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-Call 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 donors 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 [redacted] 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. [redacted] 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 [redacted]'s time in PICU, she was moved rooms several times. She was also moved rooms in ward 4B.

41. When [redacted] 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 [redacted] not to go to ward 6A. She didn't say why; she was just adamant that [redacted] 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 [redacted]'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 [redacted] was using it to brush her teeth and me and my wife were washing our hands and showering with the water. [redacted] was showering with that water too. We just assumed that [redacted] 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 [redacted] 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. [redacted] 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 [redacted]'s appointment on 10 June 2019, she did say that [redacted] would be put on antibiotics during her transplant and this was to protect her. She told us that due to the full body radiotherapy, [redacted] 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 [redacted] 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 [redacted] 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 [redacted] 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. 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 drank 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: [redacted] 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 [redacted] was sent to Borders General Hospital on 3rd January 2019 for tests and was given initial diagnosis of ALL. [redacted] 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. [redacted] received out-patients treatment the rest of the time.
- January 2019: [redacted] began a four-week course of chemotherapy which was not successful.
- February 2019: [redacted] 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. [redacted] 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 [redacted] had Putida Pseudomonas. Parents were not told until Case Note Review Letter of 4th March 2020.
- 13th June 2019: [redacted] 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. [redacted] began receiving antibiotic treatment for fungal infections intravenously including Posaconazole, Gentamicin and Fluconazole.
- 22nd July 2019: On 22nd July 2019 [redacted] 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: [redacted]'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: [redacted] was put on a ventilator.
- 21st August 2019: Mark and his wife went to clear [redacted]'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 [redacted] 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 [redacted] underwent Toxic T cell treatment to help with the adenovirus.
- On the night of 28th August 2019 [redacted] 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)