

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.

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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.

FAMILY BACKGROUND

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

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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. █████ 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 █████'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. █████ 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 █████ 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 █████ was discharged in the afternoons, the consultant went through █████'s checklist and he said that █████ 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. █████ was also discharged on co-trimoxazole which was sensitive to stenotrophomonas.
34. █████ 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. ■■■■ stayed in 6A for a week or so as he had to get weaned off the IV steroids and on to oral.

38. When ■■■■ 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 ■■■■ on some topical steroids and creams to moisturise his skin and stop it peeling off.
39. ■■■■ 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. ■■■■ 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. ■■■■ stayed there until 6 January 2019

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

41. After ■■■■ 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 ██████'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 ██████ AND HIS FAMILY

STATEMENT OF DENISE GALLAGHER

A33978923

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 poed 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 pooped 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 ██████'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 ██████ got his line infection from, it was only the Case Note Review that informed me of this.

OVERSIGHT BOARD / CASE NOTE REVIEW / REPRESENTATIVE GROUPS

STATEMENT OF DENISE GALLAGHER

A33978923

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. ██████ 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 ██████ 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 ██████. 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 ██████'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 ██████'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.

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- 25th May 2018 – ██████ 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 ██████ being placed in room 15 as he had neutropenia. ██████ remained in room 20 in isolation for around 4 weeks. Shortly before ██████ 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 – ██████, 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 ██████ was receiving. When he was examined, a doctor proposed that he receive more antibiotics. Denise refused this as ██████ was already on four antibiotics and it was making no difference. The use of ██████'s central line was then stopped to give ██████ a rest. ██████ then recovers very quickly.
- 8th July 2018 – ██████ 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, ██████ is discharged home for a few days.

August 2018 – January 2019

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- August 2018 – later in early August, ██████ 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). ██████ remains in room 24 for around 3 or 4 weeks.
- August 2018 – ██████ 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 ██████ was staying there. After this ██████ was moved back to room 24 again.
- August 2018 - Towards the end of August ██████ 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, ██████ is admitted back into ward 2A. ██████ receives an ultrasound, and some slight evidence of appendicitis is found. ██████ was moved to either room 10 or 11 while decisions were made as to what to do about his stomach pains. During this time, ██████ 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 ██████'s transplant.
- 8th September 2018 – ██████ has his appendix removed and was transferred to ward 3A. On this same day, ██████'s consultant, Dr Pinto, advised that ██████ had a gram- negative infection in his blood cultures. Dr Pinto said this could have been caused by his appendicitis. ██████ was then moved back to room 1 in ward 2A later that day, where an Advanced

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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

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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.

January 2019 – February 2020

- 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.

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