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.