Scottish Hospitals Inquiry

Witness Statement of

David Campbell

1. My name is David Taylor Campbell. I was born on [redacted]. I am [redacted] years old. I am a [redacted].

2. I am the Father of [redacted]. [redacted]'s date of birth is [redacted]. He is 6 years old and due to turn 7 years old [redacted].

3. Completing this statement has been a gruesome emotional experience. Many dark painful moments have been relived and attempted to be put into some kind of context. A difficult thing to grasp, as I am still in a form of emotional limbo, not knowing what to feel 3 years on from my son's first cancer diagnosis. The reason for that being, there are still many questions left unanswered from what we experienced in that place and so a form of purgatory remains.

4. Some things are clearly evident though and what is the most fundamental to me, is that my son and the other children with their families should not have set foot in that building when their lives were so perilously ill as it was.

5. People chose to ignore recommendations that the building was not as it should have been, even back in 2015. This was highlighted by an independent report and the fact they continued to let these children continue to be admitted to this hospital, ignoring qualified substantiated advice is totally unacceptable and unforgiveable.

6. My sincerest gratitude to [redacted]' fantastic consultant and his team, I will be forever in your debt. Also the surgeons who operated swiftly removing the

tumour successfully and their theatre staff, anaesthetists, play workers and the nursing angels who are so very brilliant, we owe you his life and will continue to be ever grateful for saving him. CLIC Sargent Marion House and CCLASP, thank you. Without that support I could not have done it.

7. To the SNP Government that let this hospital be handed over and deemed fit for purpose and then let the Health Board continue to operate so inefficiently, the contracted people responsible for building a death trap for the country’s most vulnerable children causing so much distress and added psychological cruelty to us all. I hope karma finds you all soon and this inquiry brings you all to task and accountable.

8. The staff who do all they can to protect these children every day deserve so much better than a Board devoid of any compassion, candour and accepted responsibility. To the Health Board, shame on all of you.

9. To the beautiful little people we met in there that are heartbreakingly up in heaven now and not suffering in pain anymore, thank you for inspiring me, showing me how to be fearless and how to fight to be the best I could for my son as back then I had nothing left to give. Cancer is so cruel. You all deserve so much more, God love you all, thank you.

10. Finally, to all the parents, bloodly well done, we won’t hear that enough as no one really knows how much we go through.

OVERVIEW

11. My son is [redacted] [redacted]. [redacted] was diagnosed with rhabdomyosarcoma in August 2018 when he was 4 years old. [redacted] was treated in the Royal Hospital for Children (RHC) and Queen Elizabeth University Hospital (QEUH) between August 2018 and February 2019, when he finished his treatment. He

attended both hospitals as an in-patient and an out-patient regularly for six months. [redacted] still attends the QEUH for MRI scans which were three monthly and have just been extended to four monthly.

12. [redacted] spent time in ward 1A, which was a surgical ward, 2A and 3B of the RHC. Ward 2A was known as the Schiehallion Unit. Following the closure of the Schiehallion Unit in 2018, [redacted] was treated on ward 6A of the QEUH. I stayed with [redacted] on a regular basis during his treatment when he was both and in-patient and an out-patient. I can speak to the experience and I had on these wards.

13. There are some specific events that I would like to mention. I believe was prescribed preventative medications in September 2018, which may have been connected to the issues with the water supply and the then rumoured bacterial problems in the hospital. There were always ongoing construction works going on at the hospital through-out [redacted]'s time there, which I believe impacted on him. I will come on to talk about these issues and events in more detail.

FAMILY BACKGROUND

14. I live in [redacted] . I work for three weeks on a rotational basis. [redacted] stays with me at weekends when I am [redacted] and during the school holidays. If I get a day off from my work, I go to visit him.

15. I live near the water-front so when [redacted] is staying with me, we like to do a lot of things outside, including catching crabs. He used to see his grandparents most days when we stayed in Mull of Kintyre but he now sees them about once a month [redacted] just before the diagnosis.

16. [redacted] doesn't really like school just now, which I feel is a consequence of being in hospital, not being allowed visitors and separated from his peers. It's difficult for him to blend in now and do group tasks but the school have been supportive with this. He was used to being on his own at the hospital, just as we were getting him back to school, we ended up being in a similar situation, due to the country being put into lockdown as a result of Covid.

17. [redacted] has a set of friends he plays with and is adapting to school starting [redacted]. We are still very wary of him getting a bump to his head after remission. is also wary of climbing etc. just now so we are just taking everything slowly and let him find his own pace

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

Admission to hospital: August 2018

18. On 5 August 2018, I noticed that [redacted]'s eye was swelling up. He had just returned from holiday and had suffered a bump to the eye when he fell, while he was away. I decided to get it checked at A&E at the QEUH in Glasgow. This was the adult part of the hospital we went to. [redacted] was given antibiotics and we were sent home.

19. On 19 August 2018, I took [redacted] back to A&E at the RHC this time as the swelling had increased. Dr Sastry, [redacted]' Consultant, requested that Ophthalmology take a look at him. He was admitted and placed on IV antibiotics. The next day, [redacted] was given a CT scan, a tumour was identified and that evening he underwent an excision of the left orbital tumour by Mr Clements, the ENT consultant surgeon.

20. [redacted] was admitted on to ward 1A of the RHC, which if I remember correctly, was a pre-theatre or pre-diagnosis ward. He wasn't in there very long,

maybe three or four days. [redacted] got out for a night before being re-admitted to ward 3B on 23 August 2018 as ward 2A was full.

21. On 26 August 2018, [redacted] was moved to ward 2A at the RHC where he was admitted as an in-patient. Dr Sastry confirmed a diagnosis of a Rhabdomyosarcoma malignant tumour in the soft tissue of the left orbital lobe area. Although this was a rare cancer, there were possibilities of effective treatment.

[redacted]'s initial treatment: August 2018 – late 2018

22. [redacted] had, his Central Venous Line (CVL) fitted on 27 August 2018. His CVL was a Hickman Line. This was done in theatre under sedation. He also had a bilateral bone marrow aspirate and trephine biopsies done on this day too.

23. On 30 August 2018, I agreed to the treatment plan with the doctors and I signed the consent form. His treatment plan consisted of nine courses of ifosfamide, vincristine and actinomycin which were given to him intravenously. This included a mix of in-patient admissions where his chemotherapy was administered over three days, every three weeks. Some of the chemotherapy was delivered by injection and that meant that could go to CLIC Sargent House afterwards. [redacted] started the treatment on 31 August 2018.

24. [redacted] was discharged for a few days to CLIC Sargent on 3 September 2018 after being in ward 2A from 26 August 2018.

25. Between approximately 10 September 2018 and 14 September, [redacted] had his feeding tube fitted. My dates for this are approximate as he accidentally

pulled this out a couple of times. I believe the CVL was fitted earlier as his medications were all administered to him through the CVL. I originally thought he had his earlier treatment through cannulas but the medical records do not support this.

26. Throughout his treatment, [redacted] was in and out of hospital a lot, I couldn’t really keep track as it was pretty constant. He would be admitted because there was a suspected infection or a temperature spike and then he would be discharged after the infection cleared up. They didn’t keep him in unless there was a valid reason. I often felt that he was released quicker because of the ongoing building problems.

27. The procedure for a temperature spike was that whenever [redacted] spiked a temperature, which I think was anything above 38.2 degrees and we were at home, I had to phone the Schiehallion ward for advice. I bought an in-ear thermometer to have at home and we were given strips from the hospital that go under the armpit that the nurses used every hour to take a temperature. I would use the strips first and then check if it would coincide with the in-ear thermometer. This was to see the complete picture and any trend. The nurses told me that I could gauge if there was a bigger spike this way. When I phoned, they would go through everything with me and ask me to check his temperature again. I had to give the ward some notice because sometimes they wouldn’t have a bed for him so they would have to source one in wards 2B or 2C until one became available in ward 2A. Sometimes we were given our own little room in A&E before we could be taken up to the Schiehallion Ward. It used to be the case that when you called, you were told to bring your child in via A&E or ward 2B and then you would be admitted in ward 2A. After the move, you would still come in via A&E but if my memory serves me right, it was always ward 6A we went to in the adult hospital.

Experience on ward 2A: August 2018 – late 2018

28. When [redacted] was first admitted to ward 2A on 26 August 2018, I noticed there were other families living out of suitcases. Maybe they didn't know how long they were going to be in there or maybe it was psychological that they wouldn't be in the hospital that long. I knew [redacted] and I were in for the long haul so I wanted to make our room on the ward as comfortable as possible. Immediately when we were in our room we noticed a few different things. You couldn't make the room like home. For example, if you go on holiday for a week, you can make your accommodation your own. You couldn't do that here as there were other things in the room which made it difficult to set it up. It was like a cell. It was just a bland space. There was absolutely nothing [redacted] was familiar with. You'd like to make it homely but it was very difficult. You didn't want it to be a home in the first place so it was psychological too. Most young children like to play on a floor. You can't keep them off a floor when they're playing with cars and other toys but that wasn't possible on this floor as it was dirty. The only playing options he had were in the bed or on a chair.

29. There was a playroom in ward 2A which [redacted] used a lot when he wasn't neutropenic. He wanted to go there all the time because that was where he saw toys or he could interact with other children. A lot of the time it wasn't possible to take him to the playroom because there were things like chickenpox going around. My dad used the playroom with him too when he visited as you could go in with [redacted] and speak to other parents or grandparents. It got [redacted] off his iPad for a while. The games in there were really good and well stocked. The corridors in the RHC were wide enough that we could go for a walk and get some exercise with the trollies [redacted] had attached to him and not have to worry about getting past anyone else doing the same with their child. It was set up with the focus on the children. had two trollies, like giant coat hangers attached to him, one was for his diet through his nasal tube and the other one was for his central line. If I

was on my own with him, I had to use a hand for each of the trollies with him going ahead. If he took off, I had to drop the trollies and catch him because if he pulled his central line out, he would be dead.

30. [redacted] would sometimes start fighting with me if I tried to rein him in for a many matters. He would scratch me and hit me and he became really strong when he couldn't go home. He would try and throw himself on the floor, I would try to pick him up to stop him from hurting himself with the cable that was attached to his chest. He would try and pull it out so he had bands put on it round his chest to stop him doing that. He became reliant on "wiggly" the name the kids give to the central line as it stopped a lot of painful cannulas having to be inserted in the back of his hands to administer anything.

31. There was a play worker there that was really good with [redacted]. I wish I could remember her name. She would come in to the room and brings toys with her and interact with him. Some of the charities would come up and do puppet shows and that really helped. He was stuck to his iPad otherwise and eventually he just went into himself.

32. [redacted] responded well to the play leaders. When he was allowed, he would go down to the hospital Radio Lollipop room and would interact with the staff there. That helped him cope with the difficult aspects of treatment. The play leaders would also do things with teddies as well to show him his central line and engage with him about this.

33. Another benefit of the playroom was that it gave children the chance to bond with the other children. Meeting older children was good for [redacted] too. He was able to see how brave they were and it helped when he was getting some of his treatment as he'd want to be seen as being brave too. It was almost like a competition.

34. There was a parent's kitchen which I used quite a lot. It had a sofa, radio and a TV. I could speak to other parents there who were going through the same thing as we were and could relate to how we were feeling. It would depend on who was with me, how long I used it for. Any time I was there, [redacted] wouldn't let me out of his sight, but when he was sleeping and the nurses came in to do their tasks, they used to tell me to take five minutes. If my brother was visiting, I'd get a bit longer.

35. There was a fridge in the parent's kitchen too so whenever I needed to make dinner for myself or [redacted], I could keep that in the fridge. Visitors would sometimes watch [redacted] for me when I went to make a tea or a coffee. You were able to bring your own things in and you'd be allocated your own space in the fridge and cupboard for it.

36. There was a cinema on the ward. It showed all the new films. [redacted] loved the cinema and it was a huge thing for the other children too. Adults could sit at the side and you would see all the children's faces light up when the music started. It was their treat. Their chance to be normal. The kids could still go even if they were attached to units containing medical equipment as there were power sockets there where they could plug them in. The battery packs they were issued with for keeping their machines working, if they left their bedside, didn't last very long so the sockets made it accessible to all the kids. I think they had input from people who knew what to expect as it was all centred round the kids.

Closures of ward 2A and the move to the adult hospital: Late 2018

37. The Schiehallion Unit was named after a famous mountain. Ward 6A wasn't equipped for us climbing that mountain. In fact, the Schiehallion Unit died when it was moved from the RHC. We saw it getting further and further away from us every day. With all that was going on with the cancer

and now an unfit place for him to receive treatment, put his survival chances at a definite disadvantage.

38. There was no communication at all about the reasons for moving ward 2A to ward 6A. We were told the move was a temporary precaution. They had to get all the kids and families out so they could inspect the space. When we got to ward 6A they were putting up child friendly art work up on the walls and setting the ward up in a way that I knew it wasn't going to be a temporary thing.

39. We were told on the morning of the move, that we were being moved. A lot of the other families said, "Oh, you're going home?" because it was great seeing kids get out for a few days when you saw them going past with the suitcases. The reply was, "No, we're going into Ward 6". All the parents were asking what was happening on ward 6. We asked the nurse in charge of the ward and she told us, "Yes, there's going to be a move into the adult hospital but, everything's alright, trust the process." We weren't told why the move was happening. We asked some of the other nurses and one of the nurses unofficially told me that ward 2A and 2B had been condemned and it was "riddled". That was the word she used. It was riddled from top to toe, drains, ventilation and crumbling walls.

40. The families on ward 2A were moved to the adult hospital a week after the news report about the pigeon droppings on 19 September 2018. [redacted] and I were one of the last families to be moved from ward 2A to ward 6A. I thought our room must be okay since we were the last family on the ward. I asked the nurses, if [redacted] was ok, could we stay, but they said no and moved us. No explanation was given. I was told by a nurse that we were moving to the adult hospital and that was all the information I was given. I saw other parents leaving with suitcases and asked the nurses if they were moving too or if their child had been discharged. They said they weren't

allowed to discuss other patients. I asked other parents if they knew anything but they had been given the same answers as me from the nurses.

41. I questioned how these children with life-threatening illnesses could just be moved like that. The Schiehallion Ward is a renowned name and they were just taking them out of that place and putting them into a random ward. I would have rather taken my chances staying in ward 2A which is why I asked if we could stay. That was until we actually found out about the reason behind the moves, then we were glad to be clear of it.

Experience in ward 6A QEUH (adult hospital): late 2018 – 2019

42. When we moved to the adult hospital it was awful. There were no facilities. To leave 6A to go for a walk outside to relieve stress, it would take around 15-20 minutes just for the lift, as it was used by the general public; a confined space with all walks of life and ailments after leaving a secure ward of vulnerable neutropenic children. There was nowhere to heat a meal up for yourself. You had what was left of your child’s cold dinner if they didn’t want it, however [redacted] was on a liquid diet at that point so sometimes this was what was left over for me. Staff would come around in the morning and ask him what he wanted for his dinner that night. How was he supposed to know in the morning what he was going to feel like having at dinner time? None of the food was appealing. I couldn’t always get to Marks and Spencer’s, which was the only decent option in there. It was a long complicated journey to get there, walking past a number of people who may have been carrying infections themselves, that I could have brought back to [redacted]. I was already living on limited sleep, so journeys like this were sometimes too much. There was only one access lift and it took about 20 minutes to get down because it took so long for the lift to come. Ward 6A didn’t give any of the parents meals, it was only the kids that got meals. You couldn’t take stuff in with you from home because you

didn't know how long you were going to be in for. You were living off Marks and Spencer's sandwiches and bottles of water. You were taking up three or four at a time. There was only one access lift at that hospital so you had to mix with everybody going to all sorts of wards. I would have to leave a neutropenic boy to go down in a lift I had to share with other people. This is more relevant now with Covid for the two metre spaces, but back then, that was the kind of journey I was expected to take every day so I could eat.

43. After a while, I just didn't have the patience to do it; or by the time I got back up, I didn't even want anything anyway because I was so tired and sweating because of all the exertion. But even then I couldn't use the showers because they had to be run for five minutes according to the hospital policy and the warning signs on the wall. I also didn't trust the water. So what was I supposed to do? [redacted] was asking for a cuddle upon my return so I was having to use wet wipes, or have a shower so I could ensure that I wasn't passing on any potential bugs from the journey to Marks and Spencer's first. It was a lot of effort for a sandwich and a bottle of water so I often ended up eating what was available on the ward.

44. I asked the staff where the adult room was on 6A where I could go and get a cup of coffee. I was told there wasn't one but that I shouldn't worry, as we'd be back in ward 2A soon enough. I didn't feel too inconvenienced because I was being told that the move was only going to last a couple of days; at least that's what we were told. I was hoping in the back of my mind it was a temporary move but I really knew that this was where we were going to be now.

45. There wasn't a parent's kitchen in ward 6A and the loss of the fridge and freezer had a huge impact on [redacted]; we used to keep his favourite ice lollies in the freezer. He hated getting cannulas inserted so we used to bribe him

with an ice lolly. If he was having to get a procedure like that done to him, there had to be a reward but that was taken away when we moved to 6A.

46. The lady that came around with the tea trolley twice a day was a godsend in ward 6A otherwise I wouldn't have had a cup of tea all day. There was nowhere to make a cup of tea and you couldn't bring tea, coffee or soup from the canteen up to ward 6A as it was a hazard.

47. Not having a playroom on ward 6A was a massive loss. [redacted] was stuck in his room, isolated from everyone else. There wasn't even enough room for him to exercise in the corridor because it was too narrow. He would ask to go and see some of the other children, to be told by staff that he wasn't allowed to. You had the same bridge to cross every day, the same battles, trying to get him to understand he couldn't see other children.

48. The loss of the cinema had a huge impact on us too. The kids used to love being able to go and see a film on ward 2A. There was nothing like that on ward 6A.

49. We had the same room twice on ward 6A. It was room 1, when you first came in, it was the first door on the left. I heard a wee girl's mum crying one night. She had been told there was nothing else that the hospital could do for her daughter. I saw her through the window in room 1 but I couldn't go to her as I couldn't leave [redacted] on his own. There was no privacy there and nowhere she could have received support from other parents.

50. We had made the room as comfortable as possible on ward 2A. It had been our home and [redacted] had made some friends there but the move to ward 6A was unsettling. [redacted] wanted to go back to 2A as he was familiar with his surroundings and it was comfortable there. He was also able to see other children which he couldn't do on ward 6A.

51. Ward 6A was like a prison, an institution. There was a mobile bedding unit that you would go to get yourself and bedding for the fold out bed. In the morning, there was a breakfast trolley. You would have about 15 minutes to go and get something off the breakfast trolley and put your used bedding in the bin beside the bedding unit then you were back in your room. It really was like a jail. The televisions didn't work. They eventually got a coffee machine put in after parents in one of the groups fought for it.

52. Another thing about ward 6A was that day care was at the very bottom of 6A. You had kids, visitors, people who were picking up prescriptions and everyone else coming from outside and walking right through the ward to their day care appointment at the bottom of the ward. So everybody was traipsing through. It was just like a waiting room and it was chaos. There would be all these wee bald kids wandering about with tubes in their nose, barely standing and other kids running about past them, and going home. That would then start [redacted] asking why he couldn't go home.

[redacted]' ongoing treatment: October 2018- February 2019

53. [redacted] started cycle 3 of his chemo on 12 October 2018. This was as an outpatient in ward 6A Day Care.

54. [redacted] began cycle 4 of chemo in ward 6A on 4 November 2018. He was an in-patient as the chemo was administered through IV over a 24 hour period. He then got an injection of vincristine after that. You had to wait until he was responsive after the IV chemo and good within himself before he got discharged to CLIC or home. I changed my work from three weeks on, three weeks off to a Monday to Friday. [redacted]'s chemo fell on weekends which was good for this schedule. When he was given all of the cycles, I would stay on a Friday or a Saturday night, but usually a Saturday, with him and he would be released on the Sunday.

55. [redacted] was admitted on the 8 December 2018 as he was neutropenic and was feeling sore so I was told to take him in. The 8th to the 14 December he would have been treated with antibiotics because he wouldn't have started his chemo on the 14 December unless his bloods were good and the infection had cleared. I told Dr Sastry that [redacted] was sore and he said that it was a side-effect of the antibiotics. He could only have been in for an infection, so there would have been mention of an infection. I honestly don't know, but my gut and everything tells me that the infection was from the hospital because they wouldn't have him on all these anti-fungal drugs otherwise.

56. [redacted] was admitted on 26 December 2018 to ward 6A for an IV infusion of antibiotics. I think it was an infection although I wasn't told what he was being given and why. It would have been an infection because wouldn't have been admitted without having either an infection or constipation. That would have been the two critical reasons he would have been admitted. If he wasn't eating, that leads to the constipation so you would try a different food with him to take. When he was with me, I had to share the same bed with him because he would get tangled up with the food machine going 24/7 beside the bed. He couldn't turn over. He had to only sleep on one side so when he turned over you had to move him again. Sometimes the machine would get clogged up or it wouldn't work and you had to change the batteries. The machine had to be kept going non-stop. [redacted]. The hospital would try a different bag so [redacted] would have to go into hospital for that. There was a dietician that did everything for [redacted]. All that stuff had to be done at the hospital because that was where the team looking after him were and all his records. So, if he was going to the toilet too much you would have to take him into the hospital then too. The reason for him passing so much or being clogged up, was apparently down to an infection

of some kind or a side effect of the drugs. [redacted] stayed in hospital until 4 January 2019.

57. On 11 January 2019, [redacted] was admitted to ward 6A again with what I think was an ear infection, although I can't say that for sure. The temperature in one ear was higher than it was in his other ear. I had a briefing with Dr Sastry about [redacted] on 13 January 2019. He had a blood transfusion for platelets on 14 January 2019 to prepare him for his next round of chemo. In [redacted]' medical notes for this admission, there's an entry on his admittance notes for posaconazole, septrin and co-trimoxazole. I don't remember being told anything about these at the time. I wasn't aware of any of them being administered and I wasn't aware of the names of them until I got [redacted]' medical records. I asked what these drugs were but was told that they were just part of his treatment plan.

58. On 25 January 2019 [redacted] started cycle eight of his chemo. On 4 February 2019, there was an MRI scheduled but [redacted] had gone under the bed and wouldn't come out. I had a hell of a job getting him out. I think he was picking up on my anxiety as I felt I couldn't protect him from the stuff going on in the rooms about the environment and there was a lot of tension on the ward with everything that was going on. Knowing he was going for a MRI would have made him anxious too as he knew he would be getting put to sleep under general anaesthetic as the MRI takes about an hour. He can't lie still for that long and he was worried he wouldn't wake up again because when he had his first MRI he woke up and his eye was all bandaged up. He thought someone had stolen his eye so he thought they were going to steal the other one, so he didn't want to go to theatre because of this. The doctors eventually said that they would postpone it as he was going to end up hurting himself. I can't recall when he actually got the MRI after that, but it wouldn't have been longer than two weeks as

he had to get the MRI to see the state of the tumour that was removed and to see if anything was still there or coming back.

59. [redacted] had cycle nine of his chemo on 15 February 2019. He received platelets again in day care of ward 6A which was an overnight stay. They had to balance the platelets with fluids so it was a long, drawn-out process for the body to absorb them. They've got to test the bloods when all the cultures come together and make sure they've all levelled out. They have to check that his body hasn't had a reaction to anything in the blood.

60. During the rest of 2019, [redacted] was attending regular out-patient appointments for MRI scans. These were every three months to start with and are now every six months.

WATER: EVENTS INVOLVING WATER SYSTEMS

Water: incidents

61. We noticed as soon as we were admitted to our room on ward 2A that there were prompts in the bathroom such as signs on the wall telling you to run the water for five minutes. These signs were in every room on ward 2A. The bathroom was a wet-room and there were signs up on the walls telling you to run the shower for five minutes before you used it. If you did run the shower for four of five minutes before using it though, it would flood. There's no tray. It's a wet floor with no partition. Water would be running to the entrance of the room. You can't have a flooded room when you're trying to get in and out and dealing with your child who has been sick.

62. You were giving your child close comfort care so if they did have an accident or were sick, you had to be quick. [redacted] had a Hickman Line which

was attached to two machines so if he had been sick on his top and had other accidents, you had to try and get his pyjamas off whilst he was attached to a line and a nasal tube. To get him into the shower, you had the two trolleys to take with you. Running the shower for five minutes before using them wasn't an option.

63. The cardboard bottles containing the urine samples were kept on the bathroom floor waiting to be collected. If you ran the water for five minutes, then the water was very close to touching them and they may have been damaged from the water. Bearing in mind his urine was radioactive, I'm not sure of the impact that would have had if the urine mixed with the flooded water. If you did run the shower for five minutes, there would be chaos as the shower and toilet is all in one, so water would have run right up and you'd have swimming pee bottles all over the floor if you ran the shower for five minutes.

64. I did ask staff why we were to run the shower for five minutes before using it. I was told that it was normal practice for legionella. Other staff told me it was a standard thing that happened with all showers of that type. I asked if this was the same in a hotel so everywhere was the same. I was just given a look in response.

65. The silicone fittings in the shower were loose and the drains bubbled. There were no proper seals and with the drains bubbling too; I think this might be part of the issue connected to the infections.

66. I became aware of issues with the water in August 2018, after [redacted] and I had been in the hospital for two or three weeks. One of the cleaners was the first to mention it and she said she wouldn't let her dog drink the water in the hospital. She told me to ask for bottled water. Other parents had said not to drink it, not to bathe [redacted] in it or use it to brush our teeth. There

were loads of rumours going round that we shouldn’t use the water and the nurses never confirmed that the water was actually fine to use. They also didn’t address the rumours so it left me with a resounding fear that there was something being covered up.

67. There was also another father I used to speak to quite a lot. He said to me that I could ask the nurses for sterile water to bath my son with as he wouldn’t use the shower on his child. He said I can buy water wipes at Booker and to get as many as I could. I didn’t think anything of it at first, but when you start to see things yourself, like the water not draining away, or the filters on the taps, then you do start to think about it more and question if there is actually something wrong with the water.

68. Before all the horror stories started about the water, when I asked nurses for a drink for [redacted], they would bring in a jug of water or a jug of diluting juice for him. The nurses used to make ice lollies and ice poles on the ward as well. I’m now wondering about the impact of this if they’ve used tap water.

69. When we were moved to ward 6A, the staff started bringing in big bottles of water. I asked some of the nurses about the water and was told it was fine. Where [redacted]’ bed was in the room there was a sink directly opposite it and there was a sign on that that said, “Water not for drinking, for washing hands only”. We asked if the sink in [redacted]’ bedroom was okay to use because it didn’t make sense to us that one sink on the ward couldn’t be used but others could. Surely they were all connected?

70. If you asked the nurses about the water, some of them never used to give you a straight answer. I said I didn’t want to bathe [redacted] in the water and one of the nurses said I could try using the sterile water they provided. If there was nothing wrong, why wouldn’t she just have said that and not

suggested the sterile water? Nothing was said. It was mostly sterile water I asked for to clean [redacted] with. You get little bottles of sterile water for cleaning out syringes and things like that but anything else to clean with, I would bring in myself. That was never questioned. I got the impression the nurses didn't want to say anything bad about the water.

71. It was pretty widespread that the nurses would tell us to watch what we were doing with the water. We were told not to put him in the shower because that was critical for his central line. I had to wipe [redacted] down with wet wipes. Unless he was really bad then I would shower him quickly and afterwards I'd put gel and stuff over his legs and clean it all up because I was told that was the best kind of form of defence after anything, to stop it getting on him.

HEALTHCARE ASSOCIATED INFECTIONS

HAIs: events and physical impact

72. [redacted] was admitted to ward 2A again on 16 September 2018 with sickness. He usually always presented with a temperature first. If your child develops a temperature, you have to phone the ward to at least seek advice. There were three things you looked out for: temperature, pallor and responsiveness. We were at CLIC Sargent and I was told to take him in so he was admitted to the Schiehallion Unit but I can't remember the number of the room we were in. There was no indication of what the infection could be but he was given fluids through IV. I think it would have to be a bacterial infection that [redacted] would have as IV antibiotics are not used for viral infections.

73. [redacted] was admitted from CLIC Sargent on 1 October 2018 with an infection. This was to ward 6A and he was put on IV antibiotics but I was never told what the infection was. The information was always very vague. The term,

"A wee infection", was used a lot and it would sometimes be used when had a temperature spike. It's the terminology they used for it. That's all I was told, "There is something. It's a wee infection". This was the phrase that was continuously used. [redacted] was neutropenic at this point meaning he had no immune system and this lasted for about four weeks. He was discharged on 5 October 2018.

74. [redacted] developed an infection on 7 November 2018. He was taken to QEUH by ambulance. The infection turned out to be influenza A and he was treated for this with an IV infusion of antibiotics, then discharged. I think he was possibly given other medications at this point but I can't remember.

75. When [redacted] was admitted to hospital on 8 December, I understand that was because of an infection. I believe this was hospital acquired, but his medical records are very vague in how they describe what he was treated for.

76. [redacted] was admitted to the hospital again on 26 December with another infection. [redacted] wasn't supposed to be out of hospital but we wanted him home for Christmas as we didn't know if it was going to be his last one or not. He wasn't right all the way through Christmas. He was admitted and given IV antibiotics but we weren't given any information about the infection.

77. [redacted] was admitted to hospital again on 11 January 2019 with what they thought was an ear infection. It could maybe have been a build-up of wax from this chemotherapy treatment, we don't know.

78. I had difficulty in obtaining [redacted]' medical records. I eventually had to go to a solicitor to help me. I now have them, but there are 38 blank pages and the notes are very vague for the details that I think should have been

included. It's taken me a long time to go through them, even for someone who's not been through what we have, it would be painful to go through medical records and try to figure them out but it was worse for us. For all the critical dates I'm trying to get information from, there's nothing I can take from them. From the information that is there, I don't know what a lot of it means but it doesn't say what I think it should. I think they are far from complete and I have challenged the records through my solicitor.

79. There must be records of blood tests [redacted] had and that is what I have asked to see. When I got a screenshot from Dr Maguire, that said that could not be tested because of the effects to his body, they are very intrusive tests. So in [redacted]' whole stay in hospital, they're saying that he was only tested twice or three times for gram A and gram B negative cultures. I think this is really bizarre and I think he should have been tested every few days or every week to see if he was reacting while staying in the hospital. I think it's a complete lapse of treatment that he was not tested for these cultures that went on to apparently have catastrophic results for these children. They are not divulging the records so I think one of two things must have happened: They did test him and he was found to have these infections because he was treated with the drugs or; the antifungals stopped these things from developing because he was already covered.

80. I have found out from [redacted]' medical records that he was prescribed Tazocin which I have found out is used to treat gram positive and gram negative bacterial infections. [redacted] was given this between 12 January and 15 January 2019 as well as Gentamicin, which is used to treat several different types of bacterial infections, on 12 January 2019 and January 13 2019. I wasn't told about any of these. On 15 February 2019 to 17 February 2019, [redacted] was given Tazocin again. This was in his medical records too. I wasn't told about this at the time.

PREVENTATIVE MEDICATION

81. [redacted]'s medical notes show that on 21 September 2018, co-trimoxizole was added to [redacted]'s treatment plan. I remember at the time he was given another medication and I asked the nurse what it was for but I was just told it was better he took it and it was now part of his treatment plan. I didn't question it as I trusted the staff. The information I was given at the time was vague. I was also shown by the nurses how to administer this to [redacted] through his feeding tube. It was later on when I was researching it, that I found it was used to stop the growth of bugs that cause infections.

82. Within [redacted]'s medical notes, there is also a letter from the pharmacy providing information about [redacted]'s antifungal medications. It's in relation to a prescription for posaconazole suspension 92 mg. The letter advises that was due to have vincristine chemotherapy on 4 January 2019 and to start the posaconazole on 6 January 2019 which would have been 48 hours after his chemotherapy began. He was then to start the vincristine with every course being administered at 21 day intervals, so the plan would be that he stopped posaconazole 48 hours pre and started it again 48 hours post vincristine.

83. I can see from [redacted]'s medical records that posaconazole was only given to him for seven or eight days but you can see from the letter from the pharmacy, he was on it as part of his treatment plan. The medical notes don't reflect it correctly; he was given it more times than has been recorded. I am currently challenging [redacted]'s medical records as I think they are incorrect and I don't think they show everything. [redacted] was on the posaconazole constantly from what I can recall and it was explained to me that it was part of his cancer treatment. I saw it being injected into him. I think the medical notes are only showing a three month period but they're

difficult to work your way through and read as they are out of order and only record partial information.

84. One of the other parents was telling me that her daughter had lost one third of her hearing in one of her ears. She said everyone should have a look at the impact of the prophylactic antibiotics so I started doing my own research too. Posaconazole is recommended for those aged 13 years or above and not for long term use, only as minimum use. I'm now wondering if [redacted]' leg muscles have been impacted by its use; he's also under audiology just now for his hearing although his hearing is showing to be normal at the moment. None of the side effects were ever explained to me at any point. I googled all the medications and got my information about them from there.

85. I remember asking one of the nurses about the posaconazole, how to administer it, and about the dosage he was receiving. Some of the nurses were pregnant and others were worried about their own health issues so I wondered if they were on it too. I asked one of the nurses in ward 6A if she was on it and she just smiled at me, but didn't answer. That was a common trait in a lot of the nurses. You could tell with their body language that they were uneasy when you asked them a question about the building or the medication.

86. I may have not been told that [redacted] was getting posaconazole. However, if I ever was, then it was not fully explained why and what the gravity of taking it would be. All we got was a generic handout put under the door to say that it was a medication that the children were going to be put on as protocol, it was better to be safe than sorry. The posaconazole probably did save his life and stopped him contracting some infections. I am complaining about protocols that the hospital implemented around this drug which resulted in [redacted] having to take it. I also feel torn about the fact

he was on it to begin with as I recognise that it saved his life, but he shouldn't have had to have been put on it to begin with. He should have been in a sterile safe environment.

87. We were told that [redacted] was given all these anti-fungals and prophylactics as a precaution. It was all about them only being given as a precaution in case anything should crop up and he was never in any danger, and lo and behold, what happens after the kids are all put on these medications; the whole place is condemned. So it was utter nonsense that they didn't expect anything to happen. It's like dealing with a snake, they gave the kids these anti-venom prophylactics but let them keep having all these bugs and bacteria attack them like snakes all the time. It doesn't make it right, giving them an anti-venom and letting the snake keep biting away at them. It's absurd and that's what they've done because in that environment it was all wrong. So they seem to think by giving them the prophylactics it made it acceptable.

OTHER ISSUES RELATING TO HOSPITAL CONSTRUCTION

Hospital build issues: impact of construction works

88. The area around the windows was really cold in the winter. You could leave your food there and it would be fresh to use the next day because of the chill. [redacted] used to like sitting at the windows looking at outside life and day dreaming about getting out of hospital. I had to stop him though as it was too cold for him. This was the same in both in the RHC and the adult's hospital.

89. In the summer, the windows had the opposite impact, the room would be really hot. There was an air-conditioner in the room that looked to be operated digitally, but you were too scared to turn it on due to the rumours

about the ventilation, such as dead pigeons being in the ventilation shafts. So you had to sit in the room with no air. There were rumours about a lot of things via both staff and other parents. I overheard two ladies talking one day when I was out for a walk in the hospital grounds and they were talking about the pigeons. Sometimes you would hear people talking about pigeon droppings but then people were saying there were dead pigeons in the ventilation not just pigeon droppings. The dead pigeons in the ventilation were causing the smell to go through the hospital and because you do see a lot of pigeons at the hospital, you think that's what caused some of the issues and nobody has told you anything about it. You believed the rumours as nobody has told you anything to dispel these rumours. I did ask what was happening with the ventilation, staff just said, "Don't worry, I'm sure it's only a precaution". They were referring to the air filters.

90. One of my mates worked on the hospital when it was being fitted. He said there was a high turnover of people working on it so that the building standards were poor. It was knocked together under pressure. There were rumours about things being wrong with the water at this point too. Nothing was done by the hospital to dispel any of the rumours so when you start seeing air filters coming in and filters on the taps, you believe the rumours.

91. When I had mentioned the silicone coming off the bathroom to another parent, they said to ask maintenance to fix it. I discovered though that the maintenance person on the ward tended to not fix things when I asked them and would avoid me afterwards.

92. The move to the adult's hospital impacted [redacted] and I as there were no facilities, but even to get to the ward, you had to go in via the main entrance where the main lift was and where people were standing smoking or other people were carrying out drug deals. You used to see them at the door exchanging money. We had to go through those people and if you asked

them to move, they wouldn't. Even the security guards wouldn't move them. Other parents would wrap their children up in their arms and try to get past. There were neutropenic children trying to get into the hospital, having to go through all these people smoking and then waiting 15 minutes on the lift. It was the only way to ward 6A though so you had to go that way.

93. To get to Day Care on ward 6A, you had to go right through the adult hospital and through ward 6A too as the Day Care ward was at the back of 6A. You had to pass members of the public who were in visiting so there were lots of people in the corridors coming in and out.

94. Air filters were placed in ward 6A after a short while of us being in there. There were industrial machines that are taken into your room on the ward. They're huge machines, not like a Dyson one you'd have in your living room. They were they the size of a mini fridge. Each individual room in the ward had at least one or two and in the corridors, there was one every five metres. The nurse's station had one too. They were standalone and they were on 24 hours a day. [redacted]. Having one of these in an enclosed space is more dangerous to the kids than it is without it because it's just recirculating things. They're just drawing in and it's recirculating again. It's blowing out the other end. They weren't attached to any kind of extraction system or anything. I don't ever remember any of the filters being changed or cleaned. I asked the nurses why we had to have them on if we have the air conditioning on. I was told it was a precaution as they thought infections had been brought in from the kids' hospital.

95. The noise from the air filters used to annoy [redacted]. He would ask for them to be turned off. Every little irritant annoyed him and got him grumpy because it was making him uncomfortable. Any acute smells or noises really got to him. [redacted] asked one of the nurses that came in if the air filter could be

turned off but she said they couldn't. I asked her if we could even turn it off for a couple of hours but she said they had been told to keep them on 24/7. We could have turned them off ourselves but we had been told not to. I thought the air conditioning was alright in ward 6A until all that carry on with the air filters started as well.

96. There was always something getting done to the hospital when we were there, even when [redacted] was discharged and was only attending his MRI appointments. I still witnessed windows being replaced. The fact all the work isn't finished yet; leaves you wondering what on earth is going on. Two years have passed and they still haven't fixed whatever is wrong.

Hospital build issues: impact on [redacted].

97. There were massive physical impacts on [redacted]. What was previously normal for him, he now had to be shielded from. It was stressed to you by staff that it won't be the treatment that will kill them, it will be an infection so this is a constant worry as the chemo leaves them with no immune system.

98. [redacted] couldn't get much exercise when we moved to the adult hospital and there was nowhere for them to play. He was bed bound and had to lie on his left hand side because of the trollies and his lines.

99. I think his development has been affected to an extent due to being kept in a room all the time and nowhere really to go for exercise. There's no fluidity with him when he's running. He can't run more than 100 metres and is slightly disjointed when he does run. His shoulders are forward because he was hunched for so long in his bed.

100. There were issues with the toilet seat in the en-suite bathroom we had in ward 2A and it wasn't fixed for a while. It was loose so I couldn't sit [redacted] on

it properly. He started going in his pull-ups so that he didn't have to use the toilet. This put him back a few steps regarding his toilet training.

CLEANLINESS

101. I had some issues with the cleanliness in ward 2A. The cleaner would use a dry mop. It was the same one the cleaner used for both the bathroom and the bedroom. I'm not sure what sort of products they were using to clean with but there were never any strong smells of chemicals. Any smells like that used to make [redacted] sick. I'm not sure if they were maybe using scent free detergent. The floor was never wet and slippery either. I think someone used to go in with the big mop and clean the floor properly if we were out of the room. Even after a shower, you would still feel dirty after walking just a few steps on the floor. There was high footfall and they just never felt clean. I would never let [redacted] play on the floor. I did raise this with the staff but there was never any improvement.

102. There was a wee white board on the back of the bathroom door a bit like the ones you see on public toilets to tell you when the toilets were last cleaned and who by. The one we had sat in a plastic pocket, but the same squiggle used to stay on it for days. Sometimes it would be removed and you would just be left with the plastic pocket. There was nothing filled out regularly as there is in other places like a shopping centre or a restaurant.

103. [redacted] was in nappies and pull up pants. I was putting these in a pedal bin within the room on ward 2A. The bin wasn't emptied regularly so it used to be full and the smell would hit you straight away. It would sometimes sit for a whole day. I didn't want to be a nuisance and ask the nurses to empty it though as they were busy enough so I brought in scented nappy sacks.

104. Sometimes we could have up to seven urine samples to be collected which would be lying on the bathroom floor. I spoke to nurses and cleaners about this. They would always say "Oh, God, I'm sorry. This should have been seen to". They would say they would make sure it didn't happen again but then it would just carry on the same way. You weren't angry at the nurses but you asked who you could speak to about it. When the cleaners with the green clothes came in, you didn't want to give them a hard time either as I understand that they have their own work remit. It's not like you're in a hotel and you're going down to complain about something not being right. I didn't want to be one of these people but eventually I had to say, "Look, this is not right". If it was a normal hospital and it was me that was in it, aye, fine. But not for a child that's neutropenic. Eventually you had to say something. There was one younger guy that was there the majority of the time and another lady but no matter how many times I raised it, there was no improvement.

OVERALL EMOTIONAL IMPACT ON [redacted] AND HIS FAMILY

Overall emotional impact on [redacted].

105. By keeping [redacted] in solitude in Ward 6A, away from the other kids, he was in solitary confinement. Apart from the kids that came to his door to say hi, he would only be seeing them in passing, whereas before in the children's hospital they could all play together and the parents could speak too. Because he couldn't mix with other children, particularly when he was in ward 6A, he has struggled at school in social settings. He's going into [redacted] and he finds it difficult to interact now because he's been used to being on his own for that length of time resulting in him going into himself. He was home schooled for part of the week and the school have been trying to help to get him mixing again.

106. When [redacted] was visiting my dad at my dad's house, my dad was getting a wet room installed. [redacted] wanted to come home as it was like the hospital bathroom. It's wee things like that, which will pop up every so often. I've tried to just let him be a little boy and if he brings anything up, then I reassure him.

107. [redacted] still sleeps with his back to the door. He's very wary of people now. In the hospital when my dad came to visit him, because my dad wouldn't take him home, it had a negative impact on their relationship.

108. When [redacted] stays with me now, he will not go into his own bed. He has to sleep with me. In the hospital, he had to sleep on his left hand side to avoid his line and he still sleeps that way.

109. When [redacted] has an MRI scan, I have to tell him the day before and bribe him to go. If I tell him any further in advance, he just won't go. He doesn't want to go back.

Overall emotional impact on witness

110. I found it hard to speak to anyone at the hospital as it was mainly mums that were staying there. Some of the nurses would ask how I was but I would just tell them I was fine. I couldn't say how I was feeling.

111. I have severe trust issues now because of the lies that have been told about the hospital and the fact that no one was answering the parent's questions.

112. The overall silence regarding the hospital has led me to being paranoid and having it all on your mind all the time is dangerous. It was a stressful

situation and it became as stressful as it was dealing with the cancer, which made it too much.

113. I have been attending CCLASP counselling sessions which were organised by the Edinburgh Hospital Charity. The counsellor thought I was maybe suffering from Post-Traumatic Stress Disorder (PTSD) after my experience at the hospital, everything that happened and the fear of relapsing.

114. I had to tell my work that I was getting contacted by reporters when the issues at the hospital started appearing in the media. [redacted]. [redacted]

115. I [redacted] now but due to everything that has gone on with the hospital, I have to stay in the background. It's left me too nervous.

<u>COMMUNICATION GENERAL</u>

116. When [redacted] was first admitted, I didn't take everything in that Doctor Sastry told us about his treatment. I had contacted his secretary at a later date and Doctor Sastry had a meeting with me to explain everything which was really good of him.

117. You would ask the nurses what was going and you would get the impression that you weren't getting the full story. The example about the water; they would offer that you can bath your child in sterile water but you never got any clear answers from them that there was anything wrong with the water.

118. Some of the nurses who were in [redacted]'s care team told me they were exhausted. They appeared to be doing a lot of extra tasks. Some of the other parents used to have the nurses doing everything for them rather than do certain tasks themselves. A lot of the nurses when we were in ward 2A said they'd rather be at Yorkhill and that didn't fill me full of confidence. They would be chatting when they were in our room and a few of the nurses would say it was awful here, take us back to Yorkhill. They just didn't have a good feeling about the place and didn't like the new hospital. They wouldn't expand into why not.

119. Nurses maybe felt they couldn't stand up to the Board, even with their Union Reps. It's as if no one is willing to speak out. Like a lot of the parents, they're worried to go against the Establishment. I wonder if the nurses didn't know either or whether they were just scared for their jobs, scared that they won't work for the NHS again, never mind in the QEUH.

120. There were never any regular planned maintenance checks so when you needed something done in the bedroom, you had to speak to the nurses. The nurses were often really busy so when you asked them for something and an alarm went off, they would run to see what it was then forget to come back and speak to you or you were told someone would come and speak to you later but they never did.

121. I wasn't told everything about all the environmental preventative medication either. I was told that posaconazole was part of his chemotherapy treatment plan. I signed a consent form at the beginning of his treatment but that was from the information that this was for his cancer treatment. There were a couple of references to posaconazole in [redacted]'s medical notes. I can only remember being told that it was being brought in as part of the treatment plan and it was better for [redacted] to have it than not as it would protect him from infections but they didn't go into details about

the infections or where they were sourced from. I think this was on ward 6A and it was one of the nurses on duty who told me this. I just accepted what they told us at the time as we didn't know any better and [redacted] being put on them was to us a good thing.

122. There was a photocopied note, a flyer, put under the door that the hospital were taking measures regarding the things reported in the news and that was to reassure everyone but nobody said what the exact issues were or what the measures were either. I threw the note away. I think the note mentioned that patients were being treated with posaconazole. I asked staff what this meant and was told someone would come in and speak to me but nobody ever did.

123. On 19 September 2018, one of my friends text me to say they were closing the RHC due to wide spread infections. My friend had said it had been on the news but I knew nothing about it. I fell out with a lot of people at that time because I accused them of rumour-mongering. I said. "I'm fed up with all these rumours. I'm here and I'm trusting these people. They would have told me if there was anything going to put [redacted] in jeopardy." I did lose a lot of friends over this and all they were doing was telling me what was on the news. People believe the news. I asked some of the nurses and other parents about it but nobody knew anything. Eventually I was told by one of the nurses that someone would come and speak to me and that's all I was told. Nobody came to see me though.

124. Dr Sastry and one of the nurses came to see me in [redacted]'s room on 13 January 2019. Dr Sastry explained that there were certain things going on in the hospital and that they had been in the news. He said this meeting was to reassure me that everything is still being done for [redacted]'s care. There were things that he didn't even know that were happening but just to be rest assured that he and the nurses were doing their best for [redacted]. I can't

remember all the details. I was left assured that there was a level of care being given to [redacted] but there was nothing about the building or anything. Just reassurance on the level of care.

COMPLAINTS

125. I raised several complaints but the only written one I raised was straight to Jeane Freeman. I emailed her on 11 January 2019 and asked her to tell me what was happening with the hospital. I got a reply the same day saying she was going to ask for an update from her Senior Advisor. Surely she shouldn't have had to ask for an update when she was the Health Secretary? I never got an update and when I asked for meetings with her, I've heard nothing back.

126. When I realised that the medical records that I had been sent were incomplete, I complained to the board again and to the Case Note Review and they sent me through some screenshots of certain things that happened. The medical records were set out in a way that only a medical professional would understand. It made it difficult for me to decipher what had happened. I thought, if they can give me screenshots, what else is there, where is the evidence? There must be a record of his bloods, his urine, what he had infection-wise. I think I have copies of these.

127. I raised the environment issues and the closure of the ward with my local MSPs and MPs, Maurice Corry and Brendan O'Hara, who was the SNP one. Brendan came back to say his assistant will look into things and get back to me, but no one ever did. Maurice just wanted a photo opportunity and he declined to help when I said no.

128. My local Argyll and Bute councillor, was really good too when I raised the issues with him. He was really supportive but as I knew him, he couldn't

take on a personal case. He was going to make sure there was pipeline open to discuss things though but by that time, Jennifer Haynes who was liaison with the hospital had all been in contact with me to give me direct correspondence. After the response I got from Jonathan Best, I've not bothered to respond as I don't know how to. I've got no faith in opening up a line of dialogue with the hospital.

129. I spoke to the labour MSP Monica Lennon on 5 December 2019 about the environmental issues and the ward closure and she was the best one I dealt with. She invited me to Parliament on 10 December 2019, to the public gallery to listen to Jeane Freeman speak about issues surrounding the hospital. All she said was that the Health Board was being investigated, that the Health Board was going to be overseen by another board. She didn't even say anything about the matter, again. I'm disappointed that Jeane Freeman has said to trust the nurses and the processes. If those people we have on the Health Board are the best we have and you can't replace them, then there's no point in Scotland going for Independence. I've not got any faith in any of them now. I feel palmed off.

130. Before I went to Parliament on 10 December, I met Monica Lennon at Anas Sarwar's office in Glasgow. I think there were about 12 other families there. This is when we first saw the whistle-blower documents that were given to Anas Sarwar. He reached out to the families involved when he got hold of the documents and then I think one of Monica Lennon's constituents asked her to intervene and that is when the parliamentary stuff happened with Jeane Freeman. I don't know if the information he gave us has been made public but it's damning of the whole hospital and about records that completely disappeared from the health board computers.

131. I wrote to Jonathan Best, who is the Chief Operating Officer at NHS Greater Glasgow and Clyde, on 6 January 2020 about the secret use of prophylactics and other environmental issues. He wrote back to me and said that the first they were aware of any issues in the wards was in 2018. He said that when the hospital first opened in 2015, there was no indication of infections out with the normal realms of what you would expect to see. I believe the other independent review that looked at the issues further back than what Michael Stevens did, shows a different version of events though as there was a spike in infections in 2018 in ward 2A of the RHC and on testing the environment and the water, they found organisms that can potentially cause infections in the water supply. Mr Best told me the first indication they had that there was anything wrong in the hospital was in 2018. That's what I have in a letter from him. I think he was trying to hoodwink me as he failed to mention the evidence from the whistle blowers that Anas Sarwar shared with the parents. Mr Sarwar also told us that senior clinicians made wrong decisions prior to the closure of RHC. Apparently there was paper work showing that issues had been raised in 2015 about the hospital but it was still signed off. How can Jonathan Best assure me [redacted] didn't have a hospital acquired infection when what I witnessed says otherwise? It is difficult to expand upon this as I don't have a full set of medical records to refer to.

132. When I got Mr Best's response, alarm bells were ringing. He said [redacted] did not have any hospital acquired infections. He was quite categorical about that, but I don't know how he can say that categorically when the blood records are not there that show if he had infections or not. He stated in his letter that he was alarmed to read my concerns about [redacted] being put on prophylactics secretly and that families should have been spoken to by whoever was with the child at the time. He said all the parents were spoken to about the use of prophylactics and he was sorry for the concern and worry this had caused. He went on to explain that no patient should be

placed on medication secretly and that all families were spoken to about the appropriate use of the medication. Regular discussions were taking place and we were given a letter. I know the letter he means; it was the photocopied one about the use of prophylactics but I can't remember the exact content.

133. I also asked Johnathan Best for evidence [redacted] didn't have a hospital acquired infection but I haven't had anything back. I've stopped engaging with the Health Board. If they were carrying out testing on [redacted] for this, I wasn't aware of it so they should be able to provide his test results. I think it would be good for the kids any way to be tested for certain infections when they are due to be discharged so the parents know they're safe and what to look out for.

134. I asked an independent company to come in and test the water for me. They told me on the phone that they couldn't because there was a conflict of interest. They also told me that the NHS had the best infection controls and that the NHS was the best at testing for bacteria disorders in the water.

135. I saw Jane Grant, the Chief Executive, at the hospital on one occasion. Her and another two people in suits. I approached them and asked them about the issues with the hospital. They looked at me as if I was begging in the street and asking them for money. She didn't answer me and walked away. Now look at her on the TV, no compassion, nothing.

OVERSIGHT BOARD / CASE NOTE REVIEW / REPRESENTATIVE GROUPS

136. [redacted] was not involved in the Case Note Review. I don't know how it was decided that [redacted] wasn't part of the Case Note Review. What if [redacted] had been put on antibiotics before the blood tests had been carried out so any

bacteria didn't get the chance to grow? I don't think anyone can prove didn't have a hospital acquired infection.

137. I wrote to Professor Stevens on 27 May 2021 asking him three questions; here is a bit of what I said:

"Can the following questions be answered and backed up with hard, factual evidence, please? Number one, what were the actual testing procedures used to determine any daily infection or indeed as you say, for his non-infection as you claim in your last email and what was the frequency of this testing throughout his and indeed our own hospital stay? Number two, when was the testing regime changed to account for impending possibly infected due to other unexpected variables in the water, air or structural inadequacies presenting a danger to my son? Was testing changed after the deaths and serious illness of other children? Why wasn't I told by the hospital first that we should be extra vigilant in caring for our children instead of by the news? Three; many of the different strains of bacteria and other dangers came to light afterwards when the review published its findings. Can you tell me what actual bacteria strain or any other found anomalies my son had been tested against? All I was told about the showers was possible E. coli risk and is it not possibly a new strain was developing all the time until we were moved out of the condemned wards in the children's hospital? If he wasn't in any danger or didn't have any infection, why was he moved to the adult wing when the ward was deemed unfit?" So I've gone on like that. I can't read it all out but I'll send it to you.

138. Professor Stevens told me that Professor White would explain everything to me and that's when Professor White got Dr McGuire, who I didn't know, to go over the medical records with me. She also sent me two screen shots of [redacted]'s blood samples that I'd asked for. That's the only records of blood tests that they have for him. I asked my solicitor how to reply to them. Why are these blood tests not contained in [redacted] records?

139. I think Craig White was just trying to keep the peace so I wouldn't speak to the Inquiry. I think Craig White was appalling. His whole approach to the inquiry, the Board, meeting with families, I don't think he's reflected accurately on all of it. It's as if he's reading off a sheet. He's recommending who I speak to. They apologise for what's happened, so to me that's an admission of guilt but at the same time, they should just come out and say what's actually happened because they're saying sorry but they're not really sorry. The distress wasn't our fault. Somebody's got to take responsibility here and that goes for Craig White and Jane Grant.

140. I did ask Professor White for [redacted]'s individual medical records and he said I'd have to write away for them as per the process. I'd originally thought that when he became involved and was one of the 'big guns', that we'd be taken seriously and get answers. He's just been a puppet though. He's passes the buck.

141. I was involved with the Oversight Board but eventually these groups all roll into one and become the same thing. I did think it was effective but I think a lot of people are scared to show their hand and come forward with information while the Inquiry is going on. One of the other girl's dads is really good at getting answers from them. He's experienced in this kind of stuff and he was getting answers to some of the questions. In fact, the questions you're asking me just now, I've been asked those already by that girl's dad.

142. I'm involved with a number of groups and sub groups. I get all the notifications when there are updates. There's so many of them now. Some parents speak independently but we decided it would be better if we formed a group and discuss everything as a unit with Professor White. We felt stronger together and we might get more answers and get taken seriously as there would be less chance people could brush us off.

143. There was one lady that was very good. She was the Nursing Officer but she stood down. She was really good and you could speak to her. She was the only one I felt gave sympathy to what was going on and she didn't speak in official terms. They'd have been better having someone that knew what was going on rather than Professor Craig White's nonsense.

144. I am a member of the parents closed Facebook Group and I feel that's really a really good help. There's support available for anyone struggling. There's lot of rumours appear on it but they have someone, professional people that answer those and give you the facts.

145. I was a member of the Schiehallion Unit Support Group. It's a closed Facebook group that has been set up by parents themselves that have been involved with the Beatson or the Schiehallion ward. This group was outstanding and I got to know one of the ladies that runs it quite well. It was good for sharing information and also if you needed to offload anything on your mind. It was set up for new parents coming in and finding themselves in the same situation. At the start, you're lost and this group tells you what you need to know and what you need to do. I'd say this group was essential. If it wasn't for these groups, a lot of the parents would be left high and dry a long time ago. It's been a lifeline for us. You could also offer to help each other with shopping. It's been taken up a bit by the Inquiry though and new parents are now reading the information and that's scaring them so they're asking questions rather than being reassured.

CONCLUDING COMMENTS

146. The fact that is has taken two years to sort two wards is concerning me. The cinema is still closed and there's a vast amount of space that has all

been neglected. Something is going on. It can't just be that one section that has been condemned.

147. I think the smell from the carpark is the bullshit coming from the Health Board's offices. I have absolutely nothing positive to say about the Health Board.

148. I would like to thank [redacted]'s medical team, especially Doctor Sastry, [redacted]' consultant. I am so grateful to him for giving [redacted] the scan on 19 August 2018. He told me if we had waited another two weeks, the normal time, then the tumour would have been all through [redacted]'s eyes and nose and that would have been him. He saved my son. He's God in my eyes and can't do anything wrong. I trust him with everything. I had really good relationships with [redacted]' doctors. We were fortunate enough that ours were good. I know some of the other parents didn't get on with their consultants.

149. I noticed when I attended the hospital with [redacted] for a follow up MRI scan, that due to Covid, people were no longer allowed to congregate and smoke at the main entrance. The hospital is now taking the infection risks seriously as a result of Covid-19 but when there was a risk to child cancer patients relating to infections, they didn't.

150. As far as I'm concerned, there's people at the very top of the government who knew about the issues with the water. I'm not making direct accusations however the impression I am left with is that the First Minister of Scotland can't give straight answers. She must have seen the documents. The hand over and process have been done as there's been pressure to get SNP's flagship hospital open.

151. Due to the type of cancer [redacted] had, if he relapses, that's it for him. I don't want him dying in that place. The environment isn't clinically fit for children.

152. There are a few children no longer with us and those children were heroes. They were the ones that [redacted] and so many others going through treatment, looked up to. They did so much for the children following behind in their treatment and who have been more fortunate.

153. [redacted] sometimes mentions other kids he met on the wards. He asks if we can have them up to play. Some of these kids aren’t here anymore, how do you tell a 4-year-old that these kids have died? How do you tell him the wee girl he was friends with died of an infection? It’s heart-breaking. Sometimes I’ve just told [redacted] that they’re on holiday as you can’t tell a 4 year old their friend has died.

154. 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.