

SCOTTISH HOSPITALS INQUIRY

**Hearing Commencing
20 September 2021**

**Bundle 7 – Witness Statements for Week
commencing 1 November 2021 and the
remaining statements for those witnesses
not giving oral evidence**

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In accordance with [Restriction Order 3](#), the Inquiry has provided excerpts of the witness statement for Witness 4. The Inquiry will only provide excerpts of the statement that do not contain information that is capable of leading to the identification of the Witnesses

Scottish Hospitals Inquiry

Witness Statement of

Witness 4

OVERVIEW

1. My [REDACTED] was diagnosed with Burkitt Lymphoma, an aggressive form of cancer in [REDACTED]. [REDACTED] was treated in the Royal Hospital for Children (RHC) and Queen Elizabeth University Hospital (QEUH) between [REDACTED].
[REDACTED] was an in-patient during this time.
2. [REDACTED] spent time in ward 2A of the RHC which is known as the Schiehallion Unit. The Schiehallion Unit treats children and teenagers with cancer. Following the closure of the Schiehallion Unit, [REDACTED], was treated on ward 6A of the QEUH. [REDACTED]. I can speak to the experience which I had with [REDACTED] in the hospital.

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

3. [REDACTED] transfer us to the RHC and that it would be ward 2A. The doctor did say at that time that the RHC were having problems with the water and that [REDACTED] may not get a shower, but she said they were working on it and fixing it.

Experience in Ward 2A: August 2018 – September 2018

4. When we arrived at ward 2A, they were still getting the room ready for us. It was a transplant room we were in. That's a room where you have the outer bit where you do all your hand hygiene and put on your PPE before you go into the inner room. I think it's called a source or an isolation room or something like that.
5. ■■■ was only in that room for two or three days and then we were moved to a normal room just up the corridor which just had the bedroom and the en-suite bathroom.
6. They spent a couple of days doing blood tests and various scans. We met with Dr Chaudhury, ■■■'s consultant. She told us that ■■■ had Burkitt's lymphoma.
7. Ward 2A itself was nice. The facilities in it were good. It was clean and the nurses were always really good. The rooms had beds for the parents that folded down from the wall and could be pushed away into like a cupboard so it gave you space in the room.
8. There was a kitchen for parents to store and make their food. ■■■. We also got to talk to other parents, so we didn't feel isolated as everyone was in the same boat. There was also a kids' playroom but we were never in the playroom with ■■■.
9. The nurses' desk also had monitors that showed all the vital statistics and things like that. The monitors showed all of the stats of the kids that were in the ward, so they could keep track of them.

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

10. We had been in Ward 2A for about four to six weeks when we got a letter from the ward sister to say we were going to be moved to ward 6A in the adult hospital. It just said the date the move was going to happen and apologised for the inconvenience. The letter also said that it was something to do with the water and that it was a temporary move.
11. We packed any stuff we had for [REDACTED] the night before, so that it was easier to go the next morning. In the lead up to the move, Ward 2A was getting packed by staff and it was busy.
12. [REDACTED]. Everything was moved out [REDACTED] room and we went along a big corridor, like one of the corridors where normally people coming to the hospital wouldn't get to see.

Experience in the QEUH (adult hospital): late 2018

13. Ward 6A was just like an adult ward, just basically a big long corridor but it didn't have any facilities for parents. It didn't have anywhere for the kids to play.
14. At the time we moved we were told it was only going to be for a couple of months because they were fitting filters on the taps and fixing the issues that were there. It wasn't until we'd been there about five or six weeks that we were told that ward 2A wouldn't be reopening until the year after I think they said.
15. To access ward 6A, we had to use the main entrance to the adult hospital. That was horrendous. The entrance was full of smokers, it was just dirty and there was pigeon poop everywhere.
16. [REDACTED] the other kids were just playing in the corridor with their toys, with their drip stands behind them because there was nowhere for them to play at all.

17. There were no monitors at the nurses' station.
18. We were moved a lot in ward 6A, probably about ten times. [REDACTED]. We got very good at packing as we did it so often.
19. We weren't really given particular reasons for all the moves. One of the reasons one time was that it was to do with a health and safety audit because they'd found that the panels at the back of the bed, where everything plugged in, weren't sealed properly and it was an infection control risk.
20. I can't remember the rest of the reasons but I do remember the domestic coming in one Saturday morning and saying to me that there were moves afoot that day. [REDACTED].
21. There really wasn't much room to move at all in the room in 6A.
22. There were also no beds that folded down from the wall in ward 6A, like there had been on ward 2A. We just got these folding beds, like with the little table on top, like a guest bed. They had to ship new beds in for parents and carers after a few weeks.
23. Ward 6A really wasn't as good as 2A. [REDACTED] when you were trying to sleep at night the alarms would go off all the time. The alarms obviously alerted the nurse but they would take a wee while to get there, so long actually that we worked out how to silence the alarms. The drip would finish and the buzz: the buzz every five minutes would drive you insane. I would press [REDACTED] buzzer, look out to see if anyone was there and then just end up switching it off. I think this was a combination of the fact that the staff didn't have the monitors at the nurses' station and because there were less staff in 6A than in 2A.
24. Ward 6A ran out of dressings several times and had to go and borrow them from neighbouring wards.

25. The food was terrible. On ward 6A we had no access to a parent's kitchen so we had to just eat from the hospital. They would offer you food for dinner but you knew it was going to be awful, so you were really limited.

WATER: EVENTS INVOLVING WATER SYSTEMS

26. When we arrived in ward 2A we were told not to drink the water and were given bottled water to drink. You could wash with it though. [REDACTED].
27. There were filters on the taps in ward 2A, but some of them were just getting fitted when we got there.
28. We'd asked if [REDACTED] could have a bath on ward 6A. Staff said [REDACTED] couldn't have a bath because of the taps. They didn't have any filters on the bath taps in ward 6A at that point. [REDACTED].

CLEANLINESS

29. Ward 2A was much cleaner than 6A. I thought the adult hospital would have been cleaner, if I'm being honest. I even thought that the entrance would have been much cleaner. There were hand gels out and the domestics did clean the room but it wasn't like a thorough deep clean by any manner of means. You were lucky if they were in each bedroom five minutes. That was including the en-suite. It was like a damp wipe down of things. It wasn't anything more than that.
30. When [REDACTED] was in 6A, [REDACTED], they were measuring [REDACTED] urine output. There were a few occasions with the cardboard urine bottles, [REDACTED], there could have be two or three of them sitting full in the bathroom before anybody would come and collect them. At one point they ran out of the bottles so we just had to use just the normal ones that go inside a commode. They

then they ran out of sick bowls as well and again ■ had to use the ones for the commode. ■ .

OTHER ISSUES RELATING TO HOSPITAL CONSTRUCTION

31. I think the ventilation is a problem. The rooms in the hospital are either freezing cold or roasting hot. The thermostats on the walls didn't work so you had no way of controlling the temperature.
32. I just don't understand why you build a hospital and don't build windows that open to let in fresh air. We're all told now with COVID-19 that you're best to meet outside in the fresh air and everything else. Yet you've got a hospital that's hermetically sealed, containing any germ that's in there and can't go anywhere.

THE HEALTH BOARD

33. I think the Health Board have a lot to answer for and I don't think the hospital should have been signed off. There were too many issues like panels needing replaced and windows falling out. The whole place seemed unfit for purpose with scaffolding up, the entrance being closed, dirty, smelly exteriors. There were many contractors carrying out various jobs that really should have been completed.
34. I don't think they'd got through their snagging list. There were a lot of things that were still wrong and hadn't been rectified and I don't think the hospital had been maintained. I also don't think the water checks and the ventilation checks were up to standard. It also smelt like raw sewage outside. You would walk walked outside and all you could smell was that cesspit.

CONCLUDING COMMENTS

35. I pass the hospital a lot and I hate it. [REDACTED].
36. I would never advise anyone to go there; it's a sick building. I feel really let down because we've not had answers. That feels like people are trying to cover things up. I think with that and the water situation, it's a sick building. I don't think it promotes health.
37. I believe that the facts stated in this witness statement are true, that this statement may form part of the evidence before the Inquiry and be published on the Inquiry's website.

Scottish Hospitals Inquiry

Witness Statement of

Mark Bisset

WITNESS DETAILS

1. My name is Mark Bisset. I was born on [REDACTED]. I am [REDACTED] years old. I am [REDACTED].
2. I am the father of [REDACTED]. [REDACTED]'s date of birth is [REDACTED]. She is 9 years old.
3. I live with my wife, [REDACTED] and our five children, [REDACTED], [REDACTED], [REDACTED], [REDACTED] and [REDACTED], in [REDACTED].

OVERVIEW

4. My daughter is [REDACTED] [REDACTED]. [REDACTED] was diagnosed with Acute Lymphoblastic Leukaemia (ALL) on 3 January 2019 when she was 7 years old. She was initially treated at the Edinburgh Hospital for Sick Children (RHSC) between January 2019 and July 2019 before being admitted to the Queen Elizabeth University Hospital (QEUH) in Glasgow on 21 July 2019.
5. [REDACTED] was an in-patient in the QEUH from 21 July 2019 until 20 November 2019 and then she had another short admission in December 2019. She was discharged in December 2019 and was attending appointments at the QEUH until March 2020 before the pandemic hit us. Her care was then transferred to

the new Sick Kids in Edinburgh, when it opened, for her appointments and routine bloods. Her last appointment was March 2021. With the support of my solicitor I have prepared and provided the Inquiry with a timeline (MB/01 – appendix 1) showing the dates on which [REDACTED] attended the hospital and the wards where she was treated. The timeline is attached to this statement and I confirm that it is accurate to the best of my recollection.

6. [REDACTED] spent time in wards 6A, 4B and the Paediatric Intensive Care Unit (PICU). The Royal Hospital for Sick Children (RHC) in Glasgow was closed at this point so we were in the adult part of the hospital where they had moved all the oncology children to.

7. Initially, both my wife and I stayed in Glasgow. [REDACTED] stayed in the hospital with [REDACTED] and I had an apartment at the CLIC Sargent. CLIC Sargent is a cancer kid's charity. They've actually just changed their name to Young Lives Vs Cancer. They help families where their kid is going through cancer. The Glasgow one, I think, has ten bedrooms. So you all have your own bedroom and bathroom. There's a communal kitchen and living space then you have all your kids' rooms too including a Teenage Cancer Trust room and a playroom. Each room can sleep a family of four. In my room I had a single bed, a double bed and a pull-out single bed. When [REDACTED] was really ill, we got a second room so the family could come up and stay as well. There are two floors which are the same but the downstairs has a communal laundry area so you do your own washing. It's set up so that families can wash their own clothes in a sterile environment and don't get clothes mixed up. CLIC Sargent also offer emotional care. There was a psychologist who could speak to [REDACTED]'s brother and sisters. They offer a variety of care to the whole family, not just [REDACTED]. You're in regular contact with the charity and get assigned a social worker but not as you would know them. [REDACTED] would get vouchers for places like Build a Bear and Smyths

Toys. The older children even got a cinema voucher and a meal voucher so that they could go out. It was down the main road, directly opposite Ronald McDonald House, just a five-minute walk from the hospital. We were all given our own key and it was all wheelchair accessible. Initially, my father-in-law moved up from England to look after our other daughters. I had to move back to in October 2019 to look after our other daughters. I can speak to the experience which [REDACTED] and I had on these wards.

8. There are some specific events that I would like to mention. [REDACTED] contracted several infections when she was in the hospital. In August 2019, one of the infections, Aspergillus, was so bad that she was admitted to PICU and we were told several times by Intensive Care staff that we may lose her. We found out from the Case Note Review though that [REDACTED] had also contracted Putida Pseudomonas while she was in the hospital and she spent a week in the Sick Kids on antibiotics for this. There were issues with the building and the water supply during [REDACTED]'s admissions. I believe [REDACTED] was prescribed preventative antibiotics in 2019 which may have been connected to the issues with the water. I believe the issues with the water and the building that were present at the time, impacted [REDACTED]'s experience. I will come to talk about these issues in more detail.

FAMILY BACKGROUND

9. I live with my wife, [REDACTED] and four of our five children in [REDACTED]. [REDACTED] is the youngest. [REDACTED] is [REDACTED] years old, [REDACTED] is [REDACTED] years old and [REDACTED] is [REDACTED] years old. [REDACTED] is [REDACTED] years old but stays in his own place.

10. [REDACTED] gets on with her brother and sisters really well. When she was on the steroids, there were times where it seemed like she had roid-rage and she used to take it out on the older ones, so they copped it quite a bit. [REDACTED] is closest to [REDACTED] and [REDACTED] I would say out the four of them. [REDACTED] likes Harry Potter, she's a bit obsessed with that just now and she likes art. She's doing a lot of painting and stuff at the moment. Tik Tok, she's obsessed with that too like every other kid is. When she grows up she did want to be a nurse working with kids who have cancer but I'm not sure what she wants to be now. She changes her mind as much as the weather changes in Scotland. The main one was a nurse though. She likes football, you don't get a choice in this house. We are all Rangers daft, it's Rangers or nothing. She's a wee teddy bear supporter. She's been at a couple of games with me and is desperate to get back to it. Art is her main thing and playing football with the boys out the front. She plays with all the kids in the street but she drifted apart from her school friends due to her not being there so she's trying to build those friendships up again.
11. [REDACTED] is in primary [REDACTED] and will be going in to primary [REDACTED] after the summer. She attends [REDACTED] Primary School in [REDACTED]. [REDACTED] likes school but they all do at that age. It's when they go to high school that it changes.

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

Initial Admission to Royal Hospital for Sick Children in Edinburgh: July 2019

12. [REDACTED] was diagnosed with ALL on 3 January 2019, when she was 7 years old. We had been back and forward to the GP since she first took ill in November / December 2018. The GP thought it was Tonsillitis. One thing led to another and

the antibiotics hadn't been working. The GP sent us to Borders General Hospital on 3 January 2019, where they did a few tests and gave an initial diagnosis of Acute Lymphoblastic Leukaemia (ALL). That same day 3 January 2019, [REDACTED] was taken by ambulance to the Sick Kids (RHSC) in Edinburgh. They confirmed [REDACTED] had ALL.

13. [REDACTED] first went into the Royal Hospital for Sick Children (RHSC) on 3 January 2019 where she was admitted to ward 2. We spoke to Dr Susan Baird and Mark, but I can't remember his second name. They both said that [REDACTED] would go on a certain treatment for four weeks and this treatment is used for every child that's got leukaemia at the start. It's like a baseline treatment and it doesn't matter if you're based in Glasgow or St Ormond Street, this is the treatment that they start you with. After two weeks, they take some bone marrow and check it then they do the same again after four weeks. After the four weeks of treatment, the doctors assess the individual treatment for each child depending on how those four weeks have gone. The first lot of chemotherapy didn't work for [REDACTED] so after that, she was placed on a treatment called Regime C which has all the different chemotherapies in it and is quite an intense treatment. This was because after the first four weeks, her leukaemia levels hadn't gone down. The blocks of chemotherapy always used to last for four weeks with a test at two weeks and another one at four weeks. After four weeks of Regime C, they started talking about [REDACTED] needing a bone marrow transplant so this would be roughly the end of February that they were already checking the registers for suitable donors. You were never given anything relating to the treatment path that would show where [REDACTED] would be in six months-time from the start of treatment.

14. [REDACTED] still had to go in two or three days a week for chemo and we were giving her chemo, orally, at home. She kept going back as an out-patient

because she got temperatures and then she got re-admitted to ward 2 in February because she was poorly and was getting a bone marrow aspirate.

15. Every two weeks for about the first four months, [REDACTED] was getting surgery to have bone marrow taken so the doctors could see how she was responding to the chemotherapy and because it wasn't working, she went on to take a course of Blinatumomab for 28 days in May 2019 and this brought her levels to zero but it doesn't kill the cancer. It just manages her levels so that if a donor came up, she was good to go. We were told that a suitable bone marrow donor had been found around mid-July of 2019.

Transfer to QEUH for Bone Marrow Transplant: July 2019 - December 2019

16. We got appointments to go to the QEUH in Glasgow on 10 and 11 June 2019 because they had found a donor. The QEUH is the transplant centre for Scotland. They can't do the transplants in Edinburgh, Glasgow is the only hospital in Scotland that can do the transplants. We could have gone to Newcastle but Glasgow had availability and we thought she would be nearer home. [REDACTED] stayed at the hospital for these two days for various tests. The tests on the first day were just all blood tests to check her levels and see if she was good to go for the transplant. The second day, it was psychological tests she had to do. She had to do puzzles and maths, just stuff that she had to work out. It was to check her brain function at that time as they knew she was going for full body radiotherapy to get her ready for transplant and that can affect and damage the brain. It was to monitor and compare her from that point until she had finished the radiotherapy so they could see if her memory or anything else was affected.

17. It was during these appointments that we also visited the Beatson Centre. The Beatson Centre did radiotherapy. I don't know all of what they do there but [REDACTED] was there for radiotherapy. When we first went over, the staff at the Beatson explained everything that was going to happen to her and how they were going to do it. They told us what the radiotherapy was needed for and they told us about a certain bed and a certain way she has to lie, then she would need to turn over, so it was all explained to [REDACTED] stage by stage before she got the treatment.

18. We also met Professor Gibson on those days who told us that providing everything went okay with [REDACTED]'s transplant, she would be home within eight weeks.

19. On 21 July 2019, we went back up to the QEUH in Glasgow and [REDACTED] was admitted as an in-patient to ward 4B. This was a transplant ward. She was there to receive her bone marrow transplant. Some of the other kids there also needed the bone marrow transplant and in fact, I think some of the adults there were bone marrow transplant patients. As far as I knew it was a transplant ward for adults and children.

20. Staffing levels in there were poor. Staff were overworked. They were constantly running about daft. You felt sorry for them; every single day they looked exhausted.

21. [REDACTED] was in a room in the far-right corner. She had been in a few rooms in 4B, but I cannot remember when she was in this corner room or moved between other rooms. As you went into the room, you had the sink on the left-hand side for the doctors and nurses. Your bathroom was in the right-hand corner and it was quite a big bathroom. The bathrooms were all wheelchair

accessible. [REDACTED]'s bed was on the middle of the wall on the left-hand side of the room and the parent's bed was at the other side of it in the corner. The parent's bed was a z-bed. Not an old fashioned one but it was the same kind of thing, a fold out bed. Some of the other rooms on the ward felt smaller as I couldn't get round as easily with the wheelchair.

22. On 22 July 2019, [REDACTED] began treatment for the bone marrow transplant which was successful. She had full body intense radiotherapy for ten days as well as intense chemotherapy so she was back and forward to the Beatson Centre twice a day for four days. [REDACTED] was transported to the Beatson Centre in a taxi used by other members of the public.

23. The taxi was arranged by the hospital but it wasn't a private hire one. Sometimes, depending on traffic, it could take half an hour to get to the Beatson Centre and that was longer in the taxi. I didn't agree with this as anyone could have been in those taxis and there was a risk of infection to [REDACTED].

24. [REDACTED] had her bone marrow transplant on 1 August 2019. The marrow transplant isn't what you think when you first hear about it. It wasn't what I thought it would be either. It's like a blood transfusion; it all comes in a bag. You think it's a bigger thing than it is, you build it up but it's just like a transfusion. [REDACTED] had it carried out in her room, and it's done via a drip, and she was awake for it. It only took about an hour and a half. During this time and after, would have to stay her room, in isolation due to infection risk. [REDACTED] didn't come out of isolation though as she ended up in intensive care.

25. On 10 August 2019, [REDACTED] started to deteriorate with breathing problems and on 18 August 2019, she was transferred to intensive care after their doctors

had been in to see her. She was put on 3 litres of oxygen at this point which is quite a lot. They didn't initially know what was causing [REDACTED]'s breathing difficulties.

[REDACTED]'s admission to PICU for infection: 11 August 2019 – October 2019

26. [REDACTED] was originally put on high flow oxygen on 18 August 2019 in the PICU as her levels were low. They were monitoring her in there as it was better than her being on the ward. On 19 August, her breathing was really bad so she was put on the ventilator that morning. It was PICU staff that were providing her care but she would also be visited by the oncology staff from ward 4B in the morning. She was under PICU care but oncology still came in to monitor the situation. They just came in and had a look at her, checked with the PICU nurses what her levels had been like during the night, then they would just leave.
27. The intensive care unit was in the children's hospital. PICU I think they called it. Paediatric Intensive Care Unit so it was in the kid's hospital itself. She was always in her own room. There were some bits of PICU that had four or five beds but [REDACTED] had always had her own room as she was still post-transplant with no immune system.
28. [REDACTED] had already been on a couple of antibiotics when she was in ward 4B but in PICU she was on about 17 different medications. Oncology doctors would maybe suggest changing the antibiotics but that would be all you were told from the oncology side of things. The whole time [REDACTED] was in PICU, we only saw Dr Gibson twice. It would be her team that came in so, Dr Annmarie Ewins, Dr Sarah Pickles and Dr Pinto.

29. When [REDACTED] was first admitted to PICU, we were told it could be adenovirus that she had which affects the adenoids or graft vs host disease. Professor Gibson was who spoke to us first about adenovirus around the time when [REDACTED] was admitted to intensive care. She said that it was found in [REDACTED]'s stool sample and was causing problems, and that they would treat it with antibiotics. She did not explain where [REDACTED] could have contracted it. I overheard two PICU nurses talking about [REDACTED] having aspergillus as well on 21 August 2019 but I had only been told it was a fungal infection that had.
30. On 22 August 2019, we were told to bring our family in as it wasn't looking good for her. She was given a T-Cell Treatment, Toxic T-Cell as it's called, to treat the adenovirus on 28 August 2019. The T-Cell treatment is when they take people with certain illnesses, so someone that's had adenovirus they would take the blood from the person that's had the virus and supersize it and then give it to [REDACTED]. As the blood from the donor has already had the virus, it attacks the virus in [REDACTED]. It was a hospital in Germany that did this. We went to the apartment at CLIC Sargent that night. Early the next morning, we got a call to say [REDACTED] had had a massive bleed on her lungs and again, we were told to get the family in. They took bloods from [REDACTED] and I think it was at this point it was confirmed she had aspergillus in her blood. I'm not sure what caused the bleed but I think it was the aspergillus.
31. There were two main consultants looking after [REDACTED]'s care. There was a doctor called Cheryl but I can't remember her second name and a Dr Chris Kitson. Dr Kitson moved [REDACTED] from the ventilator to the oscillator ventilator on 1 September 2019. This is the one where they turn her on her belly and shake her to try and loosen any blood that was clotted in her lungs as there would've been dry blood. It didn't get a response.

32. On 2 September 2019, we were given a private room in intensive care because we had to decide if we were going to switch the machines off due to the effect the aspergillus had had on [REDACTED]'s condition. The doctors at QEUH had contacted doctors in Rome and Germany as [REDACTED] was in such a precarious state. They'd been talking about an ECMO ventilator, where it takes the blood from your neck, puts oxygen into it and pumps it back into your body but they advised that the chances of her surviving that were very slim due to her condition being high risk and there was more chance of putting even more infections in her body than she already had. The way it looked for her was there was no hope. Another intensive care doctor stepped in last minute and gave her a massive dose of steroids for a few days to see how she responded and thankfully, that's what saved her.
33. During [REDACTED]'s time in PICU, the doctors would do ward rounds where about twelve people would come in the room. There were four or five doctors from different specialisms then you had the trainees coming as well so it was quite intense every morning when they had the ward round. There was a pharmacist, an anaesthetist and I think the rest were consultants. The ward staff would tell the nurse what was decided after the ward round had been completed.
34. [REDACTED] was in intensive care for about eight weeks in total. I think it was mid - October that she was discharged from PICU as I remember her being back on ward 4B for Halloween. On ward 4B, [REDACTED] had to learn to walk again due to spending so long in intensive care and on ventilators. When she came out she couldn't walk or even wave due to muscle wastage. She went from not being able to walk to being able to use a zimmer frame. They had a table they would put her on and it would flip up and it was to help her body stay upright. It would help move her a certain way to get the blood flowing where it needed to go.

35. She was still getting antibiotics for a few weeks when she came back. [REDACTED] was there until 20 November 2019, getting intense physiotherapy twice a day before she got discharged to the CLIC Sargent. I can't remember the exact date she was discharged home but it was near Christmas so between 20 and 22 December 2019. [REDACTED] was walking with the zimmer frame at Christmas. She was still getting physio three times a week until Covid hit.
36. [REDACTED]'s treatment was only meant to last for 8 weeks but because of the adenovirus and the aspergillus, we were there for months rather than weeks. After the bone marrow transplant, there was no further chemotherapy needed, that was it. Follow up treatment was bone marrow aspirates and blood taken. She's only just now stopped going every two weeks to get bloods being taken to check her levels. [REDACTED] is due back in Glasgow at the end of this month (July 2021) as she will be two years' post- transplant so they'll do a full blood count and check her levels. They check what percentage of the bone marrow is the donor's and how much is [REDACTED]'s own bone marrow. That's her at the end of it now. That's her kicked its butt.

Experience on Wards 6A, 4B and PICU: July 2019 – December 2019

37. We weren't allowed to use the adult amenities on ward 6A at the time. We were just told the kitchen was out of commission. The kitchen had a microwave, kettle, fridge and there was a table and chairs in it. It was situated at the top of the ward. There were signs up saying it was closed for building work. The hospital rooms next to it were sealed off as well. I don't know what was being done though. Nine times out of ten when you went up to ward 6 there were at least three rooms always sealed and taped up with polythene sheets. The parent room was closed due to the number of families being told to stay in their

rooms, rooms constantly being sealed off as well as the never-ending repairs being done around the ward, so that was bad. On ward 4B there wasn't actually anywhere you could go to prepare stuff, and that's where █████ spent the majority of her time in the hospital.

38. They didn't have the parent room on ward 4 because it was an adult transplant ward. There weren't any amenities for you on that ward. █████ was in isolation due to her getting a transplant so she wasn't allowed out of her room. There wasn't really anything for her to do either so we brought stuff in for her. Although the hospital food was disgusting on ward 4, you got a cup of tea if they remembered. I had a good relationship with the folk that did the tea trolley and if it wasn't for that you wouldn't have got a cup of tea. It was like the children's bit at the bottom of the ward wasn't included in their tea round because we weren't meant to be there.

39. I think the hospital has to have a look about the amenities long-term going forward, for other families. Most children have two parents and it's like an afterthought that only one parent gets food. You don't want to leave your kid at the worst of times but the fact that there were no facilities meant you didn't go looking for food because you didn't want to leave your child

40. During █████'s time in PICU, she was moved rooms several times. She was also moved rooms in ward 4B.

41. When █████ was in ward 4B for her transplant, there was nothing for her to do. She wasn't allowed out her room due to risk of infection during the treatment. It was an isolation room she was in, which was essentially the same as any other room on the ward, except it was slightly bigger. When I went in to see her in the morning, I had to leave everything outside the room, my trainers, my jacket etc.

You had to scrub down before you went in too. I had to wipe down my chair with antiseptic wipes before I got in. It was meant to be the most sterile environment possible as [REDACTED] had no immune system at that point. Once you were in the room, that was it. You couldn't come and go. Some of the charities used to come round, some would be dressed as superheroes but they weren't allowed in [REDACTED]'s room, she just had to watch them through the window. There was a telly but it didn't really work. Channel choices were poor, not as many kids channels. CBeebies was about it and she was a bit old for that.

42. There was nothing for parents on 4B either. You would get offered a cup of tea once or twice a day and that was it. There was nothing. There were rooms available where you could go and get a cup of tea but we couldn't as [REDACTED] was in isolation. There were no kitchen facilities either.

43. The ICU was brilliant, you had the kitchen there that you could use as much as you want, you had the family waiting areas, there was everything. My family are all from [REDACTED], it's a long way to come so when they were coming up it wasn't just for a half hour visit, so the facilities in the ICU were far better.

44. We got a call from ward 4B, after [REDACTED] had been in intensive care for only a couple of days, telling me I had to come up and empty [REDACTED]'s room. We'd been told to get family up as she was so poorly yet they wanted the room emptied.

45. [REDACTED] was never out of her room on ward 4B. She had constant diarrhoea so between that, her having fevers and being on antibiotics, she couldn't always make it to the toilet.

46. The food is disgraceful in the Queen Elizabeth, we wouldn't have had any other option if it wasn't for the Marks & Spencer's and the McColl's in there. Only one parent is allowed a meal so whoever was staying got a meal and whoever was with them had to fend for themselves somewhere else. When me and my wife stayed we didn't eat the food anyway. Some of the food they served up, honestly it was disgusting, you could give it to a dog and the dog wouldn't even eat it. The choices were limited. They would come around and give you choices and you could guarantee that in the next three days, it would be the same choices again. It was repetitive.
47. When [REDACTED] made her recovery in intensive care, oncology doctors wanted to move her straight up to ward 6A and I said no, because of the way I had been treated in ICU by the oncology doctors, the fact that I'd lost trust and faith in them and the fact that when I'd been to ward 6, I'd always seen rooms sealed. I think [REDACTED] had contracted the infections she had on ward 6A because of the constant room switching due to cleaning or repairs needing to be done, as well as the flooding there was on the ward. These things would not be happening on a clean ward. She had just fought for her life and the family had been called in five times to say goodbye. Bearing that in mind as well as the stuff about the infections appearing in the media, I didn't want [REDACTED] going back to ward 6A and I told Dr Ewins this. None of the adults on ward 6A appeared to be getting ill, just the children. I was willing to take [REDACTED] home rather than have her go to ward 6A. I don't want to get anyone in trouble but some of the nurses on ward 4B said they were fully behind me because they didn't want to go back to ward 6A either. It wasn't just one or two; it was the majority of them that said that off the record. One of the nurses said to me if I went to Professor Gibson and tell her I thought it was wrong to transfer [REDACTED] back to ward 6A, that she would come with me. The nurse was against [REDACTED] being moved up there. She was

fighting for █████ not to go to ward 6A. She didn't say why; she was just adamant that █████ wasn't going. The nurses were scared to say anything in case they go into trouble though. Ward 6A is separate to ward 4B. Ward 6A is generally the adult ward but they have a lot of the same staff. These were Schiehallion nurses that I had been speaking to.

WATER: EVENTS INVOLVING WATER SYSTEMS

48. We arrived on 21 July 2019 on ward 4B at the QEUH for █████'s transplant. It wasn't until we'd been there a few days we realised that every tap had the big grey filters on them and the showers had filters on them. It was hard trying to wash your hands because you couldn't get your hands into the wash hand basin because of this big massive thing on the end of the tap. I asked what they were and I was told they were filters. The porters checked the filters over regularly and changed them every three or four weeks. There were filters everywhere, no matter where we were, they had them in intensive care, ward 4B, ward 6A, ward 6B day care, everywhere you went they had these big grey filters.
49. We never used the water to drink but █████ was using it to brush her teeth and me and my wife were washing our hands and showering with the water. █████ was showering with that water too. We just assumed that █████ couldn't drink it due to her situation but washing her hands and everything was safe so I didn't think there was any problem with it.
50. When █████ got discharged from ICU and sent back to ward 4B again, she had to move rooms because the toilet in her room blocked. I can't remember what room; it was further up the corridor.

51. When [REDACTED] was admitted to ward 4B on 21 July 2019, we were shown to our room by a nurse. The first thing she said to us was that if we wanted a drink of water, not to take it from the tap but to ask them first and they would get us fresh bottled water. She never gave us a reason for it, we just put it down to the fact that it was a transplant. I never thought anything by it at the beginning, we thought it was because the water was treated, and it was sealed bottles.

52. The first I knew there was a problem with the water was through the media. I either read it in the newspaper or saw it in the news. And then we got a press release statement that they were going to be giving out to the media but you usually got it after the media had already reported the information. Dr Gibson handed us the press statements that were going out to the media from the hospital. She had to hand it out to all the parents. It was just a print-out, nothing else. The only time we ever got one of the press releases before the story appeared in the press, was if it was a response from the hospital regarding the issues. The first statement we got was when [REDACTED] was still in ward 4B, before she went to intensive care, so that was late July or early August 2019. Then it was on BBC Reporting Scotland, I can remember seeing the cameras outside the hospital. I did ask Dr Gibson about it but all she said was that it was an ongoing situation and the press statement was in response to some of the questions that the hospital had been getting asked.

HEALTHCARE ASSOCIATED INFECTIONS

53. When [REDACTED] was admitted to PICU, we were told by oncology doctors that it may be graft vs host disease or adenovirus that was causing her breathing problems. I was then told that she had a fungal infection but no further information. It wasn't until we were in intensive care around 21st of August

2019 that I overheard one of the ICU nurses during a shift handover saying “And she’s also got aspergillus”. I interrupted them and asked if that was the name of the infection that [REDACTED] had and if it was a fungal infection. One of nurses confirmed it was. Before that, we had never been told the actual name of the infection, all we were told was that it was a fungal infection by oncology doctors. I went home and researched it and quizzed Dr Anne-Marie Ewins the next day. She told me “it might just be a contaminated sample, no guarantee but we’ll treat her anyway”. All we got from the oncology team was “it’s a fungal infection”. [REDACTED] had a BAL done, which is the suction tube that’s down the throat, to get samples. It came back then that she had aspergillus in her lungs. It was Dr Ewins that told us about the results of the BAL.

54. On 29 August 2019, when [REDACTED] had the massive bleed on her lungs, they did blood tests and that’s when it showed the aspergillus in her blood. I found out about the aspergillus after I heard one of the nurses, Kirsty, talking about [REDACTED]’s aspergillus outside the room with another nurse during a handover. I asked her about it, and she told us that [REDACTED] had aspergillus. One of the PICU doctors, Cheryl, then came and spoke to me and my wife. She explained that the test had found aspergillus in her blood, and that for the aspergillus to get into her blood, it had to have been through her lungs. She also explained that the aspergillus was the cause of [REDACTED]’s breathing problems.

55. The contaminated sample Dr Ewins told me about came from [REDACTED]’s lungs so the aspergillus had to be there the whole time. I had been asking the oncology doctors about the aspergillus but I wasn’t getting any answers. It was actually the intensive care doctor, Cheryl that told me about the results. She had a one to one with my wife and I and told us about the aspergillus. [REDACTED]’s bone marrow treatment was meant to last for eight weeks but she was in hospital for

months. I have no doubt in my mind that she was admitted for so long because she contracted the aspergillus.

56. [REDACTED] was also on steroids to try and kick start her lungs. Staff would do a mobile X-ray on her every morning to check her progress. She also got physio on her chest which looked quite aggressive but this was to try and loosen the dried blood in her lungs. They would do this three or four times, sometimes twice a day. They would suction her after this to remove anything that had come loose and put a bag on her that they would manually have to work as she was off the ventilator when this was going on. You could tell if it didn't work by looking at the bag they were using, you would be able to hear the wheezing from it. They would do this until the noise coming from the bag was clear.

57. Originally, the impact of the infections left [REDACTED] fighting for her life. It was literally four or five times we had to get the family in to say goodbye because it was looking like she wouldn't make it through the night, the treatment had come to an end and nothing else was going to work.

58. There were two or three things the oncology Doctors did when [REDACTED] was in intensive care. [REDACTED] had a bad rash, her eyes swelled up and her face was swollen, you wouldn't recognise her. Oncology doctors kept saying they thought it was graft versus host disease, but they could never be certain. Dr Anne-Marie Ewins came in one day and looked at [REDACTED] and said "She's looking good this morning" and then she left. The intensive care nurse, Kirsty, turned to me and my wife [REDACTED] and said, "Is it just me or do you think [REDACTED] looks worse this morning? Her eyes are all swollen again". So, Kirsty the nurse pulled her sheets back and [REDACTED]'s body was covered in a rash from top to toe. Bearing in mind Anne-Marie had been in ten minutes previously and said she was looking really good. [REDACTED], my wife, said to the intensive care Doctors, when

they came in, that they had to go and get oncology back because they said that she was looking great and quite clearly she wasn't.

59. This is when I really lost the trust in the oncology doctors because when Anne-Marie Ewins came back she said in front of the nurse, me, my wife [REDACTED], "Oh she seems to have deteriorated in the last half hour". She said that rather than admit she had made a mistake. That rash just doesn't appear in thirty minutes. That was it for me. It was like they were trying to hide the aspergillus, and at the same time not speak to us about it. I think they maybe didn't tell us the name of the fungal infection because of the stuff in the press about the water and the ventilation. [REDACTED]'s discharge letter didn't mention aspergillus, it just described it as a "fungal infection" and didn't name it specifically. I felt that oncology always seemed to dance around the subject of infection, they were not giving us honest answers. Nurses and intensive care doctors were the only ones giving us the full picture.

60. I think [REDACTED] caught the aspergillus in ward 4B. She hadn't been out in the community; she wasn't even outside. From the end of her treatment at the Beatson Centre, that was it, she was never out of her room on ward 4B. When first took ill with the infection, she had constant diarrhoea, she had a fever and between that and having antibiotics she couldn't even get to the toilet, we had to put her in nappies for months because it was that bad.

61. The adenovirus has been fine with long term effects, it's the aspergillus and the fact she had to get high dose steroids to save her that's left her adrenal insufficient. An intensive care doctor, I can't remember their name, told us that the steroids were likely to leave [REDACTED] adrenal insufficient when she was in the PICU. It wasn't until we were back on the ward in mid-October that we met with the renal team, and they confirmed that [REDACTED] was now adrenal insufficient

because of her treatment with high dose steroids. Now her body doesn't produce adrenalin and we have to give her three doses of steroids every day. If she falls or breaks something we have to give her an injection straight away. Her body goes into shut down because it can't handle shock. If we go into shock, the adrenal gland kicks in but with [REDACTED], it wouldn't and it can lead to organs shutting down. That's all a direct result of getting high dose steroids because of the infection she caught.

62. That's almost been two years and she's still on hydrocortisone every day to keep her going. The school had to be trained about the injection before they could let her go back. She only goes two and a half days a week because she gets tired so easily. This has changed in the last week, her body has kicked back in. Results from her last test show her body is now working. They trick the body into thinking it's ill so the adrenaline kicks in.

63. In my view, due to all the building work, the ventilation and the water supply were affected, and this had an effect on [REDACTED]. When you Google Aspergillus in a hospital environment, it can only come from ventilation, water supply or from building work. I saw it with my own eyes with the filters and being told not to drink the water. It's meant to be a sterile environment and workmen are in and out in work clothes.

PREVENTATIVE MEDICATION

64. Since she had been in on 21st of July, [REDACTED] had been on posaconazole and she had to get antibiotic treatments for fungal infections. [REDACTED] didn't have a fungal infection at the very beginning. It was Professor Gibson that said it was part of the treatment plan, to use posaconazole as [REDACTED]'s body would have no immune system during the bone marrow transplant process. She was put on

two or three anti-fungal antibiotics for it. She was already on posaconazole and then they put her on Gentamicin and fluconazole was the other one. She got all her medication intravenously.

65. ██████ had really bad diarrhoea with the antibiotics she was on. They thought it was maybe due to her TPN at first, that's a feed she was on at some point.

Preventative medication: communication

66. When we met Professor Gibson at ██████'s appointment on 10 June 2019, she did say that ██████ would be put on antibiotics during her transplant and this was to protect her. She told us that due to the full body radiotherapy, ██████ would have no immune system so she would be on a few different antibiotics to protect from things like pneumonia. You go along with what you're told as they're the experts. You believe it's part of treatment. None of the antibiotics were referred to as anti-fungals.

67. All the parents we've been speaking to, said their kids were on it. It was Glasgow parents we had been speaking to as ██████ had never needed posaconazole in Edinburgh plus it was Glasgow that was in the media. No other country gives this treatment and this has led us to believe that it was because of the hospital environment that ██████ was on the posaconazole, so it was preventative rather than 'must need'. I found this out through the media and from talking to other parents.

68. I asked Dr Anne-Marie Ewins why ██████ was on the posaconazole and we were told it was part of the treatment plan, that was all we kept getting told no matter when we asked. We were told that by Dr Pinto as well. When I challenged them saying it wasn't part of the plan they kept saying, "it is for this

hospital and that's how we do it". I had been doing my own research and had learned that posaconazole wasn't a standard as part of treatment. I had started doing my own research and speaking to other parents when things started coming out in the media about the ventilation and water.

OTHER ISSUES RELATING TO HOSPITAL CONSTRUCTION

69. When [REDACTED] was in paediatric intensive care, she got moved rooms three times, due to flooding in the room and electrical failures. The water came up from the floor at the wash hand basin. That was room 12 we were in at the time, she had been there for a couple of weeks. I remember that the room directly beside her also got flooded and it had to get sealed up for the workmen to work on it. The girl that was in that room got moved as well. I don't know her name but I think she was a young teenager. From there, [REDACTED] got moved to room 17 and she had to be moved out of there after a few days because the electrics failed on the pump stack systems.

70. At that time, she was on between 15 and 19 medicines at a time so we needed the stacks to be working. There wasn't enough power to get the drivers to work to get the medicines through. They had medicines lying on the bed because the pumps weren't working and they had them plugged into other things. The pumps administer all the different medicines at all the different rates required and times. They were powered by a big control system that hangs over the bed. Room 12 had been fixed so [REDACTED] got moved back there. It was fine by then. Then [REDACTED] got moved from room 12 to room 18 but [REDACTED] and I can't remember why she got moved. She was awake by then but still on the ventilator. She was there for a couple of weeks and eventually discharged from that room back to ward 4B.

71. Although the building works didn't directly impact [REDACTED], we were worried that any of the infections we had heard about in the press could be airborne and the building works would cause them to spread.
72. You can smell the sewage in all the rooms coming through the sinks, you smell it every day in the hospital.
73. All the building work – everything kept failing during [REDACTED]'s time there, it's disgraceful. I know it's not years old but some of the things that were wrong with it, like the water situation – not to drink the water – it's just that I've no confidence in it at all. I told them that if I could have arranged it, none of the treatment would have been done there, it would all have been done in Edinburgh. The old Edinburgh hospital, I had 100% confidence in the place and it was an old, old hospital, and I also had 100% confidence in all the staff, whereas in Glasgow, Dr Anne-Marie Ewins has made me lose confidence in all the doctors because of her behaviour in intensive care. The management of the place and refusing to speak to me speaks volumes of the hospital. Not a pleasant experience at all from start to finish.

CLEANLINESS

74. [REDACTED] had only been in ICU for a couple of days and bearing in mind we had been told to bring the family in because we were maybe having to say goodbye to her, when I got a phone call from ward 4B telling me to come up and empty [REDACTED]'s room because they needed it. Prior to [REDACTED] going down to PICU on 18 August 2019, she had been vomiting and had diarrhoea. When my wife and I went up to empty and clean the room on Wednesday 21 August, the vomit bowls were still lying about. There was a diarrhoea nappy on the bed. There

was sick in the bathroom. There was somebody's lunch lying on the fold-out bed. It hadn't been cleaned since we had left. The meal plates were still lying there with food on them.

75. In our room they didn't brush the floors, they used pads with wipes attached to them and these don't clean the room, all they do is move the dust and rubbish from one side of the room to the other. They cleaned the sink and the bathroom but they never cleaned all the equipment or the shelves or back wall. Whenever we went into the ward we had to remove our outdoor jacket and shoes and by the time I got home at night my white trainer socks were black and that was off the floor that was meant to be cleaned twice a day. This was in every room we were in, in the hospital, although the equipment was cleaned better in intensive care.

76. The biggest clean that I'd ever seen on ward 4 was when somebody from high up in the Government was coming to see it because of the concerns that had been raised in the press. They basically stripped and cleaned two rooms, they took everything out the room and cleaned it from top to bottom for the Government to come and see them. I can't remember when the visit was.

77. It was around about the time of the visit though that we noticed the cleanliness efforts being stepped up as well during that time. The rooms were getting cleaned more intensely than they had been. It went from cleaning the sinks and mopping the floors to wiping everything, and I mean everything in the room started getting wiped with alcoholic wipes. The nurses had to change every time they came into the room, gloves on, aprons on. Everything got stepped up to a higher level than it was before. That was when one of the nurses said there was a problem with ward 6 and because they worked between ward 6 and ward 4B, this was why it had to be done.

78. The way they transport kids to the Beatson Centre isn't clean either. You have kids that have had transplants or are getting them so have no immune systems, having to use public taxis to get from the QEUH to the Beatson Centre. Anyone could've been using the taxis. The ward is meant to be sterile, I'd have thought they should've had their own transport for this.

OVERALL EMOTIONAL IMPACT ON [REDACTED] AND HER FAMILY

Overall emotional impact on [REDACTED].

79. Mentally, the admission in ICU due to the infection has left [REDACTED] with a lot of scars, even now she wakes up with nightmares, and she can hear the machines beeping. She's only just started talking about being in intensive care and although she was on medication and was asleep, she can remember parts of it. Although she goes to school, she's scared to play in case she hurts herself and she needs the injection because she's been left with a fear of needles. She panics about that but thankfully we've only had to give her the injection twice since she's come home.

80. Due to the length of time [REDACTED] was in the ICU, she had to learn to walk again and she found this really hard. She had to use a wheelchair as she couldn't stay on her feet for too long and she would use a Zimmer frame too. She was quite angry for a stage and was quite aggressive towards the physios.

81. She worries whenever she's ill now too, even if it's just a cold. The whole process has had an emotional impact on her.

82. [REDACTED] still has nightmares every second night about the beeps and the machines. She panics every time she feels ill in case the cancer's going to come back and that she'll end up back in Glasgow. We're only getting this out of her now, it's taken a while for her to open up. We're still waiting to hear from Edinburgh about child psychologist appointments. Mentally, she's really struggling.

Overall emotional impact on witness

83. The emotional impact on the family has been huge. My mental health has suffered; I've been on three different antidepressants since we came home. I have serious depression and anxiety; I can barely leave the house. I got a phone call this morning from the Doctors wanting me to try cognitive behaviour therapy. I panic every time [REDACTED]'s at school because anything could happen because of her being adrenal insufficient. I don't sleep very well; my wife [REDACTED] seems to be the only one that can deal with it.

84. Those four months that [REDACTED] was in intensive care were the worst four months of my life. As well as worrying about the cancer, you had the infections to worry about too and her fighting for her life. I don't want anyone else going through this or for us to ever repeat it. Yes, she may have gotten the infection in any hospital but she had to fight for her life because of something she contracted at the hospital.

Overall emotional impact on family members

85. Initially my wife moved to Glasgow to be with [REDACTED] and I moved to the CLIC Sargent house because the treatment was only meant to last for six weeks and it would be easier than travelling the hour and a half every day from [REDACTED].

My father-in-law came up from England to stay with the girls while [REDACTED] and I were both through in Glasgow. We didn't see our daughters or son for 4 weeks. I had to move home in the October as our other three daughters were struggling mentally with not seeing me or their mum. Even though my father-in-law was staying with them, they needed us so it was the right thing for them for me to move back.

86. When [REDACTED] was really ill in intensive care, all the family had to come and stay at the CLIC Sargent for a few weeks. We were told about five times that she wouldn't make it.

87. My second youngest daughter has missed a lot of school with everything that's going on because we had to bring them up to Glasgow, she's missed a massive amount of school to be honest. My other daughter has quit school altogether. My son has split up with his partner because of everything that was going on and his state of mind was that bad as well, he's now severely depressed. He doesn't see his two-year-old.

COMMUNICATION: GENERAL

88. The communication from the hospital isn't adequate, it needs to be handled differently. I think the hospital should have tried to keep you up to date with any works that were going on in the rooms next to you to try put you more at ease. When rooms were getting sealed off, you were never told what was happening, just that there was something wrong with the room. It was never just one or two rooms either, it was a lot of rooms all the one time. Unless it involved your room, you never knew why the others weren't available. Even if they had a patient representative on the Board, someone who could deal face to face with families and media, the press statements were all we received.

89. In ward 4 where your kids are getting a transplant, you didn't have any representative coming to see you. You didn't get kept up to date with what was happening or the fact she was taken by different taxis to the Beatson Centre. I think that should have been handled better. I feel there should be someone designated to explain this a lot better and take you through rather than just tell you your taxi is here. Sometimes it was a nightmare to find the taxi outside the hospital. It was like a free for all. At the Beatson Centre though, you got a text telling you the taxi was here and the registration details etc. The first week, you were just left to it. It wasn't handled properly. They need a representative that can explain everything to you, even if they had patient transport instead of taxis, that would have made a difference. A single point of contact would have better to raise concerns with rather than just whoever happened to be there.
90. The communication was very poor, there was no explanation given for anything. There was nothing said by the hospital about the water supply, not even a press release from Professor Gibson. If it wasn't for the fact that it was on the news, you wouldn't know that this was going on and that certain antibiotics were being used for certain things. To find out that your daughter is at risk in this hospital through the news that night is unacceptable. You're living it at the time, surely it should be communicated to you as a family rather than finding out second hand in the news. We've never heard from the hospital management at all.
91. In relation to [REDACTED]'s care in intensive care, the communication with all of oncology was very poor. You got a five-minute visit every morning and that was it, you never saw the doctors again all day. It was as if they weren't interested because she was in ICU now. As I said, I lost all faith with the Doctors in oncology because of the way they were dealing with [REDACTED]. I've still not had an

apology to this day from hospital management and I've still not spoken to any of them directly. No matter how much I chased any of them down or phoned I've still not had a face-to-face meeting or a zoom meeting or a phone call with any of the hospital management.

92. The actual intensive care Doctors and nurses were amazing; I can't fault them. The Doctor, Cheryl was her name, was really good. She understood, she had seen it for herself, the way we were being treated by oncology, although no one in PICU spoke to me about oncology's role in [REDACTED]'s care. When [REDACTED] was in intensive care, it was as if oncology were no longer interested in her. Even though [REDACTED] was in PICU, she was still under oncology's care, but you were lucky if they saw her for five minutes. The nurses in intensive care and up in ward 4 never hid anything but they were too afraid to speak out. They all knew what was going on. They told you the truth about the problems with the water and why we were drinking bottled water.
93. The communication from oncology wasn't as good. The care was never poor, it was always first class and they gave [REDACTED] 100% attention and the best of care but the way intensive care explained things to you was better but, I felt oncology were always standoffish with you.
94. In relation to the safety of the hospital, I got nothing from any of the staff or management. I just got handed press statements saying this is what's going to be getting released to the media later on today.
95. When [REDACTED] got home nothing else happened with Glasgow until we got a letter from Jeanne Freeman saying that [REDACTED] was part of the Case Note Review. To me that validated everything I was trying to get answers to, nobody had been communicating until I got that letter.

COMPLAINTS

96. Around the time when [REDACTED] was an in-patient, I complained to the nurses on the wards but never got anywhere. In fact, most of them agreed with me. I went looking for people higher up but never got anywhere, there was never anyone about. I started making phone calls to a complaints line and all they said was that someone would be in touch. I think I maybe googled the number for complaints. You never actually spoke to anyone in the hospital, it was like an outside party. Nobody ever did get back in touch either. I was never made aware of any complaints policy by the staff, I only heard things from other parents on the ward.
97. I put a verbal complaint into hospital management through Professor Gibson but I've still not heard anything since. I think it was Professor Gibson I spoke to first. I complained to her about the general state of the wards, the ongoing infections and lack of transparency. She arranged a conference call with her, myself and somebody else back in September 2019 but [REDACTED] was ill so I couldn't take the call. That was it, I never had anything re-scheduled or got any letters. I tried to contact them again but I think it was a third party agency that took the information so I never heard anything back. I have never spoken to anyone from the hospital management team directly about my complaint.
98. I was seeing all the issues being reported in the news and the papers and my girl was fighting for her life and still nobody was telling me anything about the issues at the hospital and the infections. We've got a page on Facebook to keep family and friends updated on how [REDACTED] was doing. I think the press had picked up on that and STV news phoned and asked if I would speak to them but I said no. Then the Daily Record got in touch and I thought, why not? I was

getting nowhere with the hospital and I thought it might help or it might make it worse.

99. I was wanting answers so I spoke to the Daily Record and they published it on Thursday 19 September 2019. It was daily that there were stories in the paper about the hospital, around this time. There were other families that were speaking out so it wasn't like it was anything new. The Daily Record was running a story daily. My involvement with the Daily Record made it worse I think because I got a complete shutdown from staff after that, apart from the nurses in intensive care. The article said that a spokesman from NHS Greater Glasgow and Clyde stated that they were sorry to hear that the patient's family felt they hadn't been updated and that the patient had continued to be appropriately treated and the family continued to be fully informed. I hadn't been kept fully informed, that's just blatant lies. I hadn't been getting any communication from the Health Board. If you're reading that and you're still not getting any answers, it's really frustrating.

OVERSIGHT BOARD / CASE NOTE REVIEW / REPRESENTATIVE GROUPS

Case Note Review

100. I got a letter from Jeane Freeman dated 21 February 2020 and it basically said that a Public Inquiry was being held by Lord Brodie and it asked for any comments by Friday 13 March 2020.

101. We got a letter from the Case Note Review dated 4 March 2020 from Professor McQueen and Professor Marion Bain, saying that [REDACTED] was part of the Case Note Review. This was when we found out that [REDACTED] had Putida

Pseudomonas showing in her blood test taken on 12 June 2019. We were offered a call with the two of them but my solicitor couldn't access the call.

102. [REDACTED] is part of the Case Note Review. We got a one-page letter from the Review, that told us [REDACTED] had got that one infection, putida pseudomonas, and that was it. There's no real explanation and there's no mention of the other two infections either. Apart from the letter from Jeane Freeman about the Case Note Review, I've heard nothing. Because I got that letter, you could speak to somebody on a zoom call after you got your decision.

103. On 26th April this year I spoke to two members of the panel, a man and a woman, and they pointed out that I needed to pursue the aspergillus further because the review was specifically set out to look into specific bacterial infections with [REDACTED] and this was the one they found, the Putida Pseudomonas. They said that there were other children getting it at that time when [REDACTED] was visiting the hospital but they can't 100% put it down to the hospital visit at the time [REDACTED] contracted it. I get that but logic tells you that if there's other children getting it at that time when [REDACTED] was there, would there not be more chance of her getting it when she was there? I told them that the one-page reply was astonishingly bad. You're living with this almost two years later and still not getting answers and to get this one page letter is quite poor. I thought they should have a bit more consideration for the people who are going to be reading the reports, we're not all medical people and they could have made the language easier to understand for the families. I'm sick of being fobbed off.

104. [REDACTED] had visited the QEUH on 10 June 2019 and 11 June 2019. She then got bloods done in the Edinburgh hospital on the 12 June 2019 and they found putida pseudomonas in her blood then. We weren't told about that at the time,

this was in the CNR. [REDACTED] had been admitted to the hospital near that time for an infection but we had no idea it was the putida pseudomonas. She was on antibiotics for a week in Edinburgh which I mentioned earlier.

105. I don't know if the Case Note Review is going to tell the truth. I think it's a cover up. It's never been about financial gain for me, I nearly lost my daughter on more than one occasion. It's about people admitting the truth and finding out why this happened. I got sent the massive report and I can't make head nor tail of it. The more I read it and understand it, the more I'm wondering why they're not 100% confirming this. I don't think the right people are going to be held accountable, that's the way I look at it. [REDACTED] was at the QEUH for those two days in June and there's other children that were there at that time that had the same infections so I don't see how they can't confirm that [REDACTED] definitely got it from the hospital. She was only in Glasgow, I can't see where else she could have gotten it.

106. Towards the end of [REDACTED]'s stay in the hospital I was on the closed Facebook group. There were two other families that I spoke to who were in the rooms next to us at the CLIC Sargent House and another two on the Facebook page but I didn't really use it that much. I mostly used the families WhatsApp group, there's 27 of us on that. It's good to talk to other families that have been in that situation. The information coming through the Facebook group was quite good, a lot better than anything coming from the hospital itself but you felt like you were still getting told what they wanted you to know. It felt like you were never being told the truth because I knew what I'd witnessed with my own eyes and was living it every day. The information they were issuing to the families and the media was different to what you were living. An example of the information available on the Facebook page is attached to this statement (**MB/02**–Appendix 2).

ROYAL HOSPITAL FOR SICK CHILDREN AND ROYAL HOSPITAL FOR CHILDREN AND YOUNG PERSONS, EDINBURGH

RHSC: EXPERIENCE

107. [REDACTED] was treated at the old Sick Kids previously. When you went into ward 2, there was a buzzer you had to use to get in. You would pass the Teenage Cancer bit first, it was as you came in. You would then go round and there would be six private rooms on the ward and then there were six or seven day beds for out-patient children that would come in and get their chemotherapy then go home. There were also two Teenage Cancer Trust rooms for in-patients as well.
108. The equipment in the old Sick Kids hospital wasn't up to standard, the machines and the rooms weren't the best. When [REDACTED] got admitted on ward 2 we had to take our own blankets because the rooms were freezing as it's an old building. Even with the heating on it was still a really cold ward. [REDACTED] was in there as an in-patient from January to March 2019, wintertime, and the room was really cold at night. The windows weren't great either.
109. The room [REDACTED] was in had its own bathroom at the back. It had a bath, toilet and wash-hand basin in it. There was also a wash-hand basin in the room. There was a z-bed for me to use and there was a telly in each room. The telly worked most of the time and kept [REDACTED] occupied.
110. There was small playroom at the end of the ward. There was a play station, X-box, board games, jig saws and for the younger ones they had ride on cars that the kids could go up and down the ward in. There was plenty there and loads of art stuff. That's how [REDACTED] got into her art as there was always art stuff

she would play with. Stevie the clown used to come in three times a week to entertain the kids and then you had charity musicians coming in, they would do singing lessons. The playroom wasn't massive but they had all these outside people coming in to do things so it was really good. I think this was all organised by Edinburgh Sick Kids Charity.

111. The amenities in the old Sick Kids hospital were no good to me. I'm in a wheelchair so I couldn't go to the canteen because it was outside and up a flight of stairs. Nine times out of ten there were spare meals going on the ward so the nurses always asked if you wanted something hot so I always got looked after in there. There was also the shop outside ward 2 where you could get sandwiches, and there was the family kitchen where you could heat stuff up, in the ward. Nurses would also give you cups of tea and coffee non-stop.

112. There was only one disabled toilet though and I couldn't shower there as I couldn't get up the stairs. The showers were in an area at the top called PJs loft so I had to use the CLIC Sargent to be able to get a wash.

113. The staff were impacted as there wasn't enough room for them to be able to do their jobs. There was only one room that was suitable for me as it was the only wheelchair accessible one and that was room six. The rest of the rooms were tiny. Any more than a parent, a child and one nurse and you were squeezing for space. By the time they got their drip stands set up for the treatment, there was just no room. Staff used to moan about the lack of space and the lack of beds. If a child came in with a temperature spike, you would have to sleep in the bit where the day beds were as there was no room. In that sense, the hospital was far too small.

114. [REDACTED] was admitted to ward 2 on 13 June 2019 and she was in for about a week. She was treated with antibiotics during this time as her temperature had spiked. It was normal process for us to phone the ward when her temperature spiked, and you would then be asked to go into the ward for a minimum of 48 hours. This was to give antibiotics and make sure there was no infection showing in blood cultures. You had to be 48 hours without a temperature. [REDACTED] had been at the QEUH near the start of June and it looks as though she was maybe getting treated for this putida pseudomonas that is mentioned in her CNR. We were just told at the time that it was an infection she had.

RHCYP: EXPERIENCE

115. [REDACTED] is now getting out-patient appointments at the new Sick Kids hospital in Edinburgh. All of her aftercare is now in Edinburgh. I've asked for that as after everything that happened, I don't want to go back to Glasgow. She was there at the end of March when the new hospital opened. She just recently had to get fifteen teeth removed due to the radiation damage during her treatment for ALL. They took a bone marrow aspirate while she was under sedation and it came back negative so she's almost two years post-transplant leukaemia free.

116. The delay in opening the new Sick kids has never impacted her treatment as such even though it should've opened many moons ago. Having been to the new one, it's better for me getting around and there's better facilities there but its delayed opening never impacted us.

117. Since we've been to the new hospital the experience has been great, although you do have your worries because of what we lived through in Glasgow. You wonder if the delay was due to the same contractors and did it have the same problems. You've got that fear that anything could happen when

you're in there because it's the same building as such, but it seems better, but I've still not drunk the water. [REDACTED]'s not had any overnight stays in the new hospital, it's just been in and out, like for the dentist. It's nice and there's never been any problems but there is that bit of background fear because it's the same company and the same buildings. It's sad when you go to a building and you have fears, when it's the building you're scared of.

118. When [REDACTED]'s been to the new building she's been to the Lochranza day care ward, which is the oncology ward. Then she went to the day surgery ward for the dentist but I can't remember the name of that one. They're all names rather than numbers in that one.

119. The facilities and amenities at the new Sick Kids hospital are good and there's tea and coffee facilities, it's nice. [REDACTED] loves going there, she gets on great with all the staff, she has a great time when she visits Edinburgh. She's quite happy to go there and see everybody. We only attend as day patients and I know there's a shop downstairs, a hot food takeaway bit there too. That's all I've seen, I've not been in it long enough to see everything but what I have seen is good.

120. Comparing the old hospital to the new one, everything's far better. I've got far better access in the new hospital and there's a far better choice. The fact that Ronald MacDonald House is in the same building as the new hospital in Edinburgh is massive for families, it's huge. I'm sure families will benefit from that hugely. In Glasgow the CLIC Sargent house is across the road and although it's near, I'm in a wheelchair and it would still take me longer to get into the hospital than it would if I was actually staying in the hospital. Whereas Ronald MacDonald is in the Edinburgh hospital and it has easy access.

RHSC AND RHCYP Edinburgh: communication

121. There's been no emotional impact at all with the new hospital and there's been no problem with communication. [REDACTED]'s been to two or three different departments already and it's all done with phone calls rather than letters, appointments have been quicker, so it's been good.
122. We were told that [REDACTED] had to have her bone marrow transplant in Glasgow because it's the centre for Scotland. She could have gone to Newcastle, it depended on what was available and when, but we got Glasgow. At the time we thought it wasn't that bad, we hadn't heard anything about the QEUH before we went there ourselves, and then you hear the stories from the other parents and read the stuff in the media and then you attend and experience what we did.
123. After our experience in Glasgow I think it's quite right they took a bit longer to investigate everything and make sure it was safe. Delaying the opening of the new RHCYP in Edinburgh was the right thing to do. You do wonder if it's going to be the same situation with the water and the ventilation but at the same time you trust that they took that year longer so they could fix everything to avoid having these problems.

CONCLUDING COMMENTS

124. I don't want to go anywhere near the Queen Elizabeth hospital again. I've lost confidence in the place. The hospital itself, for being Scotland's 'super hospital', there's nothing super about it.
125. I found out from the Case Note Review that [REDACTED] had putida pseudomonas. She had been at the QEUH for tests on 10 and 11 June 2019 and then had blood tests carried out at the Sick Kids in Edinburgh on 12 June 2019 when she had been admitted due to an infection. The Case Note Review said that may or may not have contracted that from the Glasgow hospital but they couldn't say for certain. As far as we knew [REDACTED] only had the adenovirus and aspergillus when she was in the Queen Elizabeth.
126. I don't trust the Queen Elizabeth Hospital now. If I had my way I'd never, ever go back to the place again because of the experience I've had with the building and its faults. I think the Health Board have handled the situation poorly from start to finish. I think the way Jane Grant handled herself was disgraceful, she should have resigned straight away. I hope they address the safety concerns sooner rather than later. As I said, we were one of the lucky ones, my [REDACTED] came home. We don't have much to do with it anymore but I fear for the other families, other sick kids, other sick adults that have to go into the hospital. The concerns they've got with the ventilation and the water are alarming. There's always a risk of catching something else when you go into a hospital but it shouldn't be through the negligence of the building work, the ventilation or the water system. That shouldn't be happening, especially in the 21st century. It's billed as Scotland's super hospital, there's nothing super about it.

127. With the press coverage, in a way I felt vindicated because it wasn't just me thinking it was the worst or making it the worst, it was actually happening, it was real. At the same time, with the recent Panorama programme, it brings it all back, it takes you back to being in that situation. We nearly lost [REDACTED] five times, and you live it enough daily without it being on the telly. We came that close to literally switching the machines off, we were minutes away from making that decision and it brings it all back every time.

128. The impact of the lack of communication left me angry and frustrated, even to this day. We're almost two years in and we're still not getting any answers. I know the Inquiry is dealing with it now but this shouldn't have to be happening. If they had just been open and honest with the families from the beginning, we wouldn't be in this situation. I know the hospital's maybe had major problems but why hide it from the families? You send your kids to hospital to get better, not to get worse, and not to lose your kids. Some of the families did, we consider ourselves lucky because [REDACTED] came home. You know the risks involved because of the transplant side but you don't expect the risks from the building and water side of things, it just doesn't make sense why you would build a hospital right next door to a sewage plant.

129. After [REDACTED]'s treatment in Glasgow I had lost all trust in the hospital so all her after care treatment has been in Edinburgh apart from two or three times in Glasgow, only because we really had to. After Covid hit we went to Edinburgh every two weeks and then it became monthly appointments. She now has appointments every two or three months [REDACTED] was at Glasgow last month and she's due her two-year review since the transplant. This is because she's had a bone marrow transplant and Glasgow's the centre for Scotland so anything that's related to the transplant has to be dealt with in Glasgow.

130. All I ever wanted was an apology for the way [REDACTED] was treated and the way the family was treated at the time. That infection could have killed her. It's about them learning from their mistake. Looking at what's been on panorama about the hospital, they haven't learned anything. They're still covering up. I don't want to see on the news that another family has been through what we've been through. Whoever has made the mistakes, has to own up. Someone, somewhere, knows the truth but nobody will want to admit to it. That's the bit that gets me. It's not just been one or two kids, there's been loads and it's been in the adult section of the hospital too. Maybe we don't know about the impact on the adults as it was only publicised because it was affecting the children's wards.

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

APPENDIX 1 – TIMELINE (MB/01)

- November/December 2018: ██████ first took ill in November/December 2018. GP thought it could be tonsillitis and prescribed antibiotics.
- 3rd January 2019: Antibiotics were not seen to be working so ██████ was sent to Borders General Hospital on 3rd January 2019 for tests and was given initial diagnosis of ALL. ██████ was then taken to the RHSC Edinburgh on 3rd January 2019 by ambulance and her diagnosis of ALL was confirmed.
- Treated at Edinburgh between January and mid July 2019 in ward 2. ██████ was an inpatient between January and March. ██████ received out-patients treatment the rest of the time.
- January 2019: ██████ began a four-week course of chemotherapy which was not successful.
- February 2019: ██████ then began a more intense course of chemotherapy treatment called Regime C for a further four weeks.
- End of February 2019: Around the end of February 2019, they advised that a bone marrow donor would need to be found and began checking the registers for suitable donors
- May 2019: Began a 28-day course of blinatumomab in May 2019 to manage her ALL levels in case a bone marrow donor was found.
- 10th and 11th June 2019: Attended appointments at QEUH on 10th and 11th June 2019 because a bone marrow donor had been found and testing for donor compatibility and transplant viability was needed. ██████ also attended the Beatson Centre during these appointments to receive radiotherapy last week of July.

- 12th June 2019: Bloods taken at the RHSC Edinburgh on 12th June 2019. Blood test taken on 12th June 2019 found ██████ had Putida Pseudomonas. Parents were not told until Case Note Review Letter of 4th March 2020.
- 13th June 2019: ██████ admitted to RHSC ward 2 on 13th June 2019 for around a week to receive antibiotics due to a spike in her temperature.
- 21st July 2019: Admitted to QEUH on the 21st July 2019 in preparation for her bone marrow transplant where she remained until 20th November 2019 in Ward 4B in the adult hospital and ward 6A. Told by nurse when admitted to Ward 4B on 21st July not to drink the tap water and ask them for bottled water instead. ██████ began receiving antibiotic treatment for fungal infections intravenously including Posaconazole, Gentamicin and Fluconazole.
- 22nd July 2019: On 22nd July 2019 ██████ began intense radiotherapy and chemotherapy in preparation for the bone marrow treatment.
- 1st August 2019: The Bone marrow transplant took place on the 1st August 2019
- 10th August 2019: ██████'s breathing problems started on the 10th August 2019
- 18th August 2019 she was moved to intensive care (PICU) due to breathing problems and started receiving high-flow oxygen.
- 19th August 2019: ██████ was put on a ventilator.
- 21st August 2019: Mark and his wife went to clear ██████'s room in 4B as they were told the room was needed for someone else. Room still had bowls of vomit, used nappies and meal plates in it.
- 22nd August 2019, Mark was told to bring the family in because ██████ was close to death. The family were asked to come in like this on four or five occasions.
- 28th August 2019: Around the 28th August 2019 ██████ underwent Toxic T cell treatment to help with the adenovirus.
- On the night of 28th August 2019 ██████ had a bleed in her lungs.

- 29th August 2019: Mark was told that [REDACTED] was close to death and confirmed she had aspergillus in her blood.
- 1st September 2019: moved onto an Oscillator ventilator to get the blood clots out of her lungs.
- 2nd September 2019: family were given a private room in intensive care and there was a discussion with the hospital about turning the machines off.
- 2nd September 2019: another intensive care doctor gave [REDACTED] a large dose of steroids for a few days which saved her. This course of steroids left her adrenal insufficient, requiring three daily doses of steroids to maintain her levels.
- Mid- October 2019: [REDACTED] was discharged from PICU.
- End of October 2019: [REDACTED] then then returned to ward 4B until the 20th November 2019. [REDACTED] had to learn to walk again during this time. Between September and November [REDACTED] was moved around ward 4B in the intensive care unit in various rooms due to repeated flooding in the rooms.
- 20th November 2019 [REDACTED] was discharged to the CLIC Sargent.
- 20th – 22nd December 2019: Sometime between the 20th and 22nd of December [REDACTED] is discharged home. [REDACTED]'s care has now been transferred to Edinburgh at Mark's request.
- 4th March 2020: received a letter from Professors McQueen and Marion Bain informing them that [REDACTED] was part of a Case Note Review.

APPENDIX 2 – EXAMPLE FACEBOOK POSTS (MB/02)

Scottish Hospitals Inquiry

Witness Statement of

Haley Winter

WITNESS DETAILS

1. My name is Haley Winter. I was born on [REDACTED]. I am [REDACTED] years old.
I am [REDACTED].
2. I am the mother of [REDACTED]. [REDACTED]'s date of birth is [REDACTED]. He is 11 years old.
3. I live with my three children, [REDACTED], [REDACTED] and [REDACTED] in [REDACTED].

OVERVIEW

4. My son is [REDACTED]. [REDACTED] was diagnosed with Acute Lymphoblastic Leukaemia (ALL) in October 2017 when he was 7 years old. [REDACTED] was treated in the Royal Hospital for Sick Children (RHSC) in Edinburgh and the Royal Hospital for Children (RHC) in Glasgow. He attended both hospitals as an in-patient and as an out-patient. [REDACTED] now attends the Royal Hospital for Children and Young People (RHCYP) in Edinburgh for check-ups. He attends six monthly check-ups.
5. With the help of my solicitor I have prepared and 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 at appendix

1 (HW/01), the dates up to April 2018 are approximate and I confirm that it is accurate to the best of my recollection.

6. ■ spent time in wards 2A and 2B of the RHC which are known as the Schiehallion Unit. The Schiehallion Unit treats children with cancer. ■ was also an in-patient on ward 2 of the RHSC in Edinburgh. I stayed with ■ during his admissions to hospital as an in-patient and an out-patient. I can speak to the experience ■ and I had in these hospitals and on these wards.
7. Sometimes ■'s treatment was carried out by Ninewells Hospital in Dundee. It's our local hospital so if ■ had a temperature spike, it would be Ninewells we would go to. There were certain things that Ninewells could carry out, for example, they dealt with ■'s temperature spikes if he had them in between his chemotherapy sessions. There was also one time when he wasn't eating when he was in Edinburgh but was otherwise quite well and only had the TPN line in to feed him. On that occasion I asked if we could go to Ninewells to be closer to home. Other things such as his chemotherapy, bone marrow aspirations and his biopsies would have to be done in Edinburgh or Glasgow.
8. There is one event in particular I would like to mention. ■ contracted, what I now know, after I received ■'s Case Note Review (CNR), to be enterobacter cloacae, in April 2018 very shortly after being admitted to ward 2A of the RHC. There were issues with the water during ■'s time there which, in my view, impacted his experience. I will come on to talk more about this admission in more detail.

FAMILY BACKGROUND

9. I live with my three children in ■. ■ is the eldest at ■ years old, is ■ years old and ■ is ■ years old.

10. ■■■ is in primary■■■, he starts primary■■■ after this summer. He was in primary ■■■ when he was first admitted to hospital. ■■■ likes school and has loads of pals. He likes playing football, basketball, he does karate and likes gaming. Prior to ■■■'s diagnosis, his health was good but I had been saying for a few months before he was diagnosed that he had cancer. I don't know what it was, I just had a feeling. Everyone thought I was just being paranoid.

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

11. ■■■ was diagnosed with ALL in October 2017, when he was 7 years old. He went to school on Monday 23 October but he got sent home as he was feeling sick. He was alright on the Tuesday so he went back to school. My mum picked him up at lunchtime and she phoned me to say he was looking very peely-wally (pale), but I just left him as every time I'd taken him to the doctors before then they had just said it was a virus. When I took him home from my mum's, he was sick but after that he ate a McDonald's. He wasn't sick again after he ate that, so I knew it wasn't viral.
12. I put him to bed on the night of the 24 October 2017, but he looked awful, he looked like a corpse. I phoned NHS 24 and got an appointment within an hour. I went to out of hours at Ninewells Hospital in Dundee at 10:30 that night and saw a Dr Gemmel. Again he said it was just viral and I just thought, here we go again. I then said to Dr Gemmel that ■■■ looks like he's got cancer, so the Doctor started to look in ■■■'s eyelids, looked at the creases of his hands and then told me I had to take ■■■ for bloods the next morning back at Ninewells.
13. My sister came with ■■■ and me the next morning. They took ■■■'s bloods and then, I think it was Dr Shazia, took us into a room and said "Do you know

your son is anaemic"? I said "Yes he's got cancer", I could see that something was seriously wrong.

14. They then put [REDACTED] on a ward in Ninewells and started doing bloods again. A Dr Peebles came in and took us into a wee side room and told me and [REDACTED]'s dad, who had arrived by this time, that [REDACTED] had leukaemia and that he needed to go to the Glasgow hospital the next day. She explained about the treatment and was very positive that it would work.
15. Edinburgh was [REDACTED]'s catchment hospital. We were supposed to go to RHSC in Edinburgh in October 2017 but there were no beds so [REDACTED] was admitted to the RHC in Glasgow.

Admission to RHC ward 2A: 26 October – November 2017

16. We left the next day, which would be the 26 October 2017, to go to Glasgow because there were no beds in the Edinburgh hospital. [REDACTED] went by ambulance with his dad and I followed behind in the car, with my then partner [REDACTED]. My first impressions were that the hospital was really nice until I got out the car and it stank of shit.
17. We went in and [REDACTED] was admitted to Room 14 in ward 2A. I can't remember the names of who we spoke to. The next day he had surgery to have his Hickman line inserted. [REDACTED] had surgery which was done under general anaesthetic. They made a cut in his neck and inserted a line in his neck through his chest that was connected to his heart. [REDACTED] started chemotherapy on the 27 or 28 October 2017. He had two or three further surgeries to get bone marrows taken and a lumbar puncture. He was doing quite well, I think they gave him steroids too.
18. I initially thought the ward was nice. The rooms were a lot bigger than the rooms in Dundee. You had your own bathroom with a shower too.

19. When you walked into the room, there was a sink. ■■■'s bed was on the right hand side, and my bed was next to ■■■'s. It was a pull out bed. There was a wee unit too but one of the drawers was locked and used for medication. I think this was the bottom drawer.
20. There was a play room where ■■■ could go to colour in. They had games in there too but ■■■ would just take the games back to his room.
21. There was a cinema too that we went to. It was in another bit of the RHC.
22. There was a family room that parents could use. It was a wee rectangle room with a fridge, sink, water machine and a microwave. There was also a machine for boiling water. It looked more like a coffee machine than a kettle.
23. The ward also had a teenage bit which I think was used for patients who were 13 years and up.
24. ■■■ went home after 2 weeks on around about Friday 17 November 2017, with the plan being that he would receive treatment in Ninewells as an out-patient. He had to get a bone marrow aspiration on day 15 and on day 29 after chemo started. He got his first bone marrow aspiration that morning and we were discharged afterwards.

EXPERIENCE AT RHSC: November 2017 – April 2018

25. We went to clinic in Ninewells on Monday 20 November 2017, to get routine blood tests and to have ■■■'s line flushed, we were there a few times a week at that time. ■■■ then had surgery in the RHSC in Edinburgh on 24 November 2017 for second bone marrow aspiration, chemotherapy in his spine and a biopsy. ■■■'s catchment hospital was Edinburgh which is why

we were told to take him there. I wasn't happy about this, I wanted him to go to the new hospital in Glasgow, on the surface I thought it was better equipped. He was an inpatient in ward 2 in RHSC. From then until the 15 December 2017, we were just waiting for results. I had to chase these up and eventually I was told that the chemotherapy had failed. His bone marrow still had a high percentage of cancer still present.

26. ■■■ was then admitted to the RHSC ward 2 for further chemotherapy on 18 December 2017. He remained there until 5 January 2018.
27. Throughout January 2018 he was in and out of Ninewells ward 29, which was the children's ward, for temperature spikes, where he would be admitted for 48 hours or sometimes a week. Sometime during that month we were told the chemo had failed again. ■■■ was readmitted to RHSC ward 2 at the end of January for further chemotherapy. He remained there until 17 February 2018.
28. On 17 February 2018 ■■■ was transferred to Ninewells. His chemotherapy was finished and the only thing that was keeping him at Edinburgh was that was getting TPN to feed him and I requested that this be done at Dundee, for us to be closer to home. I had 2 other children and no one could come and see us. We went home that time after one night. Ultimately this chemotherapy also failed.
29. During March 2018 ■■■ attended both Ninewells and RHSC and at some point this month a discussion took place with Dr Matt in RHSC about specialist treatment that ■■■ needed. The doctors were discussing what to do next. I was told loads of stuff at this point. At one point doctors were talking about him going to Italy or Washington for treatment.

30. In March 2018, I was told [REDACTED] needed a treatment called blinatumomab, which is antibody therapy. This was a different type of chemo. If he had CD 19 and CD 22 in his blood or bone marrow, blinatumomab was used to treat it. It's a more dangerous chemotherapy so [REDACTED] had to go to Glasgow for this treatment as they had more experience in it.
31. I was told this could only take place at the RHC in Glasgow or the RHSC in Edinburgh, but they said the RHC had more experience in administering this treatment so they wanted [REDACTED] to go there.
32. During April 2018 [REDACTED] attended Ninewells and ward 2B RHC for various day care appointments. He was admitted to Ninewells on 13 April 2018 for a few days for a temperature spike.

SEQUENCE OF EVENTS WARD 2A RHC: 23 April 2018 to 25 May 2018

33. On 23 April 2018 we were given an appointment for [REDACTED] to attend ward 2B at the RHC on 26 April 2018, prior to being admitted to ward 2A to receive the specialist treatment called blinatumomab.

Experience: April 2018 - May 2018

34. [REDACTED] was admitted to a different room, room 1 on ward 2A, this time. His friend was coming in to visit him and they would play with the computer there.
35. Again we arrived at the hospital and it stank of shit. I could smell it in the car park and the hospital building. It was right next to the sewage works.
36. We were not allowed to use the water and there were filters on all of the taps. We were given bottled water to drink.

37. ■ had a Hickman line and he arrived at the hospital with it already in. On 28 April 2018, ■ had a shower and within hours he started rigoring. He developed a temperature and became unwell. He was also having seizures and shaking. The nurses thought this was to do with the chemotherapy. He had a couple of episodes of this and the nurse, Nicola, said that if he had another seizure he would have to get a cannula in.
38. He stopped fitting and the staff told me that if it happened again then they would have to remove his line. About 45 minutes later he began to fit again. My partner at the time was with me, he had gone to get a shower and all this happened when he was gone; it was so quick.
39. ■ had his central line removed on 2 May 2018 and a new one inserted on 5 May 2018 due to the infection he had picked up. His line was infected.
40. He was so scared, it was the first time he really told me how scared he was. I was lying on his bed next to him and he was frightened. They were pumping and flushing his lines and giving him medications via a cannula.
41. He was fine when we arrived and he had been well up to that point, he had been good in the 6 months up to this point. We had not experienced anything like this. This admission was really bad.
42. I told the staff that I knew it was the water. It was contaminated. I spoke to the staff on the ward and they told me that it was not the water. I knew about the sewage works nearby and thought it might be connected to that.
43. ■ finished his treatment in Glasgow and he went back to Edinburgh and continued his treatment there. He never returned to ward 2A after this episode.

44. ■ was discharged on 25 May 2018.

WATER: EVENTS INVOLVING WATER SYSTEMS

Water incidents in RHC: 2018

45. The first time we were in the RHC we just used the water as normal. We didn't have any problems.
46. The second time we were in I took pictures on 27 April 2018 of the filters on the taps in Room 1, the room we were in. The filters were on the taps in the sink in the room, the sink in the bathroom and the shower. This room was right behind the nurses' station. I have provided the Inquiry with a photo of this. This is at appendix 2 (**HW/02**).
47. The main bathroom on ward 2A was closed too. It had a big bath in it that you could use but there was a sign over the door saying it was out of use.
48. Staff were giving out bottled water and there were signs telling you not to drink the water. They took away the water coolers too.
49. I have provided the Inquiry with other photographs that I took in ward 2A. There is a photograph of a sign on one of the sinks, this is at appendix 3 (**HW/03**). There is a photograph of a sign on one of the water coolers, this is at appendix 4 (**HW/04**).

Water: Communication

50. My dad asked the boys who were in changing the filters in ■■■'s room why they were doing the work but I can't remember what they said. I asked too but they just said it was for extra protection as it's a cancer ward. These filters hadn't been there the first time we were in. They didn't tell us not to use the water to wash at that time. They just said it was for extra protection with it being a cancer ward.

51. I also posted on Facebook on 27 April 2018,

"Ok so why the fuck would you put a sick kid into a hospital where the water is contaminated. Not even allowed a bath. Looks like I will be losing the plot cos if any one of them gets an infection I swear to God I'll sue the fuckers"

52. No one told me there was anything wrong with the water, but I had a meeting with infection control the second time we were in, when I was in ward 2A, room 1. I don't remember the date, but it was me and another mum and dad. I told the woman, I don't know her name, that the water was contaminated. She asked me why I thought that and I told her the whole place stank of shit. I think the meeting had already been set up, I can't remember but one of the doctors or nurses told me it was happening. It was a quick meeting. She wrote what I said down and she said she would look into it. I never heard anything else about it.

53. I spoke to Professor Gibson but all she said was "That doesn't happen on my ward", when I complained about the water. This might have been the day before the meeting but I'm not sure.

HEALTHCARE ASSOCIATED INFECTIONS

HAIs: events and physical impact

54. On 2 May 2018, ■ still wasn't any better; he still had a temperature. He was really unwell, his heart rate dropped and I thought he was going to die. I think it was a nurse that told me that his line needed to be removed, so they took him down to surgery and removed it. He continued with antibiotics, I think tazocin and vancomycin. He got another line fitted in surgery on 5 May 2018 and they stopped the antibiotics on 9 May 2018. He was discharged on 25 May 2018 and follow up care from then was at the RHSC.
55. ■'s line was fitted with a wee green cap. This was to keep it clear of infection. We had a bag of the caps to use if we were at the RHSC or in Dundee, we had some spare if doctors had to access his line for any reason.

HAIs: communication

56. The nurses and the doctors didn't really tell us anything about any infections, they just put him spiking a temperature or rigoring down to the new chemotherapy ■ was on. The only infection we knew anything about was when he had to get the line removed. Even on 2 May 2018, when they removed his line, we were still only told it was a line infection. All the nurses said was that they had identified a line infection and it had to go to the labs so they could do tests on it and grow it over 48 hours to identify what it was.
57. Professor Gibson came and spoke to us when he got his line infection and she just said it was an infection you can grow in your gut.
58. ■ was put on caspofungin. This was after he had his line infection and it was to stop any other infections. It was Professor Gibson that I spoke to and that's all she told me.

OTHER ISSUES RELATING TO THE HOSPITAL

59. I do remember that right from the first time we went to the hospital, it stank of shit. I remember driving into the car park for the first time thinking the building looked lovely and then getting out of the car and the smell of shit was disgusting.

CLEANLINESS

60. The first time we were in, in October/November 2017, it was fine but the second time, in April/May 2018, it wasn't. When [REDACTED] really wasn't feeling well, he liked the room dark, so they just didn't come in to clean the room for four days or even empty the bins in the room, they just left you. I told the nurses, the room still needed cleaned, but I ended up doing it myself.
61. Also when we went into ward 2A room 1, on 26 April 2018, there was blood on the floor at the side of the bed, it wasn't ours. I just ended up cleaning it myself. It was alright after that, but it could have been cleaner. They came in the room in the morning, to sweep and wash the floor, clean the bathroom and give the tops a wee wipe. Later on they came in and emptied the bins again.
62. One of the nurses was leaving ward 2A, presumably to work elsewhere, and the other nurses filled up syringes and squirted all sorts of medicine, yogurt and stuff like that over her. It went all over the floor and up the walls. I didn't think that was right. They'd put plastic sheets and that up but still I didn't think that was right in a cancer ward.

OVERALL EMOTIONAL IMPACT ON [REDACTED] AND HIS FAMILY**Overall impact on [REDACTED].**

63. [REDACTED] was young and he just gets on with it. He did say a couple of times that they were killing him and that he was going to die, but generally he just thought they were just trying to make him better.

Overall impact on witness

64. It had an emotional effect on me, it was really bad. The doctors and nurses didn't listen and they made me think I was going off my head, they really didn't know why the chemotherapy wasn't working and then I felt nobody was listening to me about the water. They really didn't know what was going on with him so I just found it really hard. I did go to the doctors but they just wanted to put me on tablets and I didn't want that.

Overall impact on family members

65. It was really hard on [REDACTED] and [REDACTED]. When I was in the hospital with [REDACTED], [REDACTED] stayed with my dad and [REDACTED] stayed with his dad and his granny. They were split up but [REDACTED] had to come first, he was the priority.

COMMUNICATION: GENERAL RHC

66. When [REDACTED]'s chemotherapy wasn't working, the communication with [REDACTED]'s doctor in the RHSC was really atrocious. I had to phone them for results. Sometimes I would have to phone both Glasgow and Edinburgh hospitals to track down [REDACTED]'s results.

67. I really didn't know what [REDACTED] was being treated with most of the time, both in RHC and RHSC. No one explained it to you unless you asked. If you asked they would tell you but the staff sometimes made you feel stupid for asking questions.
68. The nurses and the doctors didn't really tell us anything about any infections, they just put it down to the new chemotherapy he was on. The only one we really knew about was when he had to get the line removed. Even then, we were only told it was a line infection and not the name of it or how he got it.
69. I didn't like Dr Gibson. She told you things and never asked you questions. I couldn't tell her anything, she was thought she was in charge of me and wouldn't listen when I tried to tell her about particular things that were going on for [REDACTED]. She spoke down to me. She thinks she knows everything. She was saying not to give [REDACTED] McDonald's food, she was just being a doctor with that but she was quite stern.
70. I only heard about the problems at the hospital when I saw the Disclosure programme on BBC Scotland. It was then that one of the mums got in touch and asked me to join a WhatsApp group. There's quite a few parents on it but some people don't want to speak up. I was gutted when I saw it and I got in touch with one of the other mums and said I wish I'd had the opportunity to speak as I could have told them their water was full of shit. I did feel vindicated though that I wasn't crazy.

COMPLAINTS

71. I raised a complaint with the doctors and nurses, I can't remember who, about my room not being cleaned. It was then that I was told someone from infection control was holding a meeting and I could attend. This meeting was not helpful, they mainly said that everything was fine and that the water couldn't be contaminated. This was the meeting that I went to just after

█ had his line infection. After that meeting finished I never heard anything about it again.

72. My step mum wanted to write in and complain but I said just to leave it. I did phone a solicitor but I never really got anywhere, it was just too much at the time.

OVERSIGHT BOARD / CASE NOTE REVIEW / REPRESENTATIVE GROUPS

73. I've never heard of the Oversight Board or of Professor White.
74. The first I heard about the Case Note Review (CNR) was when I got a letter about it but I didn't really know what it was about. I then got █'s report, which I still don't really understand. I was told by my solicitor, that in the CNR, it stated that microbiology had recommended doctors take █'s central line out in late April 2018 but the doctors decided to keep it in so he could get his blinatumomab. His line didn't actually get removed until 2 May 2018. The CNR confirmed that █ had a gram negative infection called enterobacter cloacae which was the infection that no one knew the name of in April/May 2018 and it was linked to the environment.
75. █ was really ill with the line infection he had in April 2018 and I thought he was going to die. If the CNR and this Inquiry stops other kids dying or another child going through what █ went through, then it's worthwhile.
76. I was a member of the Facebook page for parents, the Schiehallion one. I didn't look at it much, it was just for mums and dads to ask questions or if you needed help. I maybe asked if anyone else had failed chemo, but I never really paid much attention to it. I was also on the Edinburgh family one which is the Edinburgh equivalent of the Glasgow parents page set up by the hospital. I wasn't on any other one.

77. I don't think a lot of the Health Board. I spoke to someone, I think her name was Jennifer and I might have gotten an email from her. I phoned them after the Disclosure programme. I googled for a number. I don't know who she was. I wanted [REDACTED]'s medical notes – she said that [REDACTED]'s infection was nothing to do with the water.
78. I think the Health board knew there were problems at the hospital and the people at the hospital were trying to cover it up. That's why they were putting the filters on the taps.

CONCLUDING COMMENTS: RHC Glasgow

79. I'd rather drive to London every week than step foot back in that hospital, not after that TV show. It's disgusting. I hate it and I just don't understand why they could put sick people in that hospital. I don't understand why it's even open now, when you've lost people and all these people have been ill. Who even thinks it's right to build a hospital so close to a sewage plant?!

ROYAL HOSPITAL FOR SICK CHILDREN (RHSC), Edinburgh

Experience – issues impacting patient safety and care

80. [REDACTED] was mostly an in-patient, he was there before we went to Glasgow the second time, for about 4 weeks and he was an in-patient and an out-patient up until about a year and a half ago. The nurses there were really nice but it was freezing and I did have a couple of run-ins with some of the staff. One was over how cold the hospital was. I was told they couldn't do anything about it and the heating was on, but that it was an old building and the heating didn't work. Another incident took place when I had to argue that one of the nurses was giving [REDACTED] too much morphine and she didn't listen to me

but when she checked with another nurse, it was proved I was right about the morphine.

81. ■■■'s room was tiny, I just got a Z bed and a wee wardrobe. You couldn't swing a cat in it. It was so cold, you could see your own breath in the room. It was winter the first time we were there and I had to sit with my outdoor coat on.
82. I had to buy ■■■ a quilt to use there because it was so cold. I complained but I was just told the heating was on and it was an old building.
83. The ward had a mouse in it, which the nurses called "Speedy". I had gone out for a cigarette and when I came back in they said Speedy was out, running around the floor. I took my phone out and then I saw him under the door so then I sat down and he was under the washing. I tried to video him but because I had disturbed him he ran away. When I went back to my room I ordered mousetraps to put under my bed.
84. It was horrible, really cold. I made complaints to the nurse but no one did anything. Communication wasn't good when you weren't an in-patient. You had to keep phoning them to find out what was happening

Amenities

85. ■■■ was well looked after but it was just the hospital was horrible. There was only a wee tiny playroom for ■■■.
86. We had to go out the door of the ward to go to the toilet, even in the middle of the night. There was nowhere to make food or anything. There was a kitchen but I didn't use it. I just lived off takeaways as I didn't have time to cook. There was PJ's loft but I didn't use that either. There were rooms up there and you could get a shower.

87. CLIC was right across the road in Edinburgh and that was good. It was there up to about last year. That was handy. We stayed there every day when we were in, we slept there, showered and cooked there.

Impact on ■■■'s care with the delayed move to RHCYP

88. One of ■■■'s treatments was delayed. I think that was the first time we were supposed to move in March 2019, maybe by a week or a couple of weeks but I can't remember. I don't think it made much difference though.
89. I do remember though that the second time we were due to move, I think that was July 2019, everything had been moved from the old hospital and it was really empty. We were all writing on the walls because we thought we were going.
90. The other impact was that CLIC moved after the hospital was supposed to close the second time. They had the new CLIC for us to stay in which was opposite the new hospital. This meant that when the new hospital didn't open we had a 20 minute drive in the morning to get to ■■■, more in rush hour traffic. That was a bit of a joke.
91. We weren't told about the delays directly. Nurses would maybe say to you if were in for an appointment that the move had been postponed again.

ROYAL HOSPITAL FOR CHILDREN AND YOUNG PERSONS, EDINBURGH
(RHCYP)

92. I have only been to the one appointment at the new hospital and we were in and out. It was nice, much prettier and cosy but I haven't had any experience of being an in-patient.

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

APPENDIX 1 – TIMELINE (HW/01)

- 25th /26th October 2017 – ■■■ is diagnosed with ALL at Ninewells Hospital Dundee. The original plan is to move him to Edinburgh Sick Kids however there is no room there so he is moved to the QEUH hospital and admitted to ward 2A, possibly room 17.
- 27th October 2017 – ■■■ has a Hickman line inserted. ■■■ started chemotherapy either on this day or the day after. He is admitted for two weeks.
- 13th November (approx.) – ■■■ is discharged, with the plan being that he would receive treatment in Ninewells after this.
- 24th November 2017 (approx.) – ■■■ has a biopsy at Edinburgh Sick Kids.
- 15th December 2017 – Haley is advised that the chemotherapy has failed.
- 18th December 2017 – 5th January 2018 – ■■■ is admitted to Edinburgh Sick Kids ward 2 for further chemotherapy
- January 2018 - ■■■ was regularly admitted to Ninewells Dundee for temperature spikes where he would be admitted for 48 hours or sometimes for up to a week.
- 30th January 2018 (approx.) – 17th February – ■■■ is admitted to Edinburgh Sick Kids ward 2 for chemotherapy.
- 17th February 2018 – He is transferred to Ninewells Dundee. This is because his chemotherapy was going well, ■■■ was getting TPN and Haley requested for them to be moved closer to home.

- March 2018 – A discussion takes place about ■■■'s treatment at Ninewells. ■■■ was due to get a specialist treatment. This treatment could only take place at Glasgow or Edinburgh. It was deemed that Glasgow had more experience in administering this treatment. He is attending Edinburgh and Ninewells during this month.
- April 2018 – Attends Ninewells for various daycare appointments and temperature spikes.
- 26th April 2018 – ■■■ attends Glasgow where he goes to ward 2B and is admitted to 2A to receive blinatumomab.
- 28th April 2018 – ■■■ has a shower and shortly after this he develops a fever and becomes unwell, he starts having seizures. Advice is given by microbiology to remove the line (date advice was given is unknown to Haley). The line is not removed to attempt to continue with the blinatumomab treatment. Antibiotics are started by IV.
- 2nd May 2018 - ■■■ remains unwell with a fever and his line is removed.
- 9th May 2018 – Antibiotics are stopped.
- 25th May 2018 – ■■■ is discharged from Glasgow and follow up care is organised to take place in Edinburgh.

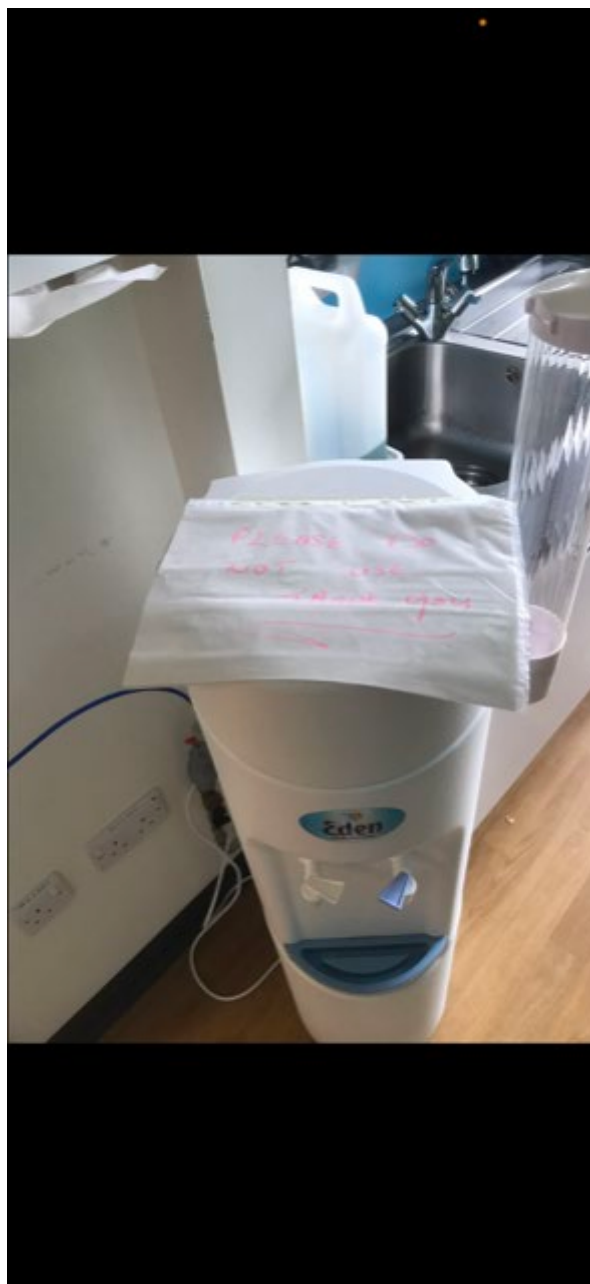
APPENDIX 2 – PHOTOGRAPH OF FILTER ON TAP (HW/02)



APPENDIX 3 – PHOTOGRAPH OF SIGN ON SINK (HW/03)



APPENDIX 4 – PHOTOGRAPH OF SIGN ON WATER COOLER (HW/04)



Scottish Hospitals Inquiry

Witness Statement of

Lesley King

WITNESS DETAILS

1. My name is Lesley King. I was born on [REDACTED]. I am [REDACTED] years old. I work in [REDACTED].
2. I am the mother of [REDACTED]. [REDACTED]'s date of birth is [REDACTED]. She is 8 years old.
3. I live with my husband, [REDACTED] and our two children, [REDACTED] and [REDACTED] in [REDACTED], [REDACTED].

OVERVIEW

4. My daughter is [REDACTED]. [REDACTED] was diagnosed with neuroblastoma in October 2018 when she was 5 years old. [REDACTED] was treated in the Royal Hospital for Sick Children ("RHSC") in Edinburgh between October 2018 and May 2020 when she finished her treatment. She attended as both an inpatient and an outpatient between those dates. [REDACTED] continued to attend at the RHSC for check-ups until it shut in March 2021 and now attends at the new Royal Hospital for Children and Young People ("RHCYP").
5. [REDACTED] spent the majority of her time in ward 2 (haematology and oncology) of the RHSC and also had brief stays in ward 3 (speciality surgery), ward 4 (orthopaedics) and the Intensive Care Unit (ICU). My husband and I stayed with [REDACTED] throughout her admissions as an inpatient and outpatient and I can speak to the experience that [REDACTED] and I had on these wards.
6. There are some specific events that I would like to mention. I have some observations about the condition of the hospital building in the RHSC and the impact that had on our experience there. I also have some observations to make about the way in which the delay to the opening of the new RHCYP

in July 2019 impacted on us. I will come on to talk about these events in more detail.

FAMILY BACKGROUND

7. I live with my husband [REDACTED] and our two children in [REDACTED]. [REDACTED] is the eldest and [REDACTED] is [REDACTED].
8. [REDACTED] is a very busy little girl. She loves the outdoors and playing on her bike and her roller skates. She loves going to the local park and we have two dogs, [REDACTED] so we are out often walking them. She has loads of hobbies and does bouldering, hillwalking and kayaking. She gets on well with [REDACTED] and they have a lovely relationship.
9. As a family we are very active and the kids have been roped into the adventures of me and my husband. We live in the countryside so we have lots of opportunities here. We hill walk and cycle together and we have kayaks and paddleboards, so we are always going out to explore.

SEQUENCE OF EVENTS: THE FAMILY'S EXPERIENCE AT THE RHSC IN EDINBURGH

Admission to hospital: 3 October 2018

10. [REDACTED] was diagnosed with neuroblastoma, which is a childhood cancer, in October 2018. In the run up to this diagnosis, [REDACTED] had had a sore tummy and was repeatedly sent home from school. There were a couple of times she was up during the night in agony and Calpol didn't seem to make any difference. We went to our GP who couldn't find anything wrong but had taken a urine sample. A few days later we were asked to go back to the GP as there was something funny with the urine sample, but they put it down to a virus in her adrenal glands. They did tell us that if it got worse that we should go to A&E. They didn't believe it was appendicitis but suggested

further tests may be necessary which could only be done in hospital. ■ got a lot worse and my husband took her to the GP who sent her straight to A&E.

11. We took her to A&E at the RHSC on 2 October 2018. They did an ultrasound and found a mass on her kidney. We got sent home and were told to come back the following day and go to the oncology department, which we did. This is where we met all of ■'s doctors for the first time. Her consultant was, and still is, Dr Angela Jesudason. The doctors told us that from the ultrasound, and from looking at ■, they could see that she had lumps in her neck, that one of her eyes were dilated and the other eye was closing. They were certain that she had cancer and needed treatment. ■ did not want them touching her as she felt awful, but they took a blood sample and sent us home. A couple of hours later they phoned us and told us to return immediately as the blood tests were troubling and suggested that some of her organs might be failing. When we returned, a second blood sample was taken and she was admitted to ward 2 which was the oncology/haematology ward. I think she was in hospital for nearly a month that time as she was so sick.

Description of Ward 2

12. ■ stayed in ward 2 95 percent of the time she was in hospital. Ward 2 was the haematology and oncology ward in the RHSC. The hospital is a big Victorian building and ward 2 was essentially one big long corridor and was like an old-fashioned nightingale ward. One side had been portioned off so that there were cubicles with glass fronts on them. There were six of these cubicles which have doors on them. There are two beds in the main area of the ward which were for overnight stays and just have curtains round them. Then there were four day-care beds in the same space. They did have curtains but I don't think they were ever pulled round.
13. The cubicles had a door that you could shut for privacy and there was a glass front with blinds that you could shut. They had windows directly out

onto the main courtyard of the hospital which was the car park. The rooms varied in terms of quality. Room 6 was the “high-end” one that everyone wanted, because it had its own toilet and bath and it had space to move around in the room. Room 5 had a toilet and washbasin and it had no window to the outside world, so you had the positive of getting a toilet, but then you got no daylight at all. And then, Room 1 was a big room, no toilet, but it was right next to the treatment room so it got very, very noisy, with all the nurses getting all the treatment together. Then there were the rooms in with middle which were fine but had no toilet. Some of the rooms in winter were absolutely freezing cold, to the point where we sellotaped the window shut, to stop the wind coming in. But equally in summer, they could be utterly roasting, because you'd get the sun coming in. We used to try and get the best cubicle depending on what time of year it was.

14. There were two treatment rooms on the ward. Treatment rooms are where they put together the chemo bags and syringes. They are also where they draw blood from children and do the minor procedures that they can't do in the rooms. At the time we were there, because day-care and the ward were in the same place, they were very busy with day-care patients coming and going. Some of the kids, usually the ones with leukaemia, tended to get their chemo as day-care patients. There were other kids who were maybe in for other procedures, or having an operation, who would be in the day-care beds.
15. Only two of the cubicles had en-suite facilities, so there were two toilets on the wards for the children. There was additionally a bathroom for the children to use. They were at the furthest end of the corridor. There were also two commodes. The trouble with the commodes is that, in most of the cubicle rooms, the commode didn't fit fully into the room so it was difficult for a parent to help a child onto the commode with the door shut and get any kind of privacy. If the child was attached to a drip stand, which they generally were, then you only had so much reach to get onto the commode. We tended to find that, at night, because of the treatment when they were flushing out the chemo, ■ would need to go to the toilet in a hurry and there

was rarely time to get up the corridor to the bathroom or go and get the commode. We ended up bringing a potty from home. ■ was young enough that she didn't mind doing that.

16. There was no toilet on the ward for parents. For infection risk, the nurses wanted parents to go elsewhere so we had to go off the ward and find a public toilet to use, which was in another part of the hospital building. If we wanted to have a shower, then we could use PJ's Loft which was an area for parents which was run by the Sick Kids Charity. It was at the very top of the building. It wasn't ideal as it was a five storey climb up the stairs and it could take half an hour to go and get a shower and then come back. There was a kitchen and a small launderette in PJ's loft, so you could go and wash clothes. There was a little sitting room, showers and bathrooms up there. There were also bedrooms, but we never actually stayed in one of the bedrooms. They were for people who were coming from a long way away. The PJ's loft facility was falling apart by the time we were using it, and it continued to fall apart. For example, there would be one shower that would work, and you had to get out of bed early to try and make sure you got that shower. The windows were rotten and couldn't shut in some of the rooms. It wasn't great, but it was somewhere useful for us to go to and we used it every morning when we were staying overnight.
17. ■ was an inpatient for most of her treatment so we would be with her 24 hours a day. We were part of the care she needed. I mean, there were some parents that didn't stay, but ■ needed additional care from us for the toilet, for cleaning herself, and for entertaining her. There was a fold-down bed for parents in every single cubicle, that you pulled down late at night. It was a comfortable camp bed. There wasn't much room once they were down. There would be two chairs during the daytime, in each cubicle, and at night time, to pull the parent bed out, you had to take the chairs out into the corridor and leave them there so you could pull the bed down at night.
18. In terms of facilities to keep the kids entertained, there was a playroom at the end of the corridor. It was quite a nice, bright room and it had TVs,

PlayStations, things like that. There was big, big bank of DVDs that the kids could take back to their room if they wanted. There were some books, colouring and drawing materials, jigsaws, toys, games. Sometimes you'd have the play specialist come in and they'd do some kind of organised fun for the kids in the playroom or out in the corridor. The play specialist would also come round the rooms each day and give the kids who couldn't make it to the playroom something to do. The staff on the ward let siblings come in and use it too as they felt it was really important that patients could still have interaction with their siblings, especially children like ■, who would be spending a long time in hospital. Sometimes parents are in there for a long time, so actually having a playroom where the "non-sick" child could go and have a play that was safe, was really handy. There was also an area for the Teenage Cancer Trust, but I didn't use this at all as it was for older kids.

19. There weren't any facilities on the ward for parents to use. There was a kitchen, but there were strict rules that parents weren't allowed into the kitchen. We would have to go and ask for one of the nurses to store our food in the fridge. We would have to go and ask one of the nurses to heat our food up for us. We were allowed two cups of tea a day, one first thing in the morning, and one at night, if the auxiliaries remembered, and had time. But otherwise, parents were expected to go out, off the ward, for anything they needed. If we wanted we could use PJs loft, but it was not easy to access. There was the shop, which was close to Ward 2, so you could get sandwiches, drinks and bits and bobs for children. It also had shampoo, and such like, if you'd forgotten anything. Although our ward was wonderful and they always had a supply of things to give you if you'd had an emergency and didn't have anything with you. There was the canteen which I only used it a few times, just because it was a bit awkward to get to. There was also a WRVS shop, down at outpatients, that you could go and get a cup of tea from, and a scone. When the hospital didn't move, they shut it just before and never reopened it for quite a long time.

20. On the ward itself there were a lot of staff. Maybe five or six doctors, from junior doctors to registrars to consultant level. On the nursing staff, I think

ten or more nurses. There were also a number of auxiliaries, student nurses, cleaners, the play specialist and the ward admin lady. I think the nursing/patient ratio was almost one to one and each morning you would be told who your nurse was for that day.

21. The nurses were the most amazing group. We had alarm buzzers in our room, and depending on how urgent your issue was, this determined which buzzer you pressed. There was an emergency buzzer which would mean all staff in the vicinity would drop everything and run. Or there was a standard normal alert button we used if the chemo bag had run out, or we needed help cleaning up a soiled child. Generally, someone would very quickly come along to see you if you pressed the normal buzzer. Some of the nurses were spectacular, in that in their head, they could almost count down to the minute as to when your drip was going to run out and they could get to the room in time to swap over for the next one. It was impressive to watch actually, because it takes a lot of time and effort to put together a chemo bag. For them to be able to coordinate all the children on the ward to be able to get their chemo at a time that allowed them to get their full schedule in, and get them home again, was impressive. The nurses cared, a huge amount.

22. Some of the nurses were trained in how to give chemo. Chemo is really regulated as to how they're able to give it. So, every time that it's given, somebody else has to be in the room to check that the nurse has done their calculations correctly, that they've set the pump correctly and they've signed off the associated paperwork for the chemo. There's a whole pile of student nurses who were pretty much only allowed to carry pee, poo, and a bottle of juice for a child, I mean, there was nothing, really, the student nurses were allowed to do on this ward except observations (temperature, O2 saturation, blood pressure etc.), because it was so specialised.

23. During daylight hours, there would generally always be about two or three doctors on the ward, as a minimum. First thing in the morning when the ward rounds took place, you get far more doctors around at that stage,

maybe four or five at that time. As the day progressed it would be down to about two or three. Overnight, there wouldn't be a doctor on the ward, but there'd be a doctor on call in the hospital, so that they would be called in should something be needed. However, almost every single time we'd get a doctor from the hospital on call pulled in, we'd end up getting a consultant coming from home to come in and help out.

█'s initial treatment: October 2018

24. When █ was admitted we were told she had cancer, and the doctors just needed to work out what type it was so they would be able to create a treatment plan. She had all sorts of tests at that stage: an MRI, a CT scan, a bone marrow sample. She was anaesthetised for those procedures. They also tried to put a Hickman line in her chest, but the position of the tumours meant that wasn't possible, so they put a femoral line in at the top of her thigh. She was anaesthetised for this too and it was essentially a long tube that goes inside the artery, which has a cap on the end so you can administer medicines, including chemo, down directly down that line. I think █'s had a double tap on it, so that she could receive chemo, but blood draws could also be taken at the same time. These lines have to be changed every seven to ten days so the challenge with that is, they had to keep anaesthetising █ every time a new one needed placing. I think █ had to go through seven rounds of chemo before the tumours had shrunk sufficiently to place the Hickman line.

25. █ was in for four weeks during this first admission. In the first few days she was having tests to establish what type of cancer she had and she also had to have blood transfusions as her blood was basically water and her heart was struggling to cope. Once they had diagnosed Stage 4 High Risk Neuroblastoma, a treatment plan was established. Neuroblastoma is a childhood cancer, so you rarely get such a thing in adults. Essentially, at some point, one cell has divided wrong, and has carried on going. It's not genetic; it's not related to any kind of environmental cause. It starts around the neural lines, so it tends to happen around the kidney, and then will go

up the spine. ■ was stage four. She had a huge mass in her stomach, around her kidney, and around her spine. It had spread across to the other kidney as well. It was running up her spine, and there were several tumours around her neck, that were quite significant. It was also in her bone marrow space. So it wasn't the bone marrow that was infected, it was actually growing within her bones, and was taking space from the bone marrow. That was why she was at the point where she had nothing in her blood, because there was no bone marrow to grow red cells, or white cells, or anything like that. This is why she required multiple blood transfusions. Essentially, she had no real bone marrow from around her jaw, to below her pelvis; that whole space of her body had just become cancerous. So when you saw the scans, her skeleton looked black, from the jawline to below the pelvis.

26. At that stage we were told the standard protocol for Stage 4 High Risk Neuroblastoma. We were told it was going to be a nine-month treatment plan, all going well. There would be eight rounds of chemo called rapid COJEC. That would be followed by surgery. Then there would be high dose chemo with stem cell rescue. That would be followed by radiotherapy, and then there would be immunotherapy. ■ would get scans after four rounds of chemo, and then again at eight rounds of chemo, for the doctors to work out what kind of progress they had made in shrinking the tumours.

27. Her chemo started a few days after she was diagnosed. She had to be treated as an inpatient as she was considered too high risk to go home at that stage. Her blood was so thin that her heart was at risk of giving out. She was also at high risk of infection and had no immune system. I think we had about two weeks in Room 1, and then another little boy who was incredibly sick needed that room, so we got moved along to another room. Room 1 tended to be used for children who were quite ill and needed to be observed closely. It was right next to the treatment room, so it was in full view of the nurses, all the time.

28. ■ was getting chemo every ten days, although it took five days to administer the chemo. She would have an infusion that lasted for 24 hours, for five days, then have a few days off, and then start the next one. I think she had three or four rounds of chemo in that first admission. She was also getting blood transfusions during this period and she was getting antibiotics. After a couple of weeks, she also had an NG feeding tube inserted into her nose down into her stomach as she was having trouble with eating. She had lost so much weight before being diagnosed. She was really sick with the chemo and even on the feeding tube we could only administer small amounts as she was being sick so often. She was on a lot of antiemetics to stop her from being so sick all the time. She was pretty much flat on her back in bed during this period and we had to get the physio in to look at her and stop her muscles from wasting.

Treatment between October and January 2019

29. Despite how ill she had been, after four weeks of treatment, the doctors considered that ■ was stable enough to be discharged and she was allowed home. She was back in ward 2 again about three days after being discharged. Because she was on a ten-day cycle of chemo, that meant we were in hospital for five days, home for a few days, back in for five days. We were also under strict instructions that if ■ got a temperature of 38 degrees or more, she had to return to hospital for 48 hours. So we were never far away. On the days when we were officially at home, we would be in for day-care for line care, or an infusion of some sort, or a check-up, or something. I think we only had something like 24 hours away from hospital at any one time. I think of the eight rounds of chemo, there was one where we were allowed to do it as day-care, only. But this meant we were in day-care for ten o'clock in the morning, and left at five at night and this would continue for the whole round of chemo.

30. During this time, ■ had multiple blood transfusions, platelet transfusions, and was getting fluids constantly. She had three surgeries to get her femoral lines changed. She was having biopsies taken from her pelvic bones, so

she needed to be anaesthetised for that too. She also got her Hickman line in during that period, on 8 November 2018. She had to go into ward 3 for a night for this to be done and it was a terrible experience.

31. Ward 3 was a surgical ward but was like a factory of children having operations. It was a dormitory style ward. There was maybe a metre and a half between beds and just enough room for a bed and a chair for a parent, and then there'd be another bed and a chair. There were children in getting their tonsils out or having other minor surgeries, and then you'd have the odd child, like ■■■, who needed additional care. There's just bed after bed full of screaming children, and worried parents. It is noisy and there are lights on all the time. They did let parents stay overnight, but they only had enough space for parent beds next to some of the beds. I wasn't allowed to sleep next to ■■■ and I had to sleep on a parent bed in the playroom at the end of the corridor, with another four or five parents. I kept coming back and forth to see ■■■ and I would sit on the chair with her for a bit. She woke up at a point when I wasn't there, and got very scared and worried, because she'd just had an operation and was feeling awful. Someone helped her to the toilet, at which point she was sick, and she soiled herself and the nurses had to help her out. Then she spiked a temperature and got moved into a cubicle, which I didn't know. I walked back to her bed and couldn't find her, and got very scared. There were three cubicles on the ward which were meant for children who had severe burns and had infection control issues. ■■■, as an oncology patient, when she spiked a temperature, trumped other children in terms of infection risk, and she got moved into a cubicle and they got moved out.

32. There was no obvious infection control protocol for ■■■ as an oncology patient. There were far fewer nurses per patient, compared to what we were used to, and the amount of space they had to move around. On top of that, the behaviour of the parents was different. In ward 2 every parent there knows that the risk of infection is incredibly high so they behave in a certain way that is respectful of others around them. Whereas, in ward 3 it was like being at a public shopping centre, to be honest. There would be

umpteen siblings who'd be running up and down screaming, touching things, moving things, and people coughing on you. It was unpleasantly scary. I'm sure the doctors washed their hands before they came in, and I'm sure the nurses were washing their hands, but that was just one layer of all the various things going on in that space. Luckily, ■ returned to Ward 2 the following day, to start chemo.

33. Once ■ finished her chemo in December 2018 there was a bit of a pause in her treatment. Around Christmas she had a really bad staph infection that had to be treated with antibiotics and then the doctors were discussing what to do next with ■. The oncologists wanted to do surgery, but the surgical team thought it was too risky. The tumours around her kidney were wrapped around blood vessels, and they were concerned that if they were to do it, she would be at high risk of bleeding out on the table. There was a lot of back and forth talking to the team in London, at Great Ormond Street and even discussions of ■ going to America for surgery. So we had a few weeks of not very much happening. We'd get a scan, we'd have a pause, we'd get a scan, we'd have a pause. I think it was about three weeks of nothing, which was quite scary, when there had been such intense treatment and then have no apparent plan.

■'s treatment between January 2019 and May 2019

34. The week beginning 24 January 2019 there was still no firm plan in place, but, as the doctors knew that they would be doing some high dose chemo in the future, they wanted to harvest some of ■'s stem cells so that they could give her some back after the high dose chemo. She had to have a light bit of chemo to make her body produce a lot of stem cells fast and then they harvested them. She had a week of chemo and then she had some blood drawn out through her Hickman line and then a machine sucks all the stem cells out and they are frozen. She was day patient for the chemo and then a week later she was in ward 2 for a couple of days as an inpatient for the stem cell harvest.

35. At this point the doctors decided to give ■ a round of another type of chemo, something called TVD chemo, until they had resolved the issue of the next stage of treatment. It was quite powerful and knocked her for six. We'd get to the point where she'd have the chemo in hospital and know she was going to spike a temperature three days later and be back in hospital. During her entire treatment plan, from October 2018 to August 2020, we weren't allowed to be more than an hour away from the hospital as if ■ spiked a temperature, the risk was that she had neutropenic sepsis. Because she had no immune system at all, she had to return to the hospital and to get antibiotics as fast as possible. Then the doctors would carry out some tests to see if she had an infection of any sort and we would know the results within 48 hours. In ■'s case, I don't think she had any infections during the TVD period, I think she just had drops in her neutrophils because of the chemo and this caused her temperature to spike and make her really ill.
36. The purpose of this chemo was two-fold. Firstly, to stop things from growing while a treatment plan was discussed and; secondly, to try and shrink the tumours a bit further to allow ■ to get some surgery. The oncologist was really determined that she wanted to get surgery before we went to high dose chemo. Because the high dose chemo works on a surface area, the smaller the mass, the less it has to work on, and the more likely it is to be successful. So if they could get in with surgery and just remove some of the material, they had more chance of success. On the other hand, at this stage, the surgical team in Edinburgh thought they had to get a hundred per cent of the tumour out to be successful, but they were really worried about all the blood vessels. After each round of chemo, ■ would be scanned and the surgical team said they were not happy to operate. So ■ ended up having four rounds of TVD chemo, which was more than would usually be given. During the 4th round of TVD, ■'s case was presented to the National Neuroblastoma Team, who discussed her, and said that they had recent evidence that suggested they didn't have to get a hundred per cent of the tumour. If they could just take as much as they could out, safely, that had a greater success rate than not at all. That was when ■'s doctors returned

to the Edinburgh surgical team who said that they would be willing to operate.

█'s surgery: 3 June 2019

37. █ underwent a major operation on 3 June 2019 to remove the mass in her abdomen. It was a seven-hour operation and the surgeons ended up removing one of her kidneys. It went well and the surgeons reckon they removed about 90 percent of the tumour in her abdomen.

38. Afterwards, █ went to ICU for two nights. It was like an open ward so the medical staff could have clear line of sight on all patients. █ had a dedicated nurse and she was very closely monitored. Once they were happy with her she was admitted to ward 3 again which we knew was going to be awful. This time we at least had a bed where I could sleep beside her. She had to go to ward 3 because they had the specialism to deal with surgical recovery, but we begged to go back to ward 2 which they let us do after a couple of days.

39. We were in ward 2 for some further monitoring just because the doctors didn't want to discharge █ so soon after such a major operation. She recovered really well from it and she was also starting to recover from the chemo. She was discharged after 3 more days.

Preparation for High Dose Chemotherapy: June 2019

40. The next stage of █'s treatment was to undergo High Dose Chemotherapy. This was super strength chemo to try and take out the rest of the cancer left after the surgery. Normal chemo will knock you flat for a few days, and then you'll start to see your cell count rebounding. High dose chemo knocks your immune system out completely for up to four to six weeks at a time. Most of the management is about the side-effects that will happen as a result of that high dose chemo. It knocks out your immune system, but it also knocks out your digestive system. It has a high risk of damaging your lungs, so your

breathing is high risk. It is also high risk for your heart and your liver. Part of the preparation for this chemo was trying to get ■ in a good condition, and part of it was also understanding the current conditions of things like her heart and lungs. So the doctors did various tests at this stage to see what her lung function and heart function was so that they had a base level that they could monitor during the chemo.

41. The plan was that ■ would have five days of one type of chemo, an hour's blast a day. She would be an inpatient, so she had to sleep overnight in the hospital, but was allowed out in the afternoon to go to play parks, or go for a walk, so long as she'd return to hospital at night. The next step was for her to get a 24-hour infusion of this other chemo. At which point, she would then be confined to her hospital room. The day after this she would get her infusion of stem cells and she would be in isolation. She would then be in isolation until her neutrophils rebounded. This can take a couple of weeks, or it can take several weeks; it all depends on the child and whether there are any side-effects.

42. When the doctors were deciding ■'s treatment plan, they were having to factor in the move to the new hospital which was due to happen on 9 July 2019. As a result of this her treatment plan was affected. Once the treatment starts it can't stop so the doctors wanted to make sure that she was at a point in the treatment that they could manage her, and the effects of this chemo, the best they possibly could. They carry out the treatment about twice a year, so they had experience. The added wrinkle was that the new hospital was going to be opening during this treatment period. There was a lot of discussion between the team, as to whether ■ should stay in Edinburgh at all, or whether they should move ■ to Glasgow. Glasgow would have added complications for us as a family, but there was also concern at that stage about the infection risk in Glasgow. It wasn't said by the by medical staff, but us parents were very concerned about moving to Glasgow. We were aware of there being reports of infection control problems in Glasgow, in particular in the paediatric oncology department. There were other patients in Edinburgh that would normally be treated in

Glasgow but whose parents had requested treatment in Edinburgh because they had lost faith in the infection control in Glasgow. Parents talk.

43. And so there was that emotional element that they would have to try and manage. They also had to look at how many patients there were in Glasgow and whether they had the capacity to deal with ■■■'s kind of treatment plan which is very resource intensive for staff. There was a discussion about the timing of ■■■'s treatment if we were to stay in Edinburgh. They had to think about the best time to do it. I know there were significant discussions between some of the doctors about whether they should wait until after the move to start the treatment; whether it should start one week before the move; or whether it should start two weeks before the move. The risk of waiting is that there is something horrible growing inside ■■■. There were so many different members of staff involved in these discussions. The oncologist, the anaesthetist, the HDU doctors, the ICU doctors, whoever might need to be drafted in needed to have a say about whether they would have the resources that would be able to respond to a child who's that sick.
44. The decision was made that ■■■ would stay in Edinburgh and the treatment would start one week before the hospital move, because that meant that her neutrophils wouldn't have dropped yet to their lowest point and it would be a safe stage in which to move her between two hospitals.

Information about the new RHCYP

45. At this point in time, all the nurses were going for tours at the new hospital, and had been for months before that. They would go off in groups on various days, and they would come back and wax lyrical about all the different resources, and what there was available. The cleaning staff would come back and rave about how clean they can make things and the auxiliary staff would come back and tell us about the parent kitchen, and the parent beds that were in the room, and the fact that there were toilets and showers in every room. We knew quite a lot about the new hospital at this stage, there

was an awful lot of talk about it. I can't remember if we got a letter from the Health Board about the new hospital.

46. From what we had heard from the staff about the new hospital, we had huge expectations about it. We were really fixated on the Isolation room that ■ was going to be in after the move because we knew how risky the treatment was. We had been told that the isolation room was going to be off a separate entrance to the ward, so there wouldn't be the normal footfall going past the room and the floor where you walked in would be clean. It also meant there was an extra set of doors between the ward and the isolation room, so again the infection risk would be reduced. Then the room itself was going to have positive pressure. That means air couldn't come in from the outside, only air from the room could go outside. That would also lower the risk of infection as dirty air can't be transferred into the room. It was going to be comfortable, it was going to be clean, it was going to be quiet. It was going to be somewhere that we could spend time together. The room itself was going to be ensuite and bigger than what we were used to. There was going to be room all around the bed and facilities for us staying overnight.

47. In terms of the ward itself, there would be a kitchen and somewhere for parents to sit. There was going to be a garden which was amazing as we could go outside with ■ in a wheelchair and experience some outside space. As I understand it, all the ward rooms would be single, ensuite rooms with a child bed and a parent bed and the day-care ward had beds that were in partially closed off rooms as well as a seating area where the kids could have chemo together. The only aspect we were not looking forward to was that we would have to pay for parking.

48. The other good thing that was going to happen was that the charity, CLIC Sargent, had previously had a house opposite the old Sick Kids Hospital. When the big move was originally announced, they'd sold that house in November 2018 and bought another one right next to the new hospital in Little France the same month. That provided lots of space, it provided

bedrooms for families who had come from far away, but it also provided care and emotional support for parents. They were going to be running support groups, and they had a masseuse that would come round, and they would have play specialists. There were going to be additional layers of support. We would be able to access that at the new hospital whereas we hadn't the whole time we'd been at the old hospital because it had been sold to coincide with the original opening date which had already been postponed.

High Dose Chemotherapy and Delay in move to the RHCYP: July 2019

49. ■'s high dose chemo started on the 1 July 2019. She was initially on bed 8 in ward 2 which is was the worst bed. It's one of the beds in the corridor with a curtain round it. It was right next to the playroom and was very noisy. We were there for a week before being moved into isolation. At this stage ■ was allowed out of the hospital during the day and she was really well.

50. On 4 July 2019 my husband phoned me from the hospital to tell me that the hospital move had been cancelled. At that stage we had minimal information about what was happening. The charge nurse had told my husband that all she knew was that the hospital move had been cancelled and ■ would be remaining in the old hospital for this treatment period. I think the staff had been taken into the lecture theatre and told the move was not happening. The following day, my husband and I swapped, so he came home and I stayed in hospital. I was given the opportunity to speak to the Chief Executive of the hospital at that point, if I wanted to. One of the nurses came to me and told me that he was on the ward to speak with parents. I declined, because I didn't think I could manage my feelings at that stage. I didn't know who was at fault at this stage, I had no idea, and I didn't want to let loose at someone who might have had no control over the situation. I think, my husband and I swapped again, a day or so later, and then Jeane Freeman, the Health Minister, was on the ward talking to the doctors. I don't think that she was speaking to the parents, just the doctors, at that stage. My husband decided he didn't want to try and speak to her, because he was

too upset at what had happened. I can't remember if we got a letter or anything in writing from the hospital explaining the delay.

51. We were just flattened by this delay and very, very scared. We'd planned this whole treatment plan around being told these new facilities were going to help manage the risks surrounding the treatment. The medical staff now had to try and manage this treatment in the old hospital with just a few days' notice. The isolation room that would normally be used for this treatment needed to be prepared. There was another child in there, who had to be moved out, so the room could be deep cleaned. Then I think the room had to sit for 24 or 48 hours after this deep clean, because they'd cleaned vents, they'd cleaned windows, they'd cleaned every single surface they could in this room. But it's just a pair of doors off the ward, right next to the playroom. Every single person walks past this door to get in and out the playroom. It really threw us, this idea that, we were already on this train of treatment, we couldn't stop, ■ had to keep going. And risks were now higher. It was a highly emotional period anyway. You know what you're doing to your child, you've been talked through at length, the risk this treatment gives her. But if we didn't do this treatment, then she's going to die. The thought that this new hospital would help to manage those risks was a great feeling. We felt lucky that we were the ones who were going to get to go to this new hospital, and the staff were going to be able to do all these additional things to manage the risks to her. Being told, when the train is already in motion, that those facilities were not for us after all and that we were going to have to stay at the old hospital was a blow.

52. It seemed that the nurses on the ward had no information of what was really going on with the move. They were just as flummoxed as to what they could do. A lot of the trouble they had is that they'd already moved a certain amount of kit to the new hospital, and the staff told us that they weren't allowed to get it back as the equipment was in clean rooms and it wasn't clear how long the move would be delayed. They had to work out how to restock their cupboards. They had had things planned so that they would be finishing up with a certain amount of patients, they'd have a few days'

break to settle into the new hospital, and then get the new patients up and running. Now they were in a situation where they had to make sure they had drugs, kit and materials, for the new set of patients they had been expecting to see in the new hospital. They couldn't pause or cancel treatment, they had to keep going, and they knew they had to get things. There was a huge amount of logistical planning going on. On a personal level for some of the staff, some of them had moved house to cope with this new hospital move, some had changed their transport plans or their childcare plans all to fit around a new hospital, and were finding their lives were in flux as much as our lives were in flux.

53. Around this time the ward was generally in a guddle. Things were getting packed up and moved off and some of the nurses would be charged with packing up and moving things over to the new hospital whilst the other nurses are trying to continue with the normal day to day work. Their heads were in a different space, because they're trying to figure out, logistically, you know, how much of this kit do we need here, and how much kit do we need to have there, to make sure they could cope with this move. It didn't make any difference to the care ■ received. She still had a nurse dedicated to her for the day.

54. In terms of changes on the ward itself, once the move was cancelled, the playroom had gone. The toys and resources had either been packed up or given away or put in the skip because there were new toys and equipment at the new hospital. So following the cancelled move there was nothing for the children to play with until the staff got permission to buy new equipment or bring things back from the new hospital. In relation to the medical side of things there wasn't really an impact on that. The staff knew what they needed for the patients that they had in the hospital, and had planned to keep the kit that would support them. Much of the kit was nearing the end of its life and they had bought new equipment to replace it which was at the new hospital. The existing kit was still in place at the old hospital. They had planned it excellently, and thought of every consequence, and had it in place. They just didn't have any additional stuff, the "just in case" stuff, so

sometimes they might have to go to another ward to get something that would normally have been on ward 2. There was also a lot of kit that was reaching the end of its lifetime in ward 2 as there would be new kit installed in the new hospital. That meant the staff were working with older pumps, sats machines, obs machines, but they were still functioning, they just weren't the brand new "whizzy" stuff that was in the new hospital.

55. At this point in time, there was some chat from the nurses that the move might happen in autumn 2019, but really that was irrelevant to us as we were concerned about what was happening with ■■■ in the present. She was moved into Room 6 on ward 2. Although it was the best room facilities wise, Room 6 was where children go to die. We'd seen some children go in there and not come out so it was a highly emotional time for us, especially given how risky this treatment was going to be. The staff had discussed using Room 1, but it didn't have a toilet so we pushed back hard against that. ■■■ wouldn't have a toilet and as parents we would have to go backwards and forwards out of the room to use the toilet so it would increase the risk of bringing in infection. It was smaller and it was noisy as it was right next to the treatment room and nurses station. So despite the connotations of Room 6, it was the best room for ■■■'s treatment to happen.

56. Although there had been an initial delay of a week in starting ■■■'s treatment to compensate for the hospital move happening in the middle of the treatment, there was no delay to ■■■'s treatment continuing once the move was cancelled. I think that we lost a day of chemo because one of the chemo fridges had been turned off in the run up to the move. Whether we can blame that on the hospital move or not I can't say for sure, but it feels like it happened in the guddle surrounding the move.

57. Once we knew that ■■■ was going into Room 6 she asked to go in early as a charity had bought toys and games for her to use during the isolation period and they were already stored in the isolation room. Although once we were in the room and the doors were shut and she realised she couldn't come out

again, she got very upset at that stage. It's a big thing for a little girl being told that she couldn't leave.

58. Once she was in the room we had to be very careful about infection control. We had to buy new stuff for her to have in the room that was still in its packaging and that could be opened in the room. We washed some of her teddies with antibacterial wash. Every other item that we took in there, we tried to wash at a high temperature. We wiped down toiletries, tablets, mobile phones before we took them into that room. If we were coming backwards and forwards from the room, because we wanted to use the toilet or go to the shop, we had a change of shoes at the doorway. I would leave my bag and coat hanging on a coat hook just outside the room. The staff would wash their hands before coming into the room, and they'd have to wear a pinny before coming in the room. If they had any form of cough or cold, they had to wear a mask. Only essential staff were allowed in, so student nurses were discouraged from coming in and a junior doctor would only be allowed in if there was a clear educational need. There was a real attempt to limit the number of people that were coming and going, and how they interacted with her.
59. Room 6 was one of the bigger rooms and there was a patient bed and then there was space to leave the parent bed out during the day, if we wanted to, as well as room for a chair and a table for ■■■ to sit at. The cleaner would come in every single morning and give the bedroom and bathroom a good clean.
60. Altogether, I think ■■■ was in isolation for four weeks. Towards the end of her admission, she was allowed out in the evenings to walk up the corridor when all the other patients were in bed. At the very end, I think she had a few days of being allowed out on the ward to mix with the other children, but was still an overnight patient. She was in hospital for the entire school summer holidays that year.

61. ■ became very ill whilst she was in the isolation room, although it was expected that this might happen. She started to be very sick, so much so that they had to switch off her food pump, and move her onto something called TPN, which means she was fed directly into the bloodstream, rather than into the stomach. She was put on a morphine drip because they were expecting her to get nerve pain. She started to get temperatures, but these were all expected. The doctors were telling us not to worry and they had it under control. Because she had a temperature spike, they had to treat her with antibiotics immediately, even if it wasn't actually an infection. A few days later they were worried about her saturation levels for her breathing and that was the first sign of a lung infection. She was put on oxygen, and the doctors were trying to work out what was causing her symptoms. They were not sure if she had a bacterial or viral infection and they started her on a broad spectrum of drugs. They were doing x-rays and ultrasounds to try and work out what was causing the infection. They wanted to do a CT scan, but they would have to anaesthetise her to do this. That would run the risk of them having to ventilate her and would effectively mean putting her in a coma which they wanted to avoid if possible. Loads of senior doctors from different departments were in her room discussing what to do with her and eventually they decided to give her an endoscopy under light sedation. They had to take her out of Room 6 for this procedure to be done, which carried with it a risk of infection and I think the results were inconclusive. I think they eventually came to the conclusion that it was fungal, and with various different treatments, they managed to get her breathing under control. She was on oxygen for about two weeks in the end and she was nearly moved to the HDU, although the ultimate decision was that she could stay on the oncology ward.

62. In parallel to the lung issue, ■ also developed a liver condition, which is something that the doctors expected might happen. They were monitoring her weight and the diameter of her tummy daily and this is how they detected this issue. They then treated this with an infusion of drugs that she got every day for 28 days. This continued even after she was out of isolation.

63. In the end, because of these issues that had arisen, ■ was in isolation for a bit longer than she might otherwise have been, but the doctors told us it would probably be between four and six weeks for the total treatment plan, including 1 week before isolation, so she was out of isolation within that period and she was discharged on 12 August 2019. The whole period up to her discharge was about managing her to stop her getting sick. She was having blood transfusions, platelet transfusions etc. For the whole stay, she had one week of chemo, and then everything else was about trying to get her back to some form of stability.

■'s treatment between August 2019 and December 2019

64. Between August and October, ■ was still getting a lot of treatment as a day-care patient. She was getting an infusion every two days for her liver, she was still getting bloods and platelet transfusions regularly. But she was allowed to stay at home and she went back to school for a while. They then had to start preparing her for the next stage in her treatment which was the radiotherapy. She had to go in and get the mask made for radiotherapy. She needed this as they were going to be targeting areas around her neck so they needed to keep her very still. She would be bolted to the table with this mask with only little cut outs for her eyes and mouth and it can be very scary for children, so they started to do some kind of hypnotherapy to try to manage her emotions during the radiotherapy. The purpose of the radiotherapy was to zap whatever's left of the cancer. There was a lot of discussion and planning involved around what the treatment would involve and it took a few weeks to set it all up.

65. The radiotherapy took place at the Western General Hospital as that is where the radiotherapy takes place. It's in the adult cancer centre so not really child friendly, but they did their best. She had a specialist nurse as a buddy and they gave her a Lego kit of the radiation machine and painted her mask like a unicorn. She was there every weekday for three weeks and it was hard but she got through it. I don't think this has changed with the

new hospital opening, I think radiotherapy still takes place at the Western General.

Immunotherapy: December 2019- May 2020

66. The last part of ■■■'s treatment was immunotherapy. ■■■ was due to get five rounds of this treatment as the doctors had identified early on that she was a slow responder so needed more treatment than was perhaps usually the case. This treatment is an attempt to create an immune response to neuroblastoma. There is a protein in neuroblastoma, and the treatment trains the body to identify that protein, and to kill that protein. It should suck up the last few cells of neuroblastoma in the body, but also in the future if anything was to grow back, it would ideally kill it before it gets a handle on the body.
67. To get this treatment, ■■■ was an inpatient and was attached to a syringe driver for ten days and the fluid was very slowly infused into her body. The first cycle can be a bit bumpy as your body reacts to the drugs. ■■■ was actually allergic to it so her first round was very bumpy and she was very sick and her digestive system gave up, which is what always happened when ■■■ got sick. She had to be fed intravenously again and they treated her with antihistamines. Her guts were inflamed and ulcerating and this caused her to develop C.difficile. This meant she had to be in isolation to stop her spreading the infection to others in the ward. She was in Room 1 for this stay and we were in for about 3 weeks due to the reaction that ■■■ had to the treatment.
68. The next round of treatment started again on 6 January 2020. It was planned for ten days, but ■■■ ended up being admitted for three weeks. She got c.diff again and was still reacting to the immunotherapy and this caused her to have a temperature and to feel quite unwell. This meant she had to go on antibiotics, which reacted with the c.diff, and it all just made her

incredibly unwell again. The same was then true with the third round. She got c.diff again, and that caused us a bit of a delay in getting home.

69. Her fourth round was in March 2020, and that's when the whole COVID situation was starting to come into play. She was put into Room 5 as she spiked a temperature and had a cough, but her COVID swab came back clear and we were shipped out of that room because someone had a cough and had to take the room from us. So we got moved to one of the ward beds in the corridor, that just had curtains, and we stayed there for the rest of the admission. Because of COVID, every time a room came free, another child with a temperature would show up, or a child with a cough would show up, and they'd have to get marshalled into one of those rooms and treated in isolation.

70. The fifth round of immunotherapy was in April 2020; COVID had kicked in and the whole ward was on lockdown. ■ had a room for this one, and once you were in, you had to have all your food and drink with you. We weren't even allowed exercise, I think, at that stage. It happened very suddenly, that the parents weren't allowed out. My husband phoned me to say he didn't have any food and had no way of getting any. A charity ended up delivering a whole pile of microwave meals to the parents. It was like this for the whole ten days, but ■ did really well during this round.

■'s ongoing care and experience in new RHCYP

71. After the immunotherapy finished, ■ had a series of scans and we got a call in May 2020 to say that she had gone into remission. She still has considerable follow up care. For the first year she saw the doctor face to face every month and then had a scan every two to three months. We have now moved to a slightly easier regime where we have a clinic every two months and scans every four months. In another year, it will move to clinics every two months and scans every six months and they do that for five years

and then ■ will be on the oncologist's books until she is 18. She will need follow up care because of some of the after effects of the chemo. We know that she will need hormone therapy replacement when she hits puberty and there might be other effects that we won't know about until she's older. She still gets dietitian support and we have access to a physio and support like that.

72. After ■ had gone into remission, we were still attending the old hospital as an outpatient. We no longer attended ward 2 and instead attended at the outpatient clinic. Oncology was the last department to move over to the new hospital so we were still attending the outpatient clinic and could see all the parts that had shut down. We then got an appointment letter which told us that the next appointment would be at the new hospital and it told us where to park and where to go.

73. We have only been at the new hospital (RHCYP) for outpatient clinic appointments, so we haven't been up to the new oncology ward that ■ should have been on back in July 2019. My husband went up to have a look, but I haven't seen it and although it would be nice to see what it is like, I don't want to have to go there. So I can't compare the ward experience in the new hospital to the old hospital, but from what I have seen of the new hospital it is impressive. It is clean, and a big, wide open space.

OBSERVATIONS ABOUT THE BUILDING

74. The old RHSC was not ideal as a hospital, although most of my attention was on the ■'s care rather than the building. The building was irritating, and the toilet situation was horrible as she had to use the commodes and potties. I felt that was really degrading, but as a five-year-old child ■ just took it in her stride, it didn't bother her. The hospital was unpleasant for parents, but then it hadn't been designed to cope with parents; it had been designed for a time of life where you drop your child off at the door and pick them up in two weeks' time. Overall, I think we tended to find that the

building was letting the staff down. I think they were trying to do this tremendous job, and the building was limiting them sometimes. For example, they were trying to look after the infection control, but you'd see plaster coming off walls in places, and the maintenance guys would be around immediately that day, trying to patch things up. It was just a constant job of them trying to patch up things, to try and keep on top of the condition of the building, so that they could do the infection control. I mean, the cleaning staff were tremendous, but there's only so much you can do with the building as it was.

75. There were also the physical constraints of the hospital. There just wasn't enough room. For example, during the ward rounds the consultant comes in, then the registrar comes in, then maybe two junior doctors are trying to look over their shoulder and see what they're doing. A pump then alarms because they need a new change of IV bag and everyone has to shuffle around so that things can be done. Those rooms are only designed for the child, the parent, and one doctor. Another example was if an ultrasound was required and the child was too ill to be moved, a portable ultrasound machine would be brought in and it is huge. To get it into the bedroom, almost all the furniture needed to be removed from the room. If the child is upset and scared, they want mum to hold their hand, but there's no room for mum. On some occasions, I had sit on the windowsill to try and hold ■■■'s hand whilst the doctors/nurses were dealing with her. Those are the kind of things that let the staff down, I felt.

76. Most days there'd be something, either just off the ward, or in the ward, that needed a bit of fixing, and fiddling. Sometimes they'd be fixed immediately, sometimes they might be out of bounds for a little bit, until they managed to fix it.

77. At one point, one of the taps in the treatment room had bacteria, it was the same one that was going on in Glasgow at the time. The water was tested every day and this tap was condemned. We were told about this by the nurses on the ward and we also had a letter delivered to us telling us what

had happened, what they were doing to address it and pretty much telling us not to worry. I got this letter from the Ward Nurse but no longer have it. Some of the parents on the ward were going back and forth to Glasgow and were fully aware of what was going on there. Then there was the period where the Glasgow ward was shut, so a lot of the nurses were deployed into our ward. I can't recall specifically when this was. Our nurses were telling us some of their observations about these Glasgow nurses, and how they didn't want to wash their hands in the taps, they didn't want to use the running water and would use bottles of distilled water. One nurse said to me, that it was like they've got PTSD, and it was as if it was scary for them to be around running water.

78. It was only this one tap that wasn't to be used. We were allowed to use the taps in the bathrooms and in the sinks in each of the cubicles. We never used the water for drinking, it was purely for hand-washing, teeth-brushing, that kind of thing. Generally, the children couldn't reach them because they were beyond the hospital bed, and they were attached to a drip-stand, so they couldn't get them. So, it was the parents and staff who would use the taps and there were sinks dotted all around the ward. Hand-washing was a continuous thing in this place. Something everyone is now used to, with COVID times, but we were already very used to washing our hands regularly. As soon as you came into the ward, you had to wash your hands, you would not have been allowed in by the nurses otherwise. Every time you touched a syringe, every time you touched a pump, every time you've touched various surfaces you would have to wash your hands again. Parents and staff worked hand in hand in relation to infection control, because infection risk is so critical for these children, who had no immune system, and so a normal cough or a cold could be utterly awful to them. If the doctors had a cold, they would come in wearing a mask that day, and they might be wearing a pinny, depending on the infection risk of the child. They would wash their hands before they touched the child, they'd wash their hands as soon as they'd touched the child as well. It was stringent infection control. Every morning the cleaners were going around all the surfaces with disinfectant, and the floors. Beds were changed every single

day, wiped down, cleaned down. When a child left the hospital, the entire contents of the room they had been in were taken out and deep-cleaned, and put back before the next child could come in.

COMMUNICATION ABOUT THE DELAY IN MOVING TO THE NEW RHCYP

79. As parents, we did not have any formal communication from the hospital or the Health Board about why the move to the new hospital had been delayed in July 2019. I only heard about the reasons for the delay from what I read in the press. It was to do with the air exchange in the isolation room, which was one of the critical flaws in the new hospital, and that was the reason why they had to stop the move. It was because the air exchange had been inappropriately put in, and it wasn't going to be sufficient for the needs of that room. I think there were also some comments and jokes from the staff on the ward about the builders in the new hospital being crap. The staff in the hospital were very open and frank with us and told us what they knew, which was not a lot. There was one point that there was some discussion that the hospital would move in autumn 2019, but our oncologist thought it was highly unlikely to happen, and sure enough, it didn't. By that point the staff didn't believe any date that they were told and were just carrying on with their jobs in the old hospital as best they could.

80. There was never any communication from the Chief Executive of the hospital, or anyone in management to us acknowledging the delay or the effects it had on the patients and families. Yes, the Chief Executive had been on the ward at the time of the delay but we were focussed on [REDACTED]'s treatment and too upset to speak with the Chief Exec at that point. It was a similar situation when the Health Secretary visited the ward. I was maybe given a post-it note of someone I could contact in senior management if I wanted to contact them. This was at the time of the delay, but as far as I am aware, we weren't given any other opportunity to speak with anyone from senior management after that. All I was aware of was things that were in the press. I saw the Health Secretary talking in Parliament and I saw quotes

in the press. There was mud-slinging going on, between the politicians, and they were very much talking about the hospital building, but they weren't talking about the patients, and the children, and the effect on those people. I found it incredibly upsetting that they weren't talking about this.

81. I don't think the way that the Hospital/Health Board handled the delay, or the communication of this, was great. I appreciate that a last minute decision was taken to delay the move, and it was taken for a good reason. The staff were communicated with, but the parents were not communicated with. We got the trickledown effect from the medical staff. We did have a wonderful nurse on our ward, who kept us parents informed, but she could only inform us of what she knew. And then, after that first initial communication from her, it was all hearsay. Which is not ideal. It is almost as if management think that because the patients in a children's hospital are children, they don't need to communicate with them. The reality is, behind all those children are parents, and guardians, who they can communicate with, but they don't communicate with terribly well.

82. Since this all happened in July 2019 I don't think we have had any communication from the Health Board in relation to the delay in the opening of the new hospital. In fact, the only thing we have had is a letter from them recently suggesting that we get in touch with the Public Inquiry. I no longer have this letter.

COMPLAINTS

83. I didn't make any formal complaint in relation to the delay, the lack of information surrounding the delay, or the failure to acknowledge the impact on the patients. I did vent my frustrations to the staff on the ward and all the nurses agreed with me. For them, children are the entire reason that they are at work each day. I also spoke to the press at that point, because I was so cross. I wanted them to centre their articles around the children as I felt that element was missing quite badly. It was really frustrating to hear the

politicians and the press banging on about the physical structure of the hospital, and not about who goes in that building, and why this building was important to them. I didn't put a formal complaint into the hospital, because I didn't know whose fault it was at that stage. We were also dealing with an incredibly sick child at that stage, and no complaint I could make would change things. It was not for me, at that stage, to make a complaint, I didn't see the value in it. I hadn't thought about making a complaint later on and, to be honest, seeing the advert for the Public Inquiry was the first time I had felt able to deal with the issue.

EMOTIONAL IMPACT OF THE DELAY

Impact on ■.

84. From ■'s perspective, she had had a shiny new toy waved in front of her, and then whipped away. She was unhappy that she never got to experience all these things that she was told she would experience in the new hospital. Oncology kids have really low expectations in life when they are undergoing treatment as all their opportunities have been whipped away from them, so little things matter. We had been told that a lovely chap had bought a little mini McLaren electric car for the new hospital that children were going to be allowed to drive themselves to surgery in. We'd been allowed one shot on it in the old hospital, and then it got put back in a cupboard because it wasn't appropriate for that space. ■ had been promised a "blue light" in the ambulance when she was being moved to the new hospital and that she was going to be a special VIP patient. She also thought she was going to get a bead for her treatment bracelet to say that she had been in an ambulance. So we had to then manage ■'s emotions as a little girl who had been promised things that didn't transpire. She was very upset when none of those things happened and would often ask when she was going to get to go to the new hospital. When it transpired that she wouldn't get to go at all, that also upset her.

Impact on witness

85. Initially when the move did not happen we were very, very upset. At the time, we were very scared that not moving to the new hospital would mean an increase in risk for ■ who was at a very risky part of her treatment. We had been told by the medical staff that they thought that they would be better able to manage the infection risks in the new hospital, so when that option was removed from us, it was a blow. Then it almost became a bit of a running joke of, "*all the things we could have had*". We used to joke that we weren't worthy of this new hospital.

86. As it transpired, one of the major problems about the new hospital was going to be the room ■ was moving to, from what the press was reporting. That being the case, ultimately, we actually felt relief that the move had been cancelled as that might have actually been a bigger risk for ■. It was a situation where we didn't know where the greater risk was; the old hospital or the new hospital.

87. It was also very upsetting for us that there was no acknowledgment of the impact that the delay in the move had had on the patients, particularly the children.

CONCLUDING COMMENTS

88. It's still incredibly tragic that the hospital move didn't happen properly the first time, because I think it is probable that, if it had, some children might have been saved, or at least they would have been saved a huge amount of discomfort and pain by having the facilities in the new hospital, but that's not for me to say.

89. By not having a hospital move, it caused a lot of emotional upheaval, and concern for patients and their families that was unnecessary. It had already been a very long build as it was. There had already been a previous delay from when it had originally meant to open, and then the move was cancelled

at the last minute. Surely the number of checks that had been done to that point meant they should have been able to catch any issues, and reduce the impact that we were all dealing with later.

90. If the Health board have contracted to someone who is an expert in building hospitals, then you'd expect them to understand the necessary requirements for building a hospital. It turns out that these contractors are behind two hospitals with major flaws. Equally, the health board only builds a hospital once every 50 years, so how much experience do they have within a health board for this kind of project? It seems to be a classic case of public sector organisations trying to project manage something they don't have much experience in. There must be lessons to be learned.

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

Scottish Hospitals Inquiry

Witness Statement of

Peter Landale

WITNESS DETAILS

1. My name is Peter Landale. I was born on [REDACTED]. I am [REDACTED] years old. I am [REDACTED].
2. I am the father of [REDACTED], born [REDACTED]. He is [REDACTED] years old.
3. I live with my wife, [REDACTED], and [REDACTED] in [REDACTED].

OVERVIEW

4. My son is [REDACTED]. [REDACTED] had a brain tumour when he was 2 which affected him quite significantly and as a result he has suffered ongoing health conditions ever since. As a result of the brain tumour [REDACTED] is partially sighted, he has endocrine issues in that his body cannot produce its own hormones, he has no short term memory and he has frontal lobe syndrome which means that, most of the time he is benign, but he can become very aggressive in certain situations.
5. As a result of the brain tumour, [REDACTED] also has an issue in that his cerebral fluid (CSF) which protects the brain, cannot drain from his brain. As a result he has what is called a shunt. The shunt is a pipe that goes into a ventricle in his brain and has a reservoir on top of the head under the skin. The pipe goes to a valve behind his ear which can regulate the pressure in his brain and which can be changed by the doctors if necessary. The pipe then goes over shoulder and into pancreas to drain the fluid. This is all internal, although the doctors can make the pipe external if they need to, for example, if there is an infection they need to deal

with. If the pressure in [REDACTED]'s brain gets too high this can cause issues to his health that can be very serious and needs immediate medical attention. If the pressure is too low then this can result in a persistent headache.

6. [REDACTED] has ongoing issues with his shunt throughout his life and he has had ongoing treatment for this within the Department of Clinical Neuroscience (DCN) within the Wester General Hospital in Edinburgh since around 2015. In 2019 and 2020 he attended the DCN regularly as an outpatient and an inpatient. He is still receiving care and treatment from the DCN and will continue to attend in future.
7. [REDACTED] spent time in Ward 31 in the DCN which is an acute neurosurgery care ward and also a post-operation ward. My wife and I stayed with [REDACTED] during all of his admissions in 2019/2020 as we had concerns about the ability of the staff within that ward to prevent [REDACTED] from becoming aggressive.
8. There are some specific events that I would like to mention. The level of care received by [REDACTED] during 2019 and 2020 within the DCN was far below the standard that we would have expected and the facilities and accommodation within the hospital were also substandard and not fit for purpose. In my view, those issues arose due to the delay in the opening of the new DCN hospital and the failure of Senior Management and the NHS Lothian Hospital Board to properly manage the project and effectively communicate the delay and the reasons therefor. In my view, this negatively impacted [REDACTED]'s experience in the hospital and I will come on to talk about these events in more detail.

FAMILY BACKGROUND

9. I live with my wife, [REDACTED] in [REDACTED]. [REDACTED] currently lives with us due to his ongoing health issues. [REDACTED] is our middle child. We have a son who is [REDACTED] and a daughter who is [REDACTED]. [REDACTED]. [REDACTED] has a good relationship with them.

10. [REDACTED] is [REDACTED] years old. As I say, as a child he suffered a brain tumour which led to whole series of health issues. Despite that he had a happy childhood and was lucky to attend the [REDACTED]. [REDACTED] they taught him how to live as independently as possible.
11. Up until 2019, when he began to suffer from a constant headache, he lived semi-independently in a flat in [REDACTED]. My wife and I also rented out the flat next door and employed carers to live there and assist him when required, although their brief was to assist him as little as possible. [REDACTED] is able to work and currently has a job [REDACTED].
12. When he was in [REDACTED], [REDACTED] was happy in his own company and struggled socially given his short term memory problems. He was, however, popular in the local area and well known in the local church, shops and restaurants. He is missed now that he is living with us here in [REDACTED]. He also liked to go swimming, go to the gym and generally walk around and explore [REDACTED].
13. At the moment he is still working, but what he can do in his spare time is limited as his constant headache is very debilitating.

SEQUENCE OF EVENTS: THE FAMILY'S EXPERIENCE AT THE DCN

Family's experience prior to 2019: 2011-2018

14. By way of background, [REDACTED] had been under the care of a dedicated Consultant Neurosurgeon when he was looked after by paediatrics in the Southern General Hospital in Glasgow. We went there as that is where we were referred when [REDACTED] originally had his brain tumour and we continued to go there until he was transferred when he became an adult.
15. In 2011, [REDACTED]'s care transferred to the Western General. As his needs are very difficult he needs a multidiscipline team. He was transferred to the care of an

endocrine consultant Professor Strachan who is very good and with whom we have a good relationship and there is good communication. He was also transferred to neurosurgery but we have never had a dedicated consultant neurosurgeon look after [REDACTED].

16. In 2013 [REDACTED] started to feel cold all the time and initially Professor Strachan thought it was his hormones and after trying different approaches with [REDACTED]'s medication, he formed the view that it might be to do with the shunt and he referred [REDACTED] to Neurosurgery for them to look at.
17. In 2015 [REDACTED] was seen by Consultant Neurosurgeon, [REDACTED]. [REDACTED] made the decision at that time to change the valve in [REDACTED]'s shunt and that did work, but it has led to a whole series of operations. [REDACTED] was pretty much in and out of hospital constantly with issues with his shunt between 2015 and 2019.
18. When [REDACTED] attended the DCN he was always seen in ward 31. Between 2015 and 2018, Ward 31 was on the top floor of the hospital. One side of ward had about 5 single rooms. The other side of the ward was a dormitory style room with 4/5 beds. In the middle of the ward was the High Dependency Unit (HDU). This was directly opposite the nurses' station and was a bank of 4 beds. Beside the HDU was the treatment room. There was also a staff kitchen which patients/families weren't supposed to use but we did sometimes. There were 4 toilets for approx. 35 patients to use, 2 at each end of the ward and 2 shower rooms. Between 2015 and 2018 the toilets would often be out of order and me and my wife would have to check they were free before taking [REDACTED] to them, so that wasn't an ideal situation, especially as he has diabetes insipidus which means that he needs to take pills to assist him with urinating and it is important that he has access to a toilet.
19. [REDACTED] would be seen as an out-patient and as an in-patient in Ward 31. If an in-patient he would usually be admitted as an emergency as there was an issue with his shunt and more often than not he would be in HDU first. He would then be

transferred to a single room so that we could manage his aggression if necessary. We would also try and get him into the same room as much as possible so that it was familiar for him.

20. In 2018 we were in and out of hospital a lot as [REDACTED] got an infection in his shunt and was very ill.

21. At the end of 2018 he had an operation on his shunt and this was successful. At the start of 2019 [REDACTED] was feeling good and was well.

22. The DCN has never been an easy hospital to go to. In respect of the building itself, it was old, there weren't any waiting rooms and the treatment room was tiny. In the bedrooms there weren't en-suite bathrooms, and the beds weren't big enough to accommodate [REDACTED] who is nearly [REDACTED] and weighs over [REDACTED] stone. Whenever he was an inpatient, we would need to take a big red cushion from his couch to put at the bottom of the bed so his legs could rest on that. The beds didn't fit through the bedroom doors without having to apply some force and in general the building was not in a great state of repair. There were rusty hinges, the TVs didn't work, paint was peeling etc. But we were happy to go because it was a hospital and [REDACTED] was getting treated. We also knew that a new hospital was on the cards.

23. Between 2015 and 2018 we could handle all of these issues because there was a consistency in the staff who dealt with [REDACTED] and it was all familiar to him. There were frequently Registrars on the ward and the nursing staff were consistent. This was important for [REDACTED] given his short term memory issues and his frontal lobe syndrome. It was important that [REDACTED] was not taken by surprise and he requires very gentle handling. As all the nurse and staff knew him, and it was not an issue. My wife and I did not have to stay with [REDACTED] all the time as we trusted that the nurses knew how to manage him.

24. In relation to [REDACTED]'s care, there were also differences compared to the Southern General Hospital. I accept that in the Southern General Hospital [REDACTED] was under paediatric care so probably got more care than is given in adult services. He had consultant who knew him really well and who was the person who mostly saw him when he visited the hospital.
25. In the DCN that level of care wasn't there from the start. We never had a care plan in place for [REDACTED] and he has never had a dedicated consultant. Although we have had dealings with [REDACTED], as far as I am aware he is not [REDACTED]'s assigned neurosurgeon and every time we went to the hospital we would be seen by a different consultant or a registrar. It always felt like there was less of a structure and the staff were always very busy.

Out-patient visits to the DCN between April and July 2019

26. In April 2019 [REDACTED] began to complain of a headache. When he lay down the headache eased, which suggested that the CSF in his brain was no longer draining off and this suggested to us that it was low pressure in his shunt.
27. I would go to ward 31 and ask for [REDACTED] to be seen. We would then have to wait in a totally inappropriate waiting room. As the hospital was preparing to move to the new hospital there was stuff everywhere like boxes and chairs. It was not a great place to be. It was also apparent that there were far fewer Registrars available. We had to wait for a long time to see someone, one time for about 7 hours. When the Registrars eventually came to talk to us their phones were constantly ringing and they were receiving messages calling them elsewhere to deal with other patients and they would often have to leave. They were clearly very busy and it had not been like this when we have previously attended between 2015 and 2018. I would say there was a noticeable decrease in the level of staff. There was also nowhere for the Registrars to talk to us, so they would be talking to us in the waiting room with everyone around or, on one occasion we were seen

in the staircase. It all felt quite chaotic and my view is that, as everyone was so busy, ██████'s case was not given proper consideration.

28. We had a discussion with Dr Mark Hughes, a registrar neurosurgeon, and he made the decision that ██████ should be admitted for intra-cranial pressure monitoring and this was planned for 25 July 2019.

29. By this time, ward 31 had moved to the first floor. It had exactly the same layout as when it had been on the top floor. I was told by staff in the hospital that the ward move had happened because of water issues on the top floor.

Announcement of the delay in the move to the new DCN: 5 July 2019

30. We knew that there was due to be a move to the new hospital on 9 July 2019. I was aware that there was information on the DCN website that a new hospital had been on the cards since 2008. There was also information on the DCN website that the move was due to happen in 2015 and this wasn't actually changed until July 2020 when the move eventually took place.

31. We had not been given any information in any official capacity about the new hospital, what its facilities would be like, or how it would benefit ██████. All we were aware of was that the staff were excited to move to the new hospital.

32. We were not given any official updates about the progress of the new hospital. There was a notice board outside ward 31 which had the date of the opening of the new hospital and this was repeatedly scored out and the new proposed date being written in.

33. As far as we were concerned, the move to the new hospital was due to take place on 9 July 2019. It just so happens that we were in the hospital on 5 July 2019 getting ██████ checked out and we were wishing all of the staff good luck with the

move and that we would see them in the new hospital. There was no feeling from the staff that they had any idea that there was to be a delay.

34. We only became aware of the delay when it was announced on the news on the evening of 5 July 2019.

35. After the move had been delayed we were given no further information about when the hospital might open from the Board or Senior management and the staff on the ward did not seem to have any idea what was happening either. As far as I was aware from having conversations with some of the staff, when the delay happened, Senior Management spoke to them all and thanked them for their hard work, but there was no information about when the move would happen.

36. The staff in the hospital were not able to give us any more information than what was on the news: That the opening was due to happen at the end of 2019, then got pushed back to spring 2020, then moved to July 2020.

37. To this day, I have had no official communication from the Hospital that the new hospital has even opened.

Experience in Ward 31: 2019/2020

38. As planned, [REDACTED] was admitted to ward 31 on 25 July 2019 for the pressure in his valve to be monitored. This monitoring was called Intra-cranial pressure monitoring. This involved putting a pin in the reservoir in [REDACTED]'s head to measure the pressure. This was done over a 48 hour period. The machine used was old and did not have a read out facility which recorded all the results of the monitoring. A junior nurse, or me and my wife, would take the readings and note them down on a piece of paper. The neurosurgeon would then look at the results and they figured out that [REDACTED] had low pressure.

39. There was another occasion later in 2019 when [REDACTED] was having the pressure monitored and the neurosurgeon asked to take a photo of the readings on his phone so that he could record them somewhere. It was another example of the equipment not being fit for purpose and archaic.
40. Following on from the pressure monitoring, the neurosurgeon decided that [REDACTED] should have an operation to replace his valve. This operation was carried out on the 31 July 2019 under general anaesthetic.
41. After the operation, [REDACTED] was returned to ward 31. He was discharged on the 1 August 2019 and this was because he had become quite aggressive after the operation as he was uncertain about what was wrong with him. He had to be restrained and sedated, so it was felt it was better if he was discharged as quickly as possible.
42. It became immediately apparent that, because the staff on ward 31 were not familiar to [REDACTED] and they seemed to lack the experience of the staff who had previously been on the ward during his last admission in 2018, me and my wife would have to be with him all the time when he was an inpatient in order to manage him.
43. [REDACTED] was re-admitted on 2 August 2019 with a stomach ache and it transpired he had an infection in his stomach which required treatment and led to further surgeries. [REDACTED] was an inpatient for around 2 weeks and it was during this admission that the various issues on ward 31 with the facilities, the equipment and the staffing became apparent.

Equipment

44. Between 2015 and 2018 the equipment that the doctors and nurses had to work with wasn't great and not new, but at least it was there. When we attended in 2019 it was clear that there was a dearth of equipment.

45. There was a lack of thermometers available and you would often have to wait 20 minutes for one to appear. There was also only one XXL cuff for taking blood pressure, which is what [REDACTED] needed given his size and inevitably that was not where it needed to be.
46. My view is that all of the equipment had gone to the new hospital and had not been replaced. The staff just thought they would get by. It was distressing for patients and made everything harder work. That was never explained to us, that is just what I thought was happening.
47. What would inevitably happen is that the nurses would appear with their trolley to do their 4 hour observations on [REDACTED]. If this was the middle of the night, they would have to wake him up. They would then realise that there was no thermometer or cuff on the trolley to allow them to do their observations and they would have to go off in search of one. By the time they had found one, [REDACTED] would have fallen asleep and they would have to wake him again. This was not ideal and could upset [REDACTED] and could lead to him becoming aggressive. This never happened before 2019. On previous occasions prior to this, the nurses were always prepared with all the equipment they needed to carry out the observations.

Facilities

48. As I have mentioned, prior to 2018 there were often issues with facilities like individual toilets and showers being out of action, but this seemed to be worse in 2019.
49. In August 2019 during [REDACTED]'s inpatient stay for his stomach infection, there were no showers at all for three days. This was over a weekend. They were out of action because of presence of bacteria. The only mention there was of bacteria was that there were notices on the shower doors and above the taps saying that there was an issue with bacteria. My recollection is that the signs specifically

mentioned the bacteria and the rooms were taped off with yellow and black tape. It was also commonly known on the ward that there were issues with the water but we weren't given any other information about this issue.

50. This was very uncomfortable for [REDACTED] who wasn't able to wash for three days and it was also a lot of work for the nurses. They were having to cart water around to give everyone bed baths.

51. Ward 31 had a regular visitor in that there was a man, who I think worked for Estates, who wandered around testing water and periodically closed down the facilities. There would be a sticker on door or note on door saying closed until further notice. I was aware of him before 2019 and if [REDACTED] was in a single room, this man would come in and test the water in the sink in the room. I don't think we were ever told not to use the water from the sink in the bedrooms at any time in 2019 or prior to 2019.

52. Other than the notices on the doors of the showers, we weren't given any other information about the bacteria. There was no apology or anything from the medical staff or from the Hospital.

53. On a more regular basis, the toilets would be closed and we would check whether they were open/free before taking [REDACTED] along as he could get cross if he was taken along and they were not available. Because he has diabetes insipidus, he needs to have regular access to a toilet to help him manage this condition.

54. A big part of our management of [REDACTED] was trying to keep him calm and these were all things that could potentially set him off. [REDACTED] never lost his temper because he could not get a shower, or go to the toilet, but it is when things are uncertain that he can react. During this period he would become aggressive mainly because he could not understand why he wasn't getting better. There were a number of occasions during this period when there was up to ten nurses holding him back. If I am there I can help in managing him, but often he has to be sedated and he can take days to recover from his outburst.

55. The other point is that the availability of showers and toilets are important. They are part of our dignity. We accept that hospitals are difficult places to be, but the facilities in the DCN were poor. Even when they were working they were poor but it was much worse when they were out of order.
56. Another issue that was clear in summer of 2019 was that, after the new hospital did not open, there must have been budget released to carry out repairs in the DCN. My view is that, because the hospital was due to move in July no work had been done on the old hospital. When the move did not happen, the old hospital had to have money thrown at it to keep it going. Throughout August/September 2019 there were constantly workmen going about and lots of work going on. There was a constant movement of people and it was not a restful place to be.
57. The nurse in charge of the ward was having to manage all of these works, along with her own staff and that must have been difficult for her.
58. The reality is that the building was not fit for purpose and these remedial works made no real difference to the hospital and it did not make anything better for the staff and patients.
59. At least one of the dormitories in ward 31 was being refurbished. This meant that the waiting room in ward 31 had been taken over by the contents of that dormitory and it remained that way for some time. Even once [REDACTED] had been discharged and we were coming back in as an outpatient to be seen, we couldn't wait in the waiting room as it was full of stuff. We had to sit on a plastic chair on the staircase to wait to be seen.
60. There was one occasion during this period when we were at the hospital having seen as an outpatient and he was feeling sick and dizzy. There was no waiting room available and [REDACTED] had to sit on the floor whilst waiting to be seen. When

the neurosurgeon came to talk to him, there was nowhere to speak to him in private so he was just talking to [REDACTED] in front of everyone else who was waiting.

61. Another example was that the treatment room was not fit for purpose. It was a small room anyway, and when the move did not happen in July 2019 it seems that the treatment room became something of a storage room for stuff that had maybe gone to the new hospital then had had to come back. If [REDACTED] needed to go into the treatment room for any reasons then we would have to spend five minutes clearing a whole load of equipment and boxes out of the way.

62. The staff coped with it all brilliantly and they would make general comments that it was hard work dealing with the uncertainty of the move and the ongoing remedial works. We would also chat in general about how appalling it was that they hadn't moved to the new hospital but they did not seem to have too much idea about when the move might actually happen.

Facilities for Families

63. As my wife and I were so concerned for [REDACTED]'s care and the need to manage him, we looked after him on a full time basis whilst he was in hospital. Generally my wife would do the day shift and I would do the night shift.

64. As [REDACTED] is an adult and was on an adult ward, we did not expect too much as it was unusual for a patient's family to be with them 24 hours a day and the ward was not set up for that, which was fine.

65. There was no bed in the room for me to sleep on, there was just a chair that pulled out a bit. We would use the toilets on the wards, we never needed to have a shower in the hospital.

66. There was a cafeteria, but I didn't really use it and it was shut at night. I used to go to a pub near to the hospital for something to eat. I would get biscuits and a cup of coffee or something on the ward round but I wasn't expecting anything.

67. The facilities weren't great, but they never have been. There were vending machines and things like that, but I was more likely to bring food in with me.

68. I have no idea what the facilities are like at the new hospital.

██████'s treatment between August 2019 and April 2020

69. After his admission in August 2019, ██████ continued to be in and out of hospital with issues surrounding his valve. He ended up having an operation on 4 October 2019 to relieve the pressure in the valve and then another operation on 12 November 2019 to change the valve and the anti-siphon device. There was a slight improvement to ██████'s headache after this, but it didn't last long.

70. ██████ referred ██████ to a paediatric neurosurgeon, Mr Kaliperumal, who was meant to have more experience in dealing with the new type of valve they wanted to give ██████. He was based in the Sick Kids hospital, not the DCN. He met with us at the DCN. The appointment was meant to be 45 minutes, but as he was coming from the Sick Kids, he was 15 minutes late, he spent 15 minutes with us and then he has to leave to get back to the Sick Kids. It was the usual story of the medical staff being extremely busy all the time. He apologised, but very briefly discussed a new valve with us, gave us some technical papers and then left. He decided that he was going to change ██████'s valve to a prograv 2.0 which is what has now.

71. ██████ had his operation to change the valve on 7 January 2020. I think he was discharged the following day.

72. After that, he was in and out of hospital to have the pressure changed in his valve. This was all done on an outpatient basis. Some of them took place in ward 31 in the treatment room and some took place downstairs in the outpatient ward.

OVERALL EMOTIONAL IMPACT ON [REDACTED] AND HIS FAMILY

Overall impact on [REDACTED].

73. We try not to talk about [REDACTED]'s experience in the DCN, but he has mentioned that it was something that he didn't enjoy. The substandard facilities and the issues with poor care and equipment certainly made his stay much less comfortable. It has impacted on his views on going into hospital and we will have to manage that the next time he needs to go into the new DCN.

Overall impact on Witness

74. Our experience in 2019 had a pretty detrimental effect on our views of DCN. It has affected mine and my wife's ability to handle hospitals and I dread to think how we would have coped if we did not have a strong marriage and access to the necessary resources to manage the situation.

75. As we were so concerned about the care [REDACTED] was receiving and the apparent inability of the nurses to manage his aggression we had to step in and effectively care for him 24/7.

76. My view is that, if we hadn't done that, there is a very good chance that [REDACTED] might have been taken out of our care and either sectioned or permanently sedated.

Overall impact on wife

77. My wife is feeling very stressed about ever having to back to the hospital. If we had to go back to the Western General I don't think I could get her to go.

78. She is also carrying the burden of being ██████'s full time carer. She has only had 4 days away from him since April 2020. Whether this is to do with his condition, or has been impacted by ██████'s experience in 2019 we don't know, but he has lost his independence which places a burden on my wife.

79. We accept that ██████ can be very difficult, but in 2018 we could go home and leave him in hospital in the care of the nurses and in 2019 we couldn't. We felt that was because of the general feeling of chaos on the ward which made it too difficult for us to get the right level of care for ██████ from the staff.

80. We are going to have to get over our stay in the DCN in 2019 and prepare ██████ for any future stays that he might have.

81. I think that us being involved in the Inquiry could also make things potentially difficult as we are going to have to deal with NHS Lothian in future when his care continues.

Overall impact on wider family

82. Both of ██████'s siblings have been affected by this. Both of them are pretty angry about ██████'s care. They understand within reason that we have to deal with the NHS and that we have to deal with what we've got. The system is the system. They have suggested that we go elsewhere for ██████'s care and, although we have had a private consultation I am not sure that it really works.

COMMUNICATION: DELAY IN MOVE TO THE NEW HOSPITAL

83. The Communication from the Board in relation to the move and then the delay of the move to the new hospital was non-existent. Everything I heard about it was on the news.

84. The staff on the ward did not know anything either and there was no information on the DCN website which was still saying the new hospital would open in 2015.

85. I have had no updates about the new hospital and, as I have said, I still haven't had any information from the Board to say the new Hospital has opened. This is even despite the issues I raised with the Deputy Chief Executive of NHS Lothian, Jim Crombie and the Interim Chair of NHS Lothian, Esther Robertson.

COMPLAINTS

86. I did not make any complaints in the ward to the Head Nurse. There were some occasions when she would come into [REDACTED]'s room and see that his headache was bad and she would get on the phone and ask a doctor to come and see [REDACTED]. But I would never go running to her with issues as she was so busy dealing with everything else on the ward.

87. I did make some complaints directly to the Board about the care that received in the DCN in summer 2019.

88. I wrote a letter to Brian Houston, the Chairman of NHS Lothian on 1 December 2019, and which I copied to all of the members of the NHS Lothian Board, expressing my dismay at the delay to the new hospital opening and the poor facilities in the DCN. I also sought assurances that the new hospital would open in spring 2020 and that the Contractors who had been appointed were up to the task.

89. Brian Houston responded on 12 December 2019 apologising for the poor conditions in the DCN and accepting that it was not an ideal environment for [REDACTED]'s care. He then went on to say that it would depend on the Contractors whether the work was completed by spring 2020 but he was confident that the deadline could be met. He also offered me a meeting with the Deputy Chief Executive, Jim Crombie.

90. I met with Jim Crombie in February 2020. I met with him in an attempt to understand the timescale for the move to the new hospital. I also went with the intention of telling him that he had a poor culture in DCN which had built up over a period of time. He didn't want to hear about the culture. He was more interested in telling me that they were on schedule to move to the new hospital in spring 2020. He tried to impress how devastated he was that the move didn't happen and I told him that the move didn't happen because he screwed it up and he now needed to make sure that the move did happen. His response to my concerns about morale was like water off a duck's back. My view was that he was telling me that it was his problem, not mine and when the new hospital opened, all his problems would be solved. That was the tenor of the meeting and I was trying to be helpful by saying that there was a wider problem.
91. I don't think the meeting was ever going to achieve anything. He offered me access to his mobile number and the number of the acute services nurse. She did text me to ask what [REDACTED] needed, but by speaking to her, I would have undermined everyone in the DCN who had worked to make things happen for [REDACTED] and I wasn't going to do that.
92. I wrote a letter to Esther Robertson, who was Brian Houston's replacement, in May 2020. I was prompted to write this letter as there was a press release saying how wonderfully they had done to get the new hospital open ahead of time and I thought "*You've got to be kidding me, who wrote that?*". Staff and patients would be looking at it and saying "*You are miles off the pace*". This letter was me venting to them to stop it and get their website and operation under control and stop these press releases saying how wonderful the management team was.
93. The response I got thanked me for my letter and said that the points raised would be addressed. I wasn't getting any real answers to any of my concerns. I took the website as a litmus test. I told Jim Crombie about the information on the website that the hospital was opening in 2015 and I also wrote to Esther Robertson

about it. It wasn't changed until the hospital moved in July 2020. I felt that it showed how management's finger was not on the button and they were nowhere close to communicating with patients, staff and potential staff that they were sorting this problem out. They had a blind spot to the fact that they had a problem. At this stage I thought about attending a Board meeting but I felt like I would be hitting my head against a brick wall and then the Public Inquiry was announced and I thought that it would be a better way to get some answers.

94. I have not had any further communication from the Board as to how they are working to resolve the issues that I raised with them. To this date I have had not one single communication from NHS Lothian about what is happening with the new hospital.

95. I am not a member of any patient/family representative groups.

CONCLUDING COMMENTS

96. ██████ had a terrible time in the DCN in 2019. His care was poor and he shouldn't have been subjected to that in the UK. My feeling is that intrinsically the fault lies with Board, Scottish Government and how the new hospital was procured.

97. Senior Management identified a problem with the DCN in 2007 and there have been no repercussions in relation to the fact they have failed dismally to deliver on a service. The result was what happened in 2019 and we were in the thick of it.

98. The facilities and environment we were provided with during the period of the delayed move also had a detrimental effect on staff. There were many occasions when things happened, such as losing the Progav 2.0, the incorrect prescription of medication and the loss of the device to change the valve setting on the Progav 2.0, where it would be fair to conclude that the non-move had a detrimental effect on the staff's ability to provide an adequate service.

99. I feared that none of that would ever come to light and the Board and others would walk away saying they had done well in building a new hospital and all the issues would be buried. Hopefully the Public Inquiry will look at all of these issues.

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

Scottish Hospitals Inquiry

Witness Statement of

Abhishek Behl

WITNESS DETAILS

1. My name is Abhishek Behl. I was born on [REDACTED]. I am [REDACTED] years old. I am [REDACTED].
2. I am the father of [REDACTED]. [REDACTED]'s date of birth is [REDACTED]. She is four years of age.
3. I live with my wife, [REDACTED], and [REDACTED] at our home in [REDACTED].

OVERVIEW

4. My daughter is [REDACTED]. At just 6 months old, following a number of seizures and other episodes, [REDACTED] was diagnosed with a one in a million neurological condition – Alternating Hemiplegia of Childhood (AHC). Only 2 children in Scotland and 55 in the UK have the condition. It involves many neurological symptoms, including paralysis, dystonia, seizures, ataxia, global development delay, epilepsy, and life threatening apnoea (breathing difficulties) requiring intubation and ventilation in Intensive Care.
5. Since being only 5 days old, [REDACTED] has been a regular attender at the Royal Hospital for Sick Children (RHSC) in Edinburgh, both as an in-patient and as an out-patient. During her many in-patient stays, [REDACTED] has most regularly been in ward 7 of the hospital, which is the Neurological ward, though she has been in several other wards.
6. I can speak to the impact on [REDACTED]'s treatment as a result of the delay in opening the new Royal Hospital for Children and Young People (RHCYP). I am also a member of the Family Council at the hospital and, in this capacity, I was able to

have a familiarisation visit with the Council to the new hospital and see the improved facilities that it would provide.

FAMILY BACKGROUND

7. ■ lives at home with me and my wife ■. She is our only child. ■ is a hospital doctor, but she is in geriatrics and internal general medicine, which is totally different from paediatrics. ■ is currently doing research work, studying for her PhD in dementia and Alzheimer's disease.
8. Despite all her challenges, ■ is a really happy child. She is bubbly and a people's person, always chatty and she loves interaction with people. She's strong and full of life and laughter. It can be really difficult for her when her condition causes paralysis or dystonia, but she is remarkably robust and has a high pain threshold, meaning that we need to take extra care if she has any bumps or accidents, because she doesn't always cry or indicate if she has done herself any damage.

SEQUENCE OF EVENTS: THE FAMILY'S EXPERIENCE AT THE OLD SICK KIDS HOSPITAL

9. Our experience with the Sick Kids hospital began on 4 August 2017 when ■ was only 5 days old. She went to A&E with twitching in her legs, known as fasciculations, and jaundice. In the first year of her life, she would go on to have about 40-50 blue light ambulance trips to A&E at the hospital, as we had to call 999 when ■ experienced severe neurological episodes/seizures.
10. On that first trip to A&E, it was one of the medical staff from neurology, the registrar ST5 or ST6 grades I think, who dealt with ■. We had actually taken a video of the fasciculation as sometimes the symptoms last only for a certain period so don't show by the time we're at the hospital. From ■ being very young, we have made loads of videos of the episodes, because we learned early

on that ■■■ would often be fine by the time we reached the hospital, so it was better that we would have the video to show what had been happening. If an episode is not controlled within a certain time, it can end up as a seizure.

11. There was no treatment needed for her neurological symptoms during that initial visit, as the episode had stopped, but the video, and future videos of different symptoms, that we had taken gave the consultant the first indication that ■■■'s condition might be related to a channelopathy, a neurological condition. This, and her seizures not responding to anti-seizure medication, are what led to getting genetics testing.
12. My wife explains a channelopathy as where, in the cell membrane, you have various channels of different kind of pumps that move the ions, like potassium, magnesium and calcium, in and out of the cell. Because of that movement, they might set off a chain of reactions where you suddenly then start contracting a muscle, or you start sending a nerve signal. If there is a problem in those channels, in the pumps that pump things in and out of the cell, then that's what they call channelopathy. It's a massive term covering different conditions, but ultimately they all have a problem with the channel and the ions going in and out of the cells, or the direction of movement, so you might not get the right signal for a nerve conduction to trigger the right movement, or it might trigger seizures.
13. I can't recall the balance between ■■■'s in-patient stays and the outpatient visits but she was often an in-patient, for the likes of 5 or 10 days at a time. The treatment often involved prolonged electroencephalograms (EEGs), which monitored brain activity. It was ■■■ who would stay over with ■■■ because she was breastfeeding at the time.
14. With the frequency of visits, ■■■ now has an anticipatory care plan. This means that the Ambulance Service knows her situation when we call them from her phone, which is in her red bag. This red bag is her emergency bag, which basically has all her medications, her epileptic drugs, oxygen, her SATs monitor, her suction and basically everything she needs. And when we give a call 999 from this phone and it goes to the emergency services, they ask us the normal first few questions and then they have an anticipatory care plan that pops up for

them as well, about [REDACTED]'s condition. So we as parents don't have to explain each and every detail of what the condition is all about, each time. It's a great platform.

15. [REDACTED] is on a large amount of medications, maybe more than 25 medications a day. This takes a lot of planning and stocktaking, because the meds have short life spans and we need to ensure that they are used in the right order. We have two cupboards dedicated just to [REDACTED]'s meds and we have a book that we have maintained since she was just two years old, where we keep a careful record of everything that she is given.
16. [REDACTED]'s first severe seizure was in October 2017, when she was around 10 weeks old. She stayed in ward 7 of the hospital for a few days while they did EEGs on her but the doctors couldn't find anything at that point.
17. [REDACTED] had further episodes in the weeks that followed. She had several hospital admissions, roughly every four days, into November 2017, including when she was an in-patient to allow the hospital to do a prolonged EEG in order to capture imagery for her seizures. Despite what were becoming continuous episodes and seizures, and an MRI scan which is quite rare for such a young child, they were still unable to diagnose the cause.
18. The pattern of further admissions, sometimes for several days at a time, continued over the next couple of months, as [REDACTED] continued to have episodes and seizures and the consultant continued to do tests. Eventually, in February 2018, when [REDACTED] was 6 months old, the diagnosis of Alternating Hemiplegia of Childhood (AHC) was made.
19. After the diagnosis, [REDACTED] continued to have episodes each week. An episode would often involve her arm going straight, her eyes deviating and going to the left, like nystagmus. Episodes could develop into seizures, which could be severe, especially when they resulted in apnoea and [REDACTED] would become dystonic and her chest wall would tighten.
20. The seizures can also involve respiratory arrests, when [REDACTED] requires intubation and ventilation in Intensive Care. This has happened six times and it is really distressing for us as well as [REDACTED]. My own view is that there should be more

support for parents in this situation, counselling perhaps, because there's nothing to prepare you for what this condition brings to your life and that of your child. It's important that we remain calm around [REDACTED] and this can be really difficult when witnessing her seizures.

21. In May 2018, there were only one or two admissions that I can recall, although there were more outpatient appointments. There was also a 5 day ambulatory EEG at home, which was to avoid a further lengthy hospital stay.
22. There were fewer admissions over the following year or so, though there was a brief admission to the Cardiology ward of the Sick Kids hospital in Glasgow in May 2019. Cardiology is shared between the Glasgow and Edinburgh hospitals and this was for [REDACTED] to have a cardiac monitor implanted, between her stomach and chest (under her chest wall), meaning that the symptoms during an episode or seizure could be relayed directly to Glasgow and recorded. It's a very impressive system.
23. During this admission, which was for two or three nights, [REDACTED] was woken very quickly from the general anaesthetic, which is not good because sleep is such an important factor with her condition. She began to deteriorate and ended up in Paediatric Intensive Care Unit (PICU) after going into respiratory arrest. We had a very bad experience with [REDACTED]'s treatment at the Glasgow hospital, including when she was left for about 40 minutes in PICU while the nurses were chatting with each other about what to do and my wife [REDACTED] had to intervene to say that they needed to put suction in her mouth before she choked with the frothing that we could see. She also had a seizure for almost an hour and there was a delay in administering medications to get her out of it. In PICU, no one came from Neurology to see [REDACTED]. Eventually the Neurology consultant came the next day, but said to us that we should give notice when [REDACTED] was coming in, as if we could predict these kind of emergency things. The facilities in the Glasgow hospital during our stay were great, like a 5 star hotel, especially compared to what we were used to in the Edinburgh Sick Kids, but our experience of [REDACTED]'s treatments was horrible. We did consider making a formal complaint but we didn't have time to do that.

24. I guess that a positive from our brief Glasgow experience was that it highlighted even more how great the medical treatment was that ■■■ was getting in the Edinburgh hospital. Maybe if we had a longer time in the Glasgow hospital we'd have seen problems with the building, but we stayed in the Ronald McDonald facility, which was great and the staff were really helpful, so our issues with the Glasgow hospital were only about ■■■'s treatment.
25. The pattern of ■■■'s attendance in Edinburgh Sick Kids continued and in June and then July 2019, she was taken to A&E and then PICU as she was not breathing. This happened regularly and she was treated. We were told to pay careful attention to ■■■'s condition after she was discharged home from PICU, as the following 24 hours were always critical. But they said that if anything happened, we should not return to that hospital and the new one would be open the following day and we must take her to the new accident and emergency as the old one would be closed. Everyone knew that the move of the hospital was due to take place at some point in the next 24-48 hours, though not when, but we could see that staff were literally packing up lots of kit, equipment and toys and things, and the staff themselves seemed excited that move was actually happening. The news was very sudden after so many prior delays.
26. Later that day, or possibly early the following day, we were astonished to read a friend's post on social media, I think it was Facebook, highlighting the news that the move wasn't actually happening after all. I don't recall the details, only that the move was delayed, and I don't think it gave timescales. We found this difficult to believe as it was a matter of hours, and certainly less than a day, since the nursing and medical staff had been saying that the move was going ahead the next day.
27. ■■■'s next attendance was in August 2019, because she was struggling to swallow. Her tongue would sometimes become dystonic, so a kind of contraction, needing hospital treatment for fluids as she couldn't swallow and she was admitted for several days on this occasion. By this time, it was noticeable that the wards had virtually no toys to keep kids occupied as they had been disposed of in preparation for the move that didn't happen. Keeping a child occupied when there are no toys or anything to distract her attention just added to the challenges.

Also, the WRVS coffee shop had shut down in preparation for the move and so there was limited options for parents in hospital with their child to get refreshments.

28. Regular visits for various treatments continued to the old hospital until February 2020, including surgery in January 2020 for placement of a gastrostomy feeding tube in her stomach, but were minimised from March to June 2020 because of the Covid pandemic. In August 2020, there was a further admission to A&E when [REDACTED] had stopped breathing and required ventilation. There followed mainly out-patient appointments for the remainder of 2020 and there was a period going into 2021, when some out-patient appointments were at the new hospital and some at the old hospital, depending on what was being treated.

29. It was in March 2021, more than 18 months after the move was supposed to have happened, when [REDACTED] was actually admitted to the new hospital for the first time. We were actually the first people in the EEG (neuro-physiology) department at the Neuro ward and [REDACTED] was actually given a certificate for being the first patient they ever had at the new place. She had several days stay as an in-patient, including for EEG monitoring, and then later had another stay (10 day stay) at the end of March/start of April. She has had further out-patient appointments since then.

Facilities at the old hospital

30. [REDACTED] was most often admitted to ward 7, the Neuro ward. It had 12 beds, with six, four and two across three cubicles, one of which was for EEG monitoring. It was important for the nurses to be able to see [REDACTED] so she was generally in the bay with six beds, as this was nearest the nurses' desk.

31. When [REDACTED] was staying over at the hospital with [REDACTED], most of the time she slept beside [REDACTED] in [REDACTED]'s bed. [REDACTED] was offered PJ's Loft to stay in, but it was quite a distance away and [REDACTED] was breast feeding so didn't want to be away from [REDACTED]. I think [REDACTED] did use PJ's loft once just to get some rest

but most times she was given a room sharing with someone else. It was a room with two beds, and you'd basically have someone sleeping in the next bed. They wouldn't mix sexes but I thought that was terrible as parents couldn't always be together if no space.

32. ■■■ was often in different wards at the hospital. She's been in wards 4, 5 and 6 at various times. This was generally if she had been admitted with a bug or infection, and needed to be in a single cubicle. There was only one such cubicle in ward 7 so it wasn't always available. When she wasn't in the Neuro ward, it was never a good experience. There would be lights on at nights, flashing lights from SATs monitors and other equipment and lots of things we didn't have to contend with in the Neuro ward, as they understood her condition. Flashing lights were a trigger for some of ■■■'s episodes but staff in the other wards wouldn't always understand this and, if we asked them to switch some of the lights off, they'd say that they needed to keep them on. As ■■■ needed a cubicle for limiting triggers and waking from sleep which is dangerous, we would often be put on another ward that had a cubicle and be a 'boarder.' It was not a good experience being a boarder. If we buzzed for advice or reviews, they would often not send the ward staff in and instead call neurology who might not be able to come to the ward for some time. Some nurses were excellent, but some made you aware that you weren't on the parent specialty ward and were a 'boarder' so they didn't learn about ■■■'s condition.

33. The WRVS canteen was fine to a point, before it closed. There was a kitchen facility in PJ's Loft, but it was difficult for ■■■■■ to get there when she had to be with ■■■. Quite often, I'd get ■■■■■ a takeaway, maybe a pizza or Chinese or something like that, to keep her going, however no hot food was allowed on the ward so we struggled to find a space to eat. Food was a real issue for ■■■■■ when she stayed at the hospital. She would be given breakfast, which was basically cereal, but left to her own devices for the rest of the day, despite the fact that she was breastfeeding ■■■. The canteen closes early most days, around 5pm, and at the weekend was often only open for a half day. There was a microwave, but it was supposed to be for patients only, so we didn't want to get staff into trouble by asking them to heat anything for ■■■■■,

taking them away from their duties. As it wasn't easy for [REDACTED] to leave [REDACTED], often she just had to wait for me to come in with food and she hadn't eaten anything except her cereal in the morning. It wasn't a good situation. A baby needs breastmilk at that young age and the mum needs foods and fluids to be able to give the baby nutrition. Sometimes there was left over food on the trolley that was going back to the canteen to be binned, and once or twice the nurse gave [REDACTED] some of the leftovers as she could see she hadn't eaten and was breastfeeding [REDACTED]. Sadly, those nurses then got into trouble for doing that.

34. Even getting drinking water for [REDACTED] was a challenge when we were there as there were no kitchen facilities for parents on the wards and the tap water in the toilets was only for washing and not for drinking. [REDACTED] had to ask staff to fill her water bottle for her, which again wasn't ideal when the staff were busy. When breastfeeding it is vital that the mum drinks lots of water otherwise there can be difficulties in maintaining breastmilk supply.
35. Before the planned move, facilities for the kids were actually pretty good on ward 7. There was the play room and play staff and there was stuff that catered for all ages, from babies and toddlers to young adults. There was a PlayStation, DVDs, all that kind of thing, so plenty to keep the kids occupied.
36. The lift in the building was poor. Often it wasn't working and, even when it was, it was the slowest lift you could imagine, to the extent that a lot of people just didn't use it.
37. Other facilities that you take for granted these days, like facilities for breastfeeding mums, just didn't exist. Most mums want privacy for that kind of thing, but their options were limited.
38. Overall, I think that the old hospital just felt like a makeshift place, where they knew for years that a new hospital was being built and they just basically made do with what was in the old place for as long as was necessary. From a non-medical point of view, I think it was very poor and the nursing staff did well just to keep it functioning.

Deterioration of facilities at old hospital

39. I mentioned that the toys had been removed in July 2019, in preparation for the move. I think it was for health and safety reasons that they couldn't be taken to the new hospital. The nurses actually gave [REDACTED] a bouncing ball she sat on that she really liked and we were able to take it home or it would otherwise have been disposed of. This was good but it became really difficult to keep [REDACTED] amused over the long period that we had to go back to the old place.
40. Thankfully the play staff were still there. In Neuro, we had Audrey. She is brilliant and she has known [REDACTED] since [REDACTED] was only days old, so Audrey can work around the lack of toys and keep her entertained. But there were other kids in there and, without toys and without books, it must just have been really difficult for them.
41. Another big loss was the WRVS cafeteria. It had actually closed before the planned move, I can't recall precisely when, but it just removed another option, especially for [REDACTED] when she was staying in the hospital. So we had to go out to the shops and fortunately there was a Victor Hugo café out at the Meadows so at least there was somewhere we could get food.
42. The main cafeteria was impossible for someone in a wheelchair to get to, stuck upstairs at the back of the building. It was crazy that it was put there in the first place.
43. We were lucky to have the Sick Kids Charity shop, but they only had a limited range of sandwiches and if you were a bit late, then everything was gone. The option then was to go outside but that meant leaving your child and if you were there on your own, this was difficult and you had to ask a nurse to watch your child when you were away. With [REDACTED]'s condition, many of the nurses were unfamiliar with it or what to look for in her symptoms so it was not easy to leave her. They were also often very busy covering the ward and didn't have free staff.
44. There was an impact on the medical equipment too. [REDACTED] had an MRI scan in July 2019 while being intubated in PICU. The staff had told us that the MRI equipment was newer and much more sophisticated at the new hospital and they said they would have preferred doing [REDACTED]'s scan at the new place, because it would

provide better imagery. ■■■'s hasn't actually had an MRI at the new hospital but I think that is because her needs have changed and she has a different consultant. But when she got the MRI that was needed in July 2019, this was done on the old MRI machine because we were still in the old hospital.

45. I likened the situation to the hospital having limped along with one leg as it prepared for the big move to the shiny new facilities but that leg was effectively chopped off too at the point that the move was postponed, because we were just expected to make do with what was left until the move eventually happened. It was already a makeshift hospital that had seen better days, which was why the new hospital was needed in the first place, but people were expected to keep it going until the new place was available.

46. I have to take my hat off to the staff who kept the place running. They were affected by the delay as well as the patients and families and they had to keep things running, making sure that patients were looked after despite the challenges of the environment.

47. The internet rarely worked and there were kids who virtually lived in the hospital who struggled to do their school coursework because they struggled to get on their websites. That had been an issue for a long time at the hospital and people were looking forward to finally leaving that problem behind them at the old place.

Experience at the new hospital

48. We have now had quite a bit of experience at the new hospital. It has more cubicles, so we're not relying only on the one EEG cubicle on the neurology ward, which at the old hospital meant us sharing with someone else when ■■■ was being treated. This makes things better for us and ■■■. And inside the glass of the doors, there are shutter-type blinds, meaning that the light outside the cubicle can be blocked out and we can darken the room when that is required. However, the light is only partly shut out so at night the light from the

door can be a lot and we had to cover with additional paper to reduce the light exposure to ■■■ which can be dangerous during sleeping times.

49. The new place also has an adjoining bed for when a parent is staying over, and a toilet adjoining the cubicle, which is such an improvement on what ■■■■■ has had to experience at the old Sick Kids.

50. While it is a huge improvement on the old hospital, there are still lots of things that I don't think are right at the new place. A lot of that is on the administration side. Things like fridges, where they seem to be owned by the catering department and nurses have no control over what food is kept or removed, are actually worse than they were before. For example if ■■■ has ketogenic food, which goes in her gastrostomy, her tummy button, we make it and she takes a little bit of it and we have to put the rest of it back in the fridge. The catering staff will sometimes remove and bin it, something we didn't have to worry about at the old hospital. Even the consultant wasn't happy about this and suggested I raised the issue through the Family Council.

51. There are other things about the new hospital, nitty gritty things like the temperature and the lighting that could be better, but I guess it's a new place for the people there as well.

52. I think the space could have been used better. There's loads of space yet the cafeteria on the ground floor seems so small. The staff and the customer service in that new cafeteria are just amazing, but I can't understand why it hasn't been given more space.

53. One of the things I think that they got wrong at the new Sick Kids hospital was the naming of the wards. They went for Scottish castle names, like Borthwick, Tantallon and Castle Mey. My daughter will struggle to pronounce the names of wards she'll be in and I really don't know why they didn't go for simpler, child-friendly names. They could have kept the Scottish theme but used something like animals or birds, so the Red Deer or the Gannet or Osprey ward. They could even have had a Unicorn ward and at least younger kids could have related to it. I don't know what consultation they did about the names, if any. The names

aren't inclusive for parents or children unable to pronounce them. They also can't differentiate them for instance the picture to describe all the wards is a castle whereas most children's hospitals use names that have multi-sensory impact so those children that can't read or speak can recognise a different picture of a different animal for instance. It must be frightening for children unable to pronounce or understand these complicated names when being orientated back to their ward after surgery or procedures. I understand that nurses may have been given a say in the names, but they had a very limited menu of options to choose from.

54. And the new wards seem to be the same colour, beige or brown. Again, they could have made them more colourful and attractive for kids and helped differentiate the wards for children of all ages, as well as those with learning disabilities, to help orientate the children to their ward.

55. One of the things that is being discussed by Family Council is the need for a six months or one year review of the new place, what's working well, what isn't and what action is needed to make things better.

COMMUNICATION

56. Communication about the delayed move was virtually non-existent. After we heard from friends on the day the move was supposed to take place in July 2019 that it wasn't happening, we got a letter, maybe 3 weeks later. It basically said that any appointments planned at the new hospital should continue at the old one. There was no information about the cause of the delay or how long it would be for, nothing really. I can't recall who sent the letter and I haven't kept a copy.

57. What was really poor was that even as a member of the Family Council, whose role is to represent the patients and families and engage with those running the hospital, I knew nothing about the delay. As a parent, I can just about accept that there was a communication failure but what is the point of the Family Council if even it didn't receive any information about the delay to the move. We knew nothing more than what we were reading in the newspapers. Fiona Mitchell was

the Director – I think of Women and Children Services - and she worked really hard with the Family Council. I think she could have told us but maybe even she didn't know what was happening.

58. We did try asking some of the nurses for an indication of how long the delay would be but they seemed to be as much in the dark as we were. They said that, like us, they still thought right up to the day of the planned move, or maybe the day before, that it was going ahead. I know that they were surprised and disappointed at the delays and I'm pretty sure that they would be happy to tell you that themselves.

59. I do actually wonder if even the managers knew what was happening. Clearly, the decisions had been taken above Fiona Mitchell's level but there was a serious failure of communication in letting those who would be most affected – the patients, families and staff – know what was going on. Though the new hospital is now up and running, I still don't think it has been communicated why there was such a delay. I can only guess it was a safety thing. There may have been good reasons and people might have actually understood and agreed with the reasons, but I can only stress again that there was no communication, either with parents directly or with the Family Council, so people were just left to get on with it and deal with the uncertainty.

60. Even when the hospital did eventually move, I don't recall any communication with me as a parent. I think I became aware through the Family Council and from the media, but I don't recall any direct engagement with parents or families.

61. As a family, we have been quite lucky because we have such regular and close contact with the nursing teams and we just need to send them a message or text them and they will give us a call straight away. Other families don't have that kind of structure in place, so the communication could be very difficult for them.

62. I think management at the Health Board need to understand that some families have kids who spend literally 100-150 days per year in the Sick Kids hospital. For these families, it's not enough to just tell them what's happening, although any communication at all would be better than what we have been used to. But they

should engage with these parents and ask them what they think about plans before making definite decisions about things. Who is better placed to comment on the proposals than families who spend such a large part of their lives at the hospitals?

IMPACT ON FAMILY

63. It's really hard to assess the impact on ■■■. She is too young to understand what's happening and for us as parents, it's our job to shelter her from the negative things about the hospital and all the uncertainty about the move. And it's not just her age but her medical condition that would make it difficult for ■■■ to understand everything that has been going on around her.
64. From a medical point of view, one big thing that ■■■ missed out was not being admitted more often. By that I mean that we tried to keep her away from the old hospital as much as possible. We knew that in the new place, we would be able to get a cubicle, like the single rooms I'd seen as part of the Family Council visit to the new hospital, and we would be able to make it dark and quiet, so we would have an environment where ■■■ would be safe and her condition would be properly catered for. We could never be certain of getting that kind of thing in the old place, so we avoided going there as much as we could.
65. We would sometimes call the old hospital the Christmas tree, because there are lots of triggers for my daughter's condition and light is a big factor that can cause her to get an episode. Bright lights trigger episodes, and noise can too, so I called it the Christmas tree because, to me, it suggests enjoyment, it's about happiness, it's about excitement, it's about festival, rather than the calm that ■■■ needs. And sometimes the hospital, pre-COVID, used to be have parties happening, with siblings and families coming in, understandably wanting to make the patient happy. But that meant it could be pretty noisy and that wasn't good for ■■■, so there were times we chose not to take her in, because we thought it might make her situation worse. At least at home we could control the environment and we

could rely on the ambulance service and the paramedics, who were always amazing.

66. As I have said, examples such as [REDACTED]'s MRI scan being done on the old equipment, when the staff had told us about the more advanced scanner that would be available at the new hospital, showed us that [REDACTED]'s medical treatment was being affected by the delayed move too.
67. From the perspective of [REDACTED] and I, as [REDACTED]'s mum and dad, the main impact on us was because of the uncertainty and the sense that we were missing out on a much better hospital experience for [REDACTED]. I have talked about just how frequently she needs to attend, and having to keep going back to that old outdated hospital, when we had been expecting the hugely improved facilities at the new place, made us really frustrated. The first admission when [REDACTED] was 5 days old was difficult for [REDACTED] who was post-natal with wounds that needed midwives as well as staff used to caring for a new mum and child together. Often in this post-natal period both mother and baby would get admitted to the post-natal ward at Simpsons at the Royal Infirmary. As [REDACTED] also had neurological symptoms as well as jaundice, she had to be admitted to the old Sick Kids hospital. This was not designed for newly post-natal mums and [REDACTED] was unable to be seen by a midwife and unable to have access to a shower easily. Had the new hospital been opened at that point, it would have been in close proximity to the maternity and post-natal wards of Royal Infirmary and she could have received the appropriate post-natal care (likely this would have helped prevent further complications she had in the coming weeks afterwards) whilst also [REDACTED] receiving the care she needed.
68. I was probably unusual in that, as part of the Family Council, I had actually been able to see what the new facilities would be like. In a way, this probably made the impact of the delay even worse, because I actually knew what [REDACTED], and we as a family, were missing out on, yet I had no idea how long we would be delayed at the old hospital.
69. The uncertainty about the delays and the lack of communication also left and me feeling really vulnerable. [REDACTED]'s treatment and wellbeing was our number

one priority, yet we had no idea when she would be able to benefit from the much improved surroundings and facilities that would be available at the new hospital. We were powerless to do anything about it and this just added to the frustrations and our own worries about what was going on.

70. I should say that we get support at home from the NHS Outreach Service, with having daily one to one support from Band 4 health care assistants. This helps cover ■■■'s needs in the morning and at night. Her condition qualifies her for the Lothian Exceptional Needs Support (LENS) Panel and this help is invaluable.

COMPLAINTS

71. We did not raise any complaints about the delays. We did consider complaining about ■■■'s medical treatment when she was in the Glasgow hospital but we had other stuff to focus on (including multiple admissions to intensive care that year) and we didn't follow this up.

REPRESENTATIVE GROUPS

72. I have mentioned that I am part of the Family Council. The Council is basically a group of parents who try to act as a voice for families who are undergoing treatment at the Edinburgh Sick Kids hospital. There are always ups and downs with the families' experiences and the Council is a supportive platform and can raise issues with the hospital management. It's not supposed to simply be a complaints platform. It is intended to be constructive and to be there for families when needed.

73. I felt quite disheartened that the Council was as in the dark about the delay to the move as everyone else. It made me doubt my role and the role of the Council and I wondered if it was an indication that the authorities didn't take us seriously in terms of the work that we do.

74. I think that communication and engagement with the Family Council has improved. I was quite closely involved in the Council's page on the Board's website and this has increased our visibility and made people want to help us. It sometimes felt like the Council's work wasn't appreciated but this is getting better now. There is still much that could be improved further though.

CONCLUDING COMMENTS

75. As a father and as a family, from our point of view, we feel happy that we are now in the new place, because it's got really good state of the art healthcare machinery to give kids the best treatment. They've also got state of the art nursing, with the consultants and doctors too, who look after the whole thing.

76. It's just such a pity that there was such a long delay in getting the new place opened. If people had been kept in touch with what was going on, the plans, the reasons for the delay and how long it would be and how things were progressing, I think they would have been more likely to accept the situation. But there was none of this. I don't blame the medical staff because, like the families, they were trying to make the best of a bad job. I still don't understand why the communication was so bad and I hope that the Inquiry can get to the bottom of that.

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

Scottish Hospitals Inquiry

Witness Statement of

Sharon Barclay

WITNESS DETAILS

1. My name is Sharon Barclay. I was born on [REDACTED]. I am [REDACTED] years old. I am a [REDACTED].
2. I am the mother of patient, [REDACTED]. She is 7 years old.
3. I live with my partner, [REDACTED], and my two children, [REDACTED]. I have two older children who are now adults and don't live with us.

OVERVIEW

4. My daughter is [REDACTED]. She was diagnosed with Acute Lymphoblastic Leukaemia ("ALL") in May 2017, on her third birthday. [REDACTED] was treated in the Royal Hospital for Children ("RHC") and Queen Elizabeth University Hospital ("QEUH") between May 2017 and October 2020 when she finished her treatment.
5. [REDACTED] was treated in the RHC on ward 2A as in-patient and on 2B as an out-patient. We basically lived in 2A for the first 10 months. [REDACTED] was in 'source'. This is when you have to stay in the bedroom, most of the time. She was also in ward 3 at one point, that's the ward for patients waiting for dialysis and transplants. She got put in there because there was no room on the unit. We were also in ward 6A in the QEUH for two nights but I don't know when that was. [REDACTED] treatment lasted for 28 months. I stayed with [REDACTED] for a lot of the

time, although I shared the care with ■ and her gran. I can speak to the experience that me and ■ had in the hospital.

FAMILY BACKGROUND

6. At home with my partner ■ and I are my two youngest children, ■, the youngest, and ■, who is ■ years old. ■ and ■, who do not live with us, are my oldest sons.

7. ■ has Down Syndrome and can't speak. I have to speak for her. She has been in and out of hospital since she was 17 weeks old. She had a large hole in in her heart and was rushed in to hospital for major surgery. Dr McLeod saved her life that day. She also caught RSV at one point and nearly died. ■ was in and out of hospital for bronchitis where she would need oxygen for a while.

8. ■ is a very lively child. She is not yet in primary school and is not at nursery. She has been kept at home for another year with me. She will go to school next year. ■ really likes music. She has a typical sibling relationship with her brother ■ who has autism.

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

Admission to Hospital: May 2017

9. ■ had a viral infection for about three weeks before her third birthday. It wouldn't go away. We went to see our GP on 30 May 2017. Our GP is at Medical Centre and he referred us to the Queen Elizabeth University Hospital that same day. He sent us to the hospital to get ■ checked over.

10. Me and ■ took her to the hospital in Glasgow. She had an X-ray carried out and the doctor said everything looked okay and that we could go home. It was

a younger doctor who did the tests in the hospital. ■ had gone to get the car from the car park. Just as we were about to get in the car park, another doctor came running out and asked us to go back in. He told me that ■ had multiple fractures all over her body. He accused me of dropping ■ on her head. I asked ■ if ■ had fallen down the steps at his mum's house as I knew I hadn't dropped her. I asked the doctor where the fractures were and he wouldn't tell me so I asked to see the scan and we went back in to the hospital.

11. I have two older boys and they had broken bones when they were younger so I knew what they looked like on scans. There were no breaks showing on the scan. There were marks up at the head area. ■ has been a head banger since she was 6 months old. This is part of her Down Syndrome so it's possible she's had trauma from that. I do my best to make sure she doesn't do it but she won't stop. I have never, ever dropped her.
12. The hospital had taken other scans and I could see clouding all over ■'s body and around her head. From my own research I was aware that this could be a sign of cancer. I asked Dr Danson straight away if ■ had cancer but he told me he couldn't confirm this as it wasn't his area. Dr Danson was a bone doctor.
13. On the same day, the 30 May 2017 he admitted ■ to ward 2A in the RHC, it is known as the Schiehallion Unit. She was in Bed 1 which is right next to the reception in the ward. At that stage I knew it was cancer, I knew that this was the child cancer unit. Lots of blood tests and DNA tests were performed over the next day and we stayed in overnight. Professor Gibson was the doctor on the ward. The next day we received the clinical diagnosis, ■ had acute lymphoblastic leukaemia ("ALL").

■■■■'s initial treatment

14. ■■■■ got lots of medications and treatments but I can't remember all of the details or dates she got them. Professor Gibson told me that they would have to do an operation to get a central line into ■■■■, then they would start chemotherapy and get all the medicines she would have to go on. I don't know what type of central line she had at first, it was plastic and yellow and was fitted by surgery under a general anaesthetic. She got steroids and Ciprofloxacin.
15. ■■■■ was in receipt of treatment for a total of 28 months and that was them shortening the treatment by six months because I was told that she would never be able to complete the chemotherapy because she wouldn't be able to take the strongest dose. She was an in-patient and out-patient during this time.
16. During her first admission, ■■■■ was an in-patient in ward 2A. She stayed in the hospital for about 10 months during that first admission.

Overall experience on Ward 2A

17. Nothing worked in ward 2A. I found it was either too hot or too cold to the point I could see her breath. I did not feel the ward was clean.
18. During the 10 months in the ward, I spent a fortune buying food from Marks and Spencers or would go without food for periods of time. I went from a size 12 to a size 4 with the stress of what was going on for ■■■■ and then the stress of how the family were being treated. I developed an eating disorder. Microwave meals for ■■■■ was also not an option. ■■■■ was already going through cancer treatment so I didn't want to irradiate her food on top of this. I felt that ■■■■ should have been offered a healthier option to eat.

19. When [REDACTED] was in source, we weren't allowed to use the kitchen facilities, if you wanted anything, you'd have to ask them and they would bring it to you. Half the time I didn't ask for anything because you would wait forever. They don't offer the adults food in the hospital, just the children. The food was worse than prison food. [REDACTED] couldn't chew. She needed soft food. What they gave her was awful. It was brought in from somewhere, not prepared on site. It was pureed to death, broccoli and green things. It smelled awful and it was microwaved every time. My daughter was already going through cancer and to me, the food she was getting was radiation food as it was microwaved. It wasn't right. There was a new kitchen on the 3rd level of the hospital, it should have been used to prepare meals for these children but it never got used. I ended up shopping in Asda and brought my own food in all the time. It cost us £4,000 just living there for that 10 months. I wasn't offered food vouchers but some families had some. It wasn't just me and [REDACTED], there were my other children who also ended up living there in [REDACTED]'s room
20. Eventually [REDACTED] was put on TPN which was extremely difficult to manage as [REDACTED] wanted to pull out her feeding tube from her nose.
21. I was also concerned with the kitchen and the non-medical facilities like the playroom. People were mixing and there was very little infection control here. There was a protocol that only patients were to play in the playrooms, but I saw families with many siblings playing in the playroom. It was one rule for one family and a different rule for others. The cleaner used to come into the room and clean the bathroom and then clean the bedroom. I challenged this because there was a poster on the wall that said that the room was cleaned everyday for 45 minutes. They cleaned once a day. The only time the room was cleaned for 45 minutes was when infection control came to inspect the room. Otherwise it was very quick. [REDACTED] was put in rooms with faeces on the cot handles and black bits of mould around the room.

22. In 2017, █████ started getting respiratory problems when she was in 2A and they were trying to force oxygen into her. I can't remember when this was. █████ doesn't agree with wires and she always tries to pull her tubes out and the wires too. They ended up bandaging her hands to stop her pulling wires out and that really restricted her with her bottles, she ended up like a kid with no limbs. I had to lift her bottle up for her to drink and they had to tape the oxygen mask onto her face. They then realised that the tape they used to hold the mask on was blistering █████'s face and when they took it off it removed her skin. It got to the point I wouldn't allow them to give her oxygen.
23. On one occasion, █████ had surgery to fit her line and the following week she was back in for chemotherapy and they injected her. That night I could see her skin getting really red round about the line so I rushed her back to the hospital the next day. Before I knew it, █████ was back in the unit and went down for surgery. Afterwards the surgeon told me that █████ had a double port fitted. He explained it was a bit of plastic but that wasn't what I had been shown on the unit. I had been shown a silver metal box with a circle where █████ was injected but this double port was different. I don't know if that's what happened and the chemo has burned her skin because it was injected in the wrong place.
24. Eventually █████ was fitted with a PICC line which was meant to last two years. This was a catheter that was fitted in █████'s arm. It's a line that's clipped off when she's getting medication and when she's not getting anything, you clip it back on. The amount of times she had been in for medication, clipping it on and off, the hospital managed to snap it themselves so that was another removal because there was no way to get food or chemotherapy into her. █████ broke this during her treatment and had to get a port fitted in 2017 or 2018 before the PICC. I was advised that █████ was going to have a single port inserted which would be a square silver box. I was shown this silver box and was under the impression this was to be fitted. Instead, a surgeon told me █████ had been fitted with a double port made of

plastic. This double port caused ■■■ to have blisters on her skin. I told them that I didn't want the plastic port inside ■■■ again and that I wanted the silver box.

25. There was only a limited amount of staff that could insert the gripper into ■■■'s chest. It was a type of needle and it moved about a lot. Every time they missed injecting into that hole, they injected my daughter's skin with a long needle. They stabbed her in the skin unwillingly a lot of times and she would freak out, she was telling me they weren't getting the right bit. She was already wound up because there was so many of us trying to pin her down to try and get the gripper needle in and then she would start uncontrollably peeing and pooing again. I couldn't cope with it because that was her telling me she was petrified.

Overall experience in the QEUH (adult hospital)

26. We were in ward 6A once when she had to go in for antibiotics but I asked to get moved out after two days because of the filters on the taps and the air filter in the room. I do not understand why the hospital needed filters if there was nothing wrong with the water.
27. I found staying in 6A extremely distressing and was only able to stay there for 1 night before I had to leave. We were asked to stay in our rooms. I could not cope with everyone having to stay in their rooms. I did not stay in 6A overnight again after this. When I returned to see ■■■ I found that the room temperature was extremely cold.

WATER: EVENTS INVOLVING WATER SYSTEMS**Water incidents in RHC**

28. I got [REDACTED] and my Gran to take me back to my house so I could have a shower there because I started to itch after using the showers in ward 2A. I got a verruca from the shower, I never had anything like that in my life. A lot of the kids said that the showers make you itch. I never had a shower in the place again after that. I stopped using the water but I'd been using it to brush my teeth before. I would have a bath and brush my teeth at home. I'd only drink bottles of juice out the machines because I refused to touch the water.
29. I noticed that [REDACTED]'s bottles were going brown and I told the staff this. I was told that I wasn't washing them properly. I explained that I was and that I had a heated steriliser unit in the room and that I was using the water from the bedroom tap. I only put so much water in each bottle before I washed them in the steriliser. Every time I washed them using the water, the silver bit at the bottom of the bottle looked like it had limescale on it, it always went brown. I put a sponge in one of the bottles and used a knife to swirl it round to clean it. When I brought it out, it had thick black stuff all over it. I knew that the water was contaminated after that but the staff told me it was all in my head. I can't remember the names of the staff, I just recognised their faces at the time.
30. All the wards had the filters on the taps, even in day care. The showers didn't have them but they were awful. Every time I had a shower it flooded. There was one time I had a shower and the water started coming into the bedroom and I had to put towels down because it was coming up the walls and stuff was floating in it. Staff left me there until the next day and then they told me I had to move room. We got moved rooms a lot, the only rooms out of the 27 rooms in ward 2A we weren't in was the teenage bit.

Water issues: communication

31. We were in ward 6A once, in the adults' hospital but I asked to get moved out after two days because of the filters on the taps and an air filter in the room. I complained about the air conditioning but was told nobody else had complained about it until I had come in.
32. I was told there was nothing wrong with the water and that it was in my head all along. I cannot remember the name of the person who told me that the issues were in my head. It was a young member of staff. This happened in 2017 in ward 2A. I was never told anything about the use of water in the ward other than that everything was fine. I was using the water as normal and doing things like brushing my teeth with it as a result.

LINE REMOVALS AND POTENTIAL INFECTIONS

33. In 2017 ■■■ had to get surgery because it looked like she had infections under her armpit at her central line. That left a massive hole under ■■■'s armpit. I took a photograph of that.
34. At that time, I asked them to remove her central line because it was infected and told them that ■■■ was a 'wire puller' but they refused to take it out and treat the infection. I went home that night and sure enough, ■■■ pulled the line out. You can see the hole and where it's green with the infection, it was like a flesh eating bug and the hole got bigger and bigger.
35. ■■■'s line was changed twice. One occasion was because ■■■ pulled the line out and the other was because the wire broke in the line and it was hanging down. There was also a point when ■■■ had a double port accidentally fitted when it should have been a single port.

36. ██████ was given treatment all the time for potential infections. I do not know if ██████ was given new antibiotics for the hole under her arm. I was told that ██████ was to receive ciprofloxacin which is an antifungal medication as part of the hospital protocol on the basis that ██████ had down syndrome. This was explained that ██████ would be more prone to getting infections from the ground. No other reason was given.

Infections: Communication

37. The hospital never, ever told me what infections ██████ had. I looked through some of the data records I got sent but I can't read them all because they get me so upset, I can't go through them. I always knew about Norovirus and Rhinovirus and one of the lab results said she had Astrovirus. There were a few other things but I can't remember what they were. I applied for her medical records from 2017 to 2019 but I'm missing 11 or 12 months of it, there's only a couple of things from 2017, it doesn't really state anything. I know the amount of infections ██████ had in the first eight or nine months but not once was I told she had an infection. I was just always told it was Norovirus or Rhinovirus. I was told about the rhinovirus by a member of staff because this staff member explained it was the common cold.

PREVENTATIVE MEDICATION

38. ██████ got Ciprofloxacin. I checked that up, it's an anti-fungal medicine. She got that from the minute she went in there, she was probably on that for about three years. I asked why she was on it and all I got told was, "It's protocol because she's got Downs Syndrome". I told them that it was so she wouldn't catch infections in their dirty hospital. They said that the hospital was clean.

Preventative medication: communication

39. ██████ had been on so much medication for years and then everything stopped. To me a child should be weaned off certain medications because side effects could happen. The only one she was left on was the Ciprofloxacin, that anti-fungal one. She was left on that for three months after her treatment. I asked why they had left her on this but I was told it was 'Downs Syndrome protocol'. It was supposed to be 6 months but the doctors stopped this after 3 months. ██████ was still visiting the hospital at this point but her cancer treatment had stopped.

OTHER ISSUES RELATING TO HOSPITAL CONSTRUCTION**Hospital build issues: impact of construction works**

40. One day when ██████ was in getting bloods done, they were doing tests on the fire alarms and that's how I knew the air conditioning never worked right. There was a gigantic vent above a telly and it blew out one day, dust and everything landed on me.
41. The air conditioning and ventilation was not adequate. I found that she was put in a room that was too cold. One of the rooms in ward 2A was so cold, I could see my breath. In general ██████ has always been at risk from developing colds and flu. I would always keep their home at a temperature of 18 degrees, no matter the time of year to keep things ok for ██████. ██████ developed respiratory problems from the room temperature in the hospital and it made her sicker than she already was. I knew the air conditioning did not work because it was too hot or too cold.
42. The windows and the doors in the bedrooms – you could turn the window and the door and they would come in on you. The internal windows could

open into the corridors. The staff could open the windows from the outside and look in, which meant that if I wanted privacy there was always a risk that the staff would just look in. They once opened the windows to wind me up and it resulted in me losing my temper with the staff.

43. There were a few windows boarded up because that many windows had fallen in on parents. The glass had come in on them.
44. All the rooms we were in were freezing. The only rooms that were warm were the care room, the desk and the two rooms behind it. I had to sleep with my jacket on one night, with three blankets, boots and tracksuit bottoms, on a camp bed that came out the wall. I couldn't even reach it to pull it down.
45. The air conditioning in the hospital did not work in the ward properly and there was poor ventilation. Room 10 in ward 2A was the worst, I could see my own breath in that room. I argued and argued with them, telling them it was too cold.
46. Any time we went to the hospital with ■■■, as an out-patient, we always had to go through A&E. They would try and put you in a room with hundreds of kids coughing and you don't know what they've got. I didn't want them anywhere near ■■■ because her immune system was so bad, no matter what was going about, she would catch it. We would then get taken up to 2A or if there weren't any rooms there, we would get put in ward 4 or ward 3C. They had A, B and C but I can't remember which different bits we were in.
47. In the kitchen there were two seats and that was it, if there was more than two people there everyone else had to stand up. If you were in source you weren't allowed to go into the kitchen and make a cup of tea but the staff were in and out all of the time using it. On one occasion, I can't remember when, the whole of 2A was put in source. There was flu type A, flu type B

and Aussie flu that was going around. Nobody was allowed to use the kitchen, no parents could get to speak to each other and we weren't allowed to use the teenage room. I asked one night if the parents could use the teenage room as it's a massive room but they said no. I asked if I could take in there because there were carpets and a juke box but again, we were told no. I couldn't stand to stay in our room on the ward 24/7 looking at the four walls. You weren't allowed up and down the corridors, you weren't allowed in the kitchen. The only other space you could get was outside and going to the park.

Hospital build issues: physical effects

48. The dust and everything that blew out the vent made ■■■ have diarrhoea and she had to go back in again. I said that whatever blew out the vent that day it made my daughter sick but they said it hadn't. That's when the pigeons were getting into the building so it could have been poo or anything.
49. This happened in ward 2A and it was at some point in 2017/2018. The room was not cleaned properly. The cleaners could not reach the vents as they were very small and high up. The dust in the vents may have contributed to ■■■ being unwell.

CLEANLINESS

50. I described the hospital as "bogging". It was filthy. The cleaner came into the room and put the mop down the toilet. She then proceeded to use that mop to wipe the floor of the bathroom and the bedroom. I asked her what she was doing. She told me it was a "two-sided mop". I've been a cleaner all my life and I know you don't get a two sided mop. The rooms were supposed to be cleaned for 45 minutes, the cleaners never did that and I asked why not. They said that the room didn't take that long to clean. The only time the room got cleaned for that length of time was when the health people came

in and you knew when they were coming. The room would get pulled apart and we would get shifted about. The next day, after they had gone, it would be back to normal. One day I looked at the cleaner's mops and she had four of what she called 'two sided mops', that was to clean 27 rooms in 2A. If you took a hard surface wipe and ran it over a surface, it came away black. The place was dirty. The place never smelled clean, or of bleach or cleaning products. It just smelled like a dirty mop.

51. ■ would never go into a normal bed so they always got her a cot. Every time I got her one, the staff would say it was clean but I took a hard surface wipe and every single bar on the cot was dirty, some had faeces on them. This happened on wards 2A and 6A.

OVERALL EMOTIONAL IMPACT ON ■ AND HER FAMILY

Overall emotional impact on ■.

52. There was a board on the wall in ■ room that has a list of 'What matters to me', it's for you to write up notices so they know how to deal with your child. ■ can't physically speak, I wrote on it, ' ■ doesn't like new faces'. She was only used to me, her dad, her granny and her brothers so I wrote on it that only two people at a time should enter the room as it made her anxious and upset. Time after time it was ignored, they were sending six people in at a time, that's too many faces for her, it just sets her off. She didn't understand. ■ got upset, she was uncontrollable. They ended up pinning her to the bed, there was pee and poo everywhere. I had to send them out the room because she was never that scared. This wasn't how ■ was, she had never done this.

Overall emotional impact on witness

53. I felt like I wasn't getting listened to, no one listened. The place was killing me, I had anorexia since I was 16 years old. I went from a size 12 to six and a half stone during that period.
54. I knew there were problems with the water but they kept telling me it was fine and it was in my head. They wouldn't listen to me about other things and I got really depressed. I didn't think anybody would listen and it was all in my head. I had lost my dad four months into [REDACTED]'s treatment. There was a psychologist who came in to the room. I told her that you had to watch the staff like a hawk because they had mucked up with [REDACTED] and if they had mucked up with her then who else would they muck up with. She just agreed with everything I said, she wouldn't even listen. I ended up looking like a total psychopath, I was constantly arguing with them all. Even at night time when I was trying to chill out, they would sit behind the desk and giggle constantly. I asked them to be quiet but they wouldn't even listen to me.

Overall emotional impact on family members

55. I had to take my son [REDACTED] out of school for six months. I was told that if he contracted chicken pox and passed this on to [REDACTED], it could kill her. No one offered us support for him during that time, no schooling. Not even for a couple of hours. He wasn't allowed in the playroom as it was only for patients, not siblings. Eventually they gave him an X-box and a PlayStation, but that was it, that was how he spent his time, every day, all day. He lived there in the hospital with us. He's recently been diagnosed with autism and was showing signs at the time.

COMMUNICATION: GENERAL

56. They observed [REDACTED] every two hours and I asked if they could send in the same staff and only two members on each shift but they didn't do that. The nurses kept coming in six at a time. That was too many for [REDACTED] to cope with, too many new faces. I told them that they weren't listening, there was no communication whatsoever.
57. [REDACTED] couldn't speak but she wasn't deaf. She understood what you were saying to her. I tried to help the nurses with [REDACTED] because if you didn't do things the way she was used to or understood, she would fight against you as she was scared. I tried to tell the nurses this but they didn't listen. They just carried on and [REDACTED] got upset.
58. In terms of the move from ward 2A to ward 6A, I found out about that from a friend whose child was an inpatient at the time. I never received official communication about it.

COMPLAINTS

59. I didn't put any of my complaints in writing but I wish I did because nobody would listen. They told me it was all in my head so I questioned why should I write things down. I knew in my heart and in my head that the water was wrong. I can't remember the names of anyone who told me this because my memory is going more and more because of my dystonia, I only remember faces but most of the girls that worked on that unit have all left.

OVERSIGHT BOARD / CASE NOTE REVIEW / REPRESENTATIVE GROUPS

60. I've never heard of the Oversight Board or heard of Professor White and [REDACTED] wasn't part of the Case Note Review.

61. I didn't join the closed Facebook group until about seven months ago. It was just Instagram I was on before so I didn't see anything like that. I only followed other families that had kids with Downs Syndrome, that had gone through the same thing as me.

CONCLUDING COMMENTS

62. I told them I wouldn't be back in their hospital and I haven't been back since apart from last Friday, 14 May 2021 because ■ had to go back for her teeth. When she was in 2A she had to get 16 of her teeth out after the chemotherapy, which made it even harder for her to eat. They left four teeth in with metal caps over them, which she still has to this day even though all her adult teeth are growing in. I asked them last Friday to remove the caps. They asked me to bring her back in three months time but she's in agony.
63. No child should be in that hospital, or adults. The water - it wasn't fixed for two years and it's still going on. It's still not opening because they can't sort the air conditioning out. At one point, on 6A, they asked the families to make fund raisers for the children to give them funds towards the air conditioning. This was after Kevin Bridges did a whole tour and gave all his money to the cancer unit, so where did that go?
64. There's poo coming into the hospital somewhere. You wouldn't build a super hospital next to a pit containing faeces. These pipes are all linked together and it's right next to the main area where the kids' bloods are tested.
65. The whole hospital is negligent. My daughter went through major heart surgery for a hole in her heart, from when she was born. This was in the old Yorkhill, and not once did she get an infection. As soon as we moved over

here, it was just infection after infection, we knew the hospital had bugs everywhere. It isn't a super hospital, it's super filthy, it is disgusting.

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

Scottish Hospitals Inquiry

Witness Statement of

Rachael Noon Crossan

WITNESS DETAILS

1. My name is Rachael Noon Crossan. I was born on [REDACTED]. I am [REDACTED] years old and I am [REDACTED].
2. I am the mother of [REDACTED]. [REDACTED]'s date of birth is [REDACTED]. He is 13 years old.
3. I live with my husband, [REDACTED], and my 3 children [REDACTED] and [REDACTED] in [REDACTED].

OVERVIEW

4. My son is [REDACTED]. [REDACTED] was diagnosed with a Medulloblastoma, which is a brain tumour, in January 2017 when he was 8 years old. [REDACTED] was treated at the Royal Hospital for Children ("RHC") and the Beatson West of Scotland Cancer Care Centre ("The Beatson") between January 2017 and December 2017, when he finished his treatment. He attended the RHC as both an in-patient and an out-patient and the Beatson as an out-patient during this period. [REDACTED] still attends the RHC as an out-patient for Magnetic Resonance Imaging ("MRIs") and reviews.
5. I have provided the Inquiry with a timeline, prepared by my solicitor, showing the dates on which [REDACTED] attended hospital and the wards where he was

treated. The timeline is attached to this statement at appendix 1 (RC/01) and I confirm that it is accurate to the best of my recollection.

6. ██████ spent time in wards 2A, 2B, 2C and 3A of the RHC. He did not spend any time in the adult hospital. ██████ was discharged on 8 September 2017 and we were never back in a ward after that. My husband and I took it in turns to go to the hospital as we had a younger daughter to look after. I can speak to the experience which ██████ and I had on these wards.

FAMILY BACKGROUND

7. I live with my husband ██████ and three children in ██████, just outside ██████. ██████ is my middle child, his brother ██████ is ██████ and his younger sister, ██████ is ██████.
8. ██████ is in ██████ year at secondary school. He was in Primary ██████ when he was first admitted to hospital. ██████ is a happy and funny boy. He likes to play football and go out with his friends. ██████ also likes to play video games and at the moment is really into Pokémon Go.
9. ██████ gets on well with his brother ██████ and his sister ██████. As a family we like to go on holiday together and enjoy days out and the cinema.

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

Initial admission to hospital: January 2017

10. ██████ became unwell in November 2016, when he was 8 years old. We took him to the GP and he ended up at The Royal Alexandra Hospital ("RAH"), in Paisley on 27 December 2016, getting tests for two days. Initially it

was thought he had a virus. We attended at the RAH again on 3 January 2017 and got sent home the same day. It was the same thing he was there for and they said it was migraines then and they did some basic tests. On 16 January 2017 we ended up at the RAH again and it was discovered that he had a brain tumour. He got transferred to the RHC that day and was admitted to ward 3A in the RHC. He was diagnosed with medulloblastoma and had surgery to remove the tumour four days later. He did not move wards or rooms during this stay and was there for exactly two weeks. He was then discharged back home.

██████'s initial treatment: End January 2017 to April 2017

11. ██████ started attending the Day Care Department on ward 2B in the RHC. This is the day care ward in the Schiehallion Unit. Wards 2A and 2B are the wards that treat children with cancer.
12. Ward 2A is the in-patient ward in the Schiehallion Unit. The room had a bed for ██████, a pull down bed for us, a sink in the room and a shower, a sink and a toilet in the bathroom. I don't really remember much else except it was very hot in the room.
13. ██████ went to ward 2B for regular tests and he also got stem cells extracted to give them back to him at the end of each cycle of chemotherapy. When he got stem cells extracted they brought a big machine into the room. There was a line that took the blood from ██████. It went into the machine and then it was put into bags that they took away and froze, to give back to him later. I'm not really sure what the machine did exactly.
14. He attended day care approximately once a week during this time and remained mainly as an out-patient apart from when he went into ward 2A on 7 February 2017 for two days, as an in-patient, to get his first line fitted. He had surgery to have the line fitted.

15. [REDACTED] was then back in ward 2A on the 13 February 2017 when they discovered they had put the wrong line in. This was then removed in surgery and a new one put in. They realised the wrong line had been put in when he went to have stem cells extracted, to give back to him at the end of each cycle of chemotherapy, and the hospital could not get anything because it was the wrong line. They had put in a dialysis line, instead of the long squiggly one and the tubes were too small. I don't know the name of the line they replaced this with. He was in for two days.
16. On 27 February 2017 [REDACTED] started at The Beatson for radiotherapy. I took him there from home, in the car. He went there once each day, Monday to Friday, for six weeks. During that time [REDACTED] attended day care in ward 2B for blood tests and he went into ward 2A for a couple of days on 10 March 2017 because he took a high temperature after a blood transfusion. He had taken an infection, I don't know what it was but they started him on antibiotics, but again I don't know which antibiotic he was on.
17. This was what they did each time [REDACTED] took a high temperature. They would give him paracetamol and start him on antibiotics straight away. They then took a blood sample and sent that away.

Experience in Ward 2A and 2B: 22 May 2017 – 29 August 2017

18. On 22 May 2017 [REDACTED] was admitted to ward 2A for chemotherapy. He was there for six days. He went in on the Monday, got his chemotherapy during that week and then on the Saturday he got his stem cells back. We were then discharged home.
19. [REDACTED] went through four cycles of chemotherapy in May, June, July and August. He got admitted to ward 2A each time for that. We then went back to Day Care in ward 2B the following week for blood tests and ambisome, after

each cycle. I don't know what the ambisome was for, just that that's what he got. He was usually only in ward 2B as a day patient once, the week after his chemotherapy, but sometimes it was twice depending on the results of his blood. [REDACTED] was then at home for the following two weeks before starting his next cycle.

20. On 1 June 2017, after his first round of chemotherapy, [REDACTED] was at home when he developed a high temperature. We took him in to day care first and they admitted him to ward 2A straight away. They gave him paracetamol, started him on antibiotics and took his blood for testing. I don't know what antibiotic it was.
21. A nurse came and told us later that [REDACTED] had developed group A Streptococcus. We had to go into isolation after that and we were in hospital for two weeks. I wasn't told how he had contracted it. I googled it and it said it was a throat infection. It wasn't in his Case Note Review so I just assumed it wasn't related to the hospital environment. It didn't delay his cancer treatment.
22. On 17 June 2017 [REDACTED] was in getting bloods taken in ward 2B and his line stopped working. It had cracked; it crystallised so he needed a new one then. He got admitted to ward 2A and went for surgery to have that done. [REDACTED] was in for 2 days.
23. On 30 June 2017 we were in ward 2B, day care, when he took a reaction to his platelets. I'm not really too sure what the platelets are but they're different from the stem cells. The stem cells they put in are his own and I think the platelets come from someone else; I don't really know. They were just part of his treatment. He just took a high temperature and came out in hives when we were in ward 2B and they admitted him to ward 2A. We were there for 2 days and they gave him antihistamines as they thought it was an allergic reaction. After he got the antihistamine, they gave him platelets each time.

24. On 17 July 2017 [REDACTED] went in for chemo, to ward 2A, until the 22 July 2017. He then went back on 24 July 2017 to ward 2B for ambisome, through his line. This was a normal part of his treatment.
25. On 28 July 2017 he got admitted to ward 2A. We had taken him because he had febrile neutropenia, a high temperature, but no infection came back in his bloods this time, so he was okay, it must have just been a bug. He got discharged home on 1 August 2017 and went back to day care on 2 August 2017 for ambisome. He went to day care once or twice after that for his routine bloods.
26. On 14 August 2017 [REDACTED] was admitted to ward 2A for chemo and then discharged on 21 August 2017. He was back in to day care on ward 2B on the 23, 24 and 25 August 2017 for ambisome and blood tests.
27. On 25 August 2017 [REDACTED] spiked a temperature when he was being monitored after he got his platelets in day care and he got admitted to ward 2A. He was there for two days and discharged on 27 August 2017.

[REDACTED]'s admission for Enterobacter Cloacae: 30 August 2017

28. On 30 August 2017 [REDACTED] went to ward 2B for a platelet transfusion. He started shaking, he was cold and had a high temperature. He got admitted to ward 2A and about two days later I was told by a Doctor, I don't know his name, that [REDACTED] had a gram negative infection and the antibiotics they were going to give him first might not work and they may need to change them. In the end he had three different antibiotics. They gave him tazocin at first and it seemed to be working and then after a few days he started to go downhill again, so they changed it to Gentamicin.
29. During this stay [REDACTED] was moved to ward 2C for two days. They said we were getting moved because a sicker child was coming in and

seemed to be ok but then he didn't get any better and they said the Gentamicin wasn't working so they put him on meropenem on 4 September 2017.

30. It was when he was in ward 2C, on 4 September 2017, my husband had gone in and found ██████ shaking again and he had a fever. My husband wanted ██████ back in 2A again, so he complained to the doctor and managed to get him moved.
31. Ward 2C was a horrible ward to be in, really not nice. I don't know exactly what it was but I don't think they were checking the temperatures enough and I don't think they understood the extra care needs of children with cancer. It was a big ward and it just seemed that they just put everyone in there from other wards; it just wasn't nice at all. They just seemed too busy, they had too many kids to look after.
32. I wasn't told anything about the antibiotics or any more about what a gram negative infection was and it was only after I got the medical notes last year that I found out it was *Enterobacter Cloacae*.
33. On 5 September 2017 ██████ got his line removed. His cancer treatment had finished and they said that although they would have liked to have left it in for another couple of months in case he needed any more tests, they had decided to remove it and they would, if he needed any other tests, just put a cannula in to do them. ██████ was then discharged on 8 September 2017. He went back to weekly day care appointments in ward 2B. We were never in ward 2A again after that. The appointments went on for about two months up until December 2017. We've not been back on the wards since then.
34. ██████ is well now, his chemotherapy was successful and all he gets now is MRIs at the RHC. The last one was in January 2021 and he's on six monthly appointments now and the next one is in August.

35. [REDACTED]'s six monthly appointments are done on the computer now and it's been fine, there's no issues with communication at all, it's been good.

Facilities in Ward 2

36. In ward 2A the facilities were fine. There were places to sit and they had the kitchen, microwave and the fridge where you could store food in. We mostly ate from Marks & Spencer because we were taking it in turns go to the hospital and we had a younger daughter to look after too. I used the facilities to make coffee and heat food up in the microwave. [REDACTED] didn't eat anything because he was tube fed. There was the play room in ward 2A also. [REDACTED] went a couple of times but it was really too young for him and he wasn't old enough for the teenagers room so he wasn't really interested. The play leaders would come into his room and he sometimes did arts and crafts or use the computer, things like that, but he was too ill most of the time to do anything. Ward 2B didn't have anything. The kids got their lunch and dinner if they were in but there was nothing for the parents.

WARD 2A: OBSERVATIONS ABOUT THE BUILDING

37. I remember that one day they were checking the air quality with some sort of vacuum type of machine. This was in our room in ward 2A. We were in a few rooms in ward 2A but I don't remember what room numbers we were in. I did ask them what they were doing and they told me it was an air quality check. It was two ladies that were doing it and they looked like they were from an outside agency because they didn't have hospital clothes on. I don't know when this was, but it must have been when we were there in 2017.
38. I also remember when we were in ward 2A some rooms had white sheets over some of the doors but I never saw any workmen. I don't know what that

was for. Again, this would have been in 2017 during the timeframe when we were in. I asked a nurse what was going on but I was told it was some work getting done. I didn't have any other problems there but I found the hospital was really warm in any ward we were in.

WARD 2A – WATER ISSUES

39. We didn't have any issues with the water at all. I think there were maybe issues with the water the following year but we weren't in-patients then.

HEALTHCARE ASSOCIATED INFECTIONS

HAls: Events

40. ██████ took unwell on 30 August 2017, when he was in ward 2B. He got admitted to ward 2A and I was only told two days afterwards that it was a gram-negative infection. There was no mention of how he got it. ██████ was quite ill at the time, his tumour had gone but the chemo made him ill because his immune system was low. The infection also made him ill or he would have been fine apart from the chemo treatment.
41. He got treated with antibiotics, he was on tazocin and gentamicin and then they changed it to meropenem. ██████ got home on 8 September 2017 and continued with an oral antibiotic but I can't remember the name of that one. After he got home, he was fine.
42. When ██████ picked up his infection all I was told was that it was gram-negative and the antibiotics might not work. That was really it, I didn't ask anything more about it as I don't like to know things, I just get on with it. If I

know too much, I don't like that, I'd rather not know at the time because it could make it worse and make me worry too much.

43. Other than this infection, ██████'s health and treatment wasn't affected by the hospital in any other way. There were no issues at all with the building or any of the facilities. I also found that the care was great.

PREVENTATIVE MEDICATION

Preventative medication: events

44. When ██████ was an in-patient he was on different medicines, Posaconazole, Acyclovir. I think the Posaconazole was an anti-fungal medication and that Acyclovir was for chicken pox or cold sores, or a virus. I don't know who told me about them but I was told by someone that ██████ was on them to prevent him getting any viruses.

OVERALL EMOTIONAL IMPACT ON ██████ AND HIS FAMILY

Emotional Effects

45. We didn't have any problem with the hospital when we were there, we were concerned later on once we heard about the issues within the hospital. It made us recall our time there and made us think about what could have happened. It's difficult now to think that it could have been worse.
46. We heard about it all on the news and then we got the letter saying we would be involved in the Case Note Review. There was no communication from the hospital prior to this. It affected us all, even ██████ knows now. He's blaming the hospital and the water for everything that happened, just because he's

reading it in the news. We were getting on with our lives but this has taken us back, you get good days and bad days especially when it's on the news.

COMMUNICATION

47. The communication I had with the hospital was fine, I never had any problems. I never had any problems about [REDACTED]'s treatment or the safety of the hospital. The communication is the same now as it was then.

OVERSIGHT BOARD / CASE NOTE REVIEW / REPRESENTATIVE GROUPS

48. I've had a letter from the Case Note Review that I mentioned earlier. This letter confirms that [REDACTED] contracted enterobacter cloacae and that it was probably a result of the hospital environment. I didn't want a meeting with them, I'd had enough by then. We just wanted to move on with family life. They've gone through a lot of stuff but whether it's true or not, right or wrong, I don't know. I don't think it's set in stone with all the "probables" and "probabilities". It's not a yes or a no.
49. I'm on the NHS GGC Paediatric Facebook group. I don't really go on it much but it's nice to see pictures of the kids and things like that. I don't take part in it and it wasn't there when we were at the hospital. I don't contact any other families or speak to them either.

CONCLUDING COMMENTS

50. I don't know how I feel about the hospital now but I hope they fix what was happening at the hospital, I wouldn't like it to happen to anyone else. The staff

were perfect, the care was great, it wasn't their fault that things were happening.

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

APPENDIX 1 – RC/01- TIMELINE

November 2016 – end of January 2017

- November 2016: ██████ became unwell. He was taken to his GP and to the Royal Alexandra Hospital, Paisley. Initially it was thought he had a virus.
- 16th January 2017: It is discovered at the Royal Alexandra Hospital that he had a brain tumour. He was transferred to the QEUH on the same day. He was admitted to ward 3A. He was admitted for 2 weeks. He did not move wards or rooms during this time. ██████ was diagnosed with medulloblastoma.

End of January 2017 - April 2017

- ██████ is discharged to his own home at the end of January 2017. He then started attending the Day Care Department for regular tests leading up to him commencing radiotherapy on the 7th April 2017. ██████ was an outpatient from January until April. He attended Day-Care approx. once a week during this time.
- February/March 2017: ██████ had a central line fitted. On this occasion he was admitted to ward 2A for 2-3 days. The wrong central line was put in the first time and this had to be replaced. This was discovered when he went to have stem cells extracted and the hospital could not get anything because it was the wrong line. Rachael cannot recall exact dates and does not know the room numbers.
- 27 February 2017: ██████ commences radiotherapy at the Beatson Hospital for 6 weeks and completed his last day on 7 April 2017.

April 2017 – August 2017

- 7th April 2017: ██████ completes radiotherapy at the Beatson Hospital.
- After 6 weeks this treatment is completed and ██████ returns to QEUH to ward 2B. He started to receive blood transfusions and stem cells.
- 22nd May 2017: ██████ is admitted to Ward 2A to commence chemotherapy. He remained an inpatient for 6 days and was then discharged home. He did not move wards at this time. Rachael cannot recall if he moved rooms.
- ██████ went through 4 cycles of chemotherapy, 1 cycle a month. May, June, July, and August 2017. He was admitted every month for this purpose to ward 2A.
- 1st June 2017: ██████ develops Strep A and was admitted for two weeks to 2A. This infection was not an infection that was linked to the hospital environment.
- 28th July 2017: Admitted to 2A due to febrile neutropenia. Blood cultures are negative.
- 1st August 2017: ██████ is discharged home
- 2nd August 2017: ██████ attends daycare to ward 2B for ambisome infusion
- 14th August 2017: ██████ is admitted to ward 2A for chemotherapy with stem cell support.
- 21st August 2017: ██████ is discharged home
- ██████ attends DayCare on the following dates: 23rd August, 24th August, 25th August: ward 2B

- 25th August 2017: During ██████'s daycare appointment he became febrile and was admitted to ward 2A. Antibiotics commenced but blood cultures remained negative.
- 27th August 2017: ██████ is discharged home.
- 30th August 2017: ██████ attended ward 2B for a platelet transfusion but became unwell. Blood cultures are taken and enterobacter cloacae is identified. He is admitted and receives antibiotics – Tazocin which he received until the 3rd September and Gentamicin which he received until the 6th September 2017.
- 4th September 2017: ██████ develops a fever and starts to receive an antibiotic called meropenem.
- 5th September 2017: ██████'s line was removed and antibiotics were stopped. He also moved wards around this time but Rachael cannot recall which ward he moved to. Possibly moved to 2C or 3C. He was then moved back to 2A during this admission.
- ██████ was discharged on the 8th September 2017 and then he returned to attending DayCare/clinic appointments for a period.
- ██████ goes to Clinic now for MRI and reviews. He has had no further admissions to QEUH to raise for the timeline.

Scottish Hospitals Inquiry

Witness Statement of

Carolanne Baxter

WITNESS DETAILS

1. My name is Carolanne Baxter. I was born on [REDACTED]. I am [REDACTED] years old. I work as [REDACTED].
2. I am the mother of [REDACTED]. [REDACTED]'s date of birth is [REDACTED] and he died on [REDACTED].
3. I live at home with my children, [REDACTED], [REDACTED] and [REDACTED] in [REDACTED].

OVERVIEW

4. [REDACTED] was born prematurely, at 28 weeks and 5 days. There had been complications with the pregnancy. [REDACTED] remained in the neonatal unit at the Queen Elizabeth University Hospital until he passed away on [REDACTED]. I don't think that the neonatal unit is part of the Children's hospital as it's at a separate bit. There aren't ward numbers there but [REDACTED] was in rooms 1, 5, 6 and 7 during his time in the hospital.

FAMILY BACKGROUND

5. [REDACTED] was very small in the incubator but he wasn't on a ventilator to start with. He ended up intubated and with the ventilator around day 13 and this made it difficult to see his facial expressions or if he was smiling. I remember him gripping my finger at one point.
6. My other kids are [REDACTED], the oldest at [REDACTED], [REDACTED] who is [REDACTED] and [REDACTED] at [REDACTED]. [REDACTED] and [REDACTED] love the outdoors and go out to play a lot.

panic. I asked the nurse something along the lines of is this the pigeon dropping strain that [REDACTED] had but she said it wasn't that strain.

12. On the 19 March 2019, so [REDACTED]'s 49th day, he had a medically managed NEC episode, necrotising enterocolitis. I didn't know this at the time and only found out later, from his post-mortem. His condition had got worse and he was put fully on the ventilator. He was having issues with his lungs as well.
13. Around this time, [REDACTED] had a broken arm and the hospital didn't tell me until 2 days after they knew about it. I was up one day with my sister and I was there all day and I was leaving that night. I was approached by the doctors and they told me that [REDACTED] had a broken arm. They chose to approach me as I was leaving even though I'd been there all day. And they had known for two days previously. I was not happy at all.
14. He was getting an x-ray, I think it was to do with his heart at this point, I can't exactly remember. But they x-rayed him and apparently the break showed up. Although they weren't looking for that, it showed up in the x-ray. They put it down to him being premature and said that he had osteopenia, which means that because of the prematurity, his bones were all soft and brittle and things. So if that was the case, why did they not do scans? Why did they not do x-rays and stuff when he was born? I just don't understand. He was not in an incubator at this stage.
15. The staff said they were treating [REDACTED]'s breathing. But he was fine until he took that infection on day 13, back on 11 February 2019, that's when [REDACTED] went downhill.
16. Around the time of the infection on 19 March 2019, [REDACTED] was put on different medications. I can't remember names and things like that as my focus was on [REDACTED] but obviously he was being treated for infections along with the other medical difficulties he was having with breathing. I was thinking, well he's in the hospital, he's getting the care and they're putting him on medication because he needs it. I didn't have any reason to think that anything bad was

going to happen. I didn't know about the NEC when I was in the hospital. I was concerned that it was all about his lungs. He did have chronic lung disease. With the lung disease, when my son was being ventilated it does damage the vocal chords and stuff as well. Reviewing his medical records now, I can see he was put on midazolam, morphine sulphate (double strength), hydrocortisone, heparin, hepsal, vecuronium, potassium chloride and vancomycin. This is the first time I have learned about these drugs and had no awareness of the names when [REDACTED] was being treated.

17. I also found out from the post mortem that my son had broken ribs which I wasn't told about, in addition to the broken arm I knew about earlier. That got me thinking that if he did have the broken ribs, did that pierce his lungs in any way and make things worse, did it add to it? I just don't know. They never told me.
18. In May 2019, [REDACTED] was to get heart surgery because one of the valves in his heart was very narrow. The heart surgery was to try and correct it and make things better. That didn't go ahead because he took yet another infection, so I was told just about a day before the operation was due to take place that it was being postponed. I can't recall the exact dates. It was too risky to put him under surgery because he took the infection. I don't remember if they said there would be an impact of delaying the operation but it was never actually carried out.
19. I can't recall what I was told about the infections, but I just know [REDACTED] was on antibiotics a lot.
20. I think I had been told that it was pulmonary hypertension that was affecting [REDACTED]'s heart rate because his heart rate was going up really quite high and then it would take a dip as well. I don't think he was born with that. He was hooked up to quite a bit of medicine and things like that as well and I think that's when we were in room one.

21. I don't know if he was actually born with the lung condition either. He was premature, I get that. But I think he would have been put on some sort of respirator straight away if he was born with a lung condition.
22. They did give me injections of some sort before I went in to have him and that was to try and develop his lungs. It was to try and mature his lungs because he was premature. I don't know what the injections were but they went right through my full body from my head and it felt dead, dead warm. I felt as if I was going to die because I felt as if I couldn't breathe properly either. But obviously they had to do that to try and make things better for [REDACTED].
23. At some point, I can't recall when, I was told by Dr Peters that my son would become deaf and blind and mute. But [REDACTED]'s eyesight and his hearing were fine at that point. His condition was deteriorating though and all the medication slowed up and he was on the ventilator and things then as well. But I felt that I was being pressurised to turn his life support off. Dr Peters also told me that I was going to need carers in my house 24/7. I just felt as if he was being quite negative and arrogant and he was putting pressure on me. I felt that a few times when he would have us in for a meeting and stuff. I felt as if they were giving up on [REDACTED].
24. [REDACTED] was now on life support and just wasn't getting any better. The pulmonary hypertension episodes were becoming more regular and his heart rate would go away up really, really fast. He would be sweating, he would be clammy to touch. All that sort of stuff. And in the end, I just couldn't bear to see him the way he was anymore. I turned the life support machine off on the basis that I was told [REDACTED] wouldn't have a quality of life.

EXPERIENCE AT THE HOSPITAL

25. In the neonatal unit, you've got the waiting area outside and then you go through the doors and you've got the nurses' station straight ahead. To the right of you is room one, I think, and across from that, room two. I'm not 100 per cent sure. And then further along there was another room just after the nurses' station. And I think

there were another two rooms after that. And there was another nurses' station. It was just the one long, straight corridor. After the last nurses' station then you had another room and I think it had several incubators in it.

26. In the babies' rooms you obviously had the incubators. There weren't always seats in the rooms but you could easily access one if you needed it, just by asking the nurse to get one if one wasn't available. You had a wee desk at the end of the incubator, that's where they nurses would write stuff down, like write on [REDACTED]'s notes and things like that.

27. For the babies' rooms, I remember one with four incubators in it. There was another one across from that but [REDACTED] wasn't in that room so I'm not too sure what that was like. Then you had another room that had eight babies in it and then the same further down in the next room and the next room again. I think there were six big rooms, where there was more than one incubator. And there were a few smaller rooms. The six big rooms were where they had between four and eight babies in them. Some of the smaller rooms were just for one baby.

[REDACTED] was put into one of them a couple of times. So he was moved around the neonatal unit on several occasions. He was in at least four different rooms within the Unit, including rooms one, five and seven, which I think were multiple rooms, and he was also in at least one room where he was just in there himself.

28. One of the room moves was to move [REDACTED] away from a baby that had an infection and I think one was to get away from a baby who was really upset and crying a lot. One move was because they were doing a deep clean. I don't remember which room number that deep clean was in but it was one of the bigger rooms. I just felt at the time the whole neonatal unit was upset because everybody was rushing about everywhere.

29. I live close to the hospital so was going up every day and then coming back home at night. I wasn't very comfortable with that to start with though because I felt guilty and things like that for not staying with [REDACTED]. I thought he was going to get better because there were times when he was turning a corner and

things were getting a wee bit better. And then he would always just take a setback. It just always seemed to be infection after infection.

30. I did stay overnight in the hospital a few times. I did stay in the neonatal unit itself. I stayed in there for a few nights in total, I can't remember exactly how long for. I remember there was an episode though when [REDACTED] took a turn for the worse and I wanted to stay close by with him. On this occasion I was put into one of the rooms that was on ground level. And this is where we saw the corridor with the pigeon droppings was, before you went into the room.
31. I think I stayed overnight maybe say 15 nights. I obviously wasn't allowed to stay in the same ward as [REDACTED] but there was a room further round, it was away round the back. I slept in there. I can't recall when that was, probably nearer the end. The room on the 1st floor for parents staying over wasn't next to the rooms that the babies were in, it was to the back of the neonatal unit.
32. The room that I was in was okay. You had a bed, there was a toilet and a shower. It had a kettle. There was a chair as well, and a table. I can't remember what else. Obviously, it was decorated and stuff like that but I just felt as if it could have been cleaner.
33. That room I wasn't too bothered about, to be honest, even although it could have been cleaned a bit more. But it was the one on the ground floor that I was put into, that got to me. The neonatal unit was on level one and the rooms on level one were fine but that room I stayed over at on the ground floor was hell.
34. The ground floor had the back entrance of the neonatal unit. You go through the main double doors and it takes you up the long corridor and that's where I saw the pigeon droppings. Then you go through the other doors and you're in the maternity bit. That's the way we'd pass the room I had stayed in.
35. I ended up in that room because the other rooms were all occupied. I was a few nights in it. I was just in it once, but for a few nights in a row. Obviously, I was worried, I didn't want to leave [REDACTED]. So I had to take it as it was the only

room available. And it was just off that corridor where I'd seen the pigeon droppings. There were two single beds in it. It wasn't carpeted. I wouldn't even have said it had vinyl, it was just a hard floor. There were no windows in the room at all, no natural light in it. It did have a toilet in it. I don't think it had a shower so I just jumped home for a quick shower. I can't recall how clean the room was, it was just really dark.

36. There was another wee kitchen type room beside it that had a sink and a microwave and a fridge. I do recall that being dirty. I had enough on my plate with [REDACTED] and didn't speak to anyone about any of the rooms.

37. Though I didn't know anything about the ventilation problems or the contaminated water at the hospital until after my son passed away, I knew from what people had told me that there were problems with the pigeons. I remember speaking to one of the other parents, actually a girl I knew, who was in the neonatal unit with her son as well, and she was talking about the pigeon droppings. I just remember having a conversation and saying it was disgusting and things like that. At the main entrance, you've got loads of traffic in and out of there as well. So if you're standing on stuff like that then you're travelling it along the hospital.

38. I was with my mum and we saw the pigeon droppings in the corridor and my mum was horrified. We noticed the pigeon droppings prior to me staying in that ground floor room. Because you could take the back entrance to the hospital, lots of people used it. We had also seen pigeon droppings at the main entrance to the neonatal unit too.

39. Mum complained three times, because the pigeon droppings were still there in the corridor for a few days after she first reported it. Eventually mum spoke to the staff again and it was cleaned right away. I don't know who it was she spoke to or what she said as I had gone ahead, upstairs to see [REDACTED] in the neonatal unit.

40. I can't recall when this happened. It was maybe around the middle of the period

██████████ was in the hospital, I can't be sure, but we didn't see any pigeon mess again after this. But one of my friends, when I was in the hospital with ██████████, worked in the neonatal unit. He worked in the storerooms and he told me that he had seen pigeon droppings in a storeroom.

WATER AND VENTILATION ISSUES

41. As I have mentioned previously, I did not experience any issues in connection with the water or ventilation problems. I was unaware of the issues until after ██████████ had passed away and I think it was the media that I learned about the problems from.

42. I do remember the sewage smell. I could sometimes smell it when I was in the neonatal unit. I didn't really think anything about it at the time, or raise it with anyone, as I was too focused on ██████████.

CLEANLINESS

43. I felt as if the cleaners were always rushing, as if they were rushing the job just to get it done and get away. It was just the pace they were working at. I felt as if they weren't spending enough time. There were times as well that the hand sanitisers weren't full, they were empty.

44. I remember when I was there once with my sister, there was a cleaner in and she had actually dropped something on the floor from her trolley. She just put it back on the trolley. I don't know what it was because I was too focused on ██████████. I also noticed that when the cleaner entered the room she didn't wash her hands. My sister reported it to one of the staff but I can't remember what they said. We were all having to wash hands, so as a cleaner myself, I know they shouldn't be any different.

45. The windows weren't cleaned very often, but again I thought nothing of it at the time. But I saw in the news that the hospital had problems with windows falling out. I wasn't aware of any of this at the time.

INFECTIONS

46. I think the infections that [REDACTED] was taking and the issues that were going on at the hospital were having an effect on him. Because he kept taking infections after infections and it was holding him back. I was washing my hands with the water which I didn't know at the time was contaminated. Then I'm going into the incubator then touching my son where he's got IV lines in. He had one in his foot, one in his hand and he had one in his head. It wasn't all at the same time. So that's what I was doing. And then you think about what the staff were doing, they were handling my son a lot more. Just thinking about it makes me paranoid and I just think, wow!

47. [REDACTED]'s medications were changed a few times. I can't remember what they were, I'm assuming antibiotics. [REDACTED] was on quite a bit of medication. I don't recall being told about what infections he had but it should all be in his case notes. And the sepsis thing I didn't even know about until it was on the post mortem.

48. Reviewing the post mortem, what I have come to find out now is that

[REDACTED] had suspected necrotising enterocolitis, suspected sepsis, gram-negative septicaemia, bacterial gram-positive sepsis and klebsiella pneumoniae. While I knew about the pneumonia and sepsis, I do not know what the other conditions are.

IMPACT ON WITNESS

49. It's been an absolute nightmare, it's been a living hell. Absolutely horrendous. I went through a stage of my depression taking a dip. And I had turned to alcohol at the weekends, I just had to blot everything out. I was just an emotional wreck. Just the thought of living without [REDACTED] and everything that's happened to him. It's just absolutely horrendous.

50. I just need to get answers as to why all the infections and the issues that are going on with the hospital. And obviously I didn't find out about the ventilation and the contaminated water until after my son had passed. It was my son's anniversary just recently. That's two years and it's still going on. I'm not as bad as I was, I have kind of picked up a wee bit. But even my kids, they were extremely worried about me as well, and my mum and my sister. I've been up and down and up and down. My depression was stable prior to the experience with [REDACTED].

51. There were times I thought I heard a baby crying in my house. I was forgetting things and stuff as well. And that's the reason why I'm being assessed for PTSD as well.

52. It's been really, really difficult and I just need to get an answer. If my lawyer comes back and says look Carolanne we've had a look into everything and there was nothing, then that's absolutely fine. But because I've discovered since then about the contaminated water and the ventilation, obviously I'm wondering if this is why he had so many infections.

IMPACT ON FAMILY

53. I mentioned that my son [REDACTED] has [REDACTED] and [REDACTED] and that I struggle to get him out the house. I know that this has got worse since

[REDACTED] passed and I'm sure it's also connected to the reason [REDACTED] doesn't socialise with anybody either

COMMUNICATION

54. I don't remember the hospital staff being the greatest at communicating with me. And I'm not the greatest at asking questions either. So I was just going with everything that they were saying and doing. There's quite a lot of medical jargon as well, like as far as his medication and antibiotics are concerned, which is why I don't remember all the names and stuff either.
55. I felt intimidated by the staff and felt they were avoiding me in case they slipped up. Maybe in hindsight looking back, they weren't telling me the full story. I didn't ask questions as I trusted what they were telling me. They also apologised to me for having missed opportunities in regards to delaying [REDACTED]'s heart surgery and not telling me about his broken bones.
56. The fact that I didn't even know that [REDACTED] had sepsis until after he had died and the post mortem was done shows that that communication was not good.
57. With his broken bones, they didn't tell me about the broken arm until two days after they knew about it. I knew they delayed telling me because I remember my sister was speaking up for me because I was just full of nerves and all that sort of stuff. And obviously I was worried and things like that. So my sister spoke to the doctor and the doctor said that she couldn't read x-rays. But then on the other hand, she said to my sister that she was going to do another x-ray and then she was going to spend time studying the screen to see how long [REDACTED]'s arm had been broken for. So it was just absolute contradiction. I can't remember the rest of the conversation. The broken ribs I didn't even know about until after [REDACTED] died.
58. They also didn't want to give me [REDACTED]'s post mortem results either. And I was horrified at that because I was saying you can't hold that back. They didn't go right into any great detail or explanation. I felt as if because I was very vulnerable that they were trying to take advantage of that. Because on the post

mortem, obviously that's where it told me about the sepsis which I didn't know about and also the broken ribs.

59. I wanted to see his post mortem. And it actually came to the point where we went up to the hospital. I already had a copy of the post mortem at this time because they did give me it eventually. And it was Dr Peters and someone else that was with him that went through the post mortem with me.

REPRESENTATIVE GROUPS

60. I was a member of the Neonatal Intensive Care Unit Facebook Group but came off it recently. Parents were using it to give updates on their kids and stuff like that. Obviously, I had to then come away from it because it was affecting me mentally as well. I think I deleted it a few months ago.

61. I'm not aware of the Case Note Review or Oversight Board so haven't been involved with any of these.

COMPLAINTS

62. We haven't raised any complaints, other than speaking to our solicitors.

CONCLUDING COMMENTS

63. I wouldn't go anywhere near the hospital again. I would go to a completely different hospital for anything if I needed to. It was just such a terrible, terrible experience. I still think about all the issues and worry that they are ongoing at the hospital.

64. This public inquiry will never be able to bring my son back, but I hope it prevents another child suffering unnecessarily and prevents another family going through what I went through.
65. I believe that the facts stated in this witness statement are true. I understand that this statement may form part of the evidence before the Inquiry and be published on the Inquiry's website.

Scottish Hospitals Inquiry

Witness Statement of

John Henderson

WITNESS DETAILS

1. My name is John Henderson. I was born on [REDACTED]. I am [REDACTED] years old. I am a retired doctor.
2. I live at my home in [REDACTED].

OVERVIEW

4. Following an operation for [REDACTED] at Gartnavel Hospital in Glasgow in April 2015, I was transferred to the Queen Elizabeth University Hospital (QEUH), where I spent several nights in ward 11D. I can speak to a number of issues about the condition of the hospital that caused me some concerns.

WITNESS BACKGROUND

5. Before my retirement, I had a long history in the health service, including spells as a doctor in different parts of the world, including the USA. I have therefore experienced a wide range of medical environments.

6. Though I continue to undergo medical treatment at Raigmore Hospital in Inverness, I am fine and I consider myself to be fortunate that there is treatment for my condition. I am active, though not as much as I once was.

EXPERIENCE AT QEUH

7. Following surgery at Gartnavel on 24 April 2015, I transferred to the QEUH on 27 April 2015. I was an in-patient in ward 11D for a few days. I can't recall precisely the length of my stay but it was less than a week, possibly 4 or 5 days.
8. I have no issues regarding my treatment in the hospital and indeed would commend both the staff and the amenities in the room that I was in in ward 11D. I can't recall the room number. I believe all the rooms in the ward were single rooms with en-suite facilities. It was very well appointed and a significant step up from the facilities that I had experienced in Gartnavel.
9. However, there were two issues that caused me concern and left me wondering if the hospital had in fact opened before it was ready.
10. My initial concerns related to the water supply in the ward. Early in the evening on the day of my arrival on 27 April 2015, a nurse or auxiliary advised me that there was no water supply and that they would not currently be able to fill my bedside water jug. They said that the problem was affecting taps and toilets, meaning that neither could be used while the issues were being investigated. It was suggested that if I had visitors coming to see me, I should ask them to bring bottled water with them for me. There was no mention of bottled water being provided by the hospital.

11. There was no indication of how long the problem would last but I was told that plumbers were working on it. Though I was fine, my concern was about how other patients might be affected and also how staff would be able to maintain basic hygiene, when there was no running water. It was one thing patients and families being unable to have a cup of tea but not being able to wash hands or use the toilet was clearly not great, both for patients and staff, in a new hospital.
12. In the event, the supply failure lasted probably no more than an hour and a half that first evening. I was fortunate as I was able to contact my partner, who brought me water and in fact came in with a pack of a dozen or 18 half litre bottles of drinking water that I was able to use and also make available for other patients.
13. Though the problem was fixed reasonably quickly, it then recurred the next night, probably for 3 to 4 hours this time. Again, there wasn't any significant impact on me personally but I'm not sure about the wider impact. The message from the staff was pretty much the same as the previous night – that they didn't know how long the problem would last but that plumbers were again working on it.
14. I felt a bit for the staff as the problem was out of their control and they were just having to make the best of it. I believe I was in the first tranche of patients in the new hospital, so I don't imagine that the staff would have had much experience of the problems. I can't fault them as I don't believe that there was any more information they could share.
15. My second concern was about the external panels on the building. From the window of my room on 11th floor, I could see two elevations of what is an X-

shaped building. I observed lengths of rubberised materials flying in the breeze. These looked like the materials that surrounded the external panels to seal them but they seemed to have come loose and some of the strips of rubber were several metres long. They seemed to be still attached at one point so were just blowing about with the wind.

16. I could also see that these rubber strips were loose around many of the panels, not just one or two. This made me wonder how safe this new building was. I wasn't certain how secure these large panels actually were and, at the very least, it seemed unlikely that they would remain water tight with all of these sealing materials already coming loose.
17. I took photographs of these loose seals around the exterior panels and have provided these to the Inquiry **[Picture JH/01 – at Appendix 1]**.
18. Since leaving the QEUH at the beginning of May 2015, I think I have had only one visit back there, to have [REDACTED] checked, as most of my ongoing treatment has been carried out at Raigmore Hospital in Inverness. I cannot recall precisely when I was back at the QEUH but I did not observe anything untoward.

COMMUNICATION ISSUES

19. I have no concerns about communication while I was in the QEUH. Given my relatively short stay in the hospital, I did not raise anything about the external panels and the loose materials around them. I did however take photographs of what I saw that I can provide to the Inquiry.

20. Similarly, it was clear that the problems with the water supply were outwith the nurses' control and I think that the staff were as open with me as they could be.

CONCLUDING COMMENTS

21. It is my view that there were major issues with the hospital that raise questions about whether it was fit to open when it did. It occurred to me that the hospital opened during the Scottish election campaign which made me wonder if there were political reasons that stopped them delaying the hospital opening. I have no idea if there was a connection, but accepting patients when there were serious faults with the building can only add to the costs of putting things right.
22. 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.

JH/01 – Appendix 1



In accordance with [Restriction Order 3](#), the Inquiry has provided excerpts of the witness statement for Witness 5. The Inquiry will only provide excerpts of the statement that do not contain information that is capable of leading to the identification of the Witnesses

Scottish Hospitals Inquiry

Witness Statement of

Witness 5

OVERVIEW

1. My [REDACTED] was diagnosed with Burkitt's lymphoma [REDACTED]. [REDACTED] was treated in the Royal Hospital for Children (RHC) and Queen Elizabeth University Hospital (QEUH) between [REDACTED].
2. [REDACTED] spent time in ward 2A and PICU 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 stayed with [REDACTED] during most of [REDACTED] admission to hospital as an in-patient. [REDACTED]. I can speak to the experience which [REDACTED] and I had on these wards.

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

Experience in ward 2A

3. They were still getting [REDACTED] room ready when we arrived at the RHC. [REDACTED] was in a room for people to get transplants done on ward 2A. [REDACTED] was only in that room for maybe two or three days and then they moved [REDACTED] further down the corridor.

4. After we had been there for a couple of days, I noticed the windows in the bedroom have got the blinds built in between the two panes of glass. I opened the blinds but I heard a drilling noise coming from a drill when I opened the curtains at 7:30 in the morning. There were four people on a cherry picker taking the cladding off from underneath the bedroom window. It was cladding they were taking off but they didn't tell us why. I think it was something to do with the Grenfell Tower. I don't think it was fireproof. They actually changed quite a lot of it, right round the side of the kids' hospital entrance.
5. When we arrived in ward 2A, we were told not to use the water. I think ■■■ had a shower there though. You were allowed to wash with it. There were filters on the bottom of the taps where the water came out. Some of them were just getting fitted when we got there.
6. Ward 2A was nice. It was clean and the nurses were fantastic. The ward had massive fridges so you'd put your name on your stuff and it could be kept in there.

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

7. We found out they were decanting all the kids to ward 6A. The hospital brought in a big private removal company. Outside in the corridors, there were the big red packing boxes, the plastic ones; there were hundreds and hundreds of them. I think it was one of the nurses that came in and told us that we were getting moved. She did apologise for the inconvenience.
8. We were told at one point we were moving because of something to do with the water. You weren't allowed to drink the tap water in ward 2A. You were allowed to wash your hands in it and that was it. There were hundreds of the two litre water bottles on the ward. Staff would hand these out for nothing.

9. On the days leading up to the move, everything got stickered for your bedroom so you knew who had the right furniture and different stuff like that. [REDACTED]. They took everything, all the furniture was moved out the room in ward 2A and taken over to ward 6A. [REDACTED] We were taken along the dark corridors that usually members of the public don't get to see. There was rubbish and broken furniture lying everywhere.
10. [REDACTED]. There were nurses waiting for us when we got to ward 6A. The move to ward 6A was one big massive convoy. It all happened in one day. It was alright but you would maybe expect one person to get moved in a hospital, not an entire unit. That's when we started thinking things were wrong. Ward 2A obviously wasn't adequate for what the kids were needing. It was all different stuff we were told as to why we were moving.

Experience ward 6A: late 2018

11. Ward 6A was just like an adult ward. It was basically a long corridor with rooms on each side. You could turn at the bottom of it and come back up as that's where the teenage kids were. The kids were playing in the corridor.
12. You had to use the main entrance of the hospital to access ward 6A and there would sometimes be drunk people there. There was pigeon shit everywhere. That's when all the scaffolding was still up because the window panels had been falling out.
13. In ward 6A, they didn't have the same patient monitor screens at the nurse's desk. Nurses were having to go to ward 6B, just across the landing to scrape up some bandages and wipes. They weren't prepared for moving all the kids and they didn't have enough supplies.

14. There wasn't a kitchen in ward 6A so they had started to feed parents but I wouldn't give that stuff to my dog. The food was awful. You were spending a fortune every day just going and getting sandwiches from the shops downstairs.
15. Ward 2A was cleaner than ward 6A. There was a red bag in the room. [REDACTED], if there were any accidents, everything would go in the red bag. In ward 6A the red bag could sit there for a couple of hours 'til somebody would take it away.
16. [REDACTED] there were alarms going off every 45 minutes or every hour and a half so you weren't getting a night's sleep. Sometimes you would have to wait for a nurse to attend. I think there was a shortage of staff in 6A. They were getting agency nurse that had never worked with kids before so they never had a clue what they were doing.
17. I don't think we were given bottled water on ward 6A. [REDACTED].
18. At the start of the corridor. The baths in these bathrooms weren't available because there were no filters on them. The whole ward had moved and the big bathroom was massive. It had two massive baths in it but it was basically just used for storage. There was even stuff lying in the baths.
19. [REDACTED] must have been moved nine or ten times in ward 6A, at least. They had to order in beds for the parents as the ward didn't have them. They shipped in beds and they were folding beds that have got a little table on top like a guest bed but there were that many complaints about them not being comfortable. The hospital then ordered new beds with thicker mattresses. You still had to fold that up in your room and try keep it somewhere out of the way.

CONCLUDING COMMENTS

20. In terms of how I feel about the hospital now, I wouldn't set the hospital on fire. It actually makes me feel sick driving past it on the motorway.
21. I think Jeane Freeman's got a lot to answer to. They only signed that hospital off because the Queen was coming on a certain day to open it.
22. I do still have concerns about the safety at the hospital. It's not just happened to ■■■; it's happened to loads of kids over the past eight years since the hospital has been open. You don't expect to go into hospital to get sick. You expect to go into hospital to get better.
23. I think that I heard that the NHS are trying to sue the contractors that built the hospital, I think that is just to pass the blame to somebody else.
24. I believe that the facts stated in this witness statement are true. I understand that this statement may form part of the evidence before the Inquiry and be published on the Inquiry's website.

Scottish Hospitals Inquiry

Witness Statement of

Lynndah Allison

WITNESS DETAILS

1. My name is Lynndah Allison. I was born on [REDACTED]. I am [REDACTED] years old.
I am [REDACTED].
2. I am the mother of patient, [REDACTED]. [REDACTED]'s date of birth is [REDACTED]. He is 18 years old.
3. I live with my partner, [REDACTED], and my son, [REDACTED] in [REDACTED].

OVERVIEW

4. My son is [REDACTED]. He was diagnosed Myelodysplasia Syndrome in September 2016 which advanced into Acute Myeloid Leukaemia in October 2016. [REDACTED] was treated in the Royal Hospital for Sick Children (RHSC or "Sick Kids") in Edinburgh and the Royal Hospital for Children (RHC) in Glasgow between September 2016 and November 2017 when he finished treatment.
5. [REDACTED] was treated in ward 2 of the RHSC in Edinburgh as an inpatient and outpatient and on ward 2A and 2B of the RHC in Glasgow as an inpatient and outpatient. I stayed with [REDACTED] throughout his treatment when he was both an inpatient and an outpatient. I can speak to the experience and I had on these wards.
6. There are some specific events I would like to mention. I believe that [REDACTED] suffered from infections whilst in ward 2A of the RHC which I believe may have

been connected to issues with the water supply. There were also various issues with the hospital building that I witnessed. I will come on to talk about these issues and events in more detail.

FAMILY BACKGROUND

7. [REDACTED] is a typical teenager. He likes motorbikes and mountain biking. He had a girlfriend prior to his treatment and she visited him in hospital a few times.
8. He gets on well with his older brothers and sisters who live nearby and when his brother, [REDACTED] is home from university they play on the Playstation and they get on well. He also gets on well with his brother [REDACTED] and they fix their motorbikes in the garden.

SEQUENCE OF EVENTS

Diagnosis and Experience in RHSC Edinburgh: September – November 2017

9. [REDACTED] was 13 and had just started second year at school on the 22 August 2016 and he had had a bad cough during the summer holidays. I had taken him over to the local hospital and they did chest x-rays and said he had pneumonia. Every time he coughed, he was sick and then the cough went away but the sickness didn't. When he went back to school he would come home sick. His dad thought he was 'at it', but I got him an appointment at the GP.
10. [REDACTED] got bloods taken at the GP on 7 September 2016 and a couple of days later, on 9 September, his results were back and his GP told me he suspected [REDACTED] had leukaemia and he was going to refer him to the Sick Kids in Edinburgh.

11. We went up to the Sick Kids on 20 September 2016. As we live in the [REDACTED], Edinburgh was the closest hospital for us. We ended up in Glasgow because [REDACTED] was part of a clinical trial that Professor Gibson was running.
12. This was [REDACTED]'s first admission to hospital. He was admitted to ward 2. As you go in the door of the ward there's a two bed unit which was for teenagers and had been done up by the Teenage Cancer Trust. It had been done up nicely and there were two bedrooms and a bathroom, which was shared between the two rooms, and a lounge area where you could watch movies. This was where [REDACTED] stayed during his admission.
13. [REDACTED] hated the Sick Kids as he had to share a bathroom with the person in the other room and, at the time he was there, the other patient was a girl. [REDACTED] had a lot of sickness and diarrhoea so he hated having to share a bathroom.
14. I could stay with [REDACTED] in his bedroom and had a fold down bed I could pull out. It was fine for the four days he was in.
15. During this admission, [REDACTED] had blood taken and a bone marrow extraction was taken to see if his cells had been turned to leukaemia. He had this done under general anaesthetic. After these tests had been done, we were told that [REDACTED] had myelodysplasia syndrome, which is a blood disorder, and that it might turn into leukaemia. At that stage I thought that it must be hereditary, as [REDACTED]'s [REDACTED] had died of that, but the doctors dismissed that as a possibility and said that only 400 families worldwide have got the hereditary gene. It turns out that it is hereditary and [REDACTED]'s [REDACTED] also has it, as does his [REDACTED] and his [REDACTED].
16. At this stage, [REDACTED] was being looked after by haematologists and oncologists and he was given anti-sickness medication. After 4 days as an inpatient he was discharged on 23 September 2016. After that he was up and down to the Sick Kids, on a Monday, Wednesday and Friday, as an outpatient

to the clinic on ward 2 so that his blood could be monitored for leukaemia. He was also receiving blood transfusions and getting things like kidney tests done.

17. When [REDACTED] was attending as an outpatient, he would go into the Teenage Cancer Trust area where there were two chairs and a TV and he would sit there and get a blood transfusion. If those two chairs were occupied by other patients, [REDACTED] had to go into the main part of ward 2 which was like a 1950s ward. [REDACTED] hated it. It was quite distressing as there were always wee kids crying because they were getting jags and other things done to them and that was quite rough.
18. There was no leukaemia in October 2016 and then when he went back to school on 18 October he went a funny colour and on 20 October he was jaundiced. By 29 October [REDACTED] really wasn't well.
19. On 9 November 2016 [REDACTED] had a bone marrow extraction at the Sick Kids in Edinburgh and that was when things were beginning to change. He was getting loads of blood transfusions. At that point, we were discussing [REDACTED]'s treatment options with the doctors. Our options were standard chemo in the Sick Kids, which would be fludarabine and I can't remember the name of the other one, just bog standard chemo and [REDACTED] was horrified. He hated the idea of sharing a bathroom while he was getting chemo. We also got offered Glasgow as a clinical trial. The clinical trial was MyeChild 01. [REDACTED] was the first case that fitted the criteria for this study. [REDACTED]'s consultant, Susan Baird, told us that the new hospital in Glasgow was absolutely amazing. All the rooms had en-suites, and, because [REDACTED] would need a bone marrow transplant, he would have to go to Glasgow for that eventually anyway as they were the only hospital who carried out those transplants. Susan Baird told us that Professor Gibson was very keen to get [REDACTED] through and we were really made to feel it would be the better option to go. [REDACTED] wanted to go as he would get his own bathroom and that was a big factor for him. So we signed up to it.

20. Glasgow wanted [REDACTED] to have a lumbar puncture to see how far on the leukaemia had come and they also wanted his central line fitted before we were admitted to Glasgow so that they could begin the chemo right away. [REDACTED] went into the Sick Kids on 23 November 2016 for this to be done under general anaesthetic. The results of that lumbar puncture showed that he definitely had leukaemia.
21. The central line was inserted in his neck and it went directly into his heart. It had tubes for injecting stuff into him with little caps on it and he got a wee bag he could put round his neck and put the tubes in if he was going for a shower, or for wearing under his clothes. It got fitted on the Wednesday 23 November and on Friday 25 November he needed another blood transfusion, which he got at the Sick Kids, and they used his central line to give him the transfusion and that's the first time it was used and the only time that it was used before going into Glasgow.

Experience in RHC: November 2016

22. [REDACTED] was admitted to the Glasgow hospital on 28 November 2016. He was admitted to ward 2A in the RHC and he was in the Teenage Cancer Trust part of the ward. It was at the end of the ward through a set of doors and separate from the rest of ward 2A. It was an eight-bedded unit and then there was a big pool room and a huge TV. That's where I was told that I could make food and there was a microwave and a kettle. [REDACTED] had his own room and it was en-suite and there was a bed for me to sleep in as well. Initially [REDACTED] thought the ward was great and he just wanted the pass for the Wi-Fi so he could play his PlayStation. It was just brand new, especially compared to the Edinburgh Sick Kids: it was amazing.
23. On 29 November 2016, I met Professor Gibson for the first time. She came along to [REDACTED]'s room and asked me to go along to the lounge area to

sign a few forms. I'm hard of hearing and it was noisy in the lounge as there were at least three other families there and the kettle was boiling and the TV was on. The only words I really heard was her saying that there was no guarantee it would work and that the clinical trial might not save [REDACTED] but it would help people in the future. Then she asked me to sign several things. I wondered if I had made the right decision, but I didn't get the chance to ask her anything as she moved on to something else. That was what she was like throughout the whole process; she wouldn't repeat herself. My sister wasn't there at that meeting, but she came to help me out for the first fortnight and I was so glad she was there because on other occasions, when we were being given information, I would ask her what had happened after the doctors left. Once she went home I was often in the dark about what was happening as I couldn't hear. I would often ask [REDACTED] what had been said, but when he was really poorly he didn't know as he wasn't in the mood to listen.

24. At the meeting with Professor Gibson on the 29 November, she told me that the plan was the [REDACTED] would get a combination of three different types of chemo and one of them would be the Mylotarg, which was the banned one. She also told me that it was likely that [REDACTED] would be an inpatient for six months. She said he would need, possibly, four rounds of chemo and then a transplant.
25. The first round of chemo started on 2 December 2016 and it was administered through [REDACTED]'s central line. The nurses would come in and give him it in his room. He had three days of randomised chemo and then on 5 December he got the banned chemo which was the trial drug. He was being monitored closely because his heart rate had gone up and his temperature went up. He had a better day on 6 December but then on 7 December we were moved into isolation, that would be into Room 20, and we were there over Christmas. The isolation rooms are on the main ward, not in the TCT. Room 20 had the special air filtration in it and it had a lobby as part of it, separated by double doors,

where you would remove your outdoor clothing, put on an apron and wash prior to entering the isolation room.

26. We got moved into isolation because the chemo had begun to take away any immune system that [REDACTED] had. We had been told that might happen depending on how his neutrophils counts were. We got moved on 7 December 2016 and his chemo ended on 11 December. That was the end of his first round. On 12 December he developed a temperature and mucositis which are blisters that start in your mouth, go right down your oesophagus, right into your stomach and right out your back passage. He had huge big blisters internally and he got a morphine driver fitted to help with that. I think this was something that was an expected reaction to the chemo.
27. [REDACTED] also developed this rash all over his body on 13 December 2016. They were big spots and Professor Gibson requested that he got a heart echo done. A heart specialist and a dermatitis specialist saw [REDACTED] and they told us that they thought the rash was coming from his heart. He was put on ketamine for the mucositis and he was on that until Monday 19 December.
28. At the time I thought that both things, the mucositis and the rash, were due to the chemotherapy, but when he the mucositis started on 12 December was up having a shower and was drinking loads of water that the nurses were bringing in for him and encouraging him to drink. The water was from the family kitchen where there was a big water filtration machine and even the nurses were filling up their water bottles from it.
29. I didn't know it at the time, but [REDACTED]'s medical records say that on 14 December 2016 he had a heart infection. He couldn't pee that day and was also sent for an echo scan. They thought the rash was coming from his heart. He was on vancomycin quite a lot, but I'm not sure what particular infection this antibiotic was for.

30. ██████████ had a lot of infections. A high temperature means that they have an infection. ██████████ was on ketamine until 19 December 2016. On 23 December, ██████████'s temperature spiked at 120 degrees Fahrenheit and I was pressing the buzzer for the nurses. He had the rigors, he was shaking that much that he was shaking himself up off the bed. I pressed the buzzer for 20 minutes and the light comes on outside his room, but nobody was coming and I eventually ran to the nurses' station and told them ██████████ had a high temperature and they all came running up the ward. So that was another infection. It had to have been an infection because he had the rigors so bad that when the nurses got into the room, ██████████ was complaining of back pain and one of the nurses thought there was a chance he could have broken his back with shaking so much because ██████████ was saying that he couldn't feel his legs. I was never told what the infection was. They gave him paracetamol intravenously to bring his temperature down then they took a blood sample. It would go up to the lab and if it grew anything then they would know what antibiotics to give him. I know this now but I didn't know that at the time. Nothing was really given in any detail about what caused the infection or why and I assumed everything was to do with the chemo because I've never seen anybody going through chemo before. I don't know if he got antibiotics on this occasion.
31. We were told that if ██████████ spiked a fever then it was an infection of some sort and standard procedure would be that they would treat it as an infection, take bloods and give him paracetamol.
32. If you pressed the buzzer in your room, you would sometimes have to wait a while for one of the nurse to come in. Obviously everybody's child isn't well and you can put your buzzer on and because the way the ward is shaped, the most ill ones would, I imagine, be nearer the nurses' desks. The lights would show who was pressing the buzzer but the norm was you would wait ten or 15 minutes unless somebody was passing and they would come in.

33. ██████████ had another bone marrow aspirate on 29 December 2016 and we had been in for four weeks at that point. Once his neutrophils count started to rise, we got moved out of strict isolation and back into the TCT, room 5. That was on 4 January 2017. He then got another bone marrow aspirate in theatre on Thursday 5 January and we were allowed home on the 11 January. The aspirate was to check whether the Mylotarg had made any significant difference to the leukaemia.

██████████'s admission to ward 2A: January-February 2017

34. ██████████ was back in on 13 January 2017 for anti-fungal and bloods. I was told that the anti-fungal treatment was just part of his overall treatment to stop him from getting any fungal infections because he had a lowered immune system. He was then re-admitted to ward 2A on 16 January 2017 for his second round of chemo. He was in room 6, then we got moved to room 4 and then we were moved to strict isolation on 25 January 2017, as his neutrophils would have been at their lowest point after the chemo. That was room 22.
35. Once he was in isolation he had a temperature on 28 January 2017. It was 38.8 degrees celsius. I never got told what this infection was. When we were in the Sick Kids, we had been told by someone that if there's a temperature then there is an infection. He got antibiotics, but I wasn't sure at the time what they were. I've since learned from his medical records that they included posaconazole and allopurinol. Throughout that round of chemo, ██████████ had loads of temperatures. He was getting platelet transfusions and his neutrophils were still at zero. On 6 February he had lymph node swelling and a temperature of 38.1 going up to 39 and he was on antibiotics. He had a temperature again on 7 February; it was 38 point something. He got a blood transfusion, an ultrasound and an x-ray on 8 February and his temperature was still up at 38.1. I was never told whether he had infections or what those infections were. It

was like I was the country bumpkin in the big city and because I was deaf I couldn't really properly hear what I was being told. They would just write him up for vancomycin and he was on that.

36. After his second round of chemo was finished, we were told that the next round of chemo would be given at the Sick Kids in Edinburgh. There was maybe a shortage of beds in Glasgow and there was room in Edinburgh. The Mylotarg chemo had finished by that point, so [REDACTED] was just getting the randomised chemotherapy which they could give him in Edinburgh. He was discharged on 20 February.

Ongoing treatment at Edinburgh Sick Kids: February – April 2017

37. Between 21 February and 6 March 2017, [REDACTED] was attending at the Sick Kids in Edinburgh and the RHC in Glasgow as an outpatient two to three times a week for tests and monitoring. On 1 March I met with Professor Gibson and she told me that [REDACTED]'s chemo would start on 6 March and it would be a five day course of chemo, with five hours of chemo and eye drops every two hours. The two chemo medications that he was getting were fludarabine and cytarabine.
38. When [REDACTED] was an inpatient he had a temperature of 38.1 on 8 March 2017 and he was started on antibiotics on 9 March. The last day of chemo was 10 March and I took him over to the CLIC Sargent house, which was just over the road, so he could have a shower. He didn't want to have a shower in the hospital as he was in the Teenage Cancer Trust room and he was having to share a toilet with a girl which he wasn't very comfortable with doing.
39. [REDACTED] found getting his chemo in the Sick Kids very stressful as he had to share a bathroom with a girl and he had diarrhoea with the chemo so he didn't like using the bathroom.

40. During this stay, [REDACTED] got put into isolation and that was in a room on the main ward. If you can imagine an old hospital ward, with all the beds in a row and the curtains and then across from those there are glass panelled rooms. We were put in one of them, but it was horrific because we were right next to all the little children. That was quite stressful. We weren't in that room for too long as they treated the Teenage Cancer Trust rooms as isolation rooms too, so he got moved back into one of those room and nobody else was allowed in and the nurses were using barrier nursing. Commodes were used to avoid using the toilets. The nurses always wore aprons and gloves, only used in that isolation room. [REDACTED] was discharged from this stay on 4 April 2017.
41. During this stay [REDACTED] had some infections. He had an infection on 8 March 2017. His temperature was 38.1 and he went onto antibiotics on 9 March. He had another temperature on 20 March and he was put on two lots of antibiotics with a temperature of 40.1.
42. He was on vancomycin for a line infection on 24 March 2017 and he was still on antibiotics on the 25th. He had a temperature of 40 degrees on the 27th so he was still on antibiotics then. He had oramorph and more antibiotics. I think he was on septrin and vancomycin. He still had a high temperature on 28 March. He was really upset because the doctors wanted to move him to intensive care on the 28th. This was because he was on oramorph and he had a high temperature. He was meant to be getting a blood transfusion but they cancelled it because of his temperature and the fact that he hardly had any neutrophils. They didn't tell me what the infection was, but he was put on antibiotics on 20 March and he was still on them on 29 March. [REDACTED] refused to go to Intensive Care because I couldn't go with him, so they left him in the Teenage Cancer Trust room with me. They must have managed to get his temperature under control as he was discharged on 4 April. I have [REDACTED]'s medical records from Edinburgh, but I can't really read the writing so I don't know if there is anything about what the infection was.

43. ██████ got home on 4 April 2017 and then the haematologist phoned the house and said that ██████ had an infection and they wanted him to go straight back in but ██████ refused to go. I took him up on 6 April to the Sick Kids for treatment but we got home again the same day. The haematologist never told me what the infection was.

██████'s admission for a bone marrow transplant: April - June 2017

44. After that, ██████ was back at the RHC in Glasgow as an outpatient on 10 April for a blood test and then as an outpatient on 18 April for a lung and kidney function test and a bone marrow aspirate to see what level his neutrophils were at. This was in preparation for ██████ going in for a bone marrow transplant on 3 May 2017.

45. ██████ was admitted to ward 2A on 3 May 2017 and was put into room 22 which is a strict isolation room. This room had the lobby type set up that I described previously. This was when he started the conditioning for his transplant. On this admission, ██████ had a massive reaction to ambisome which I think is anti-fungal medicine. He had been on that medication before and been okay. I had been told that it was part of his treatment. This time, I was sitting on the chair looking out the window, which looked down onto the reception, and ██████ said he wasn't well. I pressed the button and, just at that, a nurse was passing our room and she came in and she pushed the big red button that sets alarms off and everybody ran to the room. It was the most terrifying thing. The crash team were all round about him and I could just see his wee face. However, we survived it. Professor Gibson came in to see us that morning and said it was all going expected so far. She said his bloating was because he wasn't peeing enough but she didn't say if this was a problem.

46. On 4 May 2017 the conditioning chemo started. This chemo takes everything right down and strips down the immunity so the transplant can be done. It was Campath chemo and this caused him to get a rash, but Professor Gibson said that this was as expected and he got it again on 6 May. On 7 May he got

Thiotepa chemo. That was the one that burns the skin and he had to shower between 10:45 a.m. and 10:45 p.m. as much as he could. The medical staff would have preferred if he sat in the shower all day because the chemo seeps back out through the pores and it burns the skin. By this stage [REDACTED] was getting really weak and I said I would help him shower. That was when I became aware of how lukewarm the showers were. I was trying to turn the temperature of the water up, but it was as high as it could go. I didn't mention it to the nurses as I thought that maybe it was meant to be that temperature so children couldn't burn themselves. It meant he was freezing and I remember wrapping him up in about six towel and my dressing gown and he was under his bed covers frozen and waiting for the next shower.

47. [REDACTED] got his last chemo ever on Monday 8 May 2017 and he had a rest day on 9 May and he was meant to get his transplant on the 10th but it was delayed so they gave him antibodies and his transplant day was 12 May. The way the transplant takes place is that the transplant coordinators come in with a big bag of what looks like blood. These are the cells that have been harvested from the donor. It was given to him through his central line and it took two hours to go in. [REDACTED] looked absolutely terrible at that time.
48. After he had the transplant, his mouth was sore, possibly mucositis again, I think, and his skin was itchy. He was getting blood and platelet transfusions and he was on morphine for his sore mouth. On 18 May the transplant coordinator told us that [REDACTED]'s donor had tested positive for toxicosis. That was a worry and [REDACTED] had to get a haemoglobin transfusion, but he was tested for the toxicosis and he was negative for it so he didn't need any further treatment.
49. [REDACTED] is very competitive and he wanted to be the first person out of transplant in the fastest time. He asked the transplant coordinator what the fastest time was that anyone had got home after transplant and she told him 23 days, so he was determined to beat that. He eventually got home on the 6 June

2017, but he had to attend day care on 7 and 9 June just so he could be monitored. He was in as a day care patient on 13 June to get a bone marrow aspirate. He had to go to theatre for this but he got home the same day. He was in again as a day care patient on 20 and 27 June. This was so he could be monitored.

██████████'s admission for suspected graft versus host disease July-August 2017

50. At this time, ██████████ was losing loads of weight and 73 days after he got the transplant he was admitted to the Sick Kids in Edinburgh on 24 July 2017 because he had lost so much weight. He wouldn't let the medical staff in Edinburgh put a feeding tube in. He wanted his favourite nurse in Glasgow to do it. Glasgow agreed that they would admit him so that this could be done and he was admitted to ward 2A on 27 July. The doctors thought the weight loss might be to do with the chemo trial. He had gone from about 10 and half stone to about four and a half stone so they were concerned about him. He got a feeding tube inserted and he was in hospital until 29 August.
51. On 12 August 2017, Professor Gibson said that she thought ██████████ had graft versus host disease and that was maybe what was causing him the weight loss and having high temperatures. On 14 August he had the temperature of 39 degrees and then on the 15th and the 16th they took him away to theatre for a bone marrow and a scope. That was to see if it was the graft versus host disease in his bowel or whatever and it wasn't. Graft versus host disease is something that can happen after you have a bone marrow transplant.
52. When we went in in August 2017, ██████████ never left the room. We were in strict isolation constantly and because it was just for a feeding tube, his obs weren't getting taken as often. We went into the Sick Kids on 24 July and moved up to Glasgow on 27 July and right away ██████████ wasn't feeling well and his temperatures were spiking. This is when Professor Gibson had said that she suspected graft versus host but it's interesting because on 8 August

his medical records said he had grown something in the lab on the 14th, the 15th and the 16th.

53. When I got [REDACTED]'s medical records, there is a note saying that a Dr Peters from microbiology had phoned to say his illness was due to contaminants. I wasn't told any of this at the time and I don't know what it meant. For the whole of August his temperatures were up; which means infection. They never said it was coming from his central line.
54. He got a scope on 16 August to look in his gut to see if it was graft versus host. But it wasn't graft versus host, it was a line infection. Although I was never told that it wasn't graft versus host. The gist of what they were telling me was that, because he was spiking temperatures and he wasn't in for any treatment, he must have graft versus host disease and that'll be why he's lost all this weight, so they gave him the scope for that and it wasn't due to that. I only found that out once I got his medical records though. I wasn't told anything about his line.
55. During this admission, he was spiking temperatures throughout despite the fact he was only in to be tube fed and because he was being tube fed he wasn't eating any food and he was just drinking the hospital water. The nurses were in charge of taking care of his central line. They would come in and they would clean it and they started taking cotton buds and taking swabs off his central line that would be sent away and that was when it was like, so it's a line infection that he's got, then?
56. I wasn't actually told he had a line infection, I had surmised that because his central line was really red. If I had been told it was a line infection, I would have written it down in my diary.
57. We were in strict isolation. [REDACTED] wasn't eating. He was drinking water and obviously showering in the water and feeling like rubbish. There's a sticky pad round his central line, like a cling film kind of thing, that would often come

off because of his high temperatures, with the sweat. [REDACTED] would go in the shower without the covering on and shower then come back and then the nurses would wash his central line and put a dressing on it. Because he was sweating so much the sticky coverings for the central line were coming off almost every other minute of the day.

58. Dr Pinto, one of Professor Gibson's doctors, told me on 25 August 2017 that was getting put on the emergency list to get his central line out. His line was removed on 27 August. He didn't tell me why [REDACTED] had been put on the list. At this point he was 100 days post-transplant, that was on 20 August, and he had lots of infections from when he went in and right through this admission. By that I mean he had a constant temperature and it was coming from his central line. The doctors were trying to say that it was graft versus host. I wasn't told at the time why the central line needed to be removed. However, as I have said, [REDACTED]'s medical records state that Dr Peters wanted it noted on [REDACTED]'s records that she had phoned the ward to say that his infection was probably down to contaminants.
59. It was around this time that I met the mum of a little girl who had had a transplant a month after [REDACTED], so we were in hospital at the same time. She had told me that her daughter had a central line infection and I told her I thought [REDACTED] had one too as he was spiking a high temperature. When he was in theatre getting his line out on 27 August I was outside talking to the mum and she was telling me that she was losing her daughter. I couldn't tell her that [REDACTED] was in getting his line removed and we were getting home. I know that the little girl died shortly after that. I knew that [REDACTED] had a line infection at the same time as this little girl because that's what me and her mum were talking about and she told me that her daughter had a line infection and I said [REDACTED]'s got one too. The nurses might have mentioned that he had a line infection and that is how I was able to tell the mother this. Though I wasn't told at the time about the infection, it was clear to me from his temperature spikes and the angry red colour around his line that there was an infection. And

this was later confirmed in the Dr Peters note I subsequently saw in ██████'s medical records.

60. ██████ was discharged on 29 August 2017. It seemed quite sudden and it meant him having the feeding tube at home, which he was mortified about. The staff had to quickly show us how to use the feeding tube at home, which ██████ and I also weren't entirely comfortable about. I'm not sure why it was all so sudden. After that we were back at Glasgow and Edinburgh for outpatient appointments. We were back at Glasgow on hospital for out-patient appointments on 4, 18 and 25 September. ██████ was getting blood and platelet transfusions and he was being monitored to see that he was putting on weight. We went up again on 6 November for a kidney test and ██████'s feeding tube was coming out. We stayed in CLIC overnight and then ██████ had a heart echo and bone marrow aspirate on 7 November. Every time ██████ has had a heart scan, and that includes the rash coming from his heart, whoever is looking at the scan brings someone else in, a higher up person, and they never say anything. So I wonder if his heart was damaged with the infections or had it already been damaged by the chemo? I don't know what the outcome of the heart echo was.
61. On the 17 November 2017 we went to Glasgow and got results from the bone marrow tests. The results were that he was still in full remission and the transplant had been a success.
62. In 2018 and 2019, ██████ attended Glasgow and Edinburgh for various tests at day care, but he has not been back in the hospital in 2020 at all.
63. When I approached the Public Inquiry I put a post up on the Facebook Group that is for ward 2 patients saying that I had spoken to the Inquiry and that other people should too. We were meant to have an appointment with Professor Gibson around that time and I saw that she had read my message on Facebook. We didn't go to the appointment as I was worried about COVID at the time and

I phoned the hospital to tell them. The very next day I got a letter from Professor Gibson saying she had struck us off for failing to attend. I knew [REDACTED] would go to adult services once he was 18 but he had still to get tested. I thought she was pissed off because of what I had said in the Facebook post and also in emails that I had sent to Craig White. I had mentioned in the emails that I didn't think she was approachable. I didn't query this letter or phone her secretary to ask why this letter had been sent. Then, around May 2021, I got a phone call from the hospital that they wanted to see [REDACTED] on 25 June. Then I got a phone call from the new transplant coordinator, to say that the appointment was changed to 9 July and it's with Professor Gibson. So I don't know what happened, but I feel in my bones that it was to do with my post about the Public Inquiry.

WATER: EVENTS INVOLVING WATER SYSTEM

Water incidents in RHC

64. When [REDACTED] was in the isolation room 20 over Christmas and New Year 2016, the en-suite was constantly wet because the water wasn't draining away properly in the shower. All the shower rooms in all the rooms, even in the Teenage Cancer Trust end, were damp and the floor was always wet. I remember I would go into the shower maybe an hour or two after [REDACTED] had had a shower and my socks would get wet.
65. When [REDACTED] was getting chemo before his transplant in May 2017, he was getting the chemo that comes out through his skin and he had to wash all the time. That was when I realised that the water was lukewarm in the showers. I also noticed around this time that there was a black sludge around the drain in the shower room. I didn't touch it but it looked like it would come off if you did. I noticed that there was black staining on the drains in all the rooms we were in. I don't know if it had anything to do with the fact that there were no windows.

66. When [REDACTED] was an inpatient, we were told not to drink the water, but I can't remember when. It might have been August 2017 but I'm not sure. I think it was either at his transplant in May or in August because up to that point we had been allowed to use the water to make cups of tea, but then we were told that the water in the kitchen wasn't suitable and we were given bottles of water to use. We were told it was fine to shower and I never saw any filters on any taps. There were things on the taps to stop the water spraying everywhere but that was all. No one came in to any of the rooms that we were in and did any maintenance.
67. On 23 May 2017 I was sent home from the hospital with a sickness bug and I wasn't allowed back for 48 hours. I usually had a shower at the Ronald McDonald house, or at the CLIC Sargent house, but on this occasion I had a shower at the hospital because [REDACTED] wasn't feeling well and I didn't want to leave him. I had a shower about 10pm and woke up at 2am with pains in my stomach and sickness and diarrhoea. A nurse came in and I told her I wasn't well and she told me I needed to leave and I couldn't come back for 48 hours. I had to get my partner to come and get me at 5 in the morning and as soon as I got in the car I felt fine and I didn't have any more sickness or diarrhoea. I think that I got it from the shower. It was the only time I had a shower in the hospital and the illness came on so suddenly. As soon as I left the room and went to sit outside and wait for my partner, I was fine. I don't know if we were still drinking water from the tap at this time, or if we had been told to drink bottled water.

POTENTIAL INFECTIONS

68. When [REDACTED] was unwell in August 2017 I knew that he had an infection because I could see that something was wrong. He was in strict isolation and there was barrier nursing. I also realised that it was a line infection because he

developed a bright red rash around the line and it was very angry looking. At the time I thought that I was the one who had given him the infections.

69. I was given no information about the infection at the time. It was only two and half years later when I read the medical records that it was confirmed that it was an infection. It was only after I saw the Dispatches program with Lisa Summers that I recognised Dr Peters' name. I looked at [REDACTED]'s medical records and I saw Dr Peters' name and the information about the infection dated 18 August 2017. I don't know what the infection was. There was always an eerie feeling at the hospital and a feeling of tension that something was wrong. I felt that the staff weren't telling me something and they weren't explaining what was going on with [REDACTED]. Sometimes when the staff did speak to me I couldn't hear them because I was deaf and no one would make adjustments and take time to make sure I understood. No one has ever contacted me again and I feel very much in the dark about everything.
70. I can't say for sure how many infections [REDACTED] had. He was on environmental antibiotics the whole time he was in hospital. I thought that this was part of his chemotherapy treatment and assumed it was a drug to help with his immune system. All I knew at the time was that, if [REDACTED] had a high temperature, that was a sign that he had an infection.
71. Every single day I look at [REDACTED], I can see his central line scar and I'm aware now that his line had been infected when he was in the hospital. But I still don't know what caused the infection. There are so many unanswered questions. Did every infection he had come from the hospital or did none of them come from the hospital?
72. I feel very distressed about the lack of information I was given by the hospital at the time about [REDACTED]'s infection, and after the information about the water issues came out in the press. I feel that what happened to the little girl who died could have happened to [REDACTED] as they were both in hospital at

the same time. I could have lost him on top of his [REDACTED] who also passed away from cancer. I feel that the hospital did not tell me everything. There was no duty of candour and the hospital may have used the fact that I was deaf to their advantage.

OTHER ISSUES RELATING TO HOSPITAL BUILDING

73. I noticed that there was a smell outside the hospital. It was like raw sewage. This was in May 2017. You couldn't sit outside. I mentioned it to one of the nurses, or to the cleaner, and they told me it was snagging problems and there were workmen dealing with it. I think that was what they were told to say; that there was an issue with the drains and it was just snagging problems.
74. I also noticed that some of the window ledges outside the windows were filthy and the windows didn't open so I don't know how they could be cleaned.
75. I also remember in December 2016 there were buckets all over the ground floor catching drips of water when it was raining heavily. Again, I was told that this was snagging.
76. There was one time that a pigeon got into the building and flew about the ground floor. It's such a high height, I don't know how anyone could catch it.
77. When [REDACTED] was in one of the isolation rooms, it wasn't room 20, we looked out onto a flat bit of roof and there was an air duct and there were lots of pigeons on the roof. I've since looked at the hospital from above and those air vents aren't there. I thought I had been hallucinating, but the air vents were definitely there because I remember thinking that there were loads of pigeons sitting on top of it and I was glad the window didn't open. This was maybe around the time that [REDACTED] was going through his second round of chemo; so around January or February 2017.

CLEANLINESS

78. The cleaner on ward 2A was so friendly and was a nice, nice woman. If [REDACTED] was in isolation she would wear barrier protection, like gloves and a pinny and would take them off before she went into the next room. She would go into each room and squirt the cleaner onto the mirror. It didn't have a smell, like a hospital, disinfectant smell. Then she would sweep the floor and take her stuff and move onto the next room. What I noticed was that she wouldn't change her mop between rooms. There wasn't a big bag of mop heads for her to use. She had cleaning cloths in her pocket and sometimes she would use paper towels and then just bin them. Once the floor was washed, it never looked any different and I can't say that the room was sparkling clean.

OVERALL EMOTIONAL IMPACT ON [REDACTED] AND HIS FAMILY**Overall emotional impact on [REDACTED]**

79. [REDACTED] is trying to move on with his life but his experience has clearly had an impact on him. He pretends that everything is fine with his health, even when it is not, out of fear that he will have to go back to hospital one day. This in itself is serious as it means he will resist further treatment he may need in the future out of fear of having to go back into that hospital. [REDACTED] has said to me, and to my parents, that he would rather die than go back to that Glasgow hospital.

Overall emotional impact on witness

80. I am suffering from PTSD now. The shock of finding out what happened to the little girl who died and knowing how close [REDACTED] came to having the same outcome, because they were in hospital at the same time with an infection, has been too much to bear. I am on anxiety medication and anti-depressants. I also

live in fear about returning to the hospital and have fears for other relatives having to return to the hospital.

81. When I saw on the news that a patient had died from an infection at the hospital I knew it was the little girl who had been on the ward at the same time as [REDACTED]. I contacted her mum and asked her about this and this is how everything came out. I always knew there was something wrong with the hospital water because of the skin reactions every time [REDACTED] had a shower, but the true impact only came out when I saw the Dispatches program.

COMMUNICATION: GENERAL

82. The hospital wasn't always clear about [REDACTED]'s treatment, for example when it was ending. This meant I was not always clear about what had to happen to him in the hospital and what his options were. Maybe I couldn't take things in, or maybe it was to do with my poor hearing, but I think that there could have been better communication, for example when we were discharged quite suddenly in August 2017.
83. I did not get any information at the time about [REDACTED]'s infection and I have heard nothing since the issues all came out in the press. I contacted Craig White in October 2020 and raised queries with him about the potential infections that [REDACTED] may have been exposed to. I received a vague response back that did not answer my questions. I have copies of these emails.

Facebook Group

84. I joined the closed Facebook group and found it was useful to get practical information. It was also nice to see how the children were doing, but the information that exists on there is surface information, not much more.

CONCLUDING COMMENTS

85. I have significant fears about returning to the hospital. I feel that the lack of communication has been traumatic. How close I came to losing [REDACTED] on top of already having lost his [REDACTED] has been too much to bear. I am scared that my other relatives, who may have to return to the hospital in the future, will be exposed to other infections and I am scared that saying the wrong thing could compromise their care.
86. I do not feel that the Health Board is fit for purpose and I think that there has been a cover up. I feel that the Health Board are serving their own purposes and not looking after the most vulnerable patients.
87. The hospital still has a lot of cleanliness problems and issues that I feel could leave open the possibility for further infections. I also feel that, if the hospital covers this up and hides everything, then lessons will not be learned and the risk will be left open that others could become sick.
88. I am involved in this Inquiry because a child died of an infection in ward 2A at the same time as [REDACTED] was there and I want to prevent that happening again. My other children and family members will have to return to the hospital for care in the future and I am deeply frightened about what could happen to them if they do.
89. I believe that the facts stated in this witness statement are true, that this statement may form part of the evidence before the Inquiry and be published on the Inquiry's website.



SCOTTISH HOSPITALS INQUIRY
Hearing Commencing
20 September 2021

**Bundle 7 – Witness Statements for Week commencing 1 November 2021 and the
remaining statements for those witnesses not giving oral evidence**