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Scottish Hospitals Inquiry

Witness Statement of

Witness 1

OVERVIEW

1. My [REDACTED]. [REDACTED] was born on [REDACTED]. [REDACTED] was diagnosed with Acute Lymphoblastic Leukaemia ("ALL") on [REDACTED]. [REDACTED] was treated in the Royal Hospital for Children ("RHC") and Queen Elizabeth University Hospital ("QEUH") between [REDACTED]. [REDACTED].
2. [REDACTED] spent time in wards 2A and 2B in the RHC, these are known as the Schiehallion Unit. [REDACTED] She also received surgery in the theatres in the RHC and was admitted to the Paediatric Intensive Care Unit ("PICU") in the RHC.
3. There are some specific things that I would like to mention. [REDACTED] contracted a number of infections in her central line when in ward [REDACTED]. [REDACTED] included in the Independent Case Note Review [REDACTED]. She was prescribed preventative medication which I believe was connected to issues with the hospital environment. There were all sorts of issues with the hospital throughout our time there which, in my view, impacted on her treatment and on our family's experience. I will talk about these in more detail.

WITNESS STATEMENT OF WITNESS 1

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4. I think she was sick twice, and that maybe we saw bruises coming and we took her to the [REDACTED]. I can't remember when or even what was specifically wrong with her for us to take her to hospital. She just wasn't quite herself. [REDACTED].
[REDACTED] [REDACTED].
5. She was diagnosed not long after that and it was just a massive downfall.

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

Diagnosis and admission to the RHC

6. When we got to the hospital, [REDACTED] had been admitted to the Intensive Care Unit in the children's hospital. The staff performed a lot of tests. After a few hours we met Professor Gibson who told us that she thought [REDACTED] had leukaemia, the children's leukaemia which is ALL.
7. [REDACTED] was moved onto ward 2A in the RHC which is Schiehallion ward.

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

8. [REDACTED] to the Schiehallion ward to begin her chemotherapy treatment. I don't remember all the details of the amount of different chemotherapies and stages but it was intensive induction chemotherapy treatment.
9. We were settling into the ward. We'd met a couple of other parents by this point. We were getting the lowdown of the ward; the lowdown of our new world. Our world had crashed, absolutely crashed down in front of us. On the ward everybody's enthusiastic about everybody's chances and they're trying to will everybody on and all the rest of it. So you make friends. We made friends that are like family now.

10. [REDACTED] an induction style blast of chemo and within 5 weeks she was MRD negative. The hospital did a Minimal Residual Disease ("MRD") test to see whether or not she was MRD negative. Basically this means that she's got no leukaemia cancer cells in her body and her immune system's producing good cells.
11. At this point the doctors were quite happy with her and we were transferred to a VAC room in ward 2A.
12. VAC rooms are the transplant rooms. When you entered you had one room where you walked into and it had a sink. You had to take your shoes off, wash your hands, put on an apron, and then you were allowed to go in through the next set of doors and into the patient bedroom.

Event:

13. Every time [REDACTED] was unwell they had to put cannulas in to give them a line to feed the chemo or a line to feed antibiotics or a drip, anything that had to go through some sort of vein. The first time this happened was when she had an infection, the line had to stop being used and then staff used cannulas instead.
14. I was saying to the nurses, what do you think is wrong with her? Nobody would tell me. She'd picked up some sort of infection and it's obviously not agreeing with her. She needed to fight hard to get herself over the infection.
15. The nurses pass it onto the doctor, the doctor can't give you a serious answer, so they pass you onto the professor. Nobody could be honest with me at all when it came to anything like that.
16. Every time the staff tried to insert this cannula, [REDACTED] could feel the pain.

Hospital Acquired Infection

17. Staff were just passing it off as if it was an ordinary infection that was getting the better of her.
18. [REDACTED] This one you could see was different. The way it was eating into her body, eating into her blood stream. You could see it was totally different than the way that she was able to actually contain it.
19. When she had the infection [REDACTED], [REDACTED]'s chemo was delayed for about two weeks. Her chemo was only ever delayed due to infections. I am not aware of any other reasons for the delays. [REDACTED] was really unwell.
20. They cannot use the line in the chest when an infection is found because that would spread it. If the infection is not as serious and it can be eradicated without removing the line, they will do that, in order to avoid the distress of having to go to surgery to have the line removed. [REDACTED] would have to be fasted for 12-14 hours before surgery. On this occasion they had to wait until the infection cleared up before they fitted a new line. [REDACTED] had to be taken to theatre for a PICC line to be fitted to give her antibiotics to clear the infection. Once the infection was cleared up, she went to theatre for a new line to be fitted in her chest.
21. When I read her report from the Case Note Review, it confirms the date and timings of the infection she had.

Relapse - Admission to Ward 6A of the QUEH:

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

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

23. Most of the time it was the nurses we were chatting to I actually felt sorry for them. They were in the firing line from the parents as we were asking questions, and then they were in the firing line from management, because they weren't allowed to tell you the truth.
24. In ward 2A, the cleaners weren't great, the floor was minging after they'd cleaned it and [REDACTED] was going round after they'd cleaned it with baby wipes. It wasn't even a proper mop. It was one of those mops with the Velcro pads. They had tablets in the mop bucket but the floor was never wet. Ward 6A was still dirty. It was the same staff, the same nurses, it was the same cleaners as on Ward 2A. The scenery was better because you were up high on the sixth floor.
25. Everyone seemed to be "in source" in ward 6A. When a patient is in source, they are in isolation. They are not allowed to leave their room. A patient was put in source when they had a gut infection. They did not want the infection to spread to other patients. When a patient is in source, you are not allowed on the ward other than to walk to their room. You are not allowed to stand and speak to other parents. You are not allowed to use the facilities like the kitchen. [REDACTED] got no support from the staff. We felt like we were shut away on our own in a room.
26. [REDACTED], we didn't want to use the water. [REDACTED] used water wipes. By this time, we were told not to use the water, letters were coming round and people were talking. The communal bath was blocked off. Nobody was allowed to use it. At that point, the next stage in her treatment plan was to try to get [REDACTED] back to being MRD negative.

HEALTHCARE ASSOCIATED INFECTIONS

HAIs: events and the physical impacts

27. [REDACTED] had a line in her chest which goes to the main artery, it was a Hickman line. There are six main arteries in the body that this line could go into. [REDACTED] [REDACTED]. When [REDACTED] was being fitted, the doctors came to talk to us about [REDACTED] going into theatre and to discuss what they were going to do in the theatre. The line is used to take blood and give medication and chemo.
28. [REDACTED] had a number of infections. The other line replacements were due to infection. She had a lot of line infections when she was in ward 2A. A number of times when she had to have her line removed and replaced, it was a surgical procedure under general anaesthetic with the fasting and waiting and all that going into surgery involved.
29. When [REDACTED] had to have the line removed because of infection two surgeries would be required. The infection had to be cleared up with antibiotics before a new line was fitted.
30. Lines were removed when the staff couldn't deal with the line infection using antibiotics. They had to remove [REDACTED] central line. There were other infections too, but they managed to catch these with antibiotics. [REDACTED]. On none of these occasions could they tell us exactly what was happening with [REDACTED]. [REDACTED] There were a couple of occasions when she was admitted to PICU in the RHC. They were keeping an eye on her when she was really poorly at those times.
31. [REDACTED] did not have one infection when she was out at home on maintenance treatment [REDACTED]. Not one infection. Every infection she had was when she was in hospital as an in-patient.

32. Another thing which I raised with the nurses all the time was the frequency of the changing of the dressing round the line. [REDACTED]'s dressing would start to peel away from the line site and it would get all scabby looking. I had to constantly ask for the dressing to be changed. At one point one of them said to me, we're not allowed to change them now for a week. I asked why and I asked that they show me how to change the dressing. They said they were not allowed to change the dressing for a week, no sooner. Their reason due to stock supply. They commented that we cannot waste stock. They would give us wet wipes and tell us to make them last us.
33. Not only that, water could actually get underneath it and get to the site. Why would you let it get infected for a week? If you've got any chance of getting infection because it's curling up or whatever and it's getting exposed to water, why would you leave it a week?
34. In terms of infection prevention, the position for every kid in that ward is that they're on chemo. Chemo's whole job is to rip your immune system to shreds, basically. It doesn't matter who gets chemo, me, you, anybody, the minute you get chemo it starts to work on your immune system which leaves you susceptible to infection. It doesn't matter what age you are.

HAIs: Impact on [REDACTED]'s treatment

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

HAIs: communication

36. In terms of the hospital staff communication with me and [REDACTED] about the infections that [REDACTED] contracted, if I was rating it out of ten I would say a two. That's telling us exactly what it is, telling us how we're going to get rid of it, telling us how she got it. I would give them a two out of ten for that.
37. When it comes to the nurses and the doctors finding out if [REDACTED]'s unwell and keeping her comfortable, I would probably rate them a wee bit higher in that. They were really good and really efficient that way.
38. For the big statements they were honest, but when it came to infections, they don't tell us much. All they said was that they were growing the blood cultures in the lab for two days and we'll let you know.
39. They didn't always tell us what the infections were. We might have been told about some of the fungal ones. I can't remember the names but it's basically a gut infection. Staff would tell us about that one. But they didn't tell us when it was the blood that was infected with sepsis.
40. [REDACTED] contracted sepsis when she was in hospital. I cannot confirm the date of this.
41. At one point she was on five antibiotics. Five antibiotics in the one go, different ones. The nurses were scared for her at this point. They were frightened for her and when you see that you know how bad she is.
42. [REDACTED] had high temperatures. We used to sit and watch these high temperatures, and wish they would come down. They were off the scale. The wards have a thing called a Tempadot which measures your temperature up to 40 odd degrees maybe 42 or 45. I can't remember the exact maximum of it. The temperatures she was having at this time were taking her off the scale.

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

43. I know [REDACTED] [REDACTED], and she had one or maybe two infections that were included in the Case Note Review. She had at least one infection that the panel said was saying is connected to the water, but every infection in that place just causes heartache. I speak about the Case Note Review later on.
44. The timeline I have given the Inquiry is about two, three pages long, but it's not half of what actually happened when you look at the medical notes, what went through in that place. The timeline is just the main points that stick in our minds. There's loads of stuff under the surface that's in the notes.

PREVENTATIVE MEDICATION

45. [REDACTED] was given preventative medication at some point. First of all there were issue with the water, and the bird issue with the pigeons and then the hospital gave every single kid on the ward the same antibiotic. [REDACTED] did receive it but I can't remember the name of it. It was given to all of the kids, and at the time we were told it was to keep her safe from an infection. We weren't told every kid on the ward was getting it.
46. [REDACTED] We found out the other kids were also given the medication because every parent talks to each other, so it soon gets about. "Oh so and so has started on this today", "oh such and such has started on this today. So had [REDACTED]. Before we knew it, everybody seemed to be taking it. I think that must have continued after we left the hospital [REDACTED], because when we left there were still filters on the tap, the air purifier were in the room and the bottles of water were still there.

WATER

47. When we were on ward 2A, we noticed that signs started going up around the ward “stop using the water”, “don’t brush your teeth in the tap water”. We got a letter from the hospital which told us not to brush our teeth in the tap water.
48. I asked “are you sure this water’s actually safe, why is she getting so many infections?”
49. Obviously lies, lies, lies, as I know now. They tell you it’s fine. The staff would try and walk over [REDACTED].
50. [REDACTED] started to wipe her down around about this time in ward 2A. [REDACTED]. They were giving us bottles of water to drink as we were not allowed to touch the tap water.
51. I watched plumbers come into [REDACTED]’s bedroom, bearing in mind nobody’s been allowed in [REDACTED]’s room, to change the filters on the tap and shower heads, and I’m like why is all this happening?
52. The bottles of water were for drinking, brushing your teeth, washing your face, that sort of thing. I don’t know if [REDACTED] used them for anything other than that. But this is what I didn’t get, as the hospital are telling us to use bottled water do these things at the same time they’re washing their hands using water out of the tap. Every time they’re leaving the room, every time coming into the room.
53. The situation with the water was not much better when we moved to ward 6A in the QEUH. In fact, I had the same conversation with the head nurse on the ward there too. When we went into ward 6A, we were still given bottled water. You walked onto the ward and there were big piles of bottles of fresh still water to drink. So I asked the question [REDACTED] when we were up there as well. She told me the water was fine to be used and that all the

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

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

OTHER OBSERVATIONS ABOUT THE HOSPITAL BUILDING

55. The water wasn't the only thing wrong with that hospital. Everything was wrong with the building. On one occasion one of the big panels had fallen off and crashed to the floor. The panel fell off overnight, so I didn't see it happen. It's lucky nobody was hurt to be honest, because if that had hit somebody they are dead.
56. The rooms in ward 2A were absolutely roasting. You couldn't do anything to control the temperature. The air conditioning didn't work. There was a dial in the room and I could turn whatever way I wanted; it doesn't do anything. The staff have got a dial out in the ward, they can turn it whatever way they want; it doesn't do anything. We were always told it was broken. On a really hot, sunny day the rooms were absolutely roasting. Imagine sitting in that heat, no windows to open. Not that you would open them right enough because the smell would have been worse.
57. There's certain rooms on that Schiehallion ward which are situated at the front of the building, which is the road that the buses drive up right in front of the main hospital and children's hospital. If you are in any of these rooms round

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

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

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

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

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

PHYSICAL IMPACTS ON

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

[REDACTED] We were allowed to give her water up to a certain point, then we had to stop the water a few hours before.

OVERALL IMPACT ON THE FAMILY

The emotional impact

63. Obviously the impact on our family is caused by [REDACTED] having cancer. But the impact of her having all these infections from a place that wasn't fit for purpose made her life harder than it had to be.

[REDACTED] [REDACTED]. She spent 10 months in hospital and then 3 months out at home, [REDACTED]. If she hadn't had so many central lines her life would have been better. [REDACTED] breezed every single chemo but all these infections made her unwell, she got better and then she got another infection.

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

COMMUNICATION

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

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

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

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

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

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

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

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

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

THE INDEPENDENT CASE NOTE REVIEW

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

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

CONCLUDING COMMENTS

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

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

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

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

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

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

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

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

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

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

84. [REDACTED] other kids that are there now, and that continue to fight for their lives every day and who will fight for their lives in the future. Those kids and their parents deserve to know that their kid is in a place where there's no lies, no deceit, and that it is a place where they can actually drink the water and brush their teeth.
85. I believe that the facts stated in this witness statement are true. I understand that this statement may form part of the evidence before the Inquiry and be published on the Inquiry's website.