Scottish Hospitals Inquiry

Witness Statement of

Charmaine Lacock

WITNESS DETAILS

1. My name is Charmaine Lynnette Lacock. I was born on [redacted]. I am [redacted] years old.

2. I am the mother of [redacted]. [redacted]'s date of birth is [redacted]. She is 5 years old.

3. I live with my partner, Alfie Rawson, and our four children, [redacted], [redacted], and [redacted], in [redacted].

4. I am a [redacted]. Alfie and I [redacted].

OVERVIEW

5. My daughter is [redacted]. [redacted] was diagnosed with Acute Lymphoblastic Leukaemia ("ALL") in August 2018. [redacted] was treated in the Royal Hospital for Children ("RHC") and Queen Elizabeth University Hospital ("QEUH") between August 2018 and December 2020, when she finished treatment. [redacted] attended both hospitals as an in-patient and an out-patient for over 2 years. [redacted] still attends for check-ups. I have prepared and provided the Inquiry with a timeline showing the dates on which attended hospital and the wards where she was treated. The timeline is attached to this statement at appendix 1 (**CL/01**) and I confirm that it is accurate to the best of my recollection.

6. [redacted] was treated in wards 2A and 2B of the RHC which are known as the Schiehallion Unit. The Schiehallion Unit treats children with blood cancer.

also received treatment on other children's wards, being wards 1E, 3B and the Clinical Decisions Unit ("CDU") of the RHC. Following the closure of the Schiehallion Unit in 2018, [redacted] was treated on ward 6A of the QEUH which is the adult part of the hospital. I stayed with [redacted] during every in-patient admission with the exception of one night, and I attended all of her outpatient appointments. I can speak to the experience which [redacted] and I had on these wards.

7. My partner Alfie looked after our other children. At the time of [redacted]'s diagnosis, our youngest daughter [redacted] was only [redacted]months old, was [redacted]old and [redacted] was [redacted]old.

8. There are some specific events that I would like to mention. [redacted] contracted staphylococcus aureus infection in September 2018 when an in-patient in Ward 2A. She then contracted staphylococcus warneri infection in February 2019 when she was an out-patient during which time she was attending daycare at the hospital every couple of days for her chemotherapy treatment. In March 2019 she contracted a pseudomonas infection shortly after she received a blood transfusion in Ward 6A. She then developed a candida infection when being treated as an in-patient in Wards 3B of the RHC and 6A. During our contact with the hospital there were ongoing construction works at the hospital. I will come on to talk about these events in more detail.

FAMILY BACKGROUND

9. I live with my partner, Alfie and four children in [redacted]. [redacted] is [redacted]years old, [redacted] is years old, [redacted] is [redacted] years old and [redacted] is [redacted] years old.

10. [redacted] started nursery on [redacted] which was her birthday, and will begin[redacted]. She is a caring and loving child. She wants to be a princess, she loves all things pink, glittery and playing with her babies. She is very much "sugar and spice and all things nice". At nursery we have received reports that she is very

good at sharing and playing with others, that she is a very popular child. Everybody loves her.

11. She is very loving towards her sisters and is very close to the younger one, they are joined at the hip and do everything together. She has a good relationship with all her siblings. There is a bit of jealously sometimes because she had me to herself for so long. [redacted] wants to be the baby, the golden child and she got very used to having me to herself during her hospital stays and when she was going through treatment. It was just me and [redacted] for a lot of the time. She tries to share. The security blanket that I have to provide to comfort her is evident.

12. Following [redacted]'s diagnosis, our perspective as a family has changed. Before that we were very work orientated. Now our focus is on the family and spending time together as a family. We like to be outdoors whether it is playing in the garden or going away on trips, we want to make up for the time lost, for the childhood memories. We want to make memories together. It is all family orientated.

13. Prior to her diagnosis, [redacted] was a happy and healthy child. She hit all her targets and milestones and she never saw the GP. She had never even had a temperature, she was the easiest baby. When she was teething she just got on with it. Nothing was an issue for her.

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

Diagnosis: August 2018

14. I took [redacted] to the GP on Wednesday 15 August 2018. The night before we had been sitting on the sofa and I noticed that she had three lumps around her lymph nodes. I had been rubbing the back of her neck. They had appeared suddenly. She never had them before. Looking back now, there may have been other things that we might have missed but our youngest daughter,

was only [redacted]months old and she had been born two months premature. We thought that [redacted] was adapting to having a new little sister – that [redacted] was still trying to be the baby and she also loved babies. She went back to having a nap a couple of times a day when the baby was having a nap. She asked for milk out of a bottle, which was not like her and we thought that was to be like her baby sister. She would take her bottle of milk and lie down and fall asleep in the baby's rocker. She would play for short times with her sisters outside, then she would come in and sit at the window and watch them play.

15. There was one day that we had got the paddling pool out for the kids, was out playing then came inside and fell asleep halfway up the stairs. But we just thought she had tired herself out, that she was knackered from playing that day. We just put it down to her being tired and put her down for a nap. Her eating went down a bit and she was crying more. This was the day before we went to the GP.

16. The next day [redacted] was crying constantly, and I asked her why she was crying all the time, and she couldn't express why or what was wrong. We went to the GP on Wednesday 15 August and saw the locum GP. She looked her over, she had no fever, she felt her tummy and said that she thought it was viral. However she said that she would refer her to the hospital for blood tests, but that she was not overly concerned. I keep saying this to people when I describe this, that the GP had a mask that came over her face when she said that she was going to refer [redacted] for bloods. The GP also found that she had swollen lymph nodes in the groin area. I was told to give her paracetamol if she felt unwell but that she thought it would go away, it would pass.

17. On Friday 17 August [redacted] was falling when walking. It was unlike her as she was not a clumsy child. I said to Alfie that we had to take her back to the doctor. She would grab her head and scream, then calm down again. In between she would play but there were these moments where, this was not my child, that there was something wrong. Our neighbour was over at our house and she said that [redacted] looked pale, and I commented that it was hard to

notice when you see someone every day. All the concerns I had and coupled with the comment made about her being pale I felt I should take her back to the GP. We had looked at google and had identified worst case scenarios.

18. I took [redacted] to our own family GP on Friday 17 August 2018. [redacted] had swollen lymph nodes under her arms. He said all her lymph nodes were swollen. The GP said that he was not concerned, that it was probably viral and his own son was recovering from a virus and that two weeks later he was fine. He was not overly concerned and said that we already had the hospital referral for blood tests and to wait it out, but to come back if over the weekend something presented itself. Give her calpol, keep her comfortable and ride it out, that was the advice.

19. On the Saturday morning [redacted]'s lymph nodes were very swollen and it looked like she had the mumps, which was what we thought she had. We thought ok we can deal with the mumps. She didn't eat much that day. At that point we thought we knew what it was, that it was mumps and it was the "something" that might present over the weekend, as the doctor said.

20. On Sunday 19 August the swelling had gone down. She looked like the old [redacted]. I said to Alfie that I thought it was weird. I knew that it took a long time to recover from mumps and I felt that something was up with her. At 3pm that day she woke from her nap, her tummy was rock hard. [redacted] had not complained about her tummy. I called NHS 24. They thought that she might be constipated but given her age they referred her to Gartnavel Hospital to the out of hours doctor. I took her there immediately.

21. At Gartnavel Hospital [redacted] was seen by a nurse. She said that she looked a bit viral, at this point [redacted] was singing and dancing and she didn't look the part. We saw the doctor, and without even looking at her or touching her she said she had serious concerns. She told me to take her to A&E at the QEUH immediately. She was concerned about the swollen lump in her tummy. I said that she had been checked over by two GPs since Wednesday and that they

had checked her tummy and didn't feel anything. All I can tell you is that her tummy was never this hard. The doctor at Gartnavel told me to go immediately to A&E, not to go home and that if I didn't have a car they would call an ambulance.

22. I took [redacted] straight to A&E at the QEUH. Staff there said it was probably viral, that she was too happy and healthy and that she didn't look sick. But I am a mum and I had been on google. I asked the doctor to check her bloods and if her bloods came back all fine then we would go home but I said that until then "I am staying here". It was the fourth medical professional that we had seen since the previous Wednesday. I think it was a junior doctor who saw initially, she told me that they didn't normally take bloods from children who were so small, that they didn't want to hurt them and make them scared of the doctor. I refused to leave until they had carried out the blood tests. The junior doctor spoke to a more senior doctor, either the registrar or the consultant whoever was leading the department at the time, and they agreed to carry out the blood tests.

23. We were in the CDU. Forty minutes after the blood tests were taken, the doctor told me that the results showed that there were some irregularities. He said that [redacted] had a high white cell blood count. I said "I don't know what all of this means, are you telling me that my child has cancer?" and she said "yes" and that oncology was on their way to see us.

24. Fifteen/twenty minutes later Professor Gibson walked into the room. She told me it was leukaemia and that from the blood tests drawn from the line she could probably say what kind it was, as her count was so high. [redacted]'s white blood count was extremely high. For a normal person the white blood count sits under 10,000. The Professor said she had never seen a count so high in a child, and in a child playing. Maybe in a child on a stretcher or on life support. I am a planner and asked what the plan was, what was lying ahead. She said that if [redacted] made it through the night, and then made it to the following Friday that the hospital could insert a Hickman line and start chemotherapy.

They couldn’t begin chemotherapy or a blood transfusion immediately, there were risks in giving her a transfusion then around clotting. Her platelets were very low, everything was low except the white blood count. I was in shock.

[redacted]’s initial treatment – Admission to Ward 2A: September 2018

25. [redacted] was admitted to Ward 2A of the RHC on the evening of Sunday 19 August 2018. Ward 2A in the RHC, is known as the Schiehallion ward. was in Room 7. She began to receive high dose steroids and high glucose water infusions to rinse the leukaemia out. The more you hydrate, the more it will come out. The aim was to lower her blood count.

26. Room 7 is behind the nurses’ station and is for new patients with a new diagnosis. Within the room there was a small cabinet and a bed. As was so young the staff brought in a cot for her. There was a pull down bed for parents which could be brought down between the hours of 7pm and 9am. Outside of those hours the bed was to be folded away. There was a leather chair and a smaller plastic visitor chair. There was a side cabinet, the top drawer was locked as this was where staff stored individual patient medicines. There was an en-suite bathroom which had a shower, a toilet and a hand basin. Each of the rooms had a TV installed. Most of the TVs were broken and never worked. I was told by the nursing staff on the ward that the TVs had never worked and that it was due to the fault of contractor who built the hospital. We were told by the nursing staff that the TVs could not be fixed, that they had been done on the cheap.

27. On Monday 20 August, me and Alfie met with Professor Gibson to discuss [redacted]’s diagnosis and her treatment plan. [redacted] was diagnosed with Acute Lymphoblastic Leukaemia. We were told that she would begin Regimen B protocol. During that meeting the Professor told us that our children don’t die from cancer, they die from infections. That is the big thing, the treatment meant she would be neutropenic a lot and could catch any sort of infection. Neutropenic is when [redacted] had no resistance, she had no neutrophils. This meant she was vulnerable to infections. That is imprinted on you from that

moment on, how vulnerable she is and how we have to protect her as a family and as parents. In order to minimise the infection risk during the initial Induction phase of [redacted]'s treatment we took the decision that there would be no visitors to see her. [redacted] was supposed to start nursery but we stopped that as you know how children are when they start nursery, they bring back bugs and that could have put [redacted] at risk. Alfie and I wanted to get out of front line treatment, which is the most dangerous treatment, and we were told that would be about 7 months. With the delays that occurred to her treatment that actually took 9 months for [redacted]. For the first five cycles of treatment, received very strong chemotherapy and then after that she moved onto the maintenance treatment which was not as strong and more spread out. We took the decision to shut down the business and Alfie stayed at home to look after the girls. I stayed with [redacted] in the hospital.

28. Professor Gibson was [redacted]'s consultant. There were a team of nurses and doctors who worked alongside her. There were random nurses and doctors all the time. Within the nursing staff there was some student nurses and some individuals who had worked on the Schiehallion ward for years, and they knew more than some of the doctors.

29. During that first week of treatment the medical staff used cannulas to draw blood from [redacted] and to administer medication. The cannulas didn't last long and would collapse, after one attempt of drawing the blood, the cannulas stopped working which meant that it had to be removed and a new one had to be inserted. There was one occasion during that first week when the staff were on their third attempt at inserting a cannula when I said to Alfie, I just can't do it, I can't hold her down to put the cannula in. She was screaming. I couldn't be there. Alfie went in to the room. He held her, they tried three times and she peed on herself and all over his clothes, she was petrified. Alfie came out of the room and he was crying. After that [redacted] would say things like "Mummy, protect me and hide me", "Make sure nobody gets me". She was frightened.

30. Following that first week of treatment, [redacted]'s white blood count lowered and she was able to begin treatment. On the 24 August 2018, [redacted] had surgery to insert her Hickman line. The line was inserted by a surgical procedure, under a general anaesthetic. [redacted] fasted from 2am the morning of surgery, which for a child who is on high dose steroids is evil, but you just have to get past it. Steroids make the child moody and hungry all the time, and that hunger is horrible. Towards the end of her treatment at the hospital she was allowed to have fluids up to an hour before any surgery so I gave her diluting juice to fill her up and take the edge off the hunger, but at that point it was a fast and it was hard. It was no one's fault, that is just part of the treatment.

31. [redacted]'s line was inserted on her right hand side, an incision was made near her neck, the line was inserted under her skin and came out in her chest between her shoulder and her breast. The end of the line was dressed. The surgery was about 1 hour and a half, maybe a wee bit longer. The Hickman line can be used to administer medication and draw blood. During the procedure to insert the Hickman line, [redacted] also underwent a lumbar puncture to check what was going on with the bone marrow, and she received the first dose of methotrexate to her spine which was her first chemotherapy dose.

32. On the 25 August 2018, [redacted] started block one of her chemotherapy. This was the Induction phase of her treatment. It was supposed to be a four week course of treatment of high dose steroids and high dose chemo. It actually lasted around 6 weeks. [redacted] caught an infection towards the end of the treatment so it was an 8 week stay overall. I speak about the infection later.

33. [redacted] was on Regimen B protocol. She received vincristine in her Hickman line, and oral chemo daily. I can't remember all of the medications but it was different medications that were to be repeated in cycles during the block. Parents are provided with a sheet at the beginning of each block of treatment so that you know what the treatment plan will be and what is coming, what the program is for her. She got a lumber puncture a week later and this was a

regular procedure, and with every lumbar puncture she got methotrexate in her spine at the same time.

34. She received PEG injections to her legs which was part of the chemo, attacking the cancer in her muscles. There were lots of different chemo infusions during that first block. It was hard for her.

35. In the second week she didn't want to go to the playroom. This was because when it was time to administer medication, the staff would administer it wherever the children were. The staff would come and find the children and administer it. So if the child was in the playroom, they would administer it there. [redacted] only wanted to walk about the hallways holding my hand. This was because the staff didn't administer medication in the hallways but took the child back to their room to do so. She knew they wouldn't do anything to her in the hall. She felt cornered in the playroom.

36. In regards to the rules and protocols on the ward, none of the staff on the ward told us what the rules were, we were not taught. It was more that we found out what they were. Communications were not clear. On our first day on the ward, I was told that we would be given a tour but it didn't happen. It was day 3 before I discovered there was a parent kitchen and that was because one of the other parents showed me.

37. On Monday 20 August a charity came to the ward. [redacted] had just been admitted and she didn't have any toys in with her, Alfie had brought her blanket. It was the nursing staff who said to keep toys to a minimum. There was a scribble pad that they had given her. We took the packaging and we put it on top of a bin, we were parents on the ward and we didn't know where the correct bins were. We put some other packaging on top of the cupboard in the room. Alfie had come to see us and bring some things in. [redacted] was still young and was drinking bottles of milk. [redacted] was [redacted] months old and I was expressing milk for Alfie to take home, so he had brought a breast pump into the hospital for me, there was a scribble pad and some clothes. He also

brought [redacted] a new toy doll. The cardboard box packaging and plastic was left sitting on top of the bin on the room. The suitcase that Alfie used to bring in the belongings to us was sitting on the floor and all belongings were inside it. We took [redacted] to the playroom. The auxiliaries burst in to the room and said, "you can't have the room in a mess like that, Infection Control will have a field day if they walk into this". They began to tidy up. One of the doctors came in to see us. We didn't know that something as basic as a suitcase could be seen as an obstacle to cleaning the room. No one told us. Again if communication of the rules had been clearer at the beginning then we would have known and would have ensured we followed them. They said they would get someone from Infection Control to come and speak to us. All the infection control did was to hand us a leaflet with basic rules.

38. The leaflet was related to the protocols when your kid had an infection and about being in-source: so you can't leave your room, you have to wash your hands, someone comes to remove your bins a number of times a day. The leaflet was more around what happens if your kid has an infection and not about the rules of preventing infection.

39. During the first week we took her to the playroom on the ward. No one told us what the protocols were on the ward. We let [redacted] go into the playroom with her sisters and we did not know that the room was only for patients of the Schiehallion ward. [redacted] was playing with her siblings in the playroom, staff burst into the playroom and said that siblings couldn't be in here, that it was a sterile environment and they were asked to leave. But we didn't know, no one told us. Over time we observed that the rules were not consistently applied as we saw other families in the playroom with patients and their siblings. We have no problem with adhering to rules and the protocols, but prior to that no one told us. We had not been informed, that the playroom was only for patients for infection prevention control reasons. It was a case of learning as you go.

40. [redacted] spent most of the first block of her treatment in Ward 2A. You never stayed in one room for a long period of time. They moved us a lot in Ward 2A.

The nursing staff would literally come in and say, pack up we are moving you out. Sometimes it was the auxiliaries who would tell us. Then a few hours later someone would move you to another room, then sometimes they would remove all the furniture and seal up the room. All the staff told us was that they were cleaning the rooms. You are living out of a suitcase so you throw everything in. We stayed for maybe two weeks in Room 7, then we moved about another 4 times before they closed the ward at the end of September 2018 and we moved to Ward 6A.

Line Infection - staphylococcus aureus: September 2018

41. In September 2018, towards the end of the initial treatment block, began to develop small blisters on her skin. She had a high temperature and began to spike. Swabs were taken of her skin and bloods were drawn for cultures. She was immediately started on antibiotics, gentamicin and tobramycin or something like that. It was four times a day and via infusion. On 23 September 2018, Professor Gibson told me it was a staphylococcus infection. She did tell me the full name at that time it was tazocin. I had been told by other parents on the ward that lives could be lost when a child developed an infection, that they pull the line and it would be taken out. For that could mean going back to cannulas and I wanted to avoid that. Professor Gibson told me that the infection lived on the skin and so it must have been something that crawled in, and she was going to speak to the doctors in microbiology to see what they thought and whether they could save the line and handle it with antibiotics. I wasn't told how [redacted] might have contracted the infection or what might have caused it.

42. By this point [redacted] had been spiking a temperature for two days. It takes 48 hours for blood cultures to come back. I took [redacted] out for a walk in the hall. Professor Gibson went away for a short time and then came back to our room and she said that [redacted] had to fast from 2am the following morning because microbiology wanted the line out and it would need to be removed. The plan was that [redacted] would be down first thing for emergency surgery. Then Professor Gibson left and I was not told anymore at that stage. Bless the

woman, she had done this for so many years that she knows what she means when she says things but as a parent I heard this for the first time. I didn't know what was happening, and I was worried that [redacted] might die from the infection. Alfie left and I was on my own with [redacted]. I took her out for another walk in the hall and spoke to one of the nurses at the nurses station. Kimberley, one of the nurses asked me if Professor Gibson had been to see me. I said that she had and that [redacted] had a staphylococcus infection. All she replied was “hmm”. That was it and there was no reassurance or explanation.

43. I was worrying a bit more at that point. I am a research mum and I always want to know what we are facing. I did some research on Google that night, I wanted to know what it was and how bad it could get. I wanted to know the worse-case scenario as anything that is better than that is a bonus.

44. The next day I asked Prof what strain of staphylococcus infection [redacted] had contracted as I had been researching throughout the night. She wrote it down for me, it was staphylococcus aureus. Microbiology wanted her to take antibiotics for one week after the line removal. The line would be sent away for testing. The intention was that she would get another central line at some point but we were not sure whether that would be a port or another Hickman line. [redacted] underwent surgery that day under general anaesthetic to remove the Hickman line. When she was in theatre the surgical team inserted three cannulas, one for immediate use and two spares. I always preferred that we took the opportunity to have cannulas fitted when she was under if they were going to be required at a later point. The cannulas could be fitted anywhere, her feet, arms or the back of her hand. I was told that the line was sent for testing but I was not informed of the outcome of the tests.

45. Following the line removal [redacted] was prescribed antibiotics for a further week. She stayed on gentamicin, and tobramycin. That resulted in her being on antibiotics for nine days in total for this infection, as she started them two days before the surgery. Her IV chemotherapy was stopped for the nine days, and she took oral chemo. After she had her port placed they gave her the last

vincristine infusion to complete the first block of chemotherapy. I speak about the port surgery later on, it took place on 1 October 2018.

46. When a child in the Schiehallion Unit begins to spike a temperature, a protocol is followed as the concern is that the child has sepsis. A temperature spike is 38 degrees celcius or above. When a child has a temperature over 38 degrees they are given antibiotics: gentamicin if neutropenic and tobramycin. They are given the antibiotics intravenously four times a day. The nursing staff chart the temperature of the child every four hours. The equivalent of calpol is given to manage the high temperature. Blood cultures were taken and they took about 48 hours to come back. If an infection is identified then medication can be given to treat the infection. Generally when a child spikes a temperature the cancer treatment is stopped because children who are neutropenic are vulnerable to infection. If an infection is detected then chemotherapy treatment is immediately stopped to allow the infection to be treated. This is where delays in treatment arise, where your 7 months become 9 months.

47. If you are at home with your child and they begin to spike, during hospital hours you call Ward 2B daycare who call A&E and tell them you are coming in. When you arrive at A&E you are put into a room and then taken to the CDU who then to take bloods and, administer antibiotics. From there the child is admitted as an in-patient to wherever there is a bed and that might not be on the Schiehallion ward. It depended where there was a bed.

48. When we were on the wards, ten out of ten times I told the staff that [redacted] was spiking and asked the nursing staff to come and do a set of obs. You know your child and you are with them all the time. There was a charity called LoveOliver who handed out thermometers to parents on Ward 2A so I had my own thermometer. Sometimes you could wait up to two hours for paracetamol.

49. By way of example, there was an occasion when I had to push the nurses to get pain relief for [redacted]. [redacted] had an anal fissures at the end of the first

treatment block. Two nurses came in and started to change the dressing on the Hickman line and she was screaming out and every time she passed wind, she was in pain. It had been two hours since we asked for pain relief. She is not going to let you change the dressing when she is pain. I asked that they please go and get pain relief before they change the dressing. She was distressed. The nurses left and came back 10 minute later with paracetamol. The nurses told me that they needed to have two people sign off medication, but I said there were two of you here to change the dressing. It made sense in my book to do that first.

Move from Ward 2A RHC to Ward 6A QEUH: September 2018

50. On the 26 September 2018, Ward 2A in the RHC was closed and the children were moved to Ward 6A of the adults hospital in the QEUH. [redacted] was an in-patient in Ward 2A and had just had her Hickman line removed. We didn't find out about the move from the hospital. We found out about the move when one of our neighbours sent me a text saying that they had seen a news report on the TV that the ward was closing. They asked if we knew what they were going to do. We didn't know anything. When Alfie got the text, we asked one of the nurses about the news report and if the ward was closing. She was called Katrina. She said that she was not allowed to tell us anything about it and she ran out. One hour later the Charge nurse, Emma, came to [redacted]'s room and handed us a press release on a sheet of paper. She said that she knew we had heard about the ward closing and that we were to read the press release. There was no explanation as to the what and how.

51. All the press release said was that Ward 2A would be shutting due to a spike in the number of infections, it's why the ward would be closed. We were not told anymore. The only communications we had from the hospital was the press release, it was word for word what was all over the internet in news reports. There was nothing more and no reassurance was offered.

52. We didn't know where [redacted] would be moved to, if the children would go as a group or not, whether we would be moving with our medical teams or not.

Professor Gibson is god and she had got us this far. We didn't want to start over with a new medical team and build trust up. We had no information. The next day Professor Gibson told me that that we were going to move as a group with our medical teams but I was not told where [redacted] would be moving to. She said that the hospital would have to make a ward up for us somewhere and we would stay together. At that point it was enough for me to know what we were staying as a group and with our teams. At that point I was not as concerned about why we were moving. I was more concerned that we stayed together with the same care. It took about two weeks from the point we found out about the move to the point that we did actually move wards.

53. The TVs in Ward 2A weren't working so we couldn't even watch the news. Once we found out from our neighbour we looked up the press online and all it said was that Ward 2A would be shutting. During that period [redacted] had been in-source isolation for about 3 weeks, just me and her sitting along in the room with the blinds open. She had been on high dose steroids for seven weeks, it had been a hard time. It was like we were institutionalised and I thought [redacted] had depression. She would cry because she wanted her dad, then he would walk in and she would scream at him to leave. She had a sore head and so the lights were off, the blinds shut. Being in source was a lonely time, and if [redacted] saw kids outside in the corridor I would have to tell her that she couldn't leave the room. How do you explain that to a young kid?

54. I found out that [redacted] would be going to Ward 6A in the adult hospital the night before the move. The nursing staff told me. People spoke on the wards. The staff thought that we would remain in the children's hospital and would be put into the CDU. All the support services that our kids used were going to remain in the RHC. Those services included physiotherapy, dieticians, dentist, radiology and scanning rooms. Leaving the children's hospital to go the adults hospital meant that we would be further away from these teams and these services. For our children to get to those services they had to travel back from the adults hospital, through the corridors to get to the other departments in the

children's hospital. We had to use the shared lift, walk shared corridors with all sorts of people coughing around you. I felt this increased the risk of [redacted] catching an infection. Sometimes they would let you in the staff elevators or patient transport elevators to get back to the RHC. We felt at risk and dirty being in the adult hospital. We had avoided bringing the girls in to see [redacted] in order to reduce infection risks, and the move through to the adult hospital felt like an increased infection risk.

55. The move from Ward 2A RHC to Ward 6A QEUH happened around the 26 September 2018. We were told that the whole ward was moving which meant things like the furniture would be coming with us. In the days leading up to the move Ward 2A was a very busy place, the medical staff were trying to pack and also do their jobs on top of all that. There was a lot of pressure on the staff and it was their responsibility to pack everything up. Staff were counting supplies, some of the furniture was going to move over. Nobody on the ward knew exactly when we were moving. The staff did not know. It was maybe about two days before the move took place that we were told by staff that the move would happen on 26 September 2018.

56. The children were moved in order of vulnerability, with the most vulnerable being moved first. [redacted] was the second child moved and she was transferred early on in the morning at around 8/8:30am. [redacted] was neutropenic and she had to wear a facemask to stop her catching an infection as she was moved through the hospital. She had never worn a mask before. There was a team that moved each child, the porters, the parent and child, there was a doctor and a nurse walking with us too. The doctor was carrying an oxygen tank, which was quite scary when you don't know what you are facing. We went into the patient lift in the RHC and went down two floors. We then used the back corridors in the adult hospital to get to the lifts to travel up to the sixth floor in the QEUH. The move took place at early morning and late evening to avoid bumping into other people as we went through the hospital.

57. Ward 2A for in-patients and Ward 2B for outpatients were moved into Ward 6A. In Ward 6A there were roughly 27 rooms. Of those, roughly 16 were for in-patients. Ward 2A had around 18 in-patient rooms. So when you came in for an admission, 7 out of 10 times you didn't end up going into Ward 6A as it was full. Whilst we didn't experience it in Ward 2A, other parents told me lack of available rooms in Schiehallion was worse after the move to 6A.

58. The rest of the rooms on 6A were used for daycare patients, the old Schiehallion Ward 2B. In order to get to daycare people had to walk all the way through the ward, past all the in-patient rooms and to the end of the ward. There were no pressure rooms in Ward 6A like in Ward 2A. By pressure rooms I mean isolation rooms for transplant patients who need to be in a pressurised rooms. What that meant was that a normal room on 6A had to do the same job as a pressure room.

59. [redacted] was put into room 2 in Ward 6A. She was in-source as she had a tummy bug 3/4 days previously but hadn't had anything since then. Room 2 was so hot. It was the hottest place ever and you couldn't turn down the heating in the rooms. The nursing staff said they would call and have the heating turned down but then we later found out that it was not possible for the heating to be turned down by anyone. There was someone who came in and placed sticks up the vents to see why they were running so hot. It measured over 30 degrees.

60. The windows didn't open. We were in-source and the infection prevention control rules meant that we couldn't leave the room. I opened the door to let the room cool and I asked to move rooms. I didn't think it healthy. In any country this would be considered a heat wave and they wouldn't give us a fan to move the air about. I kept the door open and said we couldn't survive in this room with the door closed.

61. The next day [redacted] was still in-source isolation despite showing no symptoms for 3 to 4 days. We are not allowed to leave the room in line with the infection

protocol. No one had reviewed her or her notes and she had been fine and nothing else wrong with her tummy at that point. I spoke to Diane, one of the nursing staff on the ward. Diane was amazing, everyone said if you want to know something you ask her and she would go out of her way to get you out of source, run samples and call people. I said to her, you have to get us out of source, we cannot survive in this room. She reviewed [redacted]'s notes and said there was no reason for [redacted] to be in-source as she had no sickness or diarrhoea for a few days, she made a call to the doctors and finally [redacted] was allowed to come out of source. It meant we could leave the room and open the door.

62. Even if you could leave the room, you were stuck in a ward with no facilities. Ward 6A had no facilities for parents and children. There was no kitchen and no fridge to store food. I never left [redacted] to go to the shops or go anywhere so I relied on Alfie bringing food in for me. He had brought me meals in from the beginning but in 6A there was nowhere for me to store or heat up the food. The lack of kitchen resulted in more expense for parents. We had to buy food from M&S.

Description of Ward 6A

63. There was nothing for the kids in Ward 6A. There was no playroom. All they had was a couple of small tables, like a coffee table, in the hall with some chairs and some paper for the children to colour in, maybe some random toys if they felt like it. It was classed as a play area for the children. This was set up about a month after we moved. There was a lack of plugs around that area, [redacted] was often receiving medication via drip and was attached to machines. The machines had bad batteries and didn't last long when not plugged in to the mains. Around the small table there were few plugs. [redacted] could sit at the table drawing, across the opposite side of the corridor there was a plug. It meant that people passing through the corridor had to climb over the line, it was a trip risk and also increased the risk that a line is pulled out or a trip over the machine wires. All we could do was walk the hallways, but then we got into the way of the medical staff. People from all wards accessed Ward 6A to pick

up prescriptions from the hospital pharmacy and they would then have to walk all the way through the ward, so it was not ideal at all.

64. The parents asked if the hospital would consider emptying one room, not even for toys but somewhere for the kids to come together and interact. We asked for somewhere to congregate, for parents to meet to get support. There were a lot of parents of kids who were newly diagnosed and they lost out on that.

65. People spent a lot of the time in their rooms. Your morale becomes very low when stuck in a room like that. We, as parents lost the support of one another after the move to 6A. That support is such a vital part of this whole nightmare. If there was a parent of a child who was a month or so ahead of your own kid, you could ask about that and hear from them how it was. The lack of somewhere for us to meet meant we missed this. We didn’t have the support. Some days the only people that we saw were the medical team and they were not always a friendly team as they were so stressed and overworked, I think that they were always worried that they would get the flack for everything else that might go wrong on the ward. Kids and parents were left isolated in the patient rooms due to lack of facilities. Ward 2A felt like a children’s ward and 6A didn’t; there was a noticeable difference.

66. There are a number of charities that came to visit Ward 2A. There was Les Hoey which provided toys and i-pads for the kids. There was Team Jack that offered music therapy classes and [redacted] went to those, they were really good. The hospital radio staff would come to Ward 2A to play games with the kids. There were some smaller charities what came to Ward 2A. One of these brought a snack trolley for the kids and [redacted] could get crisps or a fruit shoot. It was not about what the kids got, the charity staff and volunteers tended to be people who had been through what I was going through. It was so important to have that to hold on to. When you are told your child has cancer you think that they are going to die. These people had come through the other side, that interaction and support was so important. Even now I think the parents all walk away with some sort of PTSD about the situation you have been through with

your kid, whether they are going to die. You think that every moment might be your last one.

67. In Ward 6A there was none of this and no charities. We were made to stay in our rooms. When we were in Ward 6A it appeared that there were always a number of kids in-source more than in Ward 2A. There were maybe around 10/11 of the 20 odd rooms insource at one time. The parents joked on the ward, that if you are vocal and your kid is playing in the hallway then you go into source. We always use to joke “what is the outbreak this time?”, “why is everyone in source?”.

68. For example, just before Christmas 2018 I spoke to the staff as it did not feel like Christmas. There was no spirit, and I know that it is not their responsibility to create that but coming from a ward where there were a lot of things for kids to do, we had nothing.

69. The clown doctors still came to visit on Ward 6A. They were entertainment provided by the hospital I think, but they were for all children in the RHC. They would come round the wards blowing up balloons and making the children laugh doing silly things, but it was for a short time. Sometimes if [redacted] was in source and the clown doctors came up to the window of the room, it was worse as they waved and then moved on quickly. It was a big deal for the kids. The hospital radio staff came to Ward 2A to play games with the kids.

[redacted]’s treatment - Consolidation Phase, the second block of treatment: October 2018

70. On the 1 October 2018 which was seven days after the line removal, [redacted] returned to surgery to have a port fitted under a general anaesthetic but the doctors couldn’t really decide on what they were going to do for her central line. As parents we don’t really get much of a choice about the central line. Professor Gibson said that a port would be better for [redacted]. The skin goes over the port and there is no line coming out of her body. The Hickman line cannot go into water and there is a risk of the line coming out if it is pulled. We

were always so concerned about the Hickman lines being so fragile as they just dangle there. The port does not have the same risks. It was fitted to the same side, [redacted]'s right side. You don't see it, it is like a wee button that sits under the skin and there is an entry in the neck and it goes into the heart. The port is accessed using a needle that punches into the port under the skin, then into the line and medication can be administered that way.

71. A few days later in the first week in October 2018, [redacted] was discharged from Ward 6A and was able to go home. This was the first time since her initial admission in August 2018. She was only home for 3 to 4 days and then was re-admitted to Ward 6A in the QEUH again. What tends to happen between blocks of chemotherapy is that the children get a block of treatment and then one week off before beginning the next four week block. For [redacted] she did not get a break between the first and second blocks. This was because the medical team felt that we couldn't lose a week off and had lost too much time. It had taken us eight weeks to get out of the first block. By that point she had been off chemo for a few weeks so that the infection could be treated. That led to a delay in treatment overall.

72. At the beginning of October, [redacted] was admitted to ward 6A to start the second block of chemotherapy which is the Consolidation phase. She received a cocktail of drugs one of which was Cytarabine which she got twice a week, and every time she had that drug she spiked a temperature. With every spike we had 48 hours in hospital. We spent most of that block in hospital with [redacted] as an in-patient with temperature spikes, it was every couple of days she had a Cytarabine spike. Protocol requires that we had to go in and began antibiotics just in case it was sepsis. During this phase of treatment, [redacted] was admitted to Ward 6A for any temperature spikes.

73. The second block of chemotherapy lasted 6/7 weeks. It got to the point that the medical staff decided to push through the temperature spikes and carry on with her chemotherapy. I was told that the temperature spikes during this block were related to the Cytarabine.

[redacted]'s third block of chemotherapy: November 2018 to December 2018

74. On 12 November 2018, [redacted] commenced her third block of chemotherapy. This was a hard block, a nightmare. She was on high dose methotrexate. The high dose methotrexate was part of a clinical trial. She took oral chemo every day. Every 2 weeks she had to go in for in-patient treatment. On a Monday night she would go into the hospital for pre-theatre and for an intravenous pre-flush. On the Tuesday she would go to theatre for an intrathecal methotrexate injection into her spine and at the same time the staff performed a lumbar puncture. Then after that procedure they gave her a methotrexate intravenous infusion lasting 24 hours, along with a glucose flush to wash out the chemo. Then [redacted] was given another glucose flush to clean out and keep her at a safe level. After the first session [redacted] was discharged on 17 November 2018. As soon as the count is clear you can go home. For most kids it was five days in and then home.

75. On 22 November 2018, [redacted] was at home and began throwing up blood on the Wednesday night through to Thursday morning and she was throwing up with brown blood granules in it. She was always quite sicky from the treatment and this lasted all through her treatment. I called the ward and they told us to bring her in. On the way to the hospital in the car she threw up pure blood. We arrived at the hospital and [redacted] was admitted to Ward 3B in RHC, I think. Staff said she has mucositis and they began to administer antibiotics. She was given IV anti-sickness medication.

76. [redacted] was admitted to a double door isolation room on ward 3B. When [redacted] ended up on other wards, she was admitted to a double door isolation room if one was available. Only if there was a more vulnerable child would she go into a normal patient room.

77. Ward 3B was a renal ward I think, maybe also surgical. If you needed a doctor, you could call for a doctor but sometimes they would send one of the

Advanced Nurse Practitioners ("ANP"). The ANPs are amazing. You don't have the same access at the same times to the Schiehallion medical teams when you are on other wards. Sometimes we had to get one of the Schiehallion ANPs to come down and talk to the nurses on the other wards, they'd tell them to trust us to trust the parents as we know when our kids need something. There was one particular time that [redacted] was on oral morphine as and when needed for the anal fissure as it was the only thing that would numb the pain. The nurses on 3B refused to give it to me. As they said they didn't think she looked like she needed it. One of the ANPs from Schiehallion came down to talk to them and eventually she was given it. It was not to overdose her or sell it off on the black market, it was because she needed it.

78. Our kids get treated so different to other kids probably because of their vulnerabilities. I felt that when we were on the other wards that [redacted] was considered sick but not sick enough so we didn't get the attention. In their own ward the Schiehallion kids are treated so differently.

79. In Ward 3B we were confined to the room and we did not have access to the other facilities on the ward. This was due to [redacted] being vulnerable to infection. We were not allowed anywhere. The first time we were there they slipped up and said we could use the playroom so we did. We didn't know that we shouldn't. The toys in the playroom were disgusting, they were old and dirty. It showed me how much money people invest in the Schiehallion ward. It was a "posh" ward by comparison to the rest of the hospital; it was so different. Alfie and I did a toy drive for the playroom in Ward 3B when [redacted] was there, to get them some new toys for the kids as things were in such a state. We donated two huge bags of toys.

80. Occasionally on other wards we asked the ANP for a pass so we could go to the outdoor play park at the RHC. We did it very occasionally. The play park was quite modern as it was fairly new. We kept our distance from others. She knows about being neutropenic and she knows not to touch her mouth. Hand

hygiene is part of her history now, we would come back in and wash hand and change her clothes. The play park was amazing if you could get there.

81. It might sound horrible to say this but in a way I felt relief at not being on the ward with the Schiehallion staff. I felt that the staff attitude toward me was that I was not wanted on the ward and I didn't want to be somewhere I was not wanted. So in that sense I felt free. For [redacted], I was concerned as we were not where we needed to be in terms of her medical care, we weren't with her team. It could be hard managing her medication when were not on the wards with her team. It fell on the parent to keep checking it.

82. On Sunday 25 November 2018 I asked for a day pass as by this time she was well in herself once the sickness was under control. We went out of the hospital for a couple of hours. [redacted] was in Ward 3B for three days until the 25 November which was the day before she was due to begin chemotherapy. Later that day she was moved to Ward 6A as chemotherapy infusions can only be given on the Schiehallion ward.

83. On 26 November 2018 she began her next treatment in that treatment block. She started her pre-op cycle again, so received the pre-op fluids. Normally that is run at 70ml an hour. When this happened she peed all the time. She was still in nappies and I would change her overnight a couple of times. Sometime it was every two hours as she would pee so much. That began on the Monday night. On the Tuesday morning I said to the staff that [redacted] was not peeing. They told me it was fine and maybe she had been dehydrated. But I said she had been in hospital since Thursday and had been on fluids and was not excreting. They said they would keep an eye on it. [redacted] was taken in to theatre and given the lumbar puncture and the methotrexate injection, then the methotrexate flush and glucose infusion.

84. I raised a concern with three different nurses and a doctor. On the Wednesday morning around 9am I raised it with a doctor and said she had barely peed overnight. The doctor asked if she had maybe peed and I had not seen it. I

was changing her nappies and she had not done the toilet. The doctor decided to check her weight at a 12 noon and again at 6pm to see if she was retaining fluids. When she was checked at 6pm she was up to 800 grams. Then all of a sudden it was an emergency and they had to get her to pee. They gave her Lasix to make her pee. [redacted] began to pee and it was all blood. Because the methotrexate was stuck inside her for so long it had burned her insides and all of her soft cells her mouth, her gut, and her bum – everything was burned. She was lying there and blood was running from her mouth and her bum was sore. She was placed on gut rest and was started on a morphine driver and it made her sleep for 7 days straight. They stopped her chemotherapy and started her on the patient nutrition that goes into the central line.

85. The same day the nurse came in and tried to give her oral chemo. [redacted] had an NG (nasogastric) tube in and you have to aspirate before you put anything down to make sure it is in the right place. You normally get stomach fluids coming back up. I aspirated and it was blood that came out. I told the nurse that it was blood coming out of her tube. I said there is no chance I am putting oral chemo into her tummy when she is on gut rest. The nurse left and spoke to the doctor and told her I refused to give [redacted] her chemotherapy. The doctor came in to see me and I explained that if she was on gut rest that she should be on full gut rest as it didn't make sense to give her chemotherapy when she was like that. They agreed that she could come off oral chemo. This was now the beginning of December and she was an in-patient recovering from this until she was discharged on the 24 December 2018.

Social media posts: 24 December 2018

86. Alfie and I had some run ins with the staff about social media posts. Before [redacted] was discharged on the 24 December 2018, Alfie and I were called to a meeting with Professor Gibson. She said, "I am not on social media and I want to say that we are not treating your child as a guinea pig". This referred to a Facebook post that Alfie had posted on Facebook about [redacted] being treated like a guinea pig. We understood that the methotrexate that [redacted] was

receiving in this block was on a clinical trial. This showed me that the hospital staff were monitoring our social media posts. A couple of times they would refer to things that we posted on Facebook. It was always monitored and they would call us out on it. It was just another bit of what was going on. I was already speaking out about what was going on and I felt victimised. It didn't help the relationship between my family and the medical team.

87. Alfie put up a post saying that we were going to pull [redacted] off all high dose methotrexate. It was an unusual way to use that drug and was a trial. At the meeting on the 24 December 2018, Professor Gibson acknowledged we were upset. She said go home and cool down and we will have another meeting on the 27 December to discuss the treatment plan.

88. [redacted] was discharged and me and Alfie went home to discuss this. We didn't want her to continue with the high dose methotrexate. We didn't really want her to be on the trial in first place. The only reason we stuck to the trial was because it would have been easier for her during maintenance phase of treatment. She wouldn't require any IV medication as she had already had heavy front line treatment. At this point we decided to take her off the trial as she had a bad reaction on it. It got to the point that during that time in December 2018 that I sent Alfie a picture and she looked like she was dead, a corpse, she was grey. The first round was bad and it made her sick, the second one made her really ill and there were two more to go. Professor Gibson said that the next two rounds of methotrexate might be okay. But we decided to pull her off the trial. That meant that [redacted] went back to the standard protocol and she finished that block on vincristine and the other standard medications.

89. Professor Gibson was always the one who had to raise the social media things with me, or difficult things with me. When [redacted] had the pseudomonas infection she came in and said to me, "I am here to tell you that the line is coming out because everyone is too scared to come in and tell you", and she

was referring to the other doctors. I speak about the pseudomonas event later on.

90. There was another incident relating to social media in September 2019. [redacted] was in with a fever. We got there at 11am in the morning and it was 8pm at night. They had nine attempts over hours to insert a cannula, it was long drawn out day for someone who is constantly spiking. We had been in since 11am that morning and she had been spiking all day. I asked that they give her oral antibiotics as it was better than nothing. As she was not neutropenic at the time they agreed to give her oral antibiotics. She was so tired and drained when the doctors left. All she wanted to do was to see her favourite nurse Susie. Susie was not on duty but there as another nurse who had very similar features to Susie, we fobbed her off that this was Susie. [redacted] had not been an in-patient for around 6 months at this point. [redacted] went to have a cuddle with the other nurse. The nurses head came down as she was cuddling [redacted] and you couldn't see her face. I took a picture of the nurse cuddling [redacted] and you couldn't see who the nurse was, and posted it on Facebook. I put up a comment that after everything that she has been through all she wants was a cuddle from her favourite nurse, and how important these relationships with the nurses were.

91. Two hours later one of the nurses came to see me and asked me to remove the photo from Facebook. I didn't take it down. I made it private. The next morning Emma Somerville, the charge nurse came to see me, she said you posted a photo of a nurse on Facebook and you can't do that. I showed her the photo and said it was a beautiful post and inspiring, and that frankly the NHS could do with anything positive coming their way at this moment in time. I told her it was private. She said it was nice and that I was to send it to her and she could send it on to the nurse but that I couldn't put it on Facebook.

92. There was another occasion a few days later when I was asked about social media posts. We are members of a parents group on Facebook and one weekend another parent must have posted a complaint on the group about the

service received from the ward. The Facebook group is set up by parents for parents of children of the Schiehallion ward. I hadn't even see this post. The Charge nurse, Emma came to my room and asked if I knew anything about it. She assumed it was me who made the post. I knew nothing about it. She must have heard something or saw something and automatically assumed it was me. I asked "isn't my Facebook a private account?" They told us that all social media is being monitored. A few weeks ago I was speaking to one of the parents. She was pulled up in daycare about posting updates about her kid, his treatment and situation and she was told not to post on Facebook. You are not even allowed to post any updates about your kid. We are being monitored.

The Cryptococcus outbreak in Ward 6A: December 2018 to January 2019

93. On 31 December 2018 [redacted] was admitted with another temperature spike. It was managed in the usual way in line with the protocol. We don't know what it was but could have been the common cold.

94. During the month of December 2018 there was the Cryptococcus outbreak in Ward 6A, although we didn't know about it at the time and we found out afterwards. During that time I saw rooms being blocked off in the ward, I think rooms 11-13 were closed. The rooms were being taped off, the doors were closed and you couldn't go in there. At the time, we heard about a death on the ward, but it was a cancer ward and these happened on the ward. At that point we were none the wiser about the outbreak; we knew nothing. During that whole month [redacted] was an in-patient in Ward 6A. She was neutropenic and was recovering from the methotrexate event.

95. The staff told us the rooms were closed due to building works, renovations or mould in the showers. No one really seemed to know, or maybe they knew but didn't want to tell us. When we were in Ward 6A they would say things like if you see any loose strips in the showers or anything that looks like it is coming apart, tell us as it increases risk of infection.

96. During December 2018 I did not personally ask what was going on in the ward at that time. [redacted] was ill during that time, she was my focus during that time and I hardly left the room. I didn't pay much attention and was not interested enough to ask. You run into other parents from time to time and they update you.

97. In January 2019, we learned in the press about the Cryptococcus infections. This was after [redacted] was discharged. It was the 21 January 2019 when we found out. We saw that there were rumours that a young boy had died and an older woman a couple of days later in ward 6A. The news mentioned that the ward was closing because of the deaths. The same day that the news broke, [redacted] was admitted to the hospital for a temperature spike. She was not admitted to ward 6A. Instead she was admitted to CDU which was Ward 1C next to A&E in the QEUH. She was one of the first patients there. Ward 6A was closed for about 6 weeks. She started antibiotics and blood cultures were taken, nothing came back. It was a random spike.

98. We knew from the news that Ward 6A was closed due to Cryptococcus and the hospital staff told us that the ward was closed when we arrived. Later, on the 21 January 2019, that day we had a meeting with Professor Gibson and the doctor who was the head of microbiology, or infection control. I can't remember her name. We had demanded a parents meeting with the medical team and we wanted this to be an open parents meeting for lots of parents of children on the ward, it was better to have this as a group so we could all ask questions. Sometime when you are in groups you can bounce off one another and it triggers memories so you can ask questions. They refused to hold an open meeting. So I met with Professor Gibson and the other doctor that day.

99. During that meeting I said to the doctor who was the microbiology or infections control doctor, "You knowingly put my kid at risk". She said she would have to be severely immune compromised to be at risk, and I said that she was neutropenic for that whole month. But the doctor said that was not long enough. I thought that was a load of rubbish.

Prophylactic Medication

100. When [redacted] started her initial treatment for ALL, she was given a prophylactic anti-fungal called pozaconazole. At the time we were told it was part of the treatment and all kids were on it. We were not told why she had to take it. Being a new parent through the door you really don't care what medication you give your kid as long as they survive. During the meeting on 21 January 2019 I asked why [redacted] was on pozaconazale and Professor Gibson said it was because of all the building work going on in the hospital. I told her that I spoke to other parents in Dundee and Edinburgh and their kids don't get it. Professor Gibson said that it was because there was always something going on in the Glasgow hospital and that the dust particles travel and it was to prevent anything happening to them. She said it was prophylactic due to hospital environment and the building work going on. The would do regular checks to see the levels in the kids bloods, they wanted the kids to have enough but not too much of the pozaconazole, if that makes sense. It was obviously a big deal for the medical staff to monitor this, they would lower the dose or up the dose. [redacted] took pozaconazole 4 times a day.

101. I am a member of a Facebook group called mumcology. It is an international leukaemia group. A mum in America posted that her child had the candida infection and that her child was being given posaconazole to treat it. I knew that fungal infections posed a real risk to our children. I thought about this and realised, if posaconazole is only being given to treat a confirmed fungal infection why is [redacted] on it? I then began to wonder why [redacted] had to take it 4 times a day if she didn't have an infection. I asked about it. The nurses said that all the children in their care received this. The first time I asked Professor Gibson about it was on the 21 January 2019. By this point [redacted] had been on the medicine since August 2018.

102. I am not a hippy mum. If you have to need medicine you get it. If the hospital had sat us down and said these are the risks involved and these are the side effects then I would have felt informed enough to make an informed decision and live with the consequences, but we were we were never given that opportunity. [redacted] finished treatment in November 2020. She has ongoing tummy issues and has done through the whole treatment. We don’t know if this is due to the treatment or the prophylactic medication. She has an ongoing tummy ache and other paediatricians are investigating it. She has been placed more at risk and we were not informed. The side effects of pozacoanzole hit your liver and your kidneys, but we just don’t know the impacts yet. Oncology are not interested as she is not on treatment anymore.

103. I know the child cancer patients in Dundee and Edinburgh are not on pozaconazole because I am a member of a Facebook group and I asked a question about it. Some parents responded to say their kids didn’t take that medication.

Delayed intensification: January 2019 to March 2019

104. In January 2019 [redacted] was in her fourth block of chemotherapy which was the delayed intensification phase. During that block they stopped her pozaconazole and she was given an ambisome infusion which was administered every 2 days. It was a prophylactic infusion. She took that medication for the whole block and tit lasted up to mid-March 2019. During that block they throw everything at the patient. It is an intense block of chemotherapy and [redacted] was given every drug that she had been give during the previous three blocks. Before the block her consultant said that she was worried as she didn’t know how [redacted] would react.

105. Surprisingly [redacted] responded well. Some days she would receive four infusions and would be singing and dancing, we kept waiting for it to hit her but it didn’t. She was fine. At the start of the block the Schiehallion daycare was

moved from Ward 6A to the ward that was next to the theatre recovery. Maybe it was ward 2C in the RHC.

106. On the 31 January 2019 [redacted] told me she was itchy. I couldn't see anything on her skin. I don't know what might have caused it, but it might have been a side effect of oral morphine. We were at home and I called the Ward, they told me to give her piriton. The response is very much wait and see and carry on. We never found out what the cause was and she was not admitted as an in-patient on this occasion.

107. [redacted] had one temperature spike during that treatment block and she was admitted to Ward 3B in the RHC. This was on 20 February 2019. They ran blood cultures and we were told that it was a staph infection, the nurses did not tell us the full name at the time. It is staphylococcus warneri and we only found out once we got [redacted]'s medical records. They just told us it was a gram positive infection and that it was something that lives off your skin. When [redacted] developed that infection she was an out-patient. Prior to that she had been in fairly regular contact with the daycare facilities for infusions every couple of days. She only had a temperature spike and she was off her food slightly. She was not that ill during this infection.

108. [redacted]'s chemotherapy was stopped to treat this infection. She had a week of antibiotics. She was on the same antibiotics as the previous infection. She didn't lose the port and central line on this occasion and I don't know why it was different this time round. They told me during the first infection in September 2018 that the infection would stick to the line and that every time you use the line it flushes the bacteria into the system and it makes them even more sick. They did not stop using the line and there was no requirement to remove her line. She was discharged on 25 February 2019.

109. On the 15 March 2019 [redacted] had a blood transfusion. This was her last day of front line treatment. She was well in herself. It was in the daycare centre at Ward 6A. She got it through her port using the needle. A blood transfusion can

take most of the day, five hours for the infusion and you have to cross match the blood. I can't remember what room [redacted] was where the waiting room is, the second to the right where the doctors desk are. I can't remember the room number.

Pseudomonas infection: March 2019

110. On 19 March 2019 [redacted] developed a temperature spike. She was admitted to Ward 6A. The medical team began to run the protocols. She was started on IV antibiotics and blood cultures were taken. On the 21 March 2019 the results of the cultures came back and Professor Gibson told me that [redacted] had pseudomonas. She said it was a life-threating infection and we would have to take one day at a time. The night before Professor Gibson confirmed it was pseudomonas one of the nurses had told me it was a gram-negative infection. So all that night I googled types of gram-negative infections and what they could be. When Professor Gibson told me it was pseudomonas, I said that I had read about it but Professor Gibson didn't say anything else. Just that it was a very serious infection and then she left.

111. Professor Gibson can be quite intimidating to a lot of parents. Anne-Marie, one of the more junior doctors came to the room, and I asked if pseudomonas was a hospital acquired infection? I told her I had read that it used to be a well-known hospital acquired infection and was associated with poor hand hygiene and contaminated equipment or things like that. She quickly washed her hands and left and said she would get Professor Gibson to speak to me. A short time later Professor Gibson came back into the room and she said something like, "in answer to your question, is this because of the hospital water, the answer is no". I said, "I didn't ask if it was about the water I asked if it was a hospital acquired infection". And she said no and that she would get microbiology to come and speak to me. Microbiology never came to speak to us. I was never told how [redacted] contracted the infection, other than it was not from the water.

112. [redacted] was already on two types of antibiotics and they added in a third antibiotic, once pseudomonas was confirmed. There was then emergency surgery to remove her port which was under a general anaesthetic. She was the first one out the door to surgery the following morning. The line was sent away for testing and I think that Prof told me that there was pseudomonas in it.

113. [redacted] was due to start maintenance the next week and she didn't need the port so it was going to come out anyway. There was a delay to her treatment block and she was neutropenic so they wouldn't have started it anyway. She didn't miss much chemotherapy at this time.

Candida Infection: March 2019

114. On the 24 March 2019 [redacted] began to develop little round circles on her knees, like bruises. It started off with just one, it looked like a pimple. It had a dark ring around it, like a pocket of pus. We keep an eye on her as we need to know where bruises come from, as it can be a sign of low platelets. She was still in Ward 6A receiving antibiotics for the pseudomonas. I asked the doctor about the thing on her knee. She had been in bed the whole time and hadn't fallen over. We were in source and she couldn't get out. At that point I was complaining about the general state of the hospital, how dirty the hospital was. When we were admitted on the 19 March 2019 there were hair all over the shower of the previous person who had been in the room, there were coffee stains all over the floor, there were bandages left in the drawer in the bathroom. I wouldn't let [redacted] on the floor as the floor was dirty; the ward was dirty.

115. I asked the doctor what these spots were. He said just to keep an eye on it. They drew lines around the mark, the next day they drew a mark around a second mark. Then the marks got bigger. Then they called in dermatology doctors who examined her and said it was candida, a fungal infection. He was convinced in what he saw. I showed him pictures from a few days before so he could see how it developed. She was already back on pozaconazole again

and they prescribed ambisome infusion too. She was on two anti-fungal treatments and it seemed to do the trick. Her neutrophils were very low at this point, they were 0.2. I saw on the Facebook group that if a child in neutropenic and the fungal infection can supress the neutrophils you have, and if they are zero there can be no coming back from that. I asked if they could give her a G-CSF infusion to artificially kick-start the bone marrow. I spoke to the doctor on the ward, they went away to consider it. They spoke to Professor Gibson who was not on the ward at the time. Professor Gibson considered this and agreed to give her a G-CSF infusion, she was given two infusions. Over the course of the two days the marks on her knees disappeared. I don't know what G-CSF stands for. I was told by the doctor in America that fungal infection is a biological war and that you want to try and quickly erase the count and kick start the bone marrow. He told me that 0.2 is better than 0. So the G-CSF infusion can kick-start something.

116. Professor Gibson was away at a conference when this was going on. She came in a couple of days later and the marks had disappeared. She said that it was not a fungal infection. I asked why she was on two sets of anti-fungals if it was not a fungal infection and said that had been confirmed by dermatology. Professor Gibson said we could go home and that was always the carrot on a stick, you could go home. We never had any confirmation of what it was. [redacted] began the ambisome on the 25 March and stopped it on the 29 March which was when Professor Gibson saw her.

117. She stopped taking pozaconazole as soon as she started maintenance and she had her port removed.

[redacted]'s treatment – the maintenance phase: April 2019 to November 2020

118. From 1 April 2019 to 13 November 2020, [redacted] was on maintenance chemotherapy treatment. That lasted for just over a year and a half. For [redacted] that was oral chemo medication every day. On a Tuesday she would have an oral methotrexate. Every 12 weeks she had to go in for a lumbar

puncture. She had an antibiotic called Ceptrin that she had to take every weekend, it was a prophylactic antibiotic. She would go in on a monthly basis. Every two weeks a nurse came out so see her to take bloods.

119. [redacted]'s last in-patient admission was to Ward 6A in September 2019. This was for a period of 48 hours with a common cold. We had another spike in December 2019 on Christmas eve, but she was taken to the hospital in Ayr. She didn't go to the Queen Elizabeth in Glasgow.

120. [redacted] is supposed to see the hospital every three months now. During treatment they told us we would never be away from the hospital, that it would be two weekly, then monthly then three monthly. [redacted]'s last chemo was in November 2019, and she had outpatient appointment two weeks after that in November 2019 and then another one two weeks after that just before Christmas. Then Professor Gibson said to me that they didn't know what to do with off-treatment kids and that they would write to me. I called the ward in second week of January 2021 and she said that it was only monthly that she needed to see us now. And then we received the appointment and it is now three monthly. So we have another year of three monthly appointments and then after that we are on our own. The hospital said that we would probably spot a relapse before they can pick this up in a blood test.

121. Now if I call about [redacted]'s tummy ache, they tell me to take it to the GP. They tell me that it is not an oncology problem.

September 2019: Meeting with Jeane Freeman

122. Annemarie Kirkpatrick and I contacted Jeane Freeman in approximately July 2019. We raised the issues with the hospital with her. We thought that the that the environment put our children at risk. We asked for a meeting with her on behalf of parents as we wanted answers.

123. A couple of meetings were set up with Jeane Freeman and the parents. They took place in September 2019 in the Central Hotel in Glasgow. In the meeting other parents were sharing their experiences. The stories were very similar to ours and I heard some stories from people I'd never even met before. Some children had suffered more infections, others fewer infections or not at all.

124. After that meeting I said to Alfie that the things we raised with Jeane Freeman at that meeting, it was nothing new to her. She was well aware of everything we told her. Jeane Freeman played the role during the meeting. She acted shocked and embarrassed and she apologised to the parents. She promised to look at things and promised we would get answers. She was put on the spot there, but this was not news to her. She knew about all of this already but she did a good job of acting surprised.

125. [redacted] spiked soon after that, so I was put in a difficult situation. We always found out what was going on with the hospital through the media and me and Anne-Marie Kirkpatrick were trying to raise the issues via the media. We tried to force the meeting with Jeane Freeman by using the media. I had to go back to the hospital with [redacted] soon after that meeting as she spiked on 26 September 2019.

126. Towards the end of [redacted]'s treatment there was a lot of hostility towards me, I was one of the initial two parents that went to Jeane Freeman and who spoke out about what was happening. I speak about that later on.

127. I was not there to make friends, I was there to get [redacted] healthy and for her wellbeing. If I had a question about her health I will ask it. There was some sombre feeling towards me and I wonder if that if why staff didn't pop in to see [redacted], because they didn't want to be there with me.

WATER

128. From the beginning of [redacted]'s diagnosis and from the date of her first admission in August 2018 in Ward 2A, there were contractors who would come into the patient rooms every week and put a bottle of crystals down the hand basin and the shower. They told us it was part of the cleaning routine. They never told us what and why, just that it was part of the cleaning regime to keep things nice and healthy.

129. There were grey filters on the taps. From the beginning we were told not to drink the water from the taps as it was not clean for drinking, we were to drink bottled water. If we needed water we were to ask to the staff on the ward who would bring us bottled water.

130. There were signs up in the parents kitchen in ward 2A saying not to fill the kettle up from the tap, we were to use bottled water in it. I have a photo from Ward 2A showing this sign in the parents kitchen.

131. This continued all the way through from Ward 2A to 6A, for [redacted]'s whole time in the hospital. It was bottled water for drinking the whole time for her.

132. Initially [redacted] did use the water to get washed. Early on in her treatment I had spoken to one of the other mums on Ward 2A, and she said to me that she had bathed her son twice and after each time he had developed a line infection. So we stopped bathing her in the water after that, we used wet wipes and alcohol rub. When [redacted] went in for her line removal in September 2018, one of the junior doctors came into see her before the surgery. I don't want to name him as he was amazing. He came in with a check list and one of the questions is "when was the last time [redacted] had a bath or shower?". I told him that she hadn't taken a bath or shower in around 4 weeks, and he asked me what I did

to clean her. I told him I used wet wipes and gave her a bed bath using bottled water, that we used alcohol rub. I told him that I had spoken to one of the other mums who told me about infections in her child, I said that I didn't want to take that risk. And he said, "if this was my kid I wouldn't put her in that water either". I said to him, "why say this to me now, why not tell every parent at the start who comes in that door?"

133. If we had been told from the start, that there were suspicions about the water then we would have known the risks from the start and could have been cautious. If they told us we would have been fine with it, we wouldn't have felt lied to or betrayed because what other option did we have? For the hospital to put our kids at risk, that was the unforgiving part for me. Knowing that there was something or that it was possibly something in the water and they just left it.

Other issues with the building

134. There was comments from staff that the hospital was not safe. One of them mentioned that it would be parents in hospital beds in 20 years-time as the hospital environment was not safe. That was based on general conversations with parents and staff. The consensus among everyone was that it was not safe. Staff were telling me that they were concerned about their own health, that they were healthy and were concerned for their own health never mind having a sick child in this environment. All these things make you scared of the hospital and the environment and who you could trust.

135. Alfie and I were in the RHC one day, around the start of [redacted]'s treatment when one of the windows fell out the hospital building. I can't remember what floor and where it occurred but I remember it happening, hearing the loud thud as it fell out.

136. During [redacted]'s treatment there has been constant construction work at the hospital. The cladding has been removed from outside the building and there is

a scaffolding around the building. They were doing something with green foam, taking it out and putting something else in. When that was going on the front entrance to QEUH was blocked off for a time. There was always something going on.

137. There are cracks everywhere in the walls, which for a new building I found surprising. One day Alfie and I were waiting for [redacted] to come out of surgery and we were sitting near the surgical wards in the RHC. We saw cracks all over the walls and remarked on it. I wondered if it was a sign of subsidence in the ground.

138. There are people constantly painting the interior of the building; again this surprised me for it being a new hospital.

139. The shower floors came up in Ward 6A. The edges of the wet floors came up. There were signs up asking you to report this if you saw it. There was an issue with the strips from the ceiling coming down when we were in Ward 2A. The shower room was built so it was wet walls with a lining over the concrete to make it water proof. Bits of the floor and skirting would come up.

PHYSICAL AND EMOTIONAL EFFECTS

Physical effects on [redacted]

140. I fear that there are possible long term side effects from the medication used to treat the pseudomonas infection. We don’t know the impacts of that medication. Did it contribute to her tummy issue that we are dealing with now? I worry her quality of life has been impacted due to the infections.

141. She likes to be in a dark room and listen to the iPad on her own. Everything with her is full volume and I wonder if she has suffered any hearing loss related to her treatment in the hospital. One side effect of pozaconazole is hearing loss. When we speak to her she can and does hear us though.

142. [redacted] always asks to wear sunglasses. And we have wondered if she has sensitivity to light. When we are outside she always asks for sunglasses as it is too bright and the light is hurting her eyes. I wonder if it could be linked to the treatment. I grew up in a hot and sunny country and our house is always cool and dark. When we go out she mentions her eyes.

Emotional effects on

143. [redacted] knows not to touch the water in the hospitals and knows there are bugs in the water. She has a fascination with going to the toilets there, so we arrive and she wants to go to the toilet and she says "don't worry, I know not to touch the water". At Crosshouse Hospital she was able to wash her hands, she was able to bath her toy baby in the hospital bath, something we never did to her or with her in the QEUH. I couldn't find any reports about the QEUH not being safe, so it is hard for her to understand why she can't use the water at her own hospital but she can at another hospital.

144. She has a lot of anxiety about her losing friends as that was the environment she was in, her friends would be there and then disappear from her life.

145. [redacted] has finished her treatment and every night she still needs to sleep in our bed. We have to make sure that "nobody gets her". I remind her she is at home and she is safe.

146. [redacted] is not scared of the dark, but she is scared of people touching her in the dark. We have had to mention to nursery that [redacted] does not have the realisation that "this is my body" and her "no-no" areas. We have to re-introduce it all, as much as she is cuddly with us she is scared of interaction with others but she just let's people do it to her. She was used to people coming in and take blood overnight, take obs and do whatever they wanted and she got used to it, so she needs to learn that again. The hospital just leave you.

147. I think it is cruel to give a family a terminal diagnosis of cancer and then put them in a room with no psychological support. We are not in treatment now and we are away from the hospital environment but our family is falling apart. We have a six year old with more issues that I can name. Me and Alfie, our relationship has suffered. [redacted]'s relationship with her siblings has suffered. She wants to be the golden child, but she can't be and she has to share me with her sisters. Maybe these are all things that are normal under the circumstances. There was no support and we were stuck in a room and that was it. There was no support.

148. We asked for a referral for counselling and it took a year for them to come back to us. They said it was just for me and Alfie but we need support for the girls too. [redacted] was really affected. She is worried that I leave her. She woke up one day and I was gone, [redacted] was gone. She didn't see us for months at a time. We were trying to shield the girls from seeing [redacted] like that, looking back now maybe we shouldn't have. Maybe it would have avoided a different kind of issue. It is hard.

Emotional effects on witness

149. In relation to the hospital, I don't trust anything that anybody says to me. We have been lied to our faces. We have doctors promise us that the hospital was safe and then you see things in the news, that a kid has died.

150. I put so much pressure on myself to keep [redacted] healthy and alive, that if anything happened to her it would be my fault that I would have failed her. If her cancer comes back I feel it would be my fault as I didn't spot it in time. I feel that we walk away from this with PTSD at a high level. [redacted] was in the hospital 2/3 weeks ago. I called NHS 24 as she had a sore tummy, they told me to give her medication. The next morning I called back as she was screaming out in pain and NHS 24 told me to take her in to A&E and we will check her over. I just burst in to tears at the thought of going back, the thought that there might be something wrong with her and then taking her into that environment. What we witnessed in the building and being in that environment,

I don't think I can go through it again - it is just too much. At the same time I know if we have to do it again that I have to push on with it.

151. I hate the hospital. As much as I am thankful that they saved her, I hate every part of it. It feels like a death trap, I feel that every time I go there I put my kid at risk. It is definitely not a place that I want to go back to. It doesn't help that I did not always have good relationship with the staff. There were a couple of bust ups and we fell out. It is hard when you are in that situation, you are on your own. I am not saying I was right all the time but I felt like I was making valid points. It didn't help and it is definitely not a place I want to go back to. It would be amazing if [redacted] could keep on getting better and stay away from there.

Complaints

152. I complained in March 2019 about the state of the room in Ward 6A. At that point the floor had not been cleaned in five days. The shower had hair in it and there were coffee spills and marks on the floor. The charge nurse came into my room and she had the head of housekeeping. I said to her that I had so many issues about the cleanliness in the hospital. They had one mop that they used to clean everything. The bedpans could sit in the rooms for twelve hours maybe more. If the child is in source they want to check the bedpans. But they could sit there for eight, ten, twelve hours.

153. I had a rant. I pointed out that they tell us that infection kills our kids, but that they should look at the state of the hospital. I said if you come to my house you would say this was not acceptable. Now we work in partnership and I am telling you this environment is not acceptable. The Charge nurse was very hostile towards me. The head of housekeeping said that the floors had been cleaned twice a day, every day. I told her I had photos and that the floors had not been cleaned. It was like they didn't believe me.

154. I also made a complaint about [redacted]'s nursing care. At the beginning of

[redacted]'s treatment the nurses were in to see [redacted] a lot in Ward 2A. Towards the end of [redacted]'s contact with the hospital, the regular nursing staff came in less and less and it was student nurse taking blood pressure and observations. The only time you saw a nurses was when they would administer medication. I did raise a complaint about this, if my kid is lying there and she is not well and you send random students in to take obs how can you monitor if she is getting better or worse. How can a nurse write a report if they were not there. We have her medical notes and from what was recorded there was not a lot about her medication condition, but more observations about me and the family, personal things. Everything on the parent, the point of having nurses is so that they perform the obs. I found that they wrote a lot of personal things in [redacted]'s medical notes, but didn't record medical information. The couldn't have written a report from the notes. This happened in Ward 6A.

155. Sometimes the wrong doses of medication were given. Half the incidents were not recorded in the case notes. They would give us half a dose of what [redacted] should have or more than she should have. I felt I had to look after her. I complained about that too. If you tell me that I need to give her medication at a certain time I stop what I am doing and give it to her. Sometimes her chemo could be two hours late when we were in hospital. The nurses came back and said they had a window to administer medication. I felt the hospital staff were dismissive of me when I raised this.

COMMUNICATION

Communication: general

156. In general communications from the hospital are really poor. The teams try their best. If you want something higher up you have to ask for it. I am still waiting to speak to microbiology about the pseudomonas infection, two years and a bit later.

157. Communication from the hospital might have changed during [redacted]'s treatment, but I am not sure if it has been for the better. Changes have been for face value and they have not been valuable.

158. NHS GGC set up a Facebook group. It contains information about the ward, but it is not in-depth information and is face-value and not much more. Things like “we are setting up a new deli trolley”. It feels like this is a group they were told to set up to keep face value, it doesn’t really mean much. There is a bit of feedback but not much.

159. Craig White was appointed as a parent liaison point. I asked Craig White and Marion Bain for the raw data of the water sampling. We found out that there was another child who got pseudomonas within a few days of [redacted]. We wanted to know if the water samples had been tested and if anything showed up in the water. We wanted to know if pseudomonas was in the water. We asked for the test results for the water for that period. They came back and said they would have to process the test results for us and put it into layman’s terms. Alfie worked in health and Safety for years and he can read a water report, he can interpret the raw data. So we responded and said please just give us the raw data, then they wrote back and said there is so many thousands of results. We only wanted the data for that period, we didn’t want it all. They were just stalling and were not going to give it to us anyway.

160. When the Case Note Review was published, the report said that they didn’t have the water data we sought from the Board. There were always people coming on to the ward to sample the water and the air filters. So I was shocked when the Case Note Review said there was no sampling and the samples that did exist were unmarked and all over the place. It looked like they knew what they were doing when they were in our rooms taking those samples.

Case Note Review

161. [redacted] was one of the children included in the Case Note Review. We weren't invited however, [redacted]'s case was simply part of it. I received an email stating they didn't want them to be shocked by the letter but [redacted] is in the study for gram negatives infections. I was told initially we would hear by summer last year, then it was the Autumn then the spring of this year (2021).

162. I have received [redacted]'s individual report. The report said that her infection was possibly caused by the conditions in the hospital. The words "possibly/probably" sounds the same to me. In legal terms it probably means something different. There was another child who was diagnosed with pseudomonas 5 days after [redacted] was diagnosed. The report concluded that they couldn't understand why the hospital did not act on these triggers and investigate this, and take water samples. There was no investigation carried out.

163. The main report involved eighty-eight children and the majority of those infections seem to have some link to the hospital. As parents we thought it might be a whitewash like everything in the past. Up until then remember we had been told by the hospital that it was safe and there were no issues. To see it in black and white that the concerns we had as parents were not for nothing, it felt like a small win. It is sad to see how many kids has been affected and this review only looked as gram-negative infections; it didn't look at all other types of infections. We are now finally moving in the right direction, we might get answers and there might be change.

164. Some of those kids have died, when we parents first started speaking out there was a child [redacted]who's mum spoke out.[redacted]died. [redacted]mum said that [redacted]chemo had to be placed on hold to deal with the infections. [redacted]cancer grew too fast and[redacted]couldn't be treated. I always think, is that something that could this have been prevented? If someone is sitting with empty arms and the kid is in a grave because of the hospital hiding things. We are one step closer to getting answers. There is some comfort that there is a public Inquiry and that it will be open and transparent.

Communication: infections

165. There was no communication in relation to infections. For the second staph infection it wasn't even the doctor who told me what it was it was the nurse in Ward 3B who came to tell me what it was. She had to go away and look it up on the notes. She said it was the same one that she had before. It was only when the hospital sent us a letter which was meant for our GP that they sent it to us by mistake, I think there might be mix up with the envelopes. It was only when we got that letter that we found out the full name of the infection.

Press Coverage

166. Me and Alfie have worked closely with the BBC. They did a Panorama episode that we were involved in. It was through pure determination to get answers that we turned to the press. It is for nothing else, no other reason other than to get to the bottom of this. We read every bit of news about the hospital in the press, not from the hospital. We could literally be in the room with the hospital staff and they would turn their backs and something would hit the press. They knew that this was going on, that this was going to happen. The news coverage has been very valuable to us as parents as without it we might not know what was happening.

Oversight Board

167. I don't know a huge amount about the Oversight Board, this is more Alfie's area. I feel that things were put in place to change the hospital, but those from the hospital that are on it will not be honest and transparent.

168. I feel that there won't be change under that culture, under Jane Grant. What we want is for Jane Grant to leave her post, and this was something raised at the parent's meeting that we had with Jeane Freeman. Her response was "I can't just pull people out of a hat to run a hospital." I mean surely you can find someone who is not going to lie to parents. The focus has been very much on

oncology but there are other vulnerable people, for example neonatal is same boat they are vulnerable people.

169. By keeping her in post, keeping her here, she knows where the bodies are buried and we expect that when you, the public inquiry, are carrying out your investigations that they will tell you that they don't have the documents or information that you are looking for. That is our fear.

CONCLUDING REMARKS

170. If [redacted] relapses she will have to go back to that hospital. I say to parents, if your child has to go back to that hospital and they contract an infection how do you live with yourself if you didn't speak up? Not everyone is as thick skinned as I am and not everyone is comfortable to come forward. It is hard for some parents as they are scared that their relationships with their medical team will be compromised.

171. There were a few occasions that I raised matters with the Health Board and got a call from Professor Gibson in response. I said to her that this is not for you, it is for the Health Board or senior management. Professor Gibson's job was to look after [redacted], the questions were for others to answer. I didn't want to compromise my relationship with her, it should be one of mutual trust. I didn't want to put her in the position. The health boards said if you have any questions, ask your medical teams which was so unfair. It is not a healthy environment for her to work in. It is not a healthy environment for our kids to be in.

172. I went to the media to get answers. Kids were getting infections, patients were dying, and when our kids were getting infections they couldn't tell us where it was from. We didn't know if the water was safe. We didn't know if the ventilation in the hospital was up to scratch. A lot of it was to do with the handling of the psedenomous infection. We didn't know how [redacted] got it. I spoke to a doctor in the USA, who said that she could only have got that

infection in her port by medical access. We don't access ports as parents that is something only the hospital does. The hospital turned around and said she was not an in-patient at the time she developed the infection but there is a 72 hours incubation period which aligns with the blood transfusion on the 15 March 2019.

173. It is the fear that drives you, I don't want someone else to go through this. My friend's daughter got psedenomous at the start of this year just after her port was accessed. It is still happening. If we don't speak up nothing will change. If we don't drive this forward the hospital will not change anything.

174. I hate the hospital. It makes me feel sick. I just don't want to be near it. I feel the Health Board is the hospital. I don't think for one moment that our team wanted to lie to us, but they were put in that position where they had to and couldn't tell us the truth. The Health Board are at the root of this. I will forever be grateful to the medical team, it doesn't matter how we feel about each other. Professor Gibson did everything she could for [redacted], not once do I look back and say she didn't have [redacted]'s best interest at heart. It was the way things were gone about that make me sick.

175. Communications are still not adequate. What I want is honesty, parents only want honesty. Come and stand next to my kids bed, even if she is dying all I want is honesty. The hospital is not known for honesty. Jason Leitch was on the ward saying that the ward was safe, that there were no issues. He came round to daycare when we started kicking off about the prophylactic antibiotics in September 2019. He visited the ward and said it was fine, we could drink the water and wash our hands. They changed one of the rooms in Ward 6A into a parent kitchen. It is the same water supply in the whole ward, how can I drink the water in the kitchen when in 90% of the rest of the ward I am told not to drink the water?

176. The Health Board put everyone in danger. The Health Board is not the medical team. It was unfair of the hospital to put the medical teams in that

position. You shouldn't have to raised things like this with your team – they're medical. They’re not management. We wanted to see Management.

177. I do have concerns about patient safety in that building. I feel that nothing has changed. When they closed the ward in September 2019 they closed the ward again and put all the kids who had lines on Cipro. This drug is only supposed to be for adults for 5-7 days and these kids were on it for months. The team could not tell them why or the reasons why the kids were on the medicine. [redacted] was never on this medicine as she didn’t have her line in at that time. I know about it from discussions from other parents.

178. When they shut the wards they put HEPA filters in the rooms in ward 6A. Now the HEPA filters are gone but what has changed? What have they done to change the water supply? Nothing has changed. The issues that were there then are still there now.

179. 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 (CL/01)

This timeline was prepared by Ms Charmaine Lacock. It was provided to the Inquiry and is referred to in her witness statement.

- 17th August 2018– [redacted] became unwell and Charmaine took her to the GP. The GP said that this was likely a viral infection. They went home but remained unwell and was very pale.
- 19th August 2018 – Charmaine takes [redacted] to A & E for further investigations at QEUH. She was transferred to CDU and late in the evening after blood tests were completed, the family were told that she likely had leukaemia. She was moved to ward 2A to room 7.
- 24th August 2018 – [redacted] has surgery to fit a Hickman line.
- 25th August 2018 – [redacted] starts block one of chemotherapy, there were multiple room moves during this time. [redacted] remained in ward 2A till the ward closed around the 26th of September 2018.
- 23rd September 2018 –[redacted] has a line infection. The line is stopped.
- 24th September 2018 – [redacted] has emergency surgery to remove the Hickman line.
- 1st week in October 2018 – [redacted] is discharged home for 3 or 4 days and was then readmitted.
- 11th November 2018– [redacted] is admitted to hospital to start her 2nd block of chemotherapy to ward 6A
- 12th November 2018 – 2nd block of chemotherapy commences.
- 17th November 2018 – [redacted] is discharged home.
- 22nd November 2018 - [redacted] is admitted to hospital because she is throwing up blood. She is admitted to ward 3B in the Children's Hospital. ..
- 26th November 2018 – [redacted] starts 3rd block of chemotherapy.
- 24th December 2018 – Meeting with Professor Gibson. [redacted] is discharged home.
- 27th December 2018 – A meeting is conducted in the hospital to discuss [redacted]'s treatment plan.

- 31st December 2018 – [redacted] admitted to hospital to ward 6A.
- 3rd January 2019 – [redacted] is discharged home after a lumbar puncture
- 21st January 2019 – [redacted] has a fever and is admitted to hospital.
- 23rd January 2019 – Put on Ambisome – infusion – she was put on this infusion every 2 days
- 31st January 2019 – Charmaine reports to a nurse that [redacted] has been itchy. No rash evident. (this is a note from [redacted]'s medical records)
- 20th February 2019 – [redacted] develops a staph infection. The line is not removed.
- 25th February 2019 – [redacted] is discharged home.
- 15th March 2019 – [redacted] had a blood transfusion at clinic
- 19th March 2019 – [redacted]'s temperature spiked and she was admitted. Blood cultures were taken
- 21st March 2019 – confirmed Pseudomonas diagnosis. [redacted] receives antibiotics for this until she recovered.
- 24th March 2019 – [redacted] develops little round circles on her knees. They looked like bruises.
- 25th March 2019 – Dermatologist examines this and confirms it is "Candida (a fungal infection)
- 25th March 2019 – She starts medication for this infection. Ambisome infusions 4 times a day and Antifungal medicine posaconozol
- 29th March 2019 – [redacted] is discharged.
- 1st April 2019 – Maintenance round of chemotherapy commences.
- 26th September 2019 [redacted] was admitted to ward 6A room 11 for 48 hours for a cold That was her last hospital admission at the QEUH.