quiet and nobody spoke to me again about it. It wasn't until I was talking about this the other day though that this all happened around the time things were kicking off at the hospital. I don't know if there's any relevance to this but we never heard back from them about the money we owed so it would make sense if it was related.

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

Appendix 1 – KS/01 – Timeline

- 20th February 2019 – [redacted] shows signs of being unwell with vomiting and did not seem himself. He attended his GP who advised that [redacted] had a viral illness. His symptoms did not improve.

- Friday 22nd February 2019 - Andrew took [redacted] to QEUH for further checks. He was monitored in accident and emergency and the staff concluded that he had a viral illness. He was sent home with calpol.

- 24th February 2019 - [redacted] attends A & E at QEUH. There were no beds available so he waited in the plaster room. A CT scan is ordered after Karen demands one (staff wanted to discharge [redacted]). Karen and Andrew find out on this day that [redacted] has a "mass" on his brain and that there was a risk it was going to haemorrhage. He is sent for an MRI scan and he then went for an 8-hour brain operation. After this operation he is transferred to ICU for 3 days approx.

- 28th February 2019: [redacted] is moved to ward 2C. He remains there for 10 days

- 6th March 2019 - [redacted] is introduced to Dr Sastry and discharged home.

- Within the same week of the 6th March– [redacted] returned to hospital and had a Hickman line fitted. He was admitted to ward 6A, room number unknown. It was a room at the end of the ward. [redacted] begins his treatment plan around this time (chemotherapy and radiotherapy). During this round of treatment [redacted] was extremely unwell with regular temperature spikes. He was moved into an isolation room and at one point he was told he had an infection. [redacted] was put on Propiconazole at the beginning of his treatment.

- 22nd April 2019 – [redacted] and the family travel to Florida so he can undergo proton therapy for 8 weeks. This was a particularly difficult journey due to the hospital not communicating with the 3 airports about [redacted]'s situation and the route being organised by the NHS without consideration for the family's situation. While he was in Florida it came to light that he had been on propiconazole. The doctors in Florida queried why this was and contacted QEUH. They were told that [redacted] was receiving this because the water at the hospital was dirty. Up until then Karen had been told that this medication was part of his chemotherapy (or had that impression).

- 21st June 2019 - The family returned to the UK. The moment returned to the UK to QEUH he was put back on Propiconazole. Shortly after returning he also had to undergo strong chemotherapy treatment because he was unable to receive this in America because of the Proton therapy. This meant he went through a period where he was an inpatient for 5 days or so and then a Daycare patient. He was continually in and out the hospital until December.

- December 2019 – [redacted] finishes treatment. His central line is removed. Once the line is removed he is able to stop the antibiotics.

- December 2020 – [redacted] develops meningitis.

- March 2020 – [redacted] has a scan and everything is shown to be clear.

- May 2020 – [redacted]'s behaviour changes, he becomes aggressive. At the end of May 2020 he attends for a scan (which was delayed due to covid)

- 1st June 2020 – The family are told that [redacted] has relapsed. At a meeting on this day with Dr Sastry and Dr Roddy, it is explained that there is an adjacent brain tumour and 3 more spots beside it. Palliative care is suggested instead of treatment by Dr Sastry. Dr Roddy says he could operate despite this palliative care suggestion. Karen and Andrew research treatment options. They find treatment and Dr Sastry denies that he has heard of this treatment, then tells them that this is not available on the NHS.

- 7th June 2020 (approx.) - Karen and Andrew speak with Dr Roddy. They discuss a possible trial treatment. Dr Roddy tells them that before they had met on the 1st June a board meeting had been held with Dr Roddy and Dr Sastry. At the meeting Dr Roddy had suggested operating, which was not backed up by the board. The decision was because of cost.
- Mid-June 2020 - After appealing the decision this was overturned and was able to get surgery and receive a trial medication. Had the family not fought for [redacted] to receive treatment, (due to the NHS saying it was too expensive) [redacted] would have likely not survived.

- [redacted] has done well since this point. He has recently had a scan and there was a fear that he had relapsed. It is now confirmed that he has not relapsed. [redacted] is still receiving chemotherapy and has a feeding tube.

Scottish Hospitals Inquiry

Witness Statement of

Aneeka Sohrab

WITNESS DETAILS

1. My name is Aneeka Sohrab. I was born on[redacted].[redacted].

2. I am the mother of[redacted].[redacted]'s date of birth is[redacted]. She is 4 years old.

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

OVERVIEW

4. My daughter is [redacted]. [redacted] was diagnosed with Acute Lymphoblastic Leukaemia (ALL), type B with mixed-lineage leukaemia (MLL) rearrangement in her cells in May 2018, when she was 18 months old. MLL is a genetic condition which shows malformation in [redacted]'s cells. This means there is a high chance of relapse.

5. I have not been able to provide a timeline detailing all of [redacted]'s contact with the hospital but I can confirm that [redacted] was treated in the Royal Hospital for Children (RHC) and Queen Elizabeth University Hospital (QEUH) between May 2018 and November 2020, when she finished her treatment. She attended both hospitals as an in-patient and as an out-patient regularly during this time.

6. [redacted]'s port-a-cath was removed in September 2020. She still attends the hospital for check-ups but her treatment ended in November 2020. She's had two visits since November and one of the staff,[redacted], has done one home visit. My last contact with the hospital was the Case Note Review notification around 21 April 2021, which led onto a meeting with Michael Stevens in July 2021. I was still left with questions at the end of this meeting though.

7. [redacted] spent time in wards 2A and 2B of the RHC, which are known as the Schiehallion Unit. The Schiehallion Unit treats children with blood cancer. [redacted] also spent time on other children's wards, being wards 3A and 3B of the RHC. Following the closure of the Schiehallion Unit in 2018, [redacted] was treated on ward 6A of the QEUH which was supposed to be the 'new' Schiehallion Unit. I was in hospital with [redacted] throughout her treatment but due to childcare commitments I was unable to stay routinely overnight with her. I was the visitor. My parents stayed when I couldn't, so did my sister occasionally. I can speak to the experience which [redacted] and I had on these wards.

8. My family experienced many things during [redacted]'s treatment at the RHC and the QEUH in Glasgow and I will share those in this statement. This will include, among other things, issues involving communication deficiencies; construction-related matters, particularly linked to water problems and infection control as well as the physical and emotional impact on [redacted] and the family. I will also speak about how the frequency of infections prevented my daughter from completing her cancer treatment. That is a major issue for me as the Case Note Review failed to acknowledge this.

9. Luckily, [redacted] responded to the cancer treatment, but the many, many infections and additional stays caused by those meant that her treatment was

not able to be fully concluded. It also meant that some of the procedures mentioned below were done on multiple additional occasions as infections were, in my view, linked to problems with the various lines and the like.

FAMILY BACKGROUND

10. I am a single mother and I live with my five children in [redacted]. [redacted] is the youngest. [redacted].

11. [redacted] is in nursery and her siblings are all schoolchildren. [redacted] was around 18 months old when she was first admitted to hospital. Before [redacted] got her cancer diagnosis, she was a chubby faced, rosy-cheeked wee girl with curly-haired bunches. She was able to walk and run around and had started talking. The children generally get along well but experience the usual sibling issues common in most families. Given what [redacted] has been through her siblings are very protective of her.

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

Admission to hospital: May 2018

12. [redacted] was diagnosed with ALL, type B with MLL rearrangement in her cells in May 2018, when she was 18 months old. Around Spring of 2018, I noticed that [redacted] had a lump on the back of her neck where lymph nodes are, they were quite abnormal in size. I was told it was just the shape of her head. I have five children and I left it; I just thought it was because every child is different. Then I took her to the pharmacist who said I should take her to the GP. He took one look at her and referred her to the QEUH. He said it might be fluid, that was what it looked like. I was Googling “mass” as that was the word the GP also used, it made me suspect it could be cancer.

13. We saw the consultant at the QEUH two to three weeks later. He initially told me that I was not to be worried, but when he started looking at [redacted] he began talking to himself. He said she had to go for a biopsy. That appointment was offered for 1 week later. The consultant said it was important to take the appointment offered as it was a cancellation and it can take a long time to schedule another one.

14. The biopsy was on a Monday in early May 2018, I think. One or two days later I was asked to bring [redacted] into Ward 2B, the Schiehallion Unit, the out-patient department. We saw Dr Shazia Chaudhury, who became [redacted]'s consultant oncologist.

15. The biopsy results revealed that the lump on [redacted]'s neck was a tumour and Shazia sent [redacted] for an MRI. That scan showed tumours in [redacted]'s neck, chest, all throughout her body and I was told at that point that it was either ALL or Acute Myeloid Leukaemia (AML) .

16. After more tests it was confirmed that [redacted] had ALL, type B with MLL rearrangement in her cells and [redacted] was admitted on the day she was diagnosed. This was the 11 May 2018 and she was admitted into Ward 2A, the in-patient ward of the Schiehallion Unit.

[redacted]'s initial treatment

17. Following diagnosis and admission, [redacted] attended the RHC and QEUH as both an in-patient and an out-patient for a period of approximately 18 months from May 2018 to November 2020. When [redacted] was first admitted she stayed in Ward 2A for around 8 weeks. She began Regimen Cy ALL 2011, a trial. It involved being given methotrexate, a chemotherapy drug. She was

given the highest dosage of medication for anyone with that type of cancer, as an 18 month old baby.

18. I was sent an immense pack about the treatment; the hospital overload you with information. I consented to the trial as I was told [redacted] was lucky to be on it. I was informed that the trial was coming to an end and a new one would be starting.

19. The information pack described the different phases of the trial and the process was explained to me by Shazia. As I've said, she was [redacted]'s oncology consultant and [redacted] was in her care. She worked under Professor Gibson. Shazia is approachable.

20. [redacted] had a variety of procedures at the RHC which were done under general anaesthetic. I cannot provide precise dates for these but, where I can recall, I'll provide them. These procedures included the following: A nasogastric (NG) tube to feed her. The NG tube was largely in place throughout [redacted]'s treatment. She was on water boluses and feeds, she's really only started eating since her treatment finished. When she was able to eat in the beginning, it wasn't enough for her, she could only manage a little food. [redacted] also had a Hickman Line and she had a port-a-cath, I'll say how that came about later. She had a number of cannulas during her treatment.

Experience on wards 2A, 2B, 3A and 3B: May 2018 until the move to Ward 6A in the adult hospital

21. During [redacted]'s treatment, she attended on many different occasions and was treated in Wards 2A, 3A and 3B but I'm afraid I can't remember the dates she was in which wards. [redacted] was treated as an in-patient and out-patient in all of those wards. These other wards were used consistently when we

were told that Ward 2A was full. It actually wasn't full, it had some rooms unavailable because of the problems, that's a different thing. The rooms had white sheets around them, there were clearly issues with the rooms that were not explained. We did not know what was going on in there, just that they were closed and unavailable to patients.

22. The playroom in Ward 2A was brilliant, a good environment for the children. It was chilled and safe; it had a sensory area. There was also a play room in Ward 3. There was also a kitchen on Ward 2A and the loss of the kitchen facilities after they closed the kitchen was hard for the parents. You also got to talk to parents in the RHC. This kitchen closed before the closure of the entire 2A ward. I can't remember when it was closed, but it was about 4-5 months before the whole ward closed.

23. The level of care and the culture is very different when comparing the Ward 3A and Ward 2A nurses. The nursing staff are nicer in Ward 3A, in a way. They are less judgmental in Ward 3A but they don't have the experience of putting the Nasogastric (NG) tube down or flushing a port, etc., that the Ward 2A nurses do. The Ward 2A nurses definitely have that valuable experience. [redacted]'s NG tube was in place pretty much throughout her treatment so that kind of expertise was important.

24. Another problem being on Ward 3A was getting seen. Although you're told that someone will come and see to your child, the way things operate with Ward 2A is that they see those within ward 2A, before they get to your child who is elsewhere in the hospital.

25. In relation to the doctors on Ward 2A, I'd use the expression, it's like getting blood out of a stone. It's very, very difficult to get to see them. For example, they say they will come and deal with your child, when she wasn't in 2A, but

they deal with the children on their ward first. [redacted] actually was a Ward 2A patient but was just located elsewhere. It wasn't good.

26. The infection control team regularly came up to the wards. The culture of the Staff on Ward 2A was to view the infection control team as "pesty". They would say "it's infection control that make us have you change rooms". I won't fault the skills on Ward 2A, they gave good care but the attitude was to blame the parents for putting stuff like tea and coffee down the drains and view other teams as pests.

27. As far as moving rooms was concerned, we'd sometimes be told 'you have to go' to this room or that room. No warning. Without exaggeration, we were moved hundreds of times. Some days I'd leave her in one room with my parents and return later that day to find her in another one.

28. [redacted] learned to deal with those changes because she had to. She just lay back and let things happen to her; it's quite sad actually.

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

29. I can't remember the exact date but we had a meeting with Shazia. She said that Ward 2A was closing and they were moving us to Ward 6A. We asked, 'Why are we moving?' Shazia said there would be work done to the ventilation or that something was wrong with the water system, maybe both. I asked if it was not all the same water in the whole hospital. It was hard for her to answer. I felt sorry for Shazia, those higher up were putting her under a lot of pressure. But I know the water is the same or else why have the filters on Ward 6A as well?

30. Parents were told nothing about arrangements for getting our kids safely to Ward 6A. There was an outrage because of the risk. The hospital barely told parents about measures to rectify build-related issues at the hospital. We might be told things like ‘You’re being moved’ to clean rooms or improve things but very little was shared. That’s another area where communication was poor. I’ve had more information from other parents about what was going on than I was told by the hospital.

31. Ward 6A was not suitable for children. I don’t know what it’s like now because we haven’t been there for a while, but there was nothing for children on Ward 6A. I think a small office may have been made available but it was not adequate for [redacted]. At some point there was a wee table that could accommodate two children at a time made available. It was situated in a hallway. If your child wanted to play there, and parents wanted to sit with them, as you would have to do, we were told we were causing an obstruction. The tables were an obstruction in the hallway when children were being taken up and down with drips stands and so on. [redacted] was left on her own a lot, with an iPad and an auxiliary sitting with her whilst I went home to look after my other children.

32. There was no kitchen at all on Ward 6A and until very late on in [redacted]’s treatment there was no way even to make coffee there. I think I used it only once to make coffee after the facilities were made available.

33. Generally you were in source anyway and not allowed out of the room. Being in source means that you are not allowed out of the room. You had to rely on others for the things you needed to be brought in to the room. If we weren’t in source, you had to go six floors down to get something heated up.

34. You got to talk to other parents on the ward when you were in the children's wards. That was lost when they moved to Ward 6A. The chance to share experiences and our concerns was lost. It was a lot to lose.

WATER: EVENTS INVOLVING WATER SYSTEMS

35. I remember that there were issues with the water almost right from the start.

36. In Ward 2A the taps started being sealed and there were signs everywhere telling us not to drink the water. I remember filters going on the taps. I think it would have been around June or July 2018. We were told by staff, probably the nurses that it was our fault the sinks were blocked because we'd been putting tea and coffee down the sinks. We were told not to wash dishes in the sinks as well. We had to leave everything on trays for staff to dispose of when we were in source.

37. My own experience of the water in 2A was that taps were blocked off; we were not allowed to use the kitchen. Not for your kettle or doing the dishes. There were signs saying not for drinking use and then white tape was put over taps. The hospital knew things but didn't tell us what was going on.

38. I feel anger because my daughter nearly lost her life several times in that hospital because of infections and it wasn't because of me putting things down the drain. It makes me see how emotionally affected I have been by these experiences. It was unavoidable.

39. A nurse or auxiliary told us the water was safe to use, I can't recall when or who, what I can recall though was that it was after the filters were put on the taps. I remember my brother came to see my dad who was looking after [redacted]; [redacted] was really sick at the time. My dad went to drink the water;

he'd been given jugs of water from the taps for drinking. My brother told him not to drink it but the auxiliary said 'Oh no, it's fine, it's safe'.

40. At one point we were given bottled water in Wards 2A and 6A. I can't recall a date.

41. I was concerned about the shower rooms in both wards 2A and 6A. When you showered, the water ran out the bathroom and into the bedroom. The bedrooms have en-suite bathrooms. You were sometimes walking in a big puddle. There are tiles on the floor and there is no shower tray or anything to stop the water running out, and it lies in the bedroom floor until someone comes and cleans it up. It just sits in the room. It depended what room you were in, some drained away properly.

42. [redacted] kept getting infections. No-one said what might have caused the infections. I was never told not to bathe her or to watch out for certain things.

HEALTHCARE ASSOCIATED INFECTIONS

HAIs: events and physical impact

43. I can talk about [redacted]'s repeated infections and other things she contracted, perhaps fungal problems but I don't remember all the dates.

44. [redacted] had sepsis many times. I know about the sepsis from the staff. I was told how to identify the signs. Before then, I didn't know what rigors were. I needed to know how to spot those things. A bit of medical training was given so I would know when to rush [redacted] to hospital; it's so serious.

45. When [redacted] got fungal infections we were discharged from the hospital. Staff couldn't get my daughter out quickly enough. They said she didn't require to be hospitalised for fungal infections, 'She's been treated, take her home'. They said it wasn't good for a child to be in hospital longer than she needs to be. With spiking temperatures too, [redacted] was put out as quickly as possible.

46. I knew of another child of similar age to [redacted], 3 years old. That child got a port fitted due to infection risk associated with her Hickman lines. I asked the hospital to fit [redacted] with a port, it is sewn inside the skin so there's less chance of infection. [redacted] had her lines replaced about four or five times due to infections. It was because of her Hickman line. It dangles down and gets on the floor. I couldn't keep [redacted] off the floor. I told the staff that I knew there would be fewer infections with a port. Still staff tried to get me to consent to another Hickman. I refused.

47. I was told by all the staff that the Hickman was better for [redacted]'s treatment; that she was too young for a port and that there actually wasn't a port available for her. I was told three lies. When it came for me to sign the consent form for the procedure to replace the line, I told them I wanted a port fitted and was told I had to make the case for that.

48. Then they sent Shazia to see me too. She took me into a meeting, very nicely. I was told that [redacted] needed the Hickman to get a certain drug. I was told that it was better for [redacted] to have a Hickman line rather than a port as she was going to get high doses of methotrexate and the line was better to get it into her veins. Then, after that meeting with Shazia about the Hickman line, an anaesthetist called Nick came in to see me for at least two hours. This is when I felt defeated. I felt absolutely slaughtered, shattered. This is really the

only time I tried to stand up for my daughter. That had more emotional impact for me.

49. Nick explained that, if [redacted] is repeatedly getting infections with her Hickman line, I would have to keep her on my hip; not to let her down. I am the mother of five children, it isn't physically possible for me to carry [redacted] all the time. Also, her development was arrested already. She'd stopped walking so, the only way to halt that was to let her try, to physically let her learn to walk again.

50. I felt bullied and agreed to the Hickman, partly because I felt that Shazia must know what was best for my child. I'm not an oncologist. The hospital staff didn't listen to me and I had so much hostility in my life already with lots of other things going on then. By agreeing, it felt like I was putting a lamb to the wolves. Unless you just sing from the hospital's hymn sheet, you're the bad one.

51. Staff were trying to calm me down because I wasn't happy about having to agree to something I wasn't comfortable with. There was never any acknowledgement that the line infections might have been from the hospital, never.

52. After I agreed to the line I found out that the child with the port was also getting methotrexate. I knew of two other [redacted]who'd had the same drug treatment as [redacted] and they had a port. One of those [redacted]was the same age as [redacted].

53. The Case Note Review information states that at least three of [redacted]'s infections could have been contracted in the hospital. She needed an

anaesthetic many times to replace her line and I wasn't once told that it could have been related to the hospital or given any information.

54. I stopped fighting for her, following the incident when staff refused to give the port. I gave up. I am very grateful for my daughter's life, others weren't so lucky. But I shouldn't have to feel grateful.

55. [redacted] had many infections, it was certainly well into double figures, including sepsis twice and fungal infections. It was a combination of line infections and temperature spikes. Staff and other parents used to comment on what a tough time she had with all her admissions, back and forward as an in-patient and out-patient. When she got infections, [redacted] was very ill. She had high temperatures and we worried about her a lot.

Maintenance Period (the third phase of chemotherapy treatment) – around May 2019

56. [redacted] went onto Maintenance about a year into her overall treatment. That phase can take about a year too. You're told by the staff that it can be the light at the end of the tunnel but it wasn't for my daughter. I was told that she was more sensitive to the cancer treatment and she was very sick with it. She was consistently in and out of hospital with infections. Some people found out the names of the infections, I didn't. It depended how strong your personality was. I wasn't able to push staff to find out. I don't actually know what staff meant by "more sensitive to the treatment" I just assumed it wasn't good, but it wasn't explained.

57. During [redacted]'s Maintenance phase, I was finally told, 'She can now get a port'. There were lots of benefits to the port. I could take her swimming, bathe

her properly. So, those excuses they'd told me before about why she couldn't get the port weren't valid anyway. I was just relieved she got the port.

Pseudomonas infection – November 2020

58. The very day that [redacted] was in the clinic to discuss removal of her line was the day that I was told she had Pseudomonas. On that day she attended hospital as an outpatient and became unwell which resulted in her being admitted.

59. That was November 2020. The Case Note Review (CNR) had already begun by then so the pseudomonas was not included in the review. It was never explained why the infection caught in November 2020 was not part of the review, and I think it should have been part of the review. There could have been a supplementary review for the problems that were still happening in the hospital.

60. What that pseudomonas infection, as late as winter 2020, tells me is that the water issues still hadn't been resolved in the hospital. If they had been, my daughter would not have developed that infection, it must have happened because of her treatment; pumped in through a sealed port, stitched into her skin. Nothing should have been able to get in there, it must have come from what was pumped into her. The room [redacted] was treated in then is still being used for other children. I am not good at remembering room numbers. What I can recall was that she was in ward 3A where she stayed until there was space in ward 6A.

61. Pseudomonas can be contracted from germs that live in soil or water. There's no soil in that hospital, it must have come from the water.

62. The physical toll on [redacted] was huge. She was having temperature spikes and I wasn't told why the infections were happening or even what they were, except when a registrar let it slip about the pseudomonas. I had asked the doctor what was wrong with [redacted] and she said that the cultures had come back saying it was pseudomonas she had. I wasn't told details about a single other infection. I was always told that [redacted] had serious infections, but I was never given a particular name. During her time in hospital, often because of infections, [redacted] regressed in both her walking and her speech. She had a tough time physically with all of that and I fear it will impact on her in future too.

63. I was told by one of the doctors about pseudomonas being a potentially fatal infection. It was unusual to be told things like that. It is a flesh-eating infection, very dangerous.

HAIs: communication

64. You're not allowed to ask questions, you have to just get on with the way staff want it and if you don't you're bullied. I fear getting [redacted]'s notes, who knows what I'll find out. A lot of what went on should be in the medical notes. But, even that simple request for the notes to be sent to my solicitor has been delayed with the hospital saying it wasn't made clear in the request that [redacted] had been treated in the RHC. They're buying time.

65. There was never any idea or concession from staff that the infections and additional admissions were linked to the building defects or infection control issues.

PREVENTATIVE MEDICATION

Preventative Medication: events and physical effects

66. As far as prophylactic medication goes, [redacted] was put on Posacanzole and another medication I cannot recall, [redacted] was also given Septrin. She was given this medication from the very beginning of treatment.

67. [redacted] was given a yellow liquid to treat the infections too. I can’t recall what it’s called, that will annoy me because she was given it so often. That was put through the Hickman line. Professor Gibson told me it was to help prevent getting infections. That was the only information we were given, nothing about them being long-term antibiotics. All that I was told was, it’s to ‘protect [redacted]’, that was the language that was used. I was not asked for consent for any of the medication.

68. [redacted] was not tolerant of that medication at all. She reacted badly; became neutropenic and she seemed to catch more infections from her siblings as her immune system was down to zero, all down to this treatment. I can’t recall when these problems were happening but it was often and [redacted] was badly affected, as I’ve said.

69. At one time, everyone in Ward 2A was put onto an antibiotic for infection control. I cannot recall the name. [redacted] had a severe reaction to that medication, it made her very sick. She had to continue taking it despite her reaction; it was only stopped later for everyone once they thought things were under control.

70. Even although the preventative medication didn’t agree with [redacted], staff said she had to keep taking it as it was needed to deal with the infections.

Preventative Medication: communication

71. I would like to know what [redacted] had and why she contracted the infections. I was told several times that [redacted] was on ‘the strongest types of antibiotics, which were ‘only given in rare cases’. It made me wonder what she had, why they were necessary. I was only told the names of the antibiotics, that they were needed ‘because of infections’. No-one told me how she could have got these infections. There was no effective communication.

72. No-one spoke to me about my medical concerns. I often asked if a Doctor was going to speak to me. They made the excuse that my having to leave the hospital to take my children to school etc., was the reason why I wasn’t spoken to. I was to blame because I wasn’t there all the time. But the doctors are there most of the day, they could have communicated with me. It felt as if I was being was being ignored because I was asking too much.

OTHER ISSUES RELATING TO HOSPITAL CONSTRUCTION

Hospital construction

73. The way the hospital has been built isn’t good. When we were going to theatre, I was holding doors open for the porter. That was because - you know when you go to McDonalds the doors are automatic? Well, the hospital doors weren’t. They were really heavy too, some were fire doors. If there weren’t two porters, you had to hold them open for the trolley. It wasn’t adequate. That meant I wasn’t able to hold [redacted]’s hand, to comfort her properly before procedures.

74. For me, the whole place should have been given more thought. The placement of the theatres in the RHC added to our stress; it was about half a mile to walk there, maybe more from Ward 6A which is in the adults hospital.

75. I found out later that the COVID patients are treated in the adult ward 7. That is the floor directly above where the children who are still being treated in Ward 6A have to be. We share lifts. There are only three lifts, it’s not enough. The children are immunocompromised. Children are being exposed to risks still. I found things out only because my Mum got COVID and she was treated there.

76. [redacted] wasn’t an in-patient when my Mum was in hospital so I didn’t have to ask about arrangements in and out of 6A for her, but my brother was going up to see my Mum and they were using the same lifts and stairs as our immunocompromised children. You can’t tell people not to touch the bannisters. The children shouldn’t have been put into 6A, it was not safe.

CLEANLINESS

77. If you’re in source, the room was cleaned twice a day. They had two mops for the full ward; to do everybody’s room, the bathrooms too. The cleaners were overworked. The wee ladies were rushed off their feet.

78. Cleaners did try but if what they’re using is contaminated, what are they going to keep cleaning? The infection control team was constantly on at the cleaners too. I saw them all the time monitoring the cleaning staff to see if they were cleaning things adequately and if they didn’t believe it was adequate they would tell them to do it again.

OVERALL EMOTIONAL IMPACT ON [redacted] AND HER FAMILY

Overall emotional impact on [redacted]

79. [redacted] has had a tough ride. Because of the strength of her chemotherapy and when comparing her with other children, even other parents would tell you that [redacted] was in and out of hospital all the time. NG tubes were consistently being changed; they came out or maybe she vomited them out. The emotional side of that as far as I can say was [redacted]'s habit of just letting it all happen to her, lying down to it. My daughter has had a life-changing experience in the hospital. It will probably impact on her for the rest of her life.

80. It has affected her behaviour; she's lost a lot. When you talk to most children they have a natural defence mechanism and protective instinct to make them wary of people they don't know. [redacted] doesn't have that anymore; she will talk to anybody and everybody. People like that but it's not natural.

81. She has had so many people poking and prodding her; the fear of going into that hospital is so severe. She doesn't like it. She fears the colour blue, it's what the anaesthetists wear, the staff wear it too. Doctors sometimes come in wearing their blue scrubs. I've asked if they can change, wear child-friendly, bright colours and name badges to show you're staff. I was told 'No'. So, the psychological impact of the colour blue is going to be long-term for her.

82. [redacted] is a child who hasn't played well for at least two and a half years of her life. It's going to have a definite impact on the rest of her life. She regressed in her behaviour and makes noises in her sleep, a kind of groaning, moaning sound. [redacted] was walking when she was diagnosed, but due to the treatment she regressed. She went back to crawling and sometimes she was just lying there. I was told that this could happen due to the treatment but she

needn’t have been hospitalised so often and had additional treatment if it hadn’t been for all the infections. There were many delays to [redacted]’s chemotherapy treatment to a point that I was worried that she would have a relapse. The treatment she missed out on she never received again. [redacted] regressed in her talking too over a period of about six months. She went as far back as to almost a vegetative state. She had to re-learn everything. The physio came in with exercises. That helped.

83. Anyone will tell you that children’s experiences in the first years in their lives are important. A lot of negative, avoidable things happened to [redacted] in the hospital.

84. Physically, the amount of times [redacted] has been admitted and been near death; sepsis and other infections, it’s too much. Even in the Case Note Review they mentioned the treatment she’d had for lines being taken out. For example, a general anaesthetic was needed twice for one line.

85. [redacted] had her line replaced at least five times due to infections, there were lots of issues with her line. It was traumatic for [redacted] to go for all the procedures in theatre. As well as the five lines in and out, she’s had lots of lumbar punctures, and other treatment too. She’s also had a few MRI scans. For all of those procedures, she was sedated.

86. I gave up fighting for her due to the emotional strain on me. There was another occasion when she was overdosed on salt, they referred to another child’s records. The doctors had been giving her the medication to make up for the loss of sodium to increase the salt in her blood because she was lacking it. One day, in the middle of the night a doctor came to me and said sorry there had been a mix up. That was it, nothing else was explained to me. I don’t know if there was a physical impact of this, she was already extremely

unwell. As I understand it there had been a mix-up with microbiology. There was also a time when they pulled the line out of [redacted]'s chest. Maybe that was their only option. She was only two or three years old at the time. She was helpless as was I, nothing I could do.

87. To this day we are still waiting for a psychiatric referral due to her behaviour.

88. Due to all the procedures [redacted] had, and at such a young age, she experienced trauma, even in anticipation of being sedated, etc. She had to be controlled physically. At one point, she was pre-medicated to help calm her down mentally. I didn't even know that was possible; it depends who you speak to but she wasn't offered that all the time she was going to theatre. It might have been better for her if I'd known it was an option.

89. [redacted]'s childish behaviour is ongoing. I think the emotional effect, is linked to the hospital's construction. When a small child goes into theatre, they need and want to be supported, their hand held etc. Because of things I've already spoken about, like having to hold doors open, that wasn't always possible, she lost out.

90. After [redacted] had been in theatre, you're given an estimate of when she'll be conscious again. [redacted] would tend to sleep extensively after theatre. But, she knew what was coming. She couldn't be contained sometimes, we couldn't always restrain her, it was easier carrying her along there. But, it's hard, heavy on the arms. [redacted] was vomiting a lot, and they had to give her anti-nausea medication.

Overall emotional impact on witness

91. Construction of the building had a significant effect; the sheer numbers of procedures for our children with cancer. [redacted] had more operations to remove her line as a result of these infections. There was also a significant distance between the ward and theatre, clearly it had not been taken into consideration when the hospital was built. More thought should have gone into how all of that would be managed including frequent trips to surgery, a good distance away from ward 6A, for all the lines, ports, lumbar punctures and the like. It wasn't well thought through. All the infections meant that these problems were experienced far more frequently than they should have been. I found it very hard.

92. I am still undergoing counselling**.** My counsellor has confirmed that many of the negative experiences are linked to the hospital.

93. My hair was coming out in clumps, I was put on Diazepam for panic attacks. It's hard to explain. You're trying to reassure your child that things will be okay while also trying to do that for yourself. There were so many times I had to take [redacted] for sedation when I had that feeling of your child falling limp in your arms, I can't put it into words. There was a physical impact on me too. Staff had to hold me up, support me, when I handed [redacted] over in theatre.

94. I remember when I went to Manchester for my nephew's wedding. I had told the hospital that I would be going and my parents were staying in hospital with [redacted]. It was all agreed. I was contacted to say that [redacted] was to be discharged suddenly. My Mum had no idea how to look after [redacted] at home so I asked if she could stay in hospital, as we'd agreed before I left. I could not risk her being with family who didn't know what to do, even how to give her

basic medication. I was told I had to return immediately and take [redacted] home. It was a terrible journey home, a strain on me. Again, I felt it was avoidable.

95. I suffer from circumstantial depression. I also worry about [redacted] having actually lost treatment, it wasn't just delayed. It's hard to get that across. As I've already said, the Case Note Review team didn't seem to get that point; they talked about delays to treatment, not lost treatment. What impact will that have on her life chances?

96. Because the communication and honesty is not there with staff I am still worried about my other children and the risk to them of the genetic condition. Staff kept saying it wouldn't affect them. But why did someone from the genetics department sit me down and ask about the cancer history in my family if it wasn't relevant? Their genetic make-up is the same as [redacted]'s. They say [redacted]'s cancer isn't hereditary but why ask me the questions? Those questions remain for me. We're still waiting on a referral to psychologists due to the impact of [redacted]'s treatment on her behaviour now. The specialists were there, the dieticians, etc., so why we are still waiting? These things worry me greatly.

Overall emotional impact on siblings

97. The impact on my other children has been a lot. It is not my fault that I am a single mother with 5 children. I felt they were degraded by not being with me, not being allowed to stay with me. I felt other families' siblings got to stay, to visit. As I had 4 other children, I was always being told to look out for them, keep them in check.

98. The children have been passed from pillar to post and lots of behavioural issues have arisen because of that. One of my daughters has started

[redacted] and I feel that my son has lost the full opportunity to bond with me because I was away so often.

99. The whole experience on them has been a worry, they have witnessed their sister go through cancer, been near to death. Their emotional wellbeing suffered, they've been to hell and back. Their mental health has been impacted.

100. The recovery from what has happened to my family will take years, it is a long and painful process. Cancer either makes you or breaks you and in our family's case, it broke us. I worry about what they have endured because of what we went through at the hospital and worry about how this will affect them as adults.

COMPLAINTS

101. I did feel like complaining sometimes but other things were going on and I felt worn out. I had fear at those times. The pseudomonas was the main time I might have complained; when I found out it had come from the hospital, which I found out by googling what was going on at the hospital. There may have been times before that but, as I've said, I'd have given up on those occasions. The pseudomonas can only have come from there; it's come from the sealed port. The only thing that can get through it, a sealed port, hard skin surrounding it, is via someone at the hospital accessing it. The port is designed to prevent things getting though it externally.

OVERSIGHT BOARD / CASE NOTE REVIEW / REPRESENTATIVE GROUPS

102. I know about the Oversight Board but haven't been part of it.

103. I recognise Professor White's name and might have been offered a meeting but I have had no direct contact with him.

104. [redacted] was included in the Case Note Review (CNR), but I feel like I didn't know enough about it. I don't know why she was included. I am unhappy about the outcome; there's no use of definitive language. It's too easy to say 'possibly' or 'perhaps'. It wasn't good enough.

105. The review also speaks about the impact of the infection and how serious it was. It said 'we concluded that the impact to be significant as the planned admission was extended by at least 10 days and 10 days of antibiotic treatment was required. The Central Venous Line (CVL) was removed and led to a six day delay in [redacted]'s chemotherapy treatment'. That's not true, the treatment was lost for reasons I've already discussed, the loss of [redacted]'s remaining chemotherapy treatment.

106. By using the words 'delay' you assume the treatment was then caught up; it wasn't. It's misrepresenting the fact that basically 16 days of treatment was missed. Anyone who isn't even a doctor knows that if you miss a few days out of your antibiotics for a urine infection, for example, the chances are, the infection will not go away or it will return. The hoped-for outcome will be diminished if you can't take the drugs. Imagine that for cancer in your child. This is going to impact on [redacted] for the rest of her life.

107. No-one from the CNR team spoke to me, they just reviewed the files. [redacted] doesn't know what's happening, she can't tell you. But I've got a voice, I can tell you but I wasn't asked. The Review has misrepresented the position.

108. I believe the CNR has been pathetic, ridiculous. Not a full, fair overview of what's happened to my child. The day it came in other parents were very, very angry. I wasn't told the Review would cover a snapshot in time. I got an email saying the Review was concluded and the pseudomonas came after that. But, they should have asked us 'Is there anything else that you feel is significant to our inquiry?' The pseudomonas was important, it's water-based and should have been included.

109. I'm on one Facebook group, Schiehallion Parents, created by the parents, for the parents. I decided not to join the one set up by the hospital group. Why should Big Brother watch over everything we're discussing? I can find out things for myself or from other parents. I wouldn't trust what the hospital told me. I can ask questions on the Schiehallion group. I don't feel the hospital-operated group is the place where people can openly share things. It was absolutely a matter of trust for me.

CONCLUDING COMMENTS

110. Can I say how I feel about the Health Board? They're corrupt, liars, stealers, killers, murderers, that's how I feel. When I say corrupt, I think they stole taxpayers' money and pocketed it and children lost their lives. Where has all the super-hospital money gone, why do £500 TVs not work? Those swanky TVs didn't work. What are you supposed to do with a two year old child who's virtually tied to a bed all day long?

111. How can they sleep knowing what they did? Children are still at risk.

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

Scottish Hospitals Inquiry

Witness Statement of

Senga Crighton

WITNESS DETAILS

1. My name is Senga Crighton. I was born on [redacted]. I am [redacted] years old. I am a [redacted] for my son [redacted].

2. I am the mother of [redacted]. [redacted]'s date of birth is [redacted]. He is 16 years old.

3. I live with [redacted] in [redacted].

OVERVIEW

4. My son is [redacted]. [redacted] was diagnosed with Medulloblastoma in February 2018 when he was 12 years old. [redacted] was treated in the Royal Hospital for Children (RHC) and Queen Elizabeth University Hospital (QEUH) between March 2018 and November 2018. [redacted]'s treatment finished in September 2018. He attended both hospitals as an inpatient and as an outpatient regularly over that time. [redacted] still attends the QEUH for check-ups, as a result of his treatment.

5. [redacted] spent time in wards 2A, 2B of the RHC which are known as the Schiehallion Unit. The Schiehallion Unit is the kids' cancer ward. [redacted] also spent time in ward 3A, which is neurology, the Clinical Decision Unit (CDU)

and PICU, all within the RHC. Following the closure of the Schiehallion Unit in late 2018, [redacted] was treated on ward 6A of the QEUH which is where the Schiehallion Unit had moved to. I stayed with [redacted] during all of his admissions to hospital as an in-patient and an out-patient. I can speak to the experience which [redacted] and I had on these wards.

6. There are some specific events that I would like to mention. [redacted] suffered septic shock in September 2018 when he was a patient in ward 2A. He also contracted a line infection in 2018. There were issues with the water supply throughout [redacted]'s time at both hospitals. I believe that [redacted] was prescribed preventative antibiotics in 2018 but I am unsure if this was normal protocol for cancer treatment or if it was connected to issues with the water supply. There were ongoing construction works at the hospital throughout [redacted]'s time there which, in my view, impacted his experience. I will come on to talk about these events in more detail.

FAMILY BACKGROUND

7. I live with my son, [redacted] [redacted], in[redacted]. [redacted] has an older brother, my other son[redacted], who is[redacted]years old.[redacted]stays with his girlfriend. [redacted] and I don't see very often now but at one point they were just kind of typical boys, messing about with each other. The two of them did mixed martial arts but then got unwell and[redacted]met a girl and moved out. We see[redacted]now and again but just when he's playing his X-box and things. [redacted] and[redacted]get on well, they have ups and downs like any brothers.[redacted]is an amateur at Mixed Martial Arts (MMA), he's done a few fights, so he's done all right. [redacted]was doing the training with him before [redacted] took unwell.

8. [redacted] has autism so he's quite happy with peace and quiet and doing his own thing. He's into his board games and Lego, he watches Star Wars and Marvel

and all that kind of stuff. He'll come out his room when he wants to or he'll stay away, he'll say to me to get out of his room if he's playing his Lego. He'll do it on his terms. There was a time he didn't go to the MMA training and [redacted]thought [redacted] was kidding when he said he was not well.[redacted]feels bad about that now.

9. [redacted], had a wee group of pals that would come round but when he went to the high school he was kind of pulling away a wee bit anyway. [redacted]'s cousin, [redacted], is the same age as him and they have always been together. So it was mainly just the two of them. They were a lot quieter than the other kids. [redacted] was kind of seeing his friends now and again but when he started taking unwell, he never really saw much of them. Since this, I don't think they know how to speak to him because he is a different boy following the operation, he's struggled a wee bit. It's not badness from the other kids, they always ask about him but the only person he gets to see is his cousin. So, he really doesn't see anybody but he's got a befriender that comes in now for five hours, to break up his day. He's got that and his cousin, who comes down and spends some time with him along with his brother who visits now and again. His dad saw him for a while but he is not here again, he comes and goes.

10. [redacted] used to like going fishing and things but now, he only likes going to shops and buying more Star Wars stuff, he's quite happy doing that. He'll even go to into Tesco, to look at toys or jigsaws, but he's not one for going out. He sometimes goes into the amusements where he does play the 2p machines and he's quite easily pleased that way. When we were in isolation, I think it actually suited him for a little while, but he's not back out where he should be. [redacted] was left with posterior fossa syndrome due to the removal of a large tumour following an operation. I think he's self-conscious about his mouth with everything being different now because of the posterior fossa syndrome. Posterior fossa syndrome is a condition that sometimes develops

after surgery to remove a brain tumor in the posterior fossa region of the brain. The other four tumours that [redacted] had, did not contribute to the posterior fossa syndrome, and were treated with chemotherapy and radiotherapy.

11. [redacted] is at [redacted]. He's started [redacted], he was doing really well until he was not so well, then he was doing school while he was up at the hospital. We put a plan in place and he was actually doing his maths and English within Clinic 12. He was doing really well until he had the operation in his leg as they couldn't provide personal care within the school. We started doing a kind of Zoom thing. He did quite like school. He did like maths and English so he's decided to stay on and try and catch up on what he's missed.

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

Admission to hospital: February 2018

12. In October 2017 [redacted] was being sick and a bit unwell. At first, we thought it was his autism, causing anxiety. Then we thought it was a winter bug, but the winter bug would not go away. He got sore heads in the mornings, and did not have a lot of energy. After Christmas and New Year, he was eating less meals and being sick a lot. We were back and forward to the doctor's. I had to fight with the doctors because they said he's a fit young man. I don't think they realised how sick he was. On 30 January 2018 we practically carried him to the doctor's. They weighed him and took his bloods. [redacted] was then referred back to the doctors on 16 February to see him again but [redacted] didn't go. He didn't like going to the doctors but he really wasn't fit to go. The weight was falling off him and the doctor said he was going to refer [redacted] to paediatrics at this point because he was losing more and more weight.

13. On 17 February 2018 I decided to take [redacted] to Crosshouse Hospital A&E because he hadn't eaten or drank anything the previous night. They kept him in and put him on a drip, they did kidney scans, because they found he had high calcium in his blood. They did abdominal and lung x-rays. On 22 February 2018, they wanted to discharge him after he began eating, he had only eaten a banana. But I insisted on more tests before he was discharged because they still hadn't found out what was wrong. They did additional tests on 23 February and that night they phoned me to tell me they'd found something in his brain. [redacted] was transferred to the Clinical Decision Unit at the RHC in Glasgow that same night as there were no beds in ward 3A, which is the neurology ward.

[redacted]'s initial treatment: March 2018

14. It was Dr Campbell, from neurology, who spoke to me and she said she was going to give [redacted] an MRI that night. They did the MRI when I was there and Dr Campbell told me she couldn't be 100 percent sure but it looked like it was a medulloblastoma from where it was positioned. She said "I can't fully say hand on heart until I go in and operate. I can't see whether it's that or not. But that's what it looks like." She said she would discuss this with her colleagues who were also specialists, like herself. They put [redacted] on oral chemo from that point until the operation was done, because it was quite aggressive, so they wanted to put him under oral chemo right away.

15. On 24 February 2018 they found tumours in his head. [redacted] was given steroids. On 2 March he had the operation to remove the biggest tumour. He was in recovery for a couple of days in PICU and then he was in ward 3A in the RHC by 5 March 2018. In between, I'm not 100 per cent sure whether he went back to the Clinical Decision Unit until there was a bed in ward 3A. But I know he was definitely in ward 3A on 5 March. On 8 March, while he was still

in 3A, [redacted] had surgery under general anaesthetic to get his Hickman line in, to get prepared for his chemo.

Experience on ward 3A: early March 2018

16. When I first went up to the ward, I thought the staff knew what they were doing with the cancer treatment but I then realised that ward 3A wasn't the cancer ward. There had been a few issues with [redacted]'s Hickman line; they were supposed to put his feed off for surgery because he was getting put to sleep for it but the feed had been left on and they couldn't do the surgery. It was just one thing after another.

17. It was a bit chaotic and nobody seemed to know what they were doing. I just felt they were out of their depth sometimes with some of the cancer patients being in there, maybe because that wasn't their field, I don't know. I kept asking when we would go downstairs to ward 2A, and the nurse – maybe the Sister, with the blue uniform - kept saying we'd need to wait on a bed becoming available. I felt the staff within the ward were constantly being dismissive. Eventually I actually went downstairs to ward 2A, myself. I asked for the lady who was supposed to come and see me, whoever she was, and they told me she wasn't there. She knew I was coming down. I just said I wanted to know when [redacted] was moving.

18. The rooms are very dark in ward 3A. I think the room we were in was an internal one. If you were in a room on that side of the hospital, there was no window so it was quite dark. The ward was also in a circle but I didn't realise that at the time as our room was on the inside.

19. I just felt lost to be honest and was left to it. No one came in to care for [redacted] and nurses only came in to administer medication. This was unsettling

for both myself and [redacted]. My son had just been diagnosed with cancer, had an operation and when he woke up from his operation, he couldn't talk or anything and was fed through a tube. I had asked for help from a lot of people including the Social Worker or Psychologist and had to wait for them to actually come and see us.

20. They sent in play specialists but because [redacted] was just lying there, there wasn't really anything he could do. He did try a wee bit. I think they actually shut the playroom at that time, or the second time he was in there. The playroom was right at the end of the ward at the other side. [redacted] had drains and things in and he wasn't doing much so they would maybe bring colouring stuff or things like that for him to do. It was the play workers who would bring it in but they didn't appear very often. [redacted] only had two board games to play with in Ward 3A. This was around March time.

21. We were nearer the exit of ward 3A. I don't know whether the play workers forgot about you because they were up this end. The way I looked at it was that they were run off their feet and sometimes they could maybe not get to you, but that was just me thinking that was what's happening.

22. Outside ward 3A, there was a room up at the very top floor called the parents' room. It wasn't clean, it was bad. In ward 3A I actually had to ask for bacterial wipes. I would take them along to the parents' room to use on the microwave because other folks used it. The cleaner probably did clean it and then the parents would go in who were not as bothered. So you're kind of limited. People used to try and bring me stuff up from home for putting in the microwave but when you try to leave items in the fridges, they would go missing. There was a small fridge there and you could just put your name on your food. The room was wide open because it wasn't in the actual ward. It

was outside in the corridor, between wards 3A and 3B. Anybody could go in there from any ward.

23. [redacted] was in room 2, I think. It was quite dark and dingy, that one. In the room, there was a three drawer unit, for the meds. There was a bed and a sink for washing your hands, and a pull down bed. It was en-suite. I'd try to pull the bed down at about five, six o'clock on the children's ward because everyone's going to bed early. I'd be lying on my bed and it was bad enough with the bleeping of the feeding machines and blood pressure machines, and then you would have people making noise as if it's daytime. Within a day or two I was quite crabbit. I would openly tell the staff, "do you think you could have a wee bit of respect? It may be your nightshift but we've been up all day." They said they were trying to do their jobs. I thought it was just horrendous, and then the lack of sleep on top of everything else, no wonder you get emotional. I complained to the staff nurse a couple of times and she said she'd have a word with the staff to keep the noise down.

Experience on ward 2A: March to May 2018

24. Ward 2A is the Schiehallion ward. [redacted] was admitted there on 20 March 2018. It goes round in a kind of half-circle, like a big crescent. When you go in there's transplant rooms to start with, then you go round the corner and there's a desk, and then further along the corridor, right up at the back, there's a Teen Zone. It's run by the Teenage Cancer Trust. Across from the desk as you go in there's a small playroom, I don't think [redacted] was ever in that one either. [redacted] got his wheelchair when we were in ward 2A, eventually. He wasn't really bothered with the playroom, there were a lot of smaller kids in there and he just couldn't be bothered with them. At that point he was doing his radiotherapy when he was in ward 2A. He had six weeks of radium

Monday to Friday and by the time he came back, he was absolutely shattered, so sometimes he couldn't be around the playroom, he'd be shattered.

25. The play leaders brought stuff to [redacted]'s room for him to do things. They were different play leaders from ward 3A. They made bead chains and had colouring in, maybe painting, with wooden letters to paint. They had a music play therapy, and there were clowns. They tried to do stuff with him but the minute [redacted] started getting a bit better he just wanted out his room.

26. They've got the cinema within the hospital. They tell you what films are on, once or twice a week, and go round the wards and ask if any kids wanted to go to the cinema that night. Volunteers come in and take the kids down to the cinema. There would be volunteers on every ward to get them into the cinema, watch a film, and then return them back to the ward. [redacted] got to see Star Wars at one time, so he was happy enough. [redacted] only went to the cinema a couple of times but they kept saying, he couldn't go if he had been under a general anaesthetic earlier in the day.

27. The parents' room in ward 2A wasn't bad. The woman was quite good at the cleaning in there. You had a microwave and hot water, that kind of thing. I'd be sitting there with my tub of porridge that you just had to put water in in the morning. They did offer toast, if you wanted it but the staff were just so busy so I just had my porridge. Then folk were starting to take other folk in there and it was becoming like a conference room. I constantly felt as if I was intruding whenever I went in because there were so many people there. Some people would not clean after themselves and I felt as if they had no respect. It ended up being only one parent at a time that was allowed in or you had to get a domestic staff member to get you stuff. We were only allowed around five minutes in the parent's room after that. I would go down for my cup of tea

for five minutes. Once you were in source you were not allowed out your room and you couldn't use the kitchen.

28. Patients would be put in source if, for example, they had a lot of sickness or loose stools or anything like that. They would tell you that you had to be put in source in case it was an infection of some kind. You have to be kept separate in case it spreads through the ward. I lost count of the amount of times [redacted] was in source and they only ever told me that it was an infection or that something had shown in his samples; they never said what was showing or what the infections were. At first I thought it was the chemo as it seemed to happen quite a lot, and absolutely every time he had chemo, even before the chemo, or if there was any bit of the runs or anything like that. [redacted] was on a feed, through the dietician but I don't think it was made up from the water in the taps, it was brought up in bottles to run through his line so I don't think the loose stools were related to the water in his feeds. I believe they were sterile bottles with the tube already attached, it was similar to a drip. I was always asking them why we were always in source. At one point, I think the full ward was in source, because you could see the stickers on people's doors that would tell you not to enter. People couldn't come in and see [redacted] as much as they could because he was in source. He couldn't get out to see anybody even if he wanted to. It was a lot, and as I say, at one point I think probably you could count on the one hand how many kids were not actually in source.

29. The ward sister in charge would tell you if you were in source. They weren't very keen on letting you out, to be honest. They would go and get what you needed, if you needed anything. The nurses were allowed in. I said to them that they were telling me I wasn't allowed out to go to Marks & Spencer's, but they were allowing nurses to go and have their lunch, and come back in and still come into my room. They were going in and out of everybody else's room. They looked at me as if to say, what do you mean?

30. At around Easter time 2018 they shut the full ward down. The ward sister said they were trying to get on top of the infection control and that they had to shut the ward down to visitors and no one was allowed in to see [redacted]. They put a note on the door, saying 'ward closed due to infection control,' or something like that. I think I've got a picture of that as well [Picture SC/01 – Appendix 1]. I was actually distraught by then because [redacted] was in that room with not much happening to him and I was just sitting there. It was terrible. The ward was shut to all visitors for about two weeks, maybe. [redacted] was in source but was allowed out to get his radiotherapy at the Beatson. He would then come straight back and get stuck in the room again.

31. Staff were saying there were a lot of unexplained infections. I asked the staff, I cannot recall who, what they were but they didn't give me names for the infections [redacted] had. They just said they didn't know, he needed antibiotics and to be in source. It was just like an unexplained infection. I felt I didn't get any information from anyone when I asked about the infections.

32. When [redacted] was in 2A he was in rooms 4, 5, 6, 15, 16, 19. Rooms 4, 5 and 6 were up at the Teen Zone, I think that was what it is called but I'm not sure. Some of them would have been when he was in for his four blocks of chemo in June, July, August and September. Those were the rooms that I remember when he was going in and out.

Discharge to CLIC Sargent House: May to November 2018

33. [redacted] was discharged from ward 2A, and went straight to CLIC Sargent on 16 May 2018, because we couldn't go home. I was there before that, around April time. It's a charity run house. They let us stay there because we couldn't get the wheelchair down in the house and we were going back and forwards for

the chemo. So right up to the end of [redacted]'s treatment, we were going back and forwards. [redacted] was in the hospital getting his treatment, and then back to CLIC to do his physio as well.

34. When you go in to the CLIC house, there's a downstairs and an upstairs. In the downstairs there are three rooms with your own toilet, it's got a shared living room and a shared kitchen for three families at the most. There's also a dishwasher. You've got the back door which leads you out to a garden with a sitting area and the laundry room. They'll give you your own washing machine, one for each set of rooms. Any soiled stuff had to go in to pink bags. You couldn't chop and change washing machines, they liked to keep on top of who was using what machine, so you had to a specific machine to use.

35. Sometimes it was myself with [redacted], another lady across from us, with her son, and I think we had a mum and dad whose son was never out of hospital, who stayed in the other room. Everything was cleaned once or twice a day by the staff there. We didn't use dish towels, you used paper towels for everything. It's a nice clean environment.

36. [redacted] was back and forward because we were over there and couldn't go home between Monday and Friday. He would do school, physio, maybe cooking in the kitchen over in the hospital, just to get his day in. He would only go back up into the ward when he was due chemo and then the minute that chemo was done, he was back out into CLIC. He would have to go in to the hospital for the first week to ward 2A and he would get out on the Sunday, all going well. He did the two treatments and if everything was all right, he could then get out. We then went over to the hospital to ward 2B on the Tuesday after to get his vincristine, which is another type of chemo that gets pushed down the line separately. You have to leave days between the vincristine and the other treatment but if everything was alright, he would get back to CLIC.

Sometimes [redacted] was unwell and he couldn't get out so he was kept on ward 2A. That went on until September when he finished his last chemo. We didn't leave CLIC because I had to move house as well in the middle of all this. We were discharged from the ward on 30th September 2018, and we left CLIC on 24 November 2018.

HAI, admission to ward 6A and completion of treatment: September 2018

37. On around 25 September 2018, [redacted] went into ward 2A for his chemo. He had pus on his Hickman line that I had noticed previously. I pointed it out to the nurse but she said it looked okay and that I should just keep an eye on it. A nurse came and put a device on the Hickman line to withdraw the pus but this made no difference. The next day, [redacted] became unwell and his temperature spiked. They eventually took him straight into ICU. It wasn't until later that I found out [redacted] had developed septic shock.

38. [redacted] got out of PICU in the RHC on 28 September 2018 and they moved him to ward 6A in the adults' hospital. It was room 25 he was in and later they said they would discharge us to CLIC as it seemed safer. I can't remember who it was that said that. She said, it's maybe safer at CLIC than here. I don't know whether they thought that the line was infected. I know there were hundreds of kids having to get lines changed time after time.

39. [redacted] was only in ward 6A for 48 hours and he was in source for that time. At that point the domestics were bringing everything to us. By the time we were in 6A, I don't even know if there was a parents' room, and if there was, I was never in it.

40. Ward 6A was set out in a complete circle as well. The only thing better than 2A was that it was higher up and you could get a better view out the window, so you got more daylight in.

41. On 30 September 2018 they said to me [redacted] was safer going to CLIC, because it was only five minutes away. I don’t know if it was safer because of all the infections that were happening but maybe he would have been better at CLIC.

42. That was us after that. We went over to the hospital for MRIs and kidney tests, and from there he finished the treatment. [redacted] got transferred down to [redacted], to the local hospital. Then it was just check-ups after that.

Experience in ward 3A: August 2020

43. [redacted] got his MRI scans every three months in 2019, in clinic 12 at the QEUH. It was to check that there was no more cancer or any tumour regrowth or anything like that. There seemed to be a build-up of fluid which was picked up right back at the start, there was a small trickle, they were leaving it to see what happened, because he wasn’t really fit enough. That’s when they decided to do the VP shunt, on 18 August 2020 because the fluid was starting to affect his balance and he was lethargic. He was admitted to ward 3A in the children’s hospital, I think it’s called neurology. This was for a week. He got a surgical procedure to get the VP shunt fitted by Doctor Campbell. Because of the fluid in the brain, they had to put a small tube inside his neck, at the side. It goes through his main artery in his neck, into his stomach. When the fluid gets to a certain level it flushes the overflow of fluid in the head, down into his stomach and he passes it out. That’s just something that would never fix itself after his operation and he had the build-up until it affected him. That was the only time he was really an inpatient again, for the shunt.

Experience in ward 3C: March 2021

44. After [redacted]'s treatment, his leg wouldn't straighten fully and he couldn't get on to his feet properly. The leg was bent from 2 March 2018 and ironically, [redacted] went into hospital on 2 March 2021, exactly 3 years later. We tried everything to get him to straighten it, the skin shrunk because the leg was at a 45 degree angle, we tried Botox and physiotherapy but nothing worked. We had a consultation with Dr McCall in orthopaedics in January 2021 and she put a stookie on [redacted]'s leg for six weeks so it didn't regress. He then got the operation on the 3 March 2021 and was in ward 3C. Doctors thought this had happened to [redacted]'s leg, partly due to the posterior fossa syndrome, and maybe partly because it had been left in that position for so long as he would always sleep in the foetal position. The skin behind his knee had shrunk. He now has a hinge bracket inside his leg to allow him to straighten his knee. His leg is now 2cm shorter than the other leg because of the operation.

WATER: EVENTS INVOLVING WATER SYSTEMS

Water incidents in RHC: 2018

45. I used the water for washing my hands and showering. There wasn't really anywhere else. I was using it at first before I went to the CLIC Sargent. I also used the water at first, with [redacted], in ward 3A. I didn't notice filters in 3A, I think that all happened once we were in 2A. After [redacted] got a lot better, and I went to CLIC, I would stay with him in the ward till 10 at night and come back over for 7 in the morning.

46. I was a bit scared of drinking the water because I always wondered if that was what was wrong with [redacted]'s line. I had put him in the shower too in ward 3A

and in ward 2A. When I was washing [redacted] I was using tap water, and if we were making meals, and cups of tea, it was also that water we were using.

47. When I was in ward 2A in 2018, they put things onto the taps and they told me they were filters. They were put in the shower and they were put in the taps and the sink. All the filters were on the shower and the sinks within the rooms but there was no signage up. I think it was a company that put them on. I asked the guy who fitted them and why they were there. He told me he didn't know, that he had just been told to do it. That happened between March and May 2018. I think they got changed over again when I was in later on, with one of [redacted]'s chemos. So they were changed, in the short time that I was there, from start to finish of the chemo. That was between May and September 2018. The second time, the filters were changed to a different one, for whatever reason. The guy came in with boxes of these things and they were taking them off, putting the new ones on with a date on it. I think it was a company again, I don't think it was the hospital, but I might be wrong.

48. When [redacted] was in ward 6A in September 2018, I had to get the patient wipes because I couldn't really get him in the shower. I wasn't willing to use the shower, because I also found out that seemingly there was an infection in the water. I stopped using the water when I heard that and also because [redacted] didn't have much of an immune system. I didn't want him to have any other issues so I stopped using it before we moved to ward 6A.

49. They brought in portable sinks as well. We were all given these portable things to use in the room, a wee sealed thing with a wee basin at the top, you put the water below it and you shut it over and pumped the water through. If I remember rightly, you used your foot to pump the water. It was bottled water you had to use to pump it through. [redacted] was not going to let me use that on him because it wasn't that warm.

50. Anybody you asked said it was just a precaution, just in case. I can't recall who it was in particular but they would come in and blame the cleaners and the cleaning for the infection. I told them I didn't think it was the cleaners, the ones I had were great.

51. They said there was bottled water available. That was after we'd all been drinking the tap water, right enough. I was drinking it with my dinner. I've got bother with my kidneys and after [redacted] got out, I went to my GP because my kidney was sore. This was after [redacted] was discharged from hospital. I provided urine samples. The results were that I had developed a bacterial infection which the doctor had never heard of, called Raoultella Ornithinolytica, which is connected to water.

Water: communication

52. I have the bits of paper handed out about infection control. I got them up in ward 2A. I had a couple of handouts. It said it was something to do with the water. They wanted the filters on as a precaution and to keep on top of it, that kind of thing. It was nothing to worry about, that's what we kept getting told, nothing to worry about.

Issues impacting patient safety and care

53. At one point when we were in ward 3A, which we were only in for two weeks, so I think was in March 2018, one of the staff members, Donald, helped me try and get [redacted] in the shower. . [redacted] wasn't talking but he was making a lot of screaming noises. We tried to get [redacted] in the shower, but he couldn't really stand, so we're trying to hold him, and sit him on the chair, just to get him under the shower. [redacted] was distraught, it was extremely painful for him.

When I look back, I think that was hurting [redacted], just the water on him, was hurting him, because he'd never had that issue before. He had sensitivities all over his body following his operation. The staff wouldn't touch [redacted] to start with so he was just lying in his bed but when we did get him in the shower, he was kind of distraught. I thought, I'm not putting him through that again. We just used a bed bath, with a basin and a sponge. He was not as mobile and so trying to move him was difficult.

54. After [redacted]'s first operation, he had secretions in his mouth and he hated it. He had to get the big dry cloths, and I had to roll them up and put them in his mouth for the secretions. He used to keep them in his mouth because he hated that dribbling. I had an issue at one point because the staff said that he was using a lot of these cloths. They had a wee moan about how many cloths he was using to get rid of the secretions in his mouth.

55. I think sometimes they kind of forgot about [redacted]'s autism as well. They were just looking at what they were presented with about [redacted]'s condition, and forgetting about everything else. I don't know how many times I had to remind them of things. In ward 2A they tried to give me a room next to the desk. I told the nurses that we didn't want that room as it was too noisy because they congregated at that desk and phones were going. They eventually got [redacted] a pair of earphones because of the noises of the buzzers.

56. On 15 March 2018, the nurses forgot [redacted]'s chemo. I challenged them and I was told that it was higher grade staff who had the key to the drugs cupboard and they were in the process of handover. I said they'd better get the handover sorted and get the key and give my son his chemo. They said it was okay, it was only an hour or so. I told them it was actually two hours since they had forgotten to give him his chemo and if I hadn't remembered, who would have? I thought these people were going to be more professional than they

were being and they seemed to be forgetting a lot of things, that people's lives were in their hands, especially with medications and kids. After that I was on edge. I just thought they would know what they were doing with the cancer thing, but a lot of the time it was quite chaotic. They really didn't know what they were supposed to be doing, and what I took from that was that sometimes when they were asking about things, they would try and blame the Doctor for not passing information on, or they would try and blame the previous shift.

57. I was a residential child carer for social work. I told the staff that I work in a children's unit and you get handovers from shifts, so you are supposed to find out what happened before. I asked why they were going into handovers and not knowing what's happening with my child? There was one man in there who tried his best, his name was Donald. He was run off his feet because everyone wanted his help because he would do his job thoroughly and always gave 100% with the care he provided..

HEALTHCARE ASSOCIATED INFECTIONS

HAIs: events and physical impact

58. On 25 September 2018, [redacted] went into ward 2A to start that cycle of chemo and I showed the nurse the pus on [redacted]'s Hickman line. It was quite red round about it so they put one of these doughnut things on it, that was supposed to draw it out. The nurse said it looked okay but to keep an eye on it. I told her that it was yellow pus but she just said to keep an eye on it. The next day, [redacted] was quite unwell, he had a high-temperature, he was very swollen, his temperature spiked. They gave him stuff every four hours to try but nothing was working. 25 September was the day they were meant to start moving them all to the adult hospital. Everybody else was getting moved but

they couldn't move [redacted] until he was stable. He was the last kid out of there. They didn't tell me it was septic shock at that time, it was later on I found out, because they had to take him straight from there and they put him straight into ICU. I can't recall which Doctor it was who told me it was septic shock.

59. [redacted] ended up unwell and he went into PICU in the RHC with septic shock, on 26 September 2018, instead of going to 6A, where he should have been going. He couldn't be given his last bag of chemo as he wasn't well enough. His heart rate had dropped, his blood pressure was up and he was flooded with antibiotics and given oxygen and that was it.

60. The Doctors were all around about him. Dr Murphy, the oncologist who gave his chemo, had come and all he'd done was touch him, and he said, did nobody think of doing that? There were a lot of doctors in the area, intensive care doctors up as well. I think they were all worried because I had already highlighted it. I don't know whether they just didn't bother and then they realised, oh, this could be serious.

61. [redacted] had a few infections and to treat the infections, they flushed [redacted]'s lines with antibiotics and they gave him medicines as well. I've got the names written down somewhere. [redacted] contracted the infections whilst in Ward 2A, he was never out of source when in that ward. It was terrible and had a big impact on my mental health. No visitors were allowed in source and we are unable to leave the room. It was mostly the nurses that would tell me about him having contracted the infections. The nurses were never able to tell us what infections [redacted] had contracted.

HAIs - delay in treatment and patient outcome

62. Because of the infection in September 2018, [redacted] wasn't allowed to get his last bag of chemo. I was worried that the last bag of chemo would make a difference to the results, because that was the end of his chemo treatment. I think [redacted] just didn't know what was going on. He couldn't stop shaking and I think I felt worse about that, than I did when they told me he had cancer. I couldn't believe he ended up with septic shock, because he had come through all that to end up with septic shock. Fortunately, it didn't have any long term effect on his health.

HAIs: communication

63. I was never told where the infections came from that [redacted] had. I just felt that if there was any type of infection it was as if they tried to put it onto you as if you, as if you weren't doing something right. They would ask things like, was [redacted] cleaning his hands? He was cleaning his hands; he was like that before he came into the hospital. I think sometimes, maybe they were looking to blame someone else.

64. They dealt with the infections as if it happened quite a lot, saying that these things happen with the chemo treatment and that kind of thing. That's the way that it was put it across to me. When [redacted] was put into source, in ward 6A, they just said it was quite serious as he had developed the sepsis and they were glad they caught it quickly.

PREVENTATIVE MEDICATION

65. When [redacted] first went into ward 2A he was prescribed Acyclovir and Posaconozole. He also got Septrin, Prophylactic painkillers and Baclofen anti-sickness drugs. He used to get something for bone marrow stimulation. [redacted] was on them for a long time. There was one time when I had phoned for

a repeat prescription and I remember Dr Murphy telling me we had to keep on them for a certain time. He was on them all the time throughout all the treatment but he still seemed to get some kind of infections, even with getting the drugs.

66. It’s hard to say if the preventative medication has had left any physical effects. [redacted] was in a chair; he wasn’t really active. There’s times when he still gets very tired and lethargic. I don’t know whether it’s just that because he’s been in the chair and he needs to build himself up, or whether it’s damage that’s been done. I won’t really know until that gets looked at.

67. I asked why [redacted] was on all the medications, but they never really said much apart from it was to help with his chemo treatment, because of his lowered immune system.

EMOTIONAL EFFECTS

68. I think [redacted] got fed up and scared. He was just a bit unsure of what was happening; which made him question everything they were giving him as well.

69. My emotions were all over the place. It was just everything, I was dealing with the hospital and all their mistakes, and then trying to move house and it was just a nightmare. The best thing that happened was when I eventually got over to CLIC and was able to get some sleep because broken sleep and everything else on top of it, wasn’t good. I ended up on anxiety medications as well, because I felt I did not want to lose the plot. I was quite assertive with the staff but I never swore, so I was quite pleased with myself because I easily could have.

70. On ward 3A nobody could give me answers to things. I'd just found out my son had cancer, he had to get an operation, he'd woken up from this operation, not talking, not doing anything and having to be fed through a tube. I felt that I was just left. A lot of the people that you're asking for help, they'd maybe get the social worker or the psychologist. You had to wait for them actually coming.

Patient outcome

71. [redacted] is due for an MRI at the end of July 2021, for the oncology side of things. I think they just check but I don't know whether they can check the shunt at the same time. Since March this year, it's just been regular follow-up visits for [redacted]'s leg. We're back up at the hospital again on 22nd July 2021, to orthopaedics.

COMMUNICATION: GENERAL

72. When it came to [redacted]'s care, for me, there was a lack of communication, or the communication systems that they used were not efficient enough. There were a lot of times I was having to tell them, "No, that's not what we said". I was usually right and it wasn't often that I wasn't. I just think the communication system was a big issue. Dr Campbell and Dr Murphy were very thorough in telling you things. When it came to the nurses, it was different, I had to find things out and they always said that they would have to ask somebody or they didn't listen to you, for example, the situation with [redacted]'s line and the sepsis. I didn't get much hope from that, especially as they were looking after my son.

73. There were times when [redacted] was supposed to be staying on a feed or it was to be upped and the nurse would say one thing and I would tell her that

another nurse had said something different about the feed. By the time they got hold of the original nurse, hours would have passed and my son's not had anything to eat. So it was silly wee things like that that made me think, surely there's a better way of doing this? The system is as good as the person that's putting the notes in. I said to them that I thought they were all on the one system, and that they all just added their wee bit in? I was told that it was only higher level people that could do that. I thought, what's the point in that, then?

74. I had a meeting with the lady that was in charge of the ward at the time, the Sister, I can't remember her name. It was after the chemo incident in March 2018. She was saying, you know, we try, and I said, I'm sorry, you maybe need to look at your communication policies or whatever you do, because they're not working, because that's all I hear. Whilst in Ward 3A, [redacted]'s soiled pyjamas shorts were just left on the floor on one occasion. He would wear pads which were not there, but the pyjama shorts were visibly soiled. They should have been getting bagged immediately but they were left on the floor. I complained to the sister in the ward. It never happened again and the sister blamed it on a lack of communication.

75. I mentioned earlier about ward 3, when the staff member who had the key for the controlled drugs cabinet. When I asked the nurse about it, she told me it was higher-grade staff that had the key, that they weren't allowed it. The person with the key was in at the handover so [redacted] didn't get his chemo on time.

76. The last couple of times I've been in the hospital, they seem to have been okay. I don't know if it was because they were shorter stays. The cracks appear when you're in longer. I think the Doctors that I've spoken to were fine, it was the nurses, really; they would always tell you they need to find out the answers or ask somebody else. The information in general has been quite

good, they go through everything with [redacted] and take their time. Even in the plaster room, the staff in there were wonderful, they talked to him. I tell them that they need to tell him everything they are going to do, before they do it, and they're good.

77. I'm a member of the closed Facebook group but I don't know when they started it up, or who started it up. I don't really go on it very often, because I'm not on the Schiehallion ward anymore. It was just if I needed a phone number or something like that. At the time there were things on it about the water but I didn't think about it at the time. I know some of the girls in the group but there's other people that I really don't know because they were maybe in before me. I think there are some parents that maybe asked about certain issues, or how do you do this, or how do you get Dr Murphy's medical secretary number? It was that kind of thing.

78. I think it's good to be able to sound off on the group because if you sound off to the nurses, everybody just gets upset. You can sound off to the group, whether you're right or wrong. Some of them have already been where you've been or they're further in the process and telling you what to do or kind of help with that. I think it's good for that.

COMPLAINTS

79. I was ready to make complaints when I was in the hospital, but they always talked me out of this. There were times when I was spoken to like a child, they would say things like, "I will come back when you are calm." That happened in any ward I was in, if I said that I was going to put a complaint in. The staff nurse in 3A eventually took me into her office and we had a meeting. She tried to talk it through. It was the same with 2A. Sometimes they would just walk away and say, I'll come back when you're calm, as if it's you. I would be trying

to ask a question and they would disregard it as if, they were the nurse and knew better. Most of the times I dealt with things there and then and the staff would try to fix the issue at that time.

80. I think Dr Murphy walked away from me one day when I was talking to him about the septic shock thing. I was still angry at the time because, by that time I knew about the water, and that the hospital environment had probably caused my son to have septic shock, and that was what I told him.

81. I also said the same thing to one of the nurses as well. I told her it was about the lies, making out as if it was our room or our cleanliness, instead of saying they thought it was about the water. I told them they were making it out that it was us. When [redacted] took septic shock I was up to high doh because I thought, I'm going through all this and this could have killed my son.

82. I think my complaints were dealt with appropriately, depending on who I spoke to. Doctor Murphy did try his best to get things sorted. It was the same with Doctor Campbell, she was straight on it. Doctor Campbell was the surgeon in ward 3A who did [redacted]'s brain operation.

83. In ward 2A the staff were moving around, like they weren't trying to be as quiet. It was just horrendous sometimes. During the night they were talking in a tone where you would think it was day time, not night time. I raised my concerns to the nurse in charge of the ward and she said she would have a word with them and keep it down a bit. I was trying to give them the benefit of the doubt. It would be alright for a bit and then it slipped back. I wasn't the only one that had to speak to them about the noise.

84. The hospital could have dealt with the complaints better but if I couldn't get the staff, or if they were busy, I felt I was getting lip service. The lasting impact

on me is that I used to think that the Doctors and nurses should know better than me, and that I could trust them fully however, now that is not the case.

OVERSIGHT BOARD / REPRESENTATIVE GROUPS

85. I have not heard about the Oversight Board. I'm part of a Whatsapp group which I think is a kind of informal patient and family representative group.

CASE NOTE REVIEW

86. I had a phone call from Jeane Freeman. I'd tried to phone her because we'd get letters in about the Case Note Review and I didn't know if my son was involved. The general letter came in first saying, [redacted] had septic shock so I phoned her up and left a message. She returned my call and I asked if she had heard anything else. She told me they still had a lot of kids to go through and [redacted] might not be one of the ones that they were looking at. It was as brief as that. I never heard anything from her after that. I still don't know if [redacted] was part of the Case Note Review.

87. That was the only contact I had with Jeane Freeman and I can't remember exactly when it was. I didn't go to any meetings with her.

CONCLUDING COMMENTS

88. I'm still wary every time we have to go in to the hospital. I probably still wouldn't use their water, even now. It's just the fear. I think they're trying to get on top of it, and the cleaning. What I did notice was that they are using disposable mops now, by the looks of it. That's an improvement, as far as I'm concerned.

89. I’m wary because if the hospital can cover things up, they can cover anything up and the trust that I used to have is no longer there. I’m not saying I don’t trust the doctors, when they’re doing their operations I’m just still wary because it can make a difference to your child.

90. I don’t trust the Health Board. I think they must have known that this would have come out eventually. Sometimes places are shut down to make big super-places that are not fit for purpose and cause umpteen problems. I just don’t get it. They should have been truthful with people.

91. The only concerns I would have now is if we had a repeat of the poor people that lost their lives through bacteria in the water, or the pigeon droppings, or whatever it was they say. I don’t know how they’re going to fix that because I don't know what these filters do, or if they’re doing the job they were supposed to.

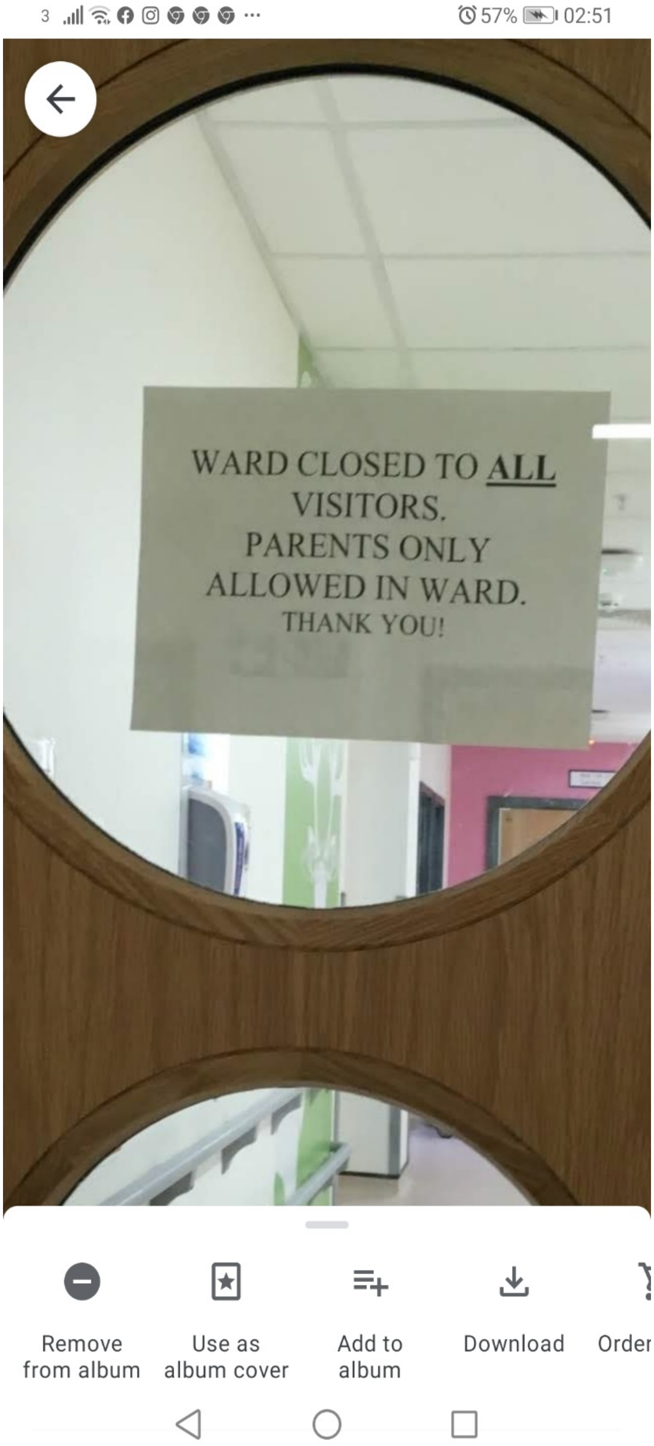
92. How are they going to fix the water? How are they going to fix that? It’s such a big hospital. I think they need to get to the full underlying issue of what’s causing the bacteria in the water. Is it the land it’s on? Or is it something that the water board could fix? It’s a lot of money to waste, unless they’re doing a portable water thing, but that’s going to cost them a fortune.

93. Another concern I have is that [redacted] and I just missed the window falling out as well. This was around July 2018. We were going over for an appointment one day and missed that window falling out by a minute. It was an external window on the 10th floor. I asked what happened and I was advised that the glass window had fallen off and smashed. You could see the missing window from outside, it was at the right hand side of the adult entrance. I was advised by other parents that two windows had fallen out before in the past.

94. I’m okay with the communications now. While I was in the hospital, it was horrendous, everyone blamed each other, and the, “wasn’t me”, the, “I don’t know about that”. Are the doctors not writing their notes? It’s a blame culture. I just wish they had been more truthful with us, because they were putting my child’s life at risk. My son had to fight for his life, I didn’t expect him to be having to fight again and again because of water issues. I don’t think it’s great what’s happened up there and they should have been more truthful.

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

SC/01 – Appendix 1



Scottish Hospitals Inquiry

Witness Statement of

Andrew Stirrat

WITNESS DETAILS

1. My name is Andrew Stirrat. I was born on [redacted]. I am [redacted] years old. [redacted].

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

3. I live with my wife, Karen Stirrat, and my three children, [redacted], [redacted] and [redacted], in [redacted], [redacted].

OVERVIEW

4. My son is [redacted]. He was diagnosed with Atypical Teratoid Rhabdoid Tumour (ATRT) in February 2019 when he was 3 years old. [redacted] was treated in the Queen Elizabeth University Hospital (QEUH) from February 2019 and is still undergoing treatment presently. He attended the hospital as an inpatient and as an outpatient regularly for over two years. [redacted] still attends the QEUH for check-ups. I have prepared and provided the Inquiry with a timeline, that my solicitor helped to create, showing the dates on which [redacted] attended hospital and the wards where he was treated. The timeline is attached to this statement (**AS/01**) and I confirm that it is accurate to the best of my recollection.

5. [redacted] spent time in wards 3A, and 3C in the RHC. He also spent time in ward 6A and another ward which is an overflow for ward 6A in the QEUH that he would sometimes get one of his treatments in but I can't remember the number of it. I remember it had isolation rooms though. Ward 6A is part of the new Schiehallion Unit after it moved to the adult hospital. The Schiehallion Unit in the RHC wasn't open when [redacted] was going through his treatment. I

stayed with [redacted] during most of his admissions to hospital as an in-patient and out-patient however, we had [redacted]'s sisters to look after too. I looked after [redacted] most of the time.

6. There are some specific events that I would like to mention. [redacted] contracted an infection in March 2019 shortly after being admitted as an in-patient to ward 6A. There were issues with the water supply during [redacted]'s time at the hospital. I believe that [redacted] was prescribed preventative antibiotics in 2019 which may have been connected to issues with the water supply. In June 2020 the hospital Board decided that [redacted] could not receive surgery and trial medication, due to the costs. We had to appeal this and had the decision overturned.

FAMILY BACKGROUND

7. I live with my wife Karen and our three children in [redacted]. The children are triplets and they are 5 years old. They were born at 27 weeks in the neo natal Queen Elizabeth University Hospital. They stayed in hospital for the first 17 weeks after they were born. Karen was with them during the day as I was working a lot of the time.

8. Before the diagnosis, [redacted] was very boisterous, very outgoing, nothing fazed him. His personality had started to develop. He had no fear, he would give everything a go. He was very friendly towards people, and anybody he didn't know, he would go and say hello to them. Because they are triplets they're like a close-knit community, they've got this sort of 'thing'.
But that was before the diagnosis. That sort of side will start to come back again. When [redacted] had the treatment he just became a different person altogether. He became very reclusive, as it were. He didn't want to associate with anybody outside, and especially when he went to the hospital for visits, he just wouldn't talk to anybody, he wouldn't acknowledge them. He disappeared into himself, put a barrier up to sort of protect himself. And that was him, every time he goes into the hospital now, he just won't talk to anyone.

9. During [redacted]’s treatment, and this included him going to America, if his sisters weren’t there, I think it would have been a completely different scenario we would be in just now. His sisters kept him normal, they still treated him as their brother, and they still had the banter, all running about, and it allowed him to still be a child, rather than somebody going through all this really invasive treatment. They just kept it normal for him. If it wasn’t for them, he'd be in a completely different place. [redacted] has always got this attitude of, nothing is going to faze me, nothing is going to get me down. If the girls weren’t there and trying to keep it normal for him, I don't know if he would have that attitude or if he'd have that fighting spirit. [redacted] was always, I want to go out, and play with his sisters, or go and do this, there's always that sort of drive, there. So if they weren’t part of the family unit, sort of thing, I dread to think of what could have happened, or where we could be.

10. [redacted]'s got a close bond with the girls. He and [redacted] are just two peas in a pod, they're very similar. He and [redacted] started to pair up, and hang about together. And so, yes, they're very close.

11. [redacted] has always wanted to play football. Because of the experience he's had, he's not been allowed to participate in all that, in case he gets a knock, however, we just found out that it was actually okay for him to start attending clubs if he wants to go. So that’s made his day, that he can go out and join a team, and kick a ball about. Interest wise, he likes YouTube, videos and things and games, he likes playing a lot of games, board games, things like that.

12. [redacted] is starting [redacted] school in August this year. He already has some friends there as he went to the nursery here too.

SEQUENCE OF EVENTS: THE FAMILY'S EXPERIENCE AT QEUH

Admission to hospital: February 2019

13. [redacted] was diagnosed with ATRT in February 2019, when he was 3 years old. He'd been at soft-play, and he'd banged his head. It wasn't anything major, but I think this is what triggered a response. He started being constantly sick for nearly 24 hours and then he started complaining of headaches. We contacted the local GP and we were told it was viral. Three days later [redacted] was really screaming in pain because of the headaches. By that point, the vomiting had sort of stopped. I phoned emergency A&E and was told again it was viral and to give him paracetamol and ibuprofen, to alleviate the pain. On the Friday, which was 22 February 2019, I took [redacted] to A&E. The doctor came in and assessed him and said, it's viral, sent us home, with ibuprofen, again. The next day [redacted] was still screaming in pain. On the Sunday, Karen took him to A&E again, and they said once again that it was viral. Karen stood her ground and said, no, this isn't right, something is not right here, so they gave him a scan. They came back and said there was a mass and within 12 hours of first going in [redacted] had a craniotomy.

14. [redacted] stayed in ICU for three days and then he was transferred to ward 3A in the RHC. Two weeks later the biopsy came back, and we were told what it was. We were just told it was a mass and that it was ATRT. The Doctors went into detail a wee bit on how aggressive it was, because we didn't know anything about that at the time. ATRT can grow from a single cell to a huge mass in just a couple of weeks. And that was really it, we went with the diagnosis, we were told that he would have a slim to none chance of surviving as it would haemorrhage.

Experience on ward 3A: late February to early March 2019

15. [redacted] was transferred to ward 3A. I think that's a post-op ward. While he was there, he loved it because they had facilities there for children. They had a sensory room which he could go into. There were facilities there for the parents, facilities there for the children. If he had been older he could have asked for a DVD player, and a telly, to watch a film. If he had been older, that facility was there for him. Compared with ward 6A, it was night and day.

16. In the sensory room, kids could relate to different things. They would have a globe with lights on it, a fibre optic cable that had coloured lights that come through it, a floor mat with stars on it, and the moon which had LEDs in it as well. There were soft, foam furnishings like a soft-play, like the shapes they could climb up and over, and balls they could play with, just a lot of stuff like that. They had a mirror, lights, and things like that in there. I don't know if it was just because of the type of surgery [redacted] was having, or to make sure his cognition was still there, and if he had any balance issues, or if he fell, you knew he wasn't going to hurt himself, because it was padded.

17. For parents, they had a kitchen area, a chill out area, so that you could go away and be out the ward. You could sit with other parents and talk about what things were going on with you, and what things were going on with them, just be able to have an adult conversation, rather than be round about a sick child all the time. When [redacted] was sleeping, you could go away and get a cup of tea or a cup of coffee. It was just a nice area to be in, and if any time he was hungry out with dinner time, you could go in there and get a slice of bread, or a wee bit of toast, or something like that, and give him that yourself.

18. There was a microwave if you had food in with you, and there was a fridge so you could bring chilled stuff in and keep it. There was a seating area, like a chill out area, and a cooking area. There was also a wee lounge with a telly in it.

19. Any overnights, I tended to do. There was a pull-down single bed, for parents staying overnight with a built-in system so it didn't hinder the space in the

room, there was a built-in wall mount storage area, so that when the bed went up it was out the way. Whereas, when he went across to 6A, none of that was catered for, because it was an adult hospital, so all the beds had fold-up camping beds, which were, not the comfiest, some of them would be a lot older than what they were intended to be used for. The bed in 3A was a lot better.

20. There was a TV in all the rooms, I think they try and have a telly on the mount in the room. And I think the one in [redacted]'s room worked. That was one of the fewer rooms where I think the telly worked. When you went into the adult hospital, even the staff said 80 percent of the tellies in the adult ward didn't work, and if you got one that worked, you should count yourself lucky.

21. When [redacted] was in the hospital, he had a nasogastric (NG) tube fitted, for feeding. On 6 March 2019, he had the Hickman line, or central line, fitted for his medication, so it might well have been at that time. I don't recall going in to get the central line put in, before he was discharged but we took him back up to the surgical ward for the surgery under general anaesthetic. He came back from getting the Hickman line done, and they showed us how to change the plaster on it, so you can do it yourself with the Hickman. He was then admitted to ward 6A.

Experience of ward 6A: early March to April 2019

22. Ward 6A is in the adult hospital. We were told by the Doctors at the time, it would be the Schiehallion, the kids' ward, that [redacted] would be going in to. We didn't know until we arrived that the Schiehallion was in the adult's hospital at that point. I think the kids had just been moved out of that into 6A. I don't know if they believed at that time it was just going to be for a short term move, and that's why they described the Schiehallion Ward in the children's hospital as, "It's this fun place to be", and it was all geared for you. I don't know if they knew at that point that the ward was going to be a long term closure. They were still describing that they were only going to be in 6A for a week or two, and then we'd move back across to the other hospital. The harsh reality is that

ward was shut for a lot longer. [redacted] spent most of his time in ward 6A, it's been a hard time.

23. When we first came into the room on ward 6A in 2019, there were two doctors, there. We only found out about [redacted] having cancer, because, one of the doctors said, “We’ll move the chair around so that the oncologist can sit down”. As soon as they mentioned, oncologist, you know that’s actually the road you're going to be doing down. And at that point, that’s when we were introduced – this is Doctor Sastry. So we'd already starting reacting, because they'd mentioned the word, oncologist, and that was us. That was our wee balloon of hopefulness burst. And then, it was straight into the facts of the protocol.

24. When we were first introduced to Doctor Sastry, that’s when we were painted a nice, warm picture about ward 6A where [redacted] was going to get treated in. Dr Sastry was [redacted]’s oncologist. We were told it was the Schiehallion ward we were going and it would be very child orientated, had games rooms, and would never have to feel out of place. There were decorations, and things like that, all for children, it was all for him, and it'll be a wonderful place, and you won't have any worries when you go there. That’s what we were told. I think [redacted] was there when we had to go to ward 6A. I think it was Doctor Sastry or Karen, [redacted]’s mum that told [redacted] directly. Dr Sastry said, it's a wonderful place, nothing to worry about, it's all for you.

25. [redacted] wouldn’t talk to anybody. Because of the different faces, he just never had a rapport with them. He never spoke to Doctor Sastry. I don't know if it was just Doctor Sastry’s bedside manner, but he just didn’t have that connection with [redacted].

26. In March 2019, [redacted] went into ward 6A, and you’ve got a three year old asking you, where’s all the pictures, where’s all the toys, where’s the special room, or the sensory room, all that stuff. You're walking into a ward that has nothing in it, it's a grey room, and they'd stencilled on a wee picture of an owl,

or something like that, onto the wall, and that’s the extent of the decorations for children in the place. There was an owl in one room, and you go into another room and it's maybe a fox, or a woodland creature. There's no games area at all, there's nothing for children. We asked where the play area was and were told there were two tables with four chairs, when you walk into the main ward, sitting in the corridor. It had some colouring pencils, and a couple of sheets of paper, and that’s it, that’s the extent of it.

27. It was like, at the last minute, they’ve arranged this ward. There's been no planning there for transferring people across. So when you come in the main door of ward 6A, you were greeted by long term rooms. You would first walk in the double doors, I think, there was an aqua therapy room in the first door when you come in. The aqua therapy room had a hydro-bath in it. We had never used it but I asked one of the nurses or auxiliaries about it and they said it was out of use as the filters for the water couldn’t be attached to it. It was never used the whole time we attended the QEUH with [redacted].

28. You would go into the rooms and they had all the filters for the water system. These were white plastic filters that clamped on to the taps of the sink in the room and the one in the bathroom. As you passed through the ward, you had the two tables and chairs sitting on the right-hand side, next to the window. You would go through another set of doors, and there would be a nurse station on the right-hand side, and there’d be like a sort of general area for the boards, so it would tell you who was in the rooms, and who's getting what, and who's their Doctor. Continuing down that corridor, there were more residential, long term stays on the left-hand side. You would get to the kitchen area in the ward, but no parent was allowed in, it was for staff only. If you wanted something out of that, you had to ask a member of staff to go and get it for you.

29. When you're going through the ward, you go through another set of doors, and you get some more rooms for long term patients, and then you had a double door at the end, that was the day-care room. Day-care was for patients

that were coming in for a check-up, or they had to receive new medications, or any equipment, or to go in and get chemo that didn't require to be an overnight stay.

30. You had all the long term care, and everybody that was coming in, every Tom, Dick and Harry walking in, in the winter and summer, walking through the ward, past kids that might be playing at the table and chairs. These kids, and the long term patients have all got very low immune systems, and you've got everyone walking by, coughing and spluttering, walking by all these rooms to get to day-care or the medication room. I thought, why not have day-care where the nurses station was and keep the general flow of people away from the long term ones. A lot of the room doors would be shut, but a nurse or Doctor would be going in and out of the rooms and be leaving it wide open. It's just insane, to know that you've got all these people that are very neutropenic, with very low immune systems, and everybody has to walk past their room to get to the day-care clinic. I just don't know why they thought that would be a good set-up.

31. In the late afternoon and early evening, the rooms going down the left-hand side were the ones that caught the sun. Those rooms were particularly warm all the time during the summer. There was no way of regulating heat in there, because of the air conditioning system through the hospital was centrally processed. If you asked for it to go down, it wouldn't make any change in the room, because all the rooms had to be changed on that side, down to the same level, for there to be an actual drop in the temperature. The rooms had blinds incorporated into the windows but a lot of the blinds didn't work. If your room was lucky enough to have a blind that worked, it cut a wee bit of sun out.

32. It was a very warm side of the hospital. They would try and do temperature checks, you're sitting in a room, and it feels as if it's about 26, 28 degrees. I wouldn't even be in a bed, and I'd be sweating. You could feel the heat in the room. I can remember them doing temperature checks and saying, "Oh he's

fighting a temperature", and I'd wonder what they meant. Rather than check his temperature and wait a couple of hours, and then come back and check it again, it was just like, "He's fighting a temperature, oh that's him, he's in isolation". I'd be thinking to myself, is this medically related, is it a bug? Half the time, it was just the temperature in the room, it was just so hot.

33. On one occasion, I asked one of the nurses to turn the temperature down. That's when we were told it was centrally controlled. That's what they'd been told to tell us – no, we can't regulate it ourselves. During the height of summer, a staff member told us you're meant to keep the room shut all the time. I think this was to stop the spread of diseases through the ward if anyone was isolating. We had just been trying to keep the rooms open to let air circulate but this wasn't allowed. There was an air filter in the room and I believe that if the door was left open, the filter didn't work properly or circulate the air the way it was supposed to.

34. The temperature was centrally processed so if you put the temperature down, it could only go down between the range on it was between, I think, 19 to 23 degrees, so there wasn't a large range. If it was sitting at 23, and you put it down to 19, you didn't really feel a difference, because you couldn't turn it on cold. There was nothing to drop it all the way down and then you've got the heat coming in from the sun. That side was really hot and it was the exact opposite on the other side. When [redacted] first went in, it was cold at night and I was asking for four blankets, I was freezing in there. [redacted] had a couple of blankets on as well, just to stay warm. I brought a sleeping bag because it was easier. I always felt I didn't want to harass the staff for bed linen, and things like that, at night because I thought they had enough to do. Plus, depending who it was that came in on the night shift, you got the impression that quite a few of them didn't want to get you a blanket as they had other things better to do.

35. In the room you just had a fold-out camp bed which hindered the space you had. It wasn't always folded up, so you had that taking up a section of the

room. There was no standard size of rooms on the ward, there were smaller rooms and larger rooms, depending where it was. Once you put that bed in, and a chair, there was very little floor space. At one point we asked to take [redacted] out the bed. The staff said we could walk around the ward but we would need a battery pack with the IV lines. You'd be lucky if you could get one of them that worked because the battery packs didn't hold a charge very well.

36. The battery packs were for the IV line, or the IV unit. Generally, they're plugged into the wall, and they're meant to have a battery pack in the unit, so that if there was a power outage or anything like that, the IV line would stop working, and it would continue to work. If you were moving between rooms, or having to be transferred between wards, the IV line would go with you, and you wouldn’t have to try and get disconnected. If you were an older child getting chemotherapy, you'd be able to go to the toilet with it, without having to get disconnected all the time. The battery pack units very seldom worked, so when you were in bed, you were stuck there, you couldn’t leave the facilities, or you couldn’t leave the room, to go for a walk, or even just leave the bed area. I know [redacted], at some points, had two of these IV units, or two poles with several IV units on each pole.

37. [redacted] had a four headed pole with medications and three IV fluid packs on it, as well as another stand which would have maybe some more pain relief, or things like that. He would have all these, and on his Hickman line, he had two ports on it. Both of them might be connected, there might be additional fluids there for when the doxorubicin, and when it ran out, they could just link the IV line straight to it, so it started to flush it out his system. He could be sitting there with two IV poles with no battery in it. If you maybe had four of these pumps on it, you could have four batteries, and nine times out of ten they wouldn’t work. So you couldn’t take him out, he couldn’t move about the room freely, you couldn’t leave the room to go and play in the so-called play area that was along the hall.

38. If I asked about the battery packs, I was told it was an ongoing thing, they'll get round to it, sort of thing. That was what the staff were getting told, they'd put in the request about the battery packs, and that's what they got told. As far as I'm aware, it was maintenance that the nurses were putting the requests in to. The battery packs for IV drips were used through-out the hospital and each ward had someone allocated to them. The machines were coded per ward so they knew where they belonged.

39. We asked about getting a floor mat, or a mat for [redacted] to play on in the room, and again, there wasn't enough of them either. Several times we asked and we were told there was none. They didn't like you knowing about where the mats were kept, because they didn't really want the mats on the floor. That was the impression we got, they didn't want the mats down, because if they were coming in to do a cleaning, and things like that, the mat was in the road. Nine times out of ten, they wouldn't have a mat for him to play on the floor, because they didn't want the mats down. Andy, one of the auxiliaries, told us where they kept them, in the storage area, which was the aqua therapy room. That was the storage area for the play mats.

40. There would be two members of staff that would give any medication to make sure it was given correctly. Nine times out of ten, the nurses themselves would not administer that medication, unless it was chemo medication. Any other medications were left for the parent to administer themselves. When [redacted] had anything that had to be given orally, like his Posaconazole, and his ondansetron, which is an anti-sickness medication, we would be left to deal with that. On numerous occasions the night shift staff would give out the medication for the morning dose but the night shift finished at about seven, and they never told you that it was there. On one or two occasions, there was medication sitting, but it was hidden by a packet of wipes, or other bits and pieces lying about. As you were doing your tidy-up or things like that, you're finding it, but nobody was letting you know they'd been sitting there.

41. The nurses there are overworked as it is, they've got a lot on their plate, and they're answering calls to go and get a bottle of water, or a cup of dilute, or something like that, or whatever you could get. They never had a large supply of food. The children might have the odd yoghurt, or sandwiches, things like that, but there wasn't a general good supply of everything. Kids on chemo, just like anyone on chemo, their sense of taste changes, and their sense of smell, so a lot of the food was awful, especially for [redacted]. He wouldn't touch it; he just wouldn't eat anything. He just said, it didn't taste right, or it tasted awful.

42. Sometimes, the catering staff wouldn't give you the right menu, or you would have stuff that was missing. On several occasions, when [redacted] was in to get a transfusion done, nobody had come in to see [redacted].[redacted]had gone in at eight or nine o'clock in the morning, and come seven or eight o'clock at night, nobody from catering had come in to see if he wanted something to eat. At that point you have to leave him on his own, you have to try and get something to eat. He'd been in for 12 hours and nobody had come in to see if he wanted a sandwich, or a cup of tea. I would say this probably happened 50 per cent of the time. When you did see catering staff and asked for stuff the dietician and the catering manager told us was available, the staff wouldn't accept your word for it and would give you the same two options.

43. There were activity coordinators who would come in every so often, but [redacted] was very reclusive at that point, he didn't want anything to do with anything. They'd bring in maybe a toy, or something he could play with himself, like a box of Lego, or something like that. But there was nothing, really, for any children to use, whereas older children were quite happy to sit down and watch the TV, or the person would bring in tablets for them to use. Before [redacted] was diagnosed, we weren't going down that route of giving iPads, and all that stuff, because we didn't want him to be associated solely with YouTube at that age, and we would want him to use it later on as a teaching aid for his studying, and things like that. So we never intended giving any of the kids anything like that at such a young age.

[redacted]’s treatment in Florida: April to June 2019

44. The hospital paid for [redacted] to go to America for proton beam therapy as at that point it was only available over there. Proton beam therapy is less invasive to healthy brain tissue whereas the standard radiation therapy, like you would get at the Beatson, is more damaging to healthy cells. The analogy that was given to us at the time was that the proton beam is like a sniper rifle so it’s focused on just a certain point and damages only the cells it’s targeted at and the general radiation is artillery so it obliterates everything. It was planned that it was just going to be me and him that was going. They then said they thought it would be too much for one person to travel and have to be with [redacted] all the time. Not that that was a bad thing, but whoever went, it gave the person no respite and time away from the situation. They asked us about another parent going, or somebody else going, to split the workload and said that both parents could go. We didn’t think it would be good that we left the girls behind, because it's a long period of time to be away from their parents and their sibling so we paid the difference for the girls to go. There was also the fact that if both of us had to attend a meeting, somebody would have to be there to look after the girls, so we took, and paid for, Karen’s mum and dad to come as well, so there was seven of us going. Karen’s mum and dad looked after the girls while we were having anything to do with the chemotherapy, or the proton therapy.

45. We left to go to America just after Easter on 22 April 2019, but we were supposed to leave two weeks before that. [redacted]'s neutrophil level just wasn’t recovering the way it should. He had an injection in the leg, which was an artificial dose for his immune system, to try and help it recover. I was shown how to give [redacted] this at home to save him going in to hospital but I wasn’t comfortable doing it. He used to scream, “Daddy, don’t hurt me”. He had an IV line of the treatment and then an injection rather than having two injections. At one point though, staff were getting ready to give [redacted] the two injections back to back. There’s supposed to a large gap in between the injections but because [redacted] was due to go on a flight, they had to consider the option of

the two injections being given rapidly to try and get his levels up but his body reacted before they had to resort to that.

46. In Florida, we had a meeting with the oncology team in Jacksonville. Our main point of reference was the Oncologist, who was from the proton beam team. He asked us why [redacted] was on posaconazole and we said we were told it was part of his chemo protocol. He told us it wasn't so we asked him what it was used for. He said that the hospital is dirty, but it might also be to do with the climate, which is a damp climate, which gives rise to infection. The main reason for the posaconazole, as far as we can tell from what was said to us, is that the hospital is dirty, it has contaminated water, and that's what we were told by the Oncologist. While we were there, he told us to take [redacted] off the posaconazole, for the full stay in Florida.

47. [redacted] never had posaconazole while we were there, at all, and he was great for it, he was running about all over the place. He had his daily radiation therapy five days a week, and he had weekends off. He was in for the morning; come lunchtime he was out. He was still lethargic, but he was still getting the chemo once a week. He never had to use the posaconazole again while we were in America. However, when we were getting ready to come home, they told us, as soon as he got on the plane, to give him the posaconazole so it was back in his system again, when he went back to Glasgow. This was because he was going back into the hospital environment at the QEUH.

Admissions as in-patient and out-patient: Ward 6A - June to December 2019

48. We got back to Glasgow on 21 June 2019. [redacted] went back into ward 6A where he received more chemotherapy. He was an out-patient for this although the chemotherapy would maybe be done over a couple of nights. [redacted] got to go home after his chemotherapy and was only ever kept in if he had an infection, or a spike of temperature, which would be classed as infectious and then he wasn't allowed to leave because he'd pose a risk to himself and others. We were never told about any specific infections but if he

presented with a temperature, [redacted] would be kept in hospital. Nurses would come in to check his obs and carry out temperature checks. As far as medication goes, I don't think there was anything extra given to [redacted] but I can't recall exactly. His immune system just wasn't really repelling anything, he would get the best care in the hospital rather than trying to come home and then come back in again for his temperature, when it went over 40. I don't remember how many occasions he was in and out between June and December but [redacted] was an in-patient for approximately four to five weeks. This was before we went to America for his Proton Beam Therapy.

49. My aunty came up to the hospital after she finished work, to help and to visit so that I could get away from the room for a wee while. She did that quite a bit, but I can't remember when it was. During the time when [redacted] was an in-patient for four or five weeks, I think he left the bed, three to four times because we couldn't get the battery packs to move about with. As a result of that, his muscles had started to waste in his legs, so they had physio in for that, because he couldn't leave the bed to move about. It was a good while before he managed to get home, but he was only home for maybe a couple of days, and then he was back for the next bout of treatment anyway.

50. The dietician had told us there was plenty of food there for [redacted] and different menus and if we asked for them we would get something on those menus for [redacted]. In ward 6A, there were no food facilities for the children themselves to store anything so you were reliant on staff providing meals. We fought that. When we came back from America, we were told by Angela, the staff nurse, that we had been given a bit of space in the fridge so we could bring in chilled yoghurts for [redacted]. He went through a phase of cucumber sticks and fresh strawberries, which he couldn't get from the hospital. They allowed us to bring a packed lunch in, so we could store it in the actual ward. Then we were told not to tell any other parents that we were getting this. It was like a bit of preferential treatment, which we didn't think was right, and obviously we didn't keep that quiet, because why should [redacted] get things above other parents who are going through the exact same thing. I think it

probably stems from the fact that, the local paper in our area had always talked about [redacted], and they liked the updates. I think it had appeared in one of the local papers, that they weren't willing to give him this stuff, and that we stood up for kids' rights, and our rights as parents, that sort of thing.

51. Nine times out of ten it was an overnight stay when going back into the hospital for chemo. The medication he had was vincristine, and the other one was called ICE. Here, in Britain, you got ICE over a period of time, and a flush afterwards. It was an overnight stay. In America, that treatment is approximately two to three hours. So you had that variation in treatment but I don't know which one was better. It meant having to stay in a hospital that wasn't clean, so you were always worried, because [redacted] had the central line as well.

Completion of [redacted]'s treatment: November 2019

52. I think [redacted] finished his treatment at the end of November 2019 and that's when his hair started growing back in. When we came back from America, they took him off the posaconazole, and they gave him ciprofloxacin, I think it's another anti-fungal medication. We researched that one, and for adults at the time, they recommended they should only be on it for two weeks, maximum. The dose [redacted] was on was for four months, and when we started to push for when he was going to come off it, after the meeting the Health Board had with the parents in November 2019, we were told that he was scheduled in to get his line removed a week later instead of the original time which was the week before Christmas. [redacted]'s treatment had finished in October/November 2019 so Karen had asked why his line was being kept in as it meant he was on this medication for longer. It felt like, as if the hospital didn't want to answer any questions Karen asked in regards to that, they just went in and [redacted] had the line removed. They had to wait and make sure there wasn't anything else they could follow up; he had to have a scan done to make sure nothing else had grown before they could remove the line in case more treatment was needed. They also carried out weekly tests on the

line. [redacted] then had his line removed earlier than originally planned. It was another general anaesthetic when that was removed. For every procedure, and any operation that [redacted] had, he always got a general anaesthetic, including the proton beam radiation therapy, and at the Beatson, which I will come on to. I think at the moment he might be sitting at 110 general anaesthetics he's had in the last year, so it's quite a few.

[redacted]'s Relapse: May 2020

53. [redacted]'s chemo finished in 2019. He had a grace period between the scans. He had the first scan after the treatment finished, which he was okay with, and then there was another scan planned for April 2020, but it was delayed because of the Covid pandemic. We waited for a month until May. We spoke to Doctor Sastry at this time, because he'd been really good to talk to in regards to the treatment. He fought for [redacted], in a lot of aspects. We asked him why the scan had been delayed. He told us that out of all the scans he does, he had 50 kids that he wanted to get scans for, but he was told that out of that list of 50 names, he had to cut it down to five that needed it more than anything else. Dr Sastry unfortunately had to cut the list down to five. He then approached the Board and said, this is the five names I've got, and then he's been told to cut it down to three. He stated [redacted] was always at the top of the list in regards to that. He's then gone back with his list of two or three names, been told to cut it down to one. At that point he said, no, I'm not doing it anymore. It's as if the Board didn't want to do the scan at all. [redacted]'s always been on Dr Sastry's list because of how quickly his disease grows, because it can grow from a single cell to a huge mass in a couple of weeks. It's very, very aggressive, very, very fast-growing.

54. We got told this over the phone, or when [redacted] had one of the clinics, I can't recall exactly when it was, but that's how we were told by the staff. I think it might have been after getting the scan, when we were told that he'd relapsed. At that point, we knew that we had to come back in and they asked us to take [redacted] in with us. We found that strange, but we took him anyway. I got a phone call at nine o'clock in the morning, from Angela the staff nurse, asking

for us to come in at half past 12 that day, for an urgent meeting. The fact that [redacted] had a scan the previous week, and then we were getting told to come in, rather than waiting a couple of days to get the scan result, you knew right away from the urgency of them reacting to that, something wasn't right.

55. The meeting was on 1 June 2020. [redacted]'s surgeon, Roddy O'Kane and Doctor Sastry were there. Angela, the staff nurse was also there, I can't remember her second name. That's when Doctor Sastry said that the scan showed that another mass had grown in his head. [redacted] had relapsed and he'd got four to 15 months to live. He told us to go home with him, there was nothing they could do, there was nothing in place. When we asked about the radiation therapy from the Beatson, we were told that wasn't available to us. We asked Roddy directly what the chances were of doing surgery, but he was very vague. His body language was off, he wouldn't look us in the eye, and he was distant. We asked why they wanted us to bring [redacted] in at that time, watching his parents break down. We were told by Doctor Sastry, that if we went and found a treatment that he could use, then they would take it from there. They offered no alternatives, there was no backup solutions. They gave us no aftercare or responses or anything like that, to deal with getting news like that. There was nothing there to help us deal with that sort of information. You were basically given that news, and told, bye, bye, see you later, let us know if you have any questions. There was no counselling, or anything like that.

56. After the initial shock wore off after a couple of days, Karen phoned Roddy directly. As it turned out, at 12 o'clock on that Monday 1 June 2020, they had a meeting and discussed all their current cases that they're dealing with. Roddy told her the plan was that he had asked us to bring [redacted] up, because he had previously planned on taking [redacted] in for surgery and was going to tell us at that meeting, but he was then instructed by the Board, and the oncology team, that he wasn't to do that, because there was no oncology protocol in place for [redacted], to back up the surgical side of it.

57. There was a lot going on after that, trying to get the treatment in place for [redacted]. On the Friday after, between 5 June and roughly a week later, it was a very hectic time, a very busy time. Karen phoned [redacted] in Jacksonville, and spoke to the chemo team there. They put her in contact with the clinical lead in Manchester, who were using a drug, the drug [redacted]'s on just now. Karen spoke to the clinical lead in Manchester. It turned out the clinical lead in Manchester is best friends with Roddy, because they trained together. He told Karen it was a pity we didn't live near Manchester, because they could have got [redacted] on this drug, almost immediately. Our response to that was that we could have been there in a couple of hours. We would have done anything for the boy, that wasn't an issue. He told Karen that because we had a neurosurgeon on our side, [redacted] was best staying where he was and they could liaise with them and the oncology team. We passed that information on to Doctor Sastry, and it seemed as if he was dragging his heels on that. He was saying, he had to get all these different rules and regulations between NHS Scotland and NHS England, or he was waiting for paperwork in regards to that, in regards to the drug as well. It turned out, the clinical lead sent all that off so it was Doctor Sastry, himself, he was just dragging his heels, and didn't want to go down that route.

58. We later found out that it's up to a Board to decide what trials they're going to be using. You'd have five doctors who are the head of their field in that regard. Out of the five, there was always one that said no to every trial. What we've been told was, it was Doctor Sastry who was the nay-sayer, he was the one who would reject everything. Doctor Sastry hinted at something: he went out of his way to get something done and it didn't work out, so he didn't believe in trials, those were his words – “I don't believe in trials”. I don't know why he said it but he didn't give us alternative options.

Surgery and admission to ward 3A: June 2020

59. We fought for [redacted] to get onto the drug eventually, and because we got an oncology backup to the surgery, the surgery was put into place so that [redacted] could get it. We were then contacted by the Beatson and told they had

a course of radiation therapy available to [redacted] as well, because we had got an oncology drug to follow up the surgery. We went from having nothing to having every door opened up and they were saying, “Oh, we can do this now”.

60. The diagnosis to address the relapse was on 1 June, so it was between 14 and 21 June 2020, that the surgery took place but I don’t know the exact date. The surgical ward is 3A, or 3B, something like that. Roddy had wanted his full surgical team in and had been hoping [redacted]’s mass wouldn’t cause any other brain haemorrhage but due to Covid, he couldn’t get his full team in any sooner. Thankfully [redacted] made it until the day the surgery could take place.

61. The surgery involved [redacted] having another craniotomy resection, which is when they discover a mass within the brain cavity, or in the skull cavity within the brain structure. They make an incision, generally behind the ear, depending on where it is, but in [redacted]'s case, it was behind the ear. That incision went almost to his other ear. That was so they could pull the skin back, and expose the bone of the skull. With [redacted]'s first resection, the mass was on his right frontal lobe, so it was on the front half of his head. They made an incision at the back and across, so that they could take a section of his skull out, and access in the brain area where the mass was, and remove it. When he had his second resection, I think they used the same incision point as before. The mass was on the posterior part of the right side of his head. When he had the first surgery, the frontal lobe one, he had been bruised. That’s full of cerebral fluid, now, there's no brain mass in the right side, the front of the right hand side of his head.

62. When [redacted] went back into hospital for his surgery in June 2020, he had been prescribed morphine to relieve the pain, and we were told the wrong dose from the hospital, on his medical records, the level of morphine that he was getting was three and a half millilitres, every four hours. We were told it was 1.2 mil. We were only giving him that, and the medication was only lasting about half an hour. We didn’t know if we could give him anymore, and

when we queried it we were told, no just give him what was on the bottle, and what was on the bottle was 1.2, and not the updated amount of 3.5 millilitres.

63. The proton beam therapy [redacted] had in April 2019 was focused on a certain area and only damaged the cells it was directly targeted at, and it had what was called a dispersion field. When the protons went into the targeted area, with the dispersion field, the proton beams didn't kill one of the cells. The cell was hit by the proton beam, but it was under this bed in the dispersion field, so it wasn't destroyed. The chemotherapy [redacted] was getting before had previously suppressed the cell from growing, so when [redacted]'s chemotherapy stopped, the cell started growing again, and that's how he had the second mass. [redacted] then had to have a second session of treatment and the surgeon had to cut away another bit of the skull on the right-hand side, to remove the mass again, and then put the bit of skull back on.

64. Roddy told us that it was one of the top five surgeries he's carried out in his career, in regards to how easy it went. I think the mass itself in [redacted]'s head was close to the brain stem, that's why Roddy wanted the full team there, to make sure that he didn't actually hit the brain stem area. He told us the mass was five millimetres away from [redacted]'s brain stem. We assumed this was a concern, but Roddy was very confident. He said five millimetres was a huge gap, he only worried about it when it was one millimetre away from it, because that would have been serious. The surgery was very good. I think they said it would take 18 to 20 hours to do the surgery, and he was in and out in 12.

65. [redacted] just bounced back from it, right after the surgery, within 24 hours. He was off morphine, and within 36 hours he was off all pain relief and was asking for a McDonald's. They try and keep you in a week before you get discharged for a major thing, and [redacted] was in for five days, because he was walking around and he was eating. It was like seeing a switch going on.

66. Since we raised the issue of the treatment with Dr Sastry, he has been very quiet. It's as if he had no interest in [redacted] who was is his patient. Any time we

would be in the hospital or on the ward, he would never come in and say hello. If you saw Dr Sastry, it would be through the window in the room and he might look up and in the window so he knew you were there but he would never come in and speak to us or acknowledge us. This happened to a point up until about Christmas with Karen and it came to a head and was resolved. Since then, he's been a lot better and he now makes a point of actually coming in and saying hello when he can, at the times when [redacted] is in the hospital.

67. [redacted] attends at the hospital once a fortnight, unless anything happens. He goes in and gets weighed, gets his bloods done, and he gets checks done because of the medication. He gets a monthly check done to do with the bromide levels in his kidneys, because of the medication. He gets an ECG done also. When he first got prescribed tazemetstat last year, he was never given an ECG so we raised that because Karen's been on a Facebook page with other people that have been using the drug, and there have been parents saying they got an ECG done every month to check and make sure. It's because the drug itself can have an impact on the heart, and the kidney function.

Admission December 2020: Meningitis

68. In December 2020, [redacted] had been complaining of a sore ear, on the right-hand side of his head, where the surgeries had taken place. The medication that [redacted] was on can cause ear infections, so we met with ENT. The ENT doctor looked at his ear and said there was an infection there, however he didn't know if it was going to cause anything. He told us to go home and if it got worse, to come back in. He was aware there was an infection there, and we were sent home, and within a couple of days, [redacted] spiked with a temperature. He was rushed in to the ICU with a temperature of 40 degrees, or something like that, and he'd been over 40 for a couple of days running.

69. At that time, we were told, by one specialist that it had come from the ear infection, but they couldn't tell me what it was because doctors had

bombarded it with antibiotics which had broken the chain. Then, later, a consultant came in and said, no it's nothing to do with the ear infection at all, I don't know what you're talking about. Karen told him what the specialist had said, and then he sort of backtracked, he didn’t know what he said, and the consultant left the room at that point. It seems to have been since the meningitis, as if they're trying to protect themselves from that, around the area of competence, to a certain extent. Now, if we have an appointment to go to the ENT, there's always a Doctor, and somebody else in the room with us, there's always a witness in the room, whereas, when we first had conversations, there wasn’t anybody.

WATER: EVENTS INVOLVING WATER SYSTEMS

70. When we first went in to the hospital in 2019, I recall seeing a sign above the sink in the main room, and also above the sink in the toilet area in ward 6A. I don’t recall seeing these in the RHC. In the main room there was a sign above the tap saying, “Do not drink this water, bottled water will be provided for you”. I noticed more recently that the sign has been reworded so it now says, “This is for hand use only”, so they’ve removed the part about not drinking the water. The sign has always said you can’t pour other liquid down the sink apart from water. It's a sink, and you can’t empty out old juice down it. The bathroom area is the same; you can't pour anything down the drain and you can't clean anything.

71. If you wanted a drink of water you had to get a bottle of water. When the kids were born in 2016, we were told then too that if you wanted water, you couldn’t drink the tap water in the wards. If you wanted to drink anything or give kids a drink, it had to be bottled water so even back then, you weren’t allowed to drink the tap water.

72. Every so often, I think it was once a week, two workman type guys in overalls would come in and they would pour a cleaning fluid down the sinks. I think it was the janitor staff or the maintenance staff, the staff with the green shirts on. They don't check to see what’s going on in the room, they just walk

straight into the room. You could be doing anything in that room, but they don't wait, they just walk in, there's no care about what's going on inside the room. They don't check to see what's going on first, they just come in, they put fluid down, and then they just walk straight back out again. A lot of times, they weren't coming in with masks on or any PPE equipment at all, they just walked straight into the room with their overalls on.

73. All the guys said that came into the rooms was that they had to clean the sinks, that was all, there wasn't any reason, they never said anything like that. I just took it as a sort of maintenance cleaning regime, or something like that. The cleaning staff would come in, it was supposed to be once a day, I think, and sometimes at the weekends they came in twice a day. There were the odd days, where nobody came in to clean anything at all. They were supposed to run the showers in the ward for three to five minutes. A couple of the cleaners did do that, and there were other ones that just didn't run the shower at all. You'd be sitting there chatting away to them, and we'd ask them, are you not meant to turn that shower on, and they'd say the next person would get it. They wouldn't tell you why they were told to do it but apparently it was to stop Legionnaires, the water build-up in the showerheads. I think someone had said to me roughly six months ago or when [redacted] was nearing the end of his treatment for the relapse about the Legionnaires. I can't remember who it was though. Someone on the ward had come down with Legionnaires and as far as I'm aware, you can only get it from water. Nobody had mentioned why they were running them, they just said it was so that you didn't get stale water.

74. There were filters on the water system, the taps. Staff told us it was to keep water at a cleaner level as it was in the Schiehallion Ward and because that had now moved to the adult hospital, they were trying to keep the same level of cleanliness and purity towards the water supply. I think it was a precautionary measure for water issues that had happened with the seagulls and the pigeon droppings, that was in the water supply. At one of the meetings we attended with Jeane Freeman, I think it was a person from

Maintenance that said the pipework had too many dead ends; when it came to a right hand junction in the pipework, rather than being a flush junction, it would be a T-shape. This meant that the top half filled with water but it couldn’t go anywhere and would go stale. Every so often there would be a surge of water that cleared it out and it would go into the main pipe system. Anas Sarwar had a report about there being too many dead ends in the pipework and all the contaminated water was getting flushed back out again. From that report, the pipework had been contaminated before when an outside pump station had diesel or pooled water going into the system. I think this was 2015 before the hospital opened. He also told us that the hospital would rather pay out in claims against the hospital than fixing it as it would cost less to pay the claims than it would to fix the pipework. Initially, we weren’t told that it was anything to do with that though.

75. I don't think it was the filters that were on at the beginning, are the ones they have on now; I think they found a better way of putting them on. There were no filters on the taps that I can recall in the RHC. The first time they appeared, it was only in ward 6A. If you went to any of the clinic areas down stairs in the RHC, they still had the water stations in the foyer, they still had no filters on all the taps down there. We were told by staff from the clinic that, if at any time, when we were at a clinic, and we needed the toilet, we were to go up to 6A, so that [redacted] wasn’t exposed to the unclean water, because the filter system wasn’t in place down the stairs at clinics in the RHC or downstairs in the adult hospital either. It wasn’t in place anywhere else in the hospital that we had been in, apart from 6A although I believe six to eight months later, they were starting to be installed downstairs.

76. There were filters on the basins and every sink that we had access to in ward 6A. I don't think they had filters on the sinks in the catering area but we weren’t allowed access to that area, it was only the taps that were in the rooms. If you wanted anything from it, you had to ask a member of staff, one of the auxiliaries, and they would go and get it for you.

77. When [redacted] was on weekly chemo, I can’t remember the exact date, I recall somebody coming in and they said there had been a new team set up to liaise with the patients in regards to what had been going on in the wards, and in regards to all the news coverage that had been going on with the water.

78. Stories were breaking in the papers in regards to water. They were just letting us personally know what was going on, and if any articles that were going to hit the papers the following day in regards to any water scandal, they would come in and talk to the parents about the article. The team that gave us the updates came in a couple of times. There would be an article coming out in the paper the next day, and they would ask if we wanted to have a discussion about it and ask any questions. You never saw them at the beginning, but then when the water thing really did kick off, this team were there to coordinate with parents, but I only met them once or twice. They said they would come in and speak to all parents on a weekly basis but they didn’t. I think I met one or two other people, over the space of a six month period, from February 2019, but I can't recall names. The first time I saw one of them would have been round about August/September 2019 when the story about contaminated water appeared in the media. The next time I saw someone, it was when a story had been leaked about the Health Board; someone had come in and told us it was going to be appearing in the press. There was very poor communication on that side of it as they didn’t speak to us weekly as promised.

CLEANLINESS

79. A lot of time you would go in to any of the wards and some of the rooms were dirty, they weren’t cleaned to a high standard. There was a fine layer of dust along the back of the lights, on the wall-mounted plugs, light switches. A lot of the rooms had facilities so you could hang clothes. The furniture is supposed to be moved on a daily basis for cleaning under it. I can recall on several occasions; it was only one certain member of staff that would do that. Other cleaners would come in, but not move the furniture. They would mop the floor that was generally walked on. If you were sitting on the chair, they wouldn’t

ask you to pull the chair out the road. Some of them did do a very thorough job, but there were others that didn't.

80. They used chemicals for cleaning the floors. When they came in cleaning, you would always have a strong smell of a bleach derivative. You always had a strong smell of chlorine when the room was getting cleaned. Sometimes it was so strong, it was catching on like the back of your throat. One weekend, the floor had been cleaned in the morning at 10, or 11 o'clock that day. Later that night, I took a shower in the room area in ward 6A, and I'd put towels down on the floor, and one of them was grey. After taking a shower, I lifted up that towel, and the colour had been stripped out it. That had been a very strong reaction to the bleach. I raised this with the cleaning staff, and I showed them the towel. I asked why chemicals were getting used and why they were so strong and getting put on the floor. In our room in 6A, [redacted] never used the toilet, he was bedridden for long periods of time, and he was in nappies, so he wasn't using the facilities within the room itself. All the rooms were en-suite on that ward.

81. My reason for reacting to that was that there were other older children that have to use the toilet, or if they had a shower, or walking about barefoot in that room but they were walking about in that. If the floor was wet or damp, you've got this strong chemical sitting on the surface. Is that going to cause sores, or damage to the other patients?

82. My concern was that the cleaning staff that had gone in on that day weren't the usual staff you would see about, and they'd used a liquid that looked as if it wasn't diluted. They poured it onto the floor, and it went down as a gel which wasn't watered down. The cleaning supervisor came in and said it wasn't bleach they were using; it was a bleach derivative. They'd been given a chart on how to breakdown the dilution of it, and it was followed to the letter. They were adamant that it had been watered down and diluted.

PHYSICAL EFFECTS

83. A lot of [redacted]'s physical health was to do with the fact that he couldn't leave the bed. He was bedridden for long periods of time, he was having muscle deterioration in his legs, which he's still recovering from to this day. He gets tired quite easily when walking for a distance, so much so that he still has a buggy to be pushed around in. For short distances, he's fine, but if he goes out for the day and he has to do quite a bit of walking, he'll get to a point where his legs are sore. He just doesn't want to walk anymore and you see the energy slowing draining from him. That's still ongoing, where he doesn't have the energy anymore. I think this is because he couldn't leave the room for exercise as there were no battery packs to allow him to do that. He was stuck in his bed most of the time. Even if he did get out of bed, he was still sitting playing and in his room due to the lack of battery packs for his drip.

HEALTHCARE ASSOCIATED INFECTIONS

84. I don't recall which infections [redacted] had. He had a number of infections while he was in hospital. We were never given any information on if it was an infection, or not. We were never given the names or any specifics about any infections [redacted] had but he was kept in whenever he had a temperature spike.

85. There was one incident, I can't recall when it was, they came in and took cultures, and we were told [redacted] was to be put into isolation. Isolation is when the parent stays in the room with the child, and you have minimal contact with anything outside the room. The child is not allowed to leave the room with their parents, it's supposed to be minimal contact but if you're needing anything from the shop, you get a window where you can leave.

86. We asked if he was officially in isolation and one member of staff said, yes, and later on another came in and said we weren't in isolation. At that point we took [redacted] out, and he had a wee walk around the ward. The following day, the original member of staff came back and asked why we didn't have an isolation sticker on the door, and that we were in isolation. It was as if the left hand didn't know what the right hand was doing. One person was telling you one thing, and another person was telling you something completely different.

PREVENTATIVE MEDICATION

87. [redacted] was on daily medication that wasn't part of the chemo. These were ondansetron, posaconazole and ciprofloxacin. [redacted] was on posaconazole from the moment he was first diagnosed which was February 2019, when he had the central line put in, until he came back from America, and then at that point it changed to ciprofloxacin. We weren't told why he was put onto that, we were just told to put him on it and take him off posaconazole. All I can think of is that he was moved on to the Ciproflaxcin to hide the fact it was someone else that cocked up but Karen is the best one to ask about this.

88. We were given a detailed flowchart of the medication [redacted] would be getting, the routine, and how often he'd be getting it. I asked about certain medications, when they went through the names of them. We were told posaconazole was part of his chemo programme. We asked what it was for, and they just said it was part of the chemo protocol. We were told it was to protect him when he was going through treatment. When you go in to hospital, you go into a wee world of your own, you take whatever the Doctor says as being the word of God because that's their job, that's what they know.

89. They went through the protocol, about certain medications, the timeline was getting them, how he would get a look at artificial boosters, once he started hitting certain medications, chemo for example. Chemotherapy would take his neutrophils to zero so he would have no immune system and would need boosters to bring his neutrophil level back up again. I didn't really know

what his neutrophil level was, but it was clarified that it would be for his immune system because it would be obliterated from the chemotherapy. [redacted] would have a very high chance of catching bugs and other diseases, from other people. The boosters were given to [redacted] by injection and I was trained how to give him those. His legs would be black and blue because of them. I only done it for a short period of time as the emotional side was too hard. I had [redacted] screaming, “Daddy, don’t hurt me”. That was too hard. I had to say to the nurses that I can’t do this anymore. It was difficult as his legs would be black and blue.

90. When we found out what the posaconazole was for, we went back and asked some of the nurses why we were giving him this. That sort of fell on deaf ears, we never really got a response to that. Again, when it was changed at that point to ciprofloxacin, we weren’t told why. At that point, we were doing our own research into these types of drugs, and finding out what they were used for, and when we got that information we asked those questions to Dr Sastry and the medical nurses round about that time. Again, it wasn’t confirmed or denied, why he was getting it.

Loss of amenity

91. I think parents would still be in the same situation they were in two years ago if we didn’t fight for facilities. We fought the Health Board for a parents’ seating area within ward 6A, which wasn’t available while [redacted] was getting treatment done and we had nowhere for [redacted] to play or for us to cook food in meaning we would have to leave [redacted] on his own in his room. I think that was one of the questions that was raised with them was why we had not had a catering area. I think we mentioned it to Anas Sarwar, MSP, as well. We also voiced our opinion to Angela, who was the staff nurse, why there was no chill out area. After January 2020, the hydrotherapy bath in 6A was removed, and they repurposed that room for a parents’ catering area. We welcomed this. It was a sort of lounge area with a microwave, a tea and coffee machine, a chill out area where parents could go to, while they were on the ward, and

they could get away from the children, and go and have an adult conversation with another parent. I don't think the hospital would have bothered doing that if we hadn’t fought for that side of it. We thought that the facilities on the adult side were poor, there was nothing really there. They built that facility after [redacted]’s treatment had finished. With Covid, we lost it again, because the parents couldn’t use it, and it became a sort of staff canteen area. But while it was getting used, it was there for the parents, which they never had in the past.

92. If I never had any dinner with me, or the two hot meal options I was given at dinnertime was something I didn’t like, I had to ask a nurse to stay with [redacted], so I could go down to the Marks and Spencer’s on the ground floor and buy something to eat from there. I then had to take it round to the only place where there were two microwaves, in the staff seating area, on the ground floor. I would need to heat my food up in a microwave that was used by most people. The place wasn’t the cleanest, there was food splattered all over the place, all the time. You're then having to take piping hot food back into a lift, to go up six floors, into a ward that’s got immune deficient patients in it, with hot food. You're carrying a tray of hot food, and going back into a room. You could possibly eat it down the stairs, but you're still having to go down, you're still staying away. If you’ve got a kid like [redacted] was, who hated when I had to leave the room, he would have tantrums. He would break down because he didn’t like it. If I was there, he knew I wasn’t going to let anything bad happen to him, and that was it. I could never leave the room, because he would be thinking something bad was going to happen to him.

93. So I was with [redacted] all the time, and then the odd times that I could get away, he wouldn’t mind if I went to the shop because he'd know he'd get a chocolate bar, or a magazine, or something like that. Nine times out of ten, he didn’t want me to leave the room, I either had to get someone to come and sit with him, or wait until I could.

EMOTIONAL EFFECTS

Overall emotional impact on [redacted].

94. I can’t tell you the emotional impact on [redacted]. His body language though, for example, up until probably November 2020, any time we'd attend a clinic and get finger pricks done for blood samples, [redacted] would always fight you on it. It would take maybe four or five of us to hold him down, to get a finger, so they could get a blood sample. I don't know if it's just maturity wise, but it was like a switch went off after November 2020 and then there was no argument. If [redacted] needed to get his finger pricked, then it was okay. You would take a finger, and he'd say to put it in that one there. It's the maturity side of it, he's just grown up a bit. Emotionally, he's very shy now, if he goes into a situation where he doesn’t know anybody, he’ll cling onto your leg, and hide away.

95. He's very, very quiet until he's sure of you, whereas beforehand it might have been 15 minutes, because he didn’t understand the situation. Now it's maybe 45 minutes to an hour before he’ll start to drop that barrier, drop that façade. It's a sort of wall he puts up when he goes into the hospital, now. He doesn’t talk to anybody; he doesn’t give them eye contact. If they ask him to do something, he won't do it. It's only now, as he's not there on a daily basis, that he's slowly coming round, he's getting more back to the way he was before.

COMMUNICATION: GENERAL

96. There was an auxiliary, Andy who was really good and he was your point of contact. He would handle any questions and anything that parents felt disgruntled about. He had been telling his bosses about problems, and nothing was getting done about it. He was one of the first ones to suggest going to the papers, and making the story public, so that they would have to respond to it, because they weren’t listening to him. They were there, trying to pass that information on, and he told us that the management didn't do anything and we needed to make the public aware of this sort of thing. At that

time, I thought we would do that, sort of like a whistle-blower, to a certain extent.

97. A lot of staff, including nurses started leaving, they told us they were getting told to lie by the Board, and from their managers. They told me they were getting told to lie to ourselves about treatment, and protocols, and a lot of them just couldn’t handle it. They never got into the job to lie, and a lot of the people left. I don't have their names, I know them to see them, and there was a couple of them who went out their way to do anything for you, or for [redacted] because they were seeing him on a daily basis.

98. I think the staff are more forthcoming now with us, because I think they know that we will question everything, we’ll stand up and defend ourselves. When we first began this journey, we were very naive, we believed the Doctor knew best, and we wouldn’t question anything that was said, or done, or anything like that. We now question the staff, question the doctor, question when they were doing something every time it was going to have an impact on [redacted]. We’ll research it, and find out if they’re giving him medication, and why they are giving him it. We’ll question everything, we’ll query it all and if we are not happy, we’ll voice that we’re not happy, whereas before we probably would have said we’ll see how it is. We don't stand for that anymore, we can't, we need to question, we need to fight it.

99. I think communication is better now than it was at the beginning, and how it was last June when [redacted] relapsed. It's a lot better than the previous time when he was in getting his chemo. If we have a query, we can phone up, and they’ve got numbers for day-care, and the Ward 6A. We can phone up at any time. If we ever have to go into A&E, we just phone up Ward 6A, and they'll phone down. That communication is still there, and any time he has to attend anything else, there will be communication, they'll be forthcoming with information, and happy to help now, more so than what it was in the past.

100. I think the communication between parents is far better than it is between the parents and staff. There’s a lot of questions and knowledge between the parents, that is shared and also given to new parents that are coming into this. I think it's a resource that should be given to parents, when they come in, without having members of staff on, i.e. in Facebook groups. We've found in the past with certain pages that are opened up on Facebook, in regard of talking about things, members of staff are signing onto it, so that they could report back, and report on what we’re saying. I know there is a closed group, but I think they were known by the hospital, and they could be used by the hospital. But they could be used by parents that were going into that, and saying, by the way, the parents have this group, that’s it there, it's a closed group, and you just have to give a wee bit of information so that you can get into it. I think that you'd get a lot more information, a lot more weight, a lot more people behind you to back you up in aspects that you wouldn’t have any knowledge about.

101. I’ve not directly dealt with Professor White. Again, Karen would speak to him more. I was there at meetings, but as a co-parent sort of thing, with other parents that were there. Karen and I had spoken about questions to put to them but she was the main one to voice those questions.

102. I was at two meetings. I think one was with Anas Sarwar, MSP, we had a meeting with him. We had another meeting with Jeane Freeman. I can't remember where it was, just that it was in the teaching part of the hospital. The Facebook members were there as well. I was there more for support for Karen, she does the logistics side of that, and voicing any questions or opinions.

103. The press coverage has had an impact in a positive way. If it wasn’t for the press a lot of things that happened on the wards, wouldn’t have happened. If we hadn’t voiced our opinion, or if [redacted]’s story wasn’t in the public domain, I think a lot of issues that we raised wouldn’t have been sorted out, like the

fridge situation, and the different foods. I don't think any of that would have been resolved.

COMPLAINTS

104. We didn’t make any formal or written complaints. There was one auxiliary who would handle a lot of questions, anything that parents felt disgruntled about, he would be the point of contact. He would be the one that was passing it onto his supervisors, and he said, it was just like it fell on deaf ears. There was no interest in them trying to accommodate parents.

OVERSIGHT BOARD / CASE NOTE REVIEW / REPRESENTATIVE GROUPS

105. I can't think of anything I’ve had to do with the Oversight Board or the independent Case Note Review. Again, Karen would probably know about that side of it. It's mainly Karen that would speak to them on a daily basis, so any other person, I don't really speak to. I’m not on the main Facebook groups, or if I'm in the Facebook groups, I don't have any direct contact with those members, it'll be Karen that’ll deal with them.

106. I don't really bother with the hospital Facebook group. I'll catch up with it when I've got time to go on it. Karen deals with that side, she's got the time to sit and talk to people.

CONCLUDING COMMENTS

107. I think the hospital is probably still about the same in the grand scheme of things. With Covid, I think they’ve changed, there's more focus on cleanliness, and PPE. We’re only in there every fortnight, now, unless [redacted]'s got a clinic to go to, but I can't comment on the wards. We don’t go into the wards, and we don't stay in 6A anymore, we’re only in to pick up medical supplies and medication for him, and he goes in and gets a thumb prick done. I can't really

comment on how the running of the is hospital now, because I'm not staying there long term.

108. I don’t think the Health Board have really changed. I believe that when this all came out about the water, they should have sacked them and I still stand on that side, that they should have sacked them. A fresher set of eyes should have come into it. I don't think they should have been able to maintain their job after having a scandal with water borne diseases, and resulting in the deaths of several children. According to any independent results that have come back, they’ve said it wasn’t the water that caused it. Anything that Anas Sarwar has had from any whistle-blowers, reports, or any documentation that we've received, it shows that it was water. I just think they're protecting their jobs; they're sitting on a board to protect the £195,000 of a salary they're getting each year.

109. I have knowledge of people, and knowledge from my family, about the medical side, and medical issues, and medication, things like that. There was talk about these water borne diseases. These have been present in the previous hospital at Yorkhill, and it's as if it's been carried across to the newer hospital. It would be from working practice, more than the site or location of the hospital. It's the way certain processes are done, that these water borne diseases are still present. They were present in the old Yorkhill Hospital, 40 years ago, and they're still present in this day and age. I know it's just down to poor procedural practice, more than anything else, or something else.

110. I understand America is mostly private practice, and we have an NHS system, which is quite different, but comparing the two medical systems, the level of care is night and day. In America, you get what you pay for. I think that’s basically what it comes down to. Obviously, America is private care, but the cleanliness level, or the maintenance from the staff is first-class in America, even when you had a basic area. I just think if they could adopt some of those ways of practice here, we would have a much better NHS system.

111. If you're on the worst journey of your life, and you want a wee bit of emotional support there, to help you along that way, I think that would be great. We didn’t have that crutch, it was a really hard journey for us especially when [redacted] relapsed and we had to fight tooth and nail for treatment so he could still be here. I think it's a hard journey for a lot of people going into that. If it was in the Schiehallion, in the children’s hospital, that would have been a bit better, but because you'd been forced into 6A there were a lot of different other factors that were in place.

112. When we came back from America, we had the money sitting to pay for the extra flights, I think it was £2,500. We had a contact in the NHS but I can't remember the name, Karen would know. We tried maybe two to three times a week, phoning this person up, leaving messages, leaving text messages, leaving emails. It was as if it fell on deaf ears, nobody was chasing it up, nobody was sending the invoice out to us so we could pay it.

113. It got to a point almost three months after getting back from America, we still hadn’t paid it. We were still getting correspondence from the person in question, who it was supposed to be getting paid to, up until the beginning of September, when everything started coming out about the ward issues. And then there was no correspondence at all, we couldn’t contact anybody, nobody was phoning us. You would think if you're due £2,500 to somebody, they would want you to pay it. We never paid it, we never got an invoice for it, we tried paying it, and nobody gave us a bill for it. As I said, we were contacting them two or three, three or four times a week. We were saying, send us an invoice, we want to pay this, we've got the money, we want to get it out the bank. We were sitting there telling them, I want to give you money, I want to give you some money. So the bill was never paid.

114. Nobody has ever contacted us in regard to the bill. It's as if they’ve gone and said something like, I don't know if we should do this, it's as if they’ve said, we won't bill them for that, and it'll be a wee bit of hush money, sort of thing, so

they won't say anything bad against us, or something like that. It's not as if we didn’t try and pay it, we tried.

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

APPENDIX 1 – AS/01 - TIMELINE

- 20th February 2019 – [redacted] shows signs of being unwell with vomiting and did not seem himself. He attended his GP who advised that [redacted] had a viral illness. His symptoms did not improve.

- Friday 22nd February 2019 - Andrew took [redacted] to QEUH for further checks. He was monitored in accident and emergency and the staff concluded that he had a viral illness. He was sent home with calpol.

- 24th February 2019 - [redacted] attends A & E at QEUH. There were no beds available so he waited in the plaster room. A CT scan is ordered after Karen demands one (staff wanted to discharge [redacted]). Karen and Andrew find out on this day that [redacted] has a "mass" on his brain and that there was a risk it was going to haemorrhage. He is sent for an MRI scan and he then went for an 8-hour brain operation. After this operation he is transferred to ICU for 3 days approx.

- 28th February 2019: [redacted] is moved to ward 2C. He remains there for 10 days

- 6th March 2019 - [redacted] is introduced to Dr Sastry and discharged home.
- Within the same week of the 6th March– [redacted] returned to hospital and had a Hickman line fitted. He was admitted to ward 6A, room number unknown. It was a room at the end of the ward. [redacted] begins his treatment plan around this time (chemotherapy and radiotherapy). During this round of treatment [redacted] was extremely unwell with regular temperature spikes. He was moved into an isolation room and at one point he was told he had an infection. [redacted] was put on Propiconazole at the beginning of his treatment.

- 22nd April 2019 – [redacted] and the family travel to Florida so he can undergo proton therapy for 8 weeks. This was a particularly difficult journey due to the hospital not communicating with the 3 airports about [redacted]'s situation and the route being organised by the NHS without consideration for the family's situation. While he was in Florida it came to light that he had been on propiconazole. The doctors in Florida queried why this was and contacted QEUH. They were told that was receiving this because the water at the hospital was dirty. Up until then Karen had been told that this medication was part of his chemotherapy (or had that impression).

- 21st June 2019 - The family returned to the UK. The moment [redacted] returned to the UK to QEUH he was put back on Propiconazole. Shortly after returning he also had to undergo strong chemotherapy treatment because he was unable to receive this in America because of the Proton therapy. This meant he went through a period where he was an inpatient for 5 days or so and then a Daycare patient. He was continually in and out the hospital until December.
- December 2019 – [redacted] finishes treatment. His central line is removed. Once the line is removed he is able to stop the antibiotics.
- December 2020 – [redacted] develops meningitis.
- March 2020 – [redacted] has a scan and everything is shown to be clear.
- May 2020 – [redacted]'s behaviour changes, he becomes aggressive. At the end of May 2020 he attends for a scan (which was delayed due to covid)
- 1st June 2020 – The family are told that [redacted] has relapsed. At a meeting on this day with Dr Sastry and Dr Roddy, it is explained that there is an adjacent brain tumour and 3 more spots beside it. Palliative care is suggested instead of treatment by Dr Sastry. Dr Roddy says he could operate despite this palliative care suggestion. Karen and Andrew research treatment options. They find treatment and Dr Sastry denies that he has heard of this treatment, then tells them that this is not available on the NHS.
- 7th June 2020 (approx.) - Karen and Andrew speak with Dr Roddy. They discuss a possible trial treatment. Dr Roddy tells them that before they had met on the 1st June a board meeting had been held with Dr Roddy and Dr Sastry. At the meeting Dr Roddy had suggested operating, which was not backed up by the board. The decision was because of cost.

- Mid-June 2020 - After appealing the decision this was overturned and [redacted] was able to get surgery and receive a trial medication. Had the family not fought for to receive treatment, (due to the NHS saying it was too expensive) [redacted] would have likely not survived.
- [redacted] has done well since this point. He has recently had a scan and there was a fear that he had relapsed. It is now confirmed that he has not relapsed. [redacted] is still receiving chemotherapy and has a feeding tube.

In accordance with Restriction Order 2 , the Inquiry has provided excerpts of the witness statement for Witness 3. The Inquiry will only provide excerpts of the statement that do not contain information that is capable of leading to the identification of the Witnesses

Scottish Hospitals Inquiry

Excerpts of the Witness Statement of

Witness 3

OVERVIEW

1. My [redacted] is [redacted] [redacted] was diagnosed with Acute Lymphoblastic Leukaemia (ALL) [redacted]. [redacted] . was treated in the Royal Hospital for Children (RHC) and Queen Elizabeth University Hospital (QEUH) between [redacted].[redacted] was an in-patient during this time, except for a period she spent at home from [redacted].

2. [redacted] spent time in wards 2A and 2B of the RHC which are known as the Schiehallion Unit. The Schiehallion Unit treats children with blood cancer. also spent time on [redacted]. Following the closure of the Schiehallion Unit in 2018, [redacted] was also treated on ward 6A of the QEUH which was supposed to be the ‘new’ Schiehallion Unit. [redacted]. I can speak to the experience which I had with [redacted] on ward 2A and ward 6A.

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

Admission to hospital: [redacted].

3. [redacted] was taken to the ICU and we were all sitting in the family visitors' room not able to believe the things that were happening. [redacted]. We were just sitting waiting for news. They let us all in, one at a time, to see [redacted] but she was unconscious.

4. Professor Gibson came in later that night and told us that she had looked under the scope and that [redacted] had leukaemia. I just couldn't get my head round it.

5. We all sat there all night talking and discussing and then they were talking about the treatment she was going to start but I couldn't really take it all in.

Experience on ward 2A: [redacted].

6. In Ward 2A we had kitchen facilities. It was well decorated out for the children who were older, things like cartoons on the wall. The only thing I would say is that it wasn't very clean. [redacted] but not everyone's cleaning is up to the same standards and when the cleaners were finished I went round on my hands and knees with wipes and stuff to wash the floor [redacted].

Experience in the QEUH (adult hospital): late 2018

7. It was October 2018 when [redacted] was moved to ward 6A. We didn't have a kitchen there. There was nothing, so if you wanted something you had to go to the canteen. If I was on my own, I would have to ask an auxiliary to sit with if I needed something to eat. You had to wait until they were available. Sometimes they were busy but nine times out of ten they were available and you could get away.

8. Sometimes you had to go away and get your thoughts together for ten minutes, so I had to go and just walk about the hospital and go back up again and feel different. Sometimes I would get really upset for nothing. I didn't know why I was upset. I knew why it was, but just out of nowhere I would start bubbling. The nurses would come in and give me a cuddle and tell me to go for a walk. So I would go away out for 10 or 15 minutes and then come back and I would be okay. You can't look after a sick kid if you're not okay yourself.

9. There were really poor facilities in ward 6A and we were moved a lot. One of the rooms they moved us to really stank, the stink that was coming through the fan was horrific. It was awful. We asked to be moved but there wasn't anywhere to move us to. We asked to be moved back to the room we'd just come out of but they said they'd already started deep cleaning it so we couldn't. We had to stay in that awful room all night. We got moved the next day.

10. We weren't given any reasons for the moves, for some reason they were just always cleaning. If they knew the infection control people were coming, which they must have got wind of, they were all cleaning, the cleaners, the auxiliaries and the nurses.

11. We sometimes didn't get any notice of a room move but it used to take us about three hours to pack up. It was very stressful. On one occasion, [redacted] had to be moved twice in one day. [redacted] didn't bother, she was just always happy and she got wheeled [redacted]. So it wasn't stressful for [redacted], she was just in different surroundings, but packing up and then unpacking was stressful for whoever was on shift that day. It was like moving house.

12. And then before we unpacked any of her clothes or took any of her toys out her bag we cleaned everything. We even cleaned the wardrobe before we would put any of [redacted]'s clothes in. We thought it was maybe not properly cleaned so we cleaned it again. We were always sort of cleaning anyway. If was sleeping you would go around and clean. When [redacted] was awake you tried

to play with her and spend time with her but when she was having her wee naps in the afternoon we just cleaned.

WATER: EVENTS INVOLVING WATER SYSTEMS

Water incidents: [redacted].

13. When we first went into hospital in [redacted] we didn't know there was anything wrong with the water. We used it to clean our teeth, we showered in it, we bathed [redacted] in it, we cleaned her teeth with it. It wasn't that first year, so it would be [redacted] – I don't know when – that we were told not to be using the water. They gave us bottled water. [redacted]. The nurses told us not to use the shower.

14. We weren't told why we couldn't use the water, but on a few occasions a man came to check the water in the wee hand sink in [redacted]'s room, where you washed your hands when you came in, and I asked him what he was doing. He said he was checking the temperature.[redacted]. He wasn't checking the temperature, he actually had a sample bottle and he took water away.

15. Later on, I don't know when, they put filters on the taps and we didn't know why. They gave us like a wee disposable sink thing that was on wheels. Every room got one, like a disposable thing that you could use instead of the bottled water. Although it was still bottled water that was going through it.

16. We weren't told why they were putting filters on the taps, we just saw them and thought what's that? But it seemed like they were coming in and putting them on when you went out to go to the bathroom or went for a drink or something and there was only one person in the room.

HEALTHCARE ASSOCIATED INFECTIONS

17. [redacted] started to get infections pretty much at the very beginning. Her temperature spiked and she used to get antibiotics quite a lot. She got built up with the steroids and then she got put on the chemo. And she had infections really quite a lot.

18. When [redacted] had infections we weren't allowed to use the kitchen. You had to go into isolation, which is a double room. So we would go into the first room, leave your bag, 'phone, everything. Scrub down, put an apron on before we could even go in and see her. She would be screaming because it was a glass partition that she was watching you through and she was wanting you. She would scream and try to get out the cot to you. But we had to do all this before we went in. If you took a bottle in, just of water or anything, you had to wash it all down. You couldn't eat anything, a sandwich, crisps, anything.

19. The isolation rooms are different from the other patient rooms on the ward. The other patient rooms are just single rooms. You just go in, you don't take your shoes off or anything. But in the isolation ones you had to remove your outdoor shoes and jackets and everything, basically.

20. [redacted] was in these rooms quite a lot. If she had a runny tummy she was moved. One of the times she was moved and we weren't allowed to use the kitchen, I was absolutely choking for a drink when I was in with [redacted] overnight and I had said to one of the nurses could I please have a drink? They said, we'll get back to you whenever we're ready. They never did come back. I was so close to drinking the tap water.

21. [redacted].I always made sure I had stuff with me after that.

22. When [redacted] had these infections her temperature always spiked. She was just burning and they used to try and get her temperature under a certain level. They sometimes got her temperature down by using cooling cloths and a fan above the bed and then she didn't need antibiotics, but if they couldn't get it down they started her on the antibiotics.

23. They had to stop [redacted]'s chemo treatment when she got infections in her line because once there's an infection in the line you can't put anything through it.

24. [redacted] had to have her line changed on a number of occasions. [redacted]. And so they had to take her to theatre. I had to hold her until she went to sleep. It was just hard to carry her down to get x-rayed to see if it had moved and it had moved. [redacted].

25. Just the thought of [redacted] have to go to theatre again was tough. She had to go to theatre for lumbar punctures and she had to go and get chemo put into her. It was hard to be with her when she was put to sleep for her surgeries because I didn't know if she was going to wake up again. I stayed with her until she was under and then we had to leave and sit outside. That was awful.

26. We were asking questions like why did she get infections and why did it happen all the time? [redacted]. Once the infection got into the line that was sort of plasticky, it just grew. Bacteria grew inside it so they couldn't use it then to put anything else in. So then that had to get removed again. You've only got so many times a line can go in, in your lifetime, never mind in what was just a couple of months.

27. I don't know who it was but we were told that [redacted] picked up one of the infections in the kitchen. It was when we were all using the kitchen, all the different families. All the kids in the ward had runny tummies. So then they shut the kitchen. That was the only answer we got, that was the only time they told me. But they shut off the kitchen for every family. They had a water machine and that went away as well. They just closed it down. I think we were moved after that so we were never in that kitchen again. It was not good for the families when they closed the kitchen.

OTHER ISSUES RELATING TO HOSPITAL CONSTRUCTION

Hospital build issues: impact of construction works

28. I noticed there were windows falling out and everything. There was scaffolding up at the adults' entrance to the building. The scaffolding was up for months. There was a shop, a WH Smith shop, and it was all scaffolding and I think four windows had fallen out in the middle of the night, because I asked somebody what had happened. The windows actually just fell out. This was in the adults' hospital, which had a different entrance.

CLEANLINESS

29. I would like to make some observations about the cleanliness in the hospital. The cleaners told me they were only allocated, 10 minutes per room. Sometimes they didn't have time to wash the floor. It wasn't adequate enough to do the whole room and the bathroom. [redacted]. So we used to clean the bathroom ourselves. We used to clean the shower room, because it was us that were using it. We cleaned [redacted]'s room, dusting and washing all her [redacted] down.

30. We did this a couple of times a day. [redacted]. That causes germs. And they told us she was taking too many infections. They told us everywhere had to be spotless. So we got OCD with the cleaning. I used to be on my hands and knees with wipes, antibacterial wipes, washing the floor. I felt as if the floor was never washed properly. [redacted].

31. [redacted]. I just felt she couldn't go on that floor, it was filthy. We had slippers, we never wore outdoor shoes or anything into her room. We wore aprons all the time and gloves. We scrubbed down as if we were nurses and doctors, because [redacted] was taking too many infections.

32. When they did the deep clean of every room in ward 2A in [redacted] they had white suits on. It was like when you see forensic people on the television, it was one

of those suits they had on. It was like a big hose thing they were using, like a steam cleaner. But we never saw them doing [redacted]'s room. We just moved and didn't go back for a nosey.

33. The cleaners also told us there were sick people everywhere and different things that were on in different wards. Some of the kids had all come down with runny tummies. But some of the cleaners spent most of the time talking to you rather than cleaning. The nurses did a lot of cleaning, the auxiliary nurses. If they were in the room, they would help you clean. If they saw you cleaning the floor, they would be like, "You shouldn't be down there".

CLIC SARGENT

34. CLIC Sargent was for the children and their families when they were in hospital. It's about ten minutes from the hospital, just a walk through the grounds. They were fantastic. I'd never heard of them before, but they were absolutely fantastic. They couldn't do enough for you. They had a washing machine, tumble drying facilities. I think there were ten rooms. The whole family could have been in it.

35. They had a laundry room, there were five washing machines and five tumble driers. So you were able to wash the clothes and tumble dry them. And it was really, really well organised.

36. They gave you vouchers so that you could order your food. You didn't have to pay for anything. [redacted]. When we first went, we could fill a freezer and get what we wanted. I would go and make their dinner if they were in the hospital. I would have [redacted] dinner ready and then I would go to the hospital so they could come home and eat it. The facilities were great in there. We wouldn't have been able to cope without it.

CONCLUDING COMMENTS

37. Apart from the cleanliness I never had any issues with the hospital. The staff were absolutely brilliant. They treated [redacted] as if she was part of the family. had a great time.

38. The nurses were lovely. When [redacted] went up the stairs, to ward 6A, it was the same nurses that came with her.[redacted].She thought it was great. The nurses were really nice to her [redacted] they were lovely. Lovely people, the nurses. They didn't mind you asking anything, they were all lovely and very good to [redacted].

39. I don't think I would like if someone close to me was going in there, because there's lots of things like, they didn't tell us what the infections were, they didn't tell us what they were called or why [redacted] was getting so many infections. They kind of brushed all that away. But [redacted] kept on and on and on at them. They just never answered any questions I asked them at all. I felt as if they kept a lot away from us.

40. They should have come clean and then [redacted] would have been more prepared,.

41. I just felt they really let us down a bit by not being truthful and answering questions to [redacted]. [redacted] used to ask a lot of questions as well. I didn't ask that many questions really because I can't take stuff in.

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

SCOTTISH HOSPITALS INQUIRY
Hearing Commencing
20 September 2021
Bundle 5 –Witness Statements for Week commencing 4 October 2021