# Scottish Hospitals Inquiry

Witness Statement of

**Christine Horne**

## WITNESS DETAILS

1. My name is Christine Horne. I was born on [redacted] . I will be [redacted] years old in about 2 weeks. I am a [redacted].

2. I am the mother of Kimberly Darroch and grandmother of [redacted]. [redacted]'s date of birth is [redacted] . [redacted] passed away on [redacted].

3. I live with my husband, Derek Horne in [redacted].

## OVERVIEW

4. My Grand-daughter is [redacted] [redacted]. [redacted] was diagnosed with Acute Lymphoblastic Leukaemia in 2012 (ALL) when she was 5 years old. After two and a half years of treatment, [redacted] went into remission. [redacted] then relapsed in January 2017 when she was 9 years old. [redacted] was treated at the Royal Hospital for Children (RHC). She attended the hospital as an in-patient and as an out-patient although it was mostly as an in-patient.

5. [redacted] spent time in ward 2A, which was known as the Schiehallion unit, of the RHC. She received treatment from January 2017 and had a successful bone marrow transplant on 15 June 2017. On or around 5 August 2017 was admitted to PICU in the RHC for six weeks, due to an infection, which we now know was connected to the water supply at the hospital. passed away at 3am on 31 August 2017, aged 10 years old.

6. I was with [redacted] during some of her admission and can speak of the experiences which my family and I had on these wards of Yorkhill Hospital and RHC/QEUH.

## FAMILY BACKGROUND

7. I live with my husband, Derek Horne in [redacted]. We are [redacted]'s grandparents.

8. [redacted] loved animals. She wasn't a girly girl and played in the garden with all sorts of insects and loved doing that. She had her own wee bit in the garden and she would collect snails and name them.

9. [redacted] loved climbing. If she went on holiday, she would find somewhere to climb. At the caravan site, Haggerston Castle, when Kimberly took her, had talked me into letting her go on this climbing thing that was really, really high. She promised me she would only go halfway and I should have known better! I had to walk away and leave her mum watching her because I couldn't watch it any further; half way wasn't enough for her and she just kept going and going to the top. She was such a tomboy. Climbing was definitely her thing. She loved football too but she wasn't very good at it.

10. [redacted] usually stayed with us a couple of times a week. She was always here one night at the weekend. Whenever she came, she would stay for the night. We had midnight feasts and watched television until midnight. She made me watch all of the Disney films, but she would watch anything, even films you wouldn't think a girl would watch; spy films, Jaws, everything. She watched anything to do with an animal, it didn't matter what kind of animal it was. There was Jurassic Park too. It didn't matter how scary a film was. We usually sat up late at night.

11. [redacted] could give you the look, the "[redacted] look", if she wasn't happy with you. She didn't have to say anything, you just got the look. She was very witty too. We miss her very much. We miss her terribly.

### [redacted]'s experience in Yorkhill: 2012-2015

12. [redacted] had previously had treatment for ALL. In September 2012 Kimberly took [redacted] to Wishaw General a few times as she had a really sore leg but the hospital kept putting it down to growing pains. It got to the stage where she was having to get carried everywhere as she just couldn't move her leg. Then Kimberly phoned me one morning and said that [redacted] had come out in wee spots on her neck. I told her we should bypass Wishaw and go to Yorkhill. Kimberly's sister had leukaemia when she was younger so we had experience of it. Nothing was getting better with [redacted] and now there were more symptoms so we went to the old Yorkhill, through their A&E department. When Kimberly was out of the room I said to the staff that [redacted]'s aunt had had leukaemia and I had my suspicions that [redacted] might too, but I hoped it wasn't.

13. [redacted] had some tests carried out which confirmed that she had leukaemia and she was admitted to the Schiehallion unit in Yorkhill. [redacted] then underwent chemotherapy treatment and after two and a half years she went into remission in 2015.

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

### Admission to Ward 2A (Schiehallion) at RHC: January 2017

14. [redacted] relapsed with ALL in January 2017 when she was 9 years old. had been in remission for just over two years I think. She had been in the hospital for a check-up in December 2016 around Christmas time, and everything was okay but obviously acute things can come on very quickly. It's not that anything was missed in December. It's just that it comes on so quickly. [redacted] was fine at Christmas but just after it, she had started to take headaches and she had a nosebleed. Kimberly took her to the doctors, but the doctor just said she was probably like every other child having colds and whatnot.

15. On 19 January 2017, which was a Sunday, we decided that we would just take [redacted] straight back into what was the new Yorkhill, which is the RHC, to have her checked again for our own peace of mind. We went in through A&E of RHC and then were taken to the triage.

16. Staff took blood tests. Dr Gibson, [redacted]'s Consultant, came down that night, at about six o'clock I think, and told us that she thought the leukaemia was back. She wanted [redacted] to stay in that night but we didn't have anything with us. We asked if we could just go home and be back for seven o'clock the next morning because she was going to go to theatre. We contacted [redacted]'s dad and he wanted to be there, we couldn't stay there without him. So we went home that night and we picked [redacted]'s dad up in the morning of 16 January 2017 and headed back to the hospital.

17. [redacted] went to theatre for a lumbar puncture and this confirmed that the leukaemia was back and she was admitted to ward 2A, or the Schiehallion ward as I call it, that same day.

**Description of Ward 2A**

18. The RHC was a super hospital. It was a big hospital and it was absolutely beautiful. Inside they had loads of things for kids to do. This was at the front entrance of the hospital building. There were lots of things for kids to do while they were waiting for clinic. There were novelty mirrors which made you look much bigger or much smaller and there was a ball game. On the ward, the bedrooms were a good size. They were bigger than the Yorkhill ones and they had the fold down bed, so you weren't squeezed in as much.

19. Down the right hand side of ward 2A were the transplant rooms. I can't remember how many transplant rooms there were. There were two in the old Yorkhill but I think there might have been four in ward 2A. They're maybe a little bit bigger than the usual bedrooms and they have filtered air. There is the bedroom where [redacted] would be in her bed and then the parent bed as you are still allowed to stay with them. There is a door from the

bedroom into an outer room with a big sink and the medicine cabinets. There's a stand because you've got to put your coat on as you can't walk into the bedroom with your outdoor coat on. Your shoes have to be changed and you've got to scrub up. There is then a door from this outer room onto the ward. If the door from the bedroom to the outer room is open, then you can't open the door that goes onto the ward. You would have to wait until the bedroom door was closed. It's like an airlock. The cleaners go in and they clean the room before you move into it. I think it's a spray or something like that and then you are allowed to go into that room.

20. Anything that was brought in to the transplant room had to be brand new in packaging. It had to be wiped down and opened and then [redacted] had to pull it out so that she wasn't actually touching the packaging. That outer room was where you did all that before you went in to the actual bedroom. That's the difference; in the normal bedrooms on the ward you went straight in from the ward, there was no outer room.

21. There were no windows open; you can't open them in any of the bedrooms. You're not allowed to. If you're in for transplant, the whole room is air filtered and it's supposed to be a certain air that goes in and out. When [redacted] was in one of the transplant rooms she was moved and I remember wondering at the time why she was getting moved. You do not go to the transplant room until you are ready for the transplant treatment. You are only in the room a few days before it. When you're in a room to get a transplant you're meant to stay in the same room. She was moved to another transplant room just up from the one she was in and that was where she stayed until she was moved to PICU. I don't know why she was moved or if it was before or after her transplant.

22. Back 30 years ago, when my daughter was going through a bone marrow transplant, she was never allowed to be moved. They said once she went into a room, you had to stay in that room. One of us would be in and gowned up to deal with her. Before you entered the room, you had to

change your shoes and make sure you were scrubbed up. It was infection control. To take [redacted] out of that room and put her in another room, I always thought that was quite odd but then, I had to say to myself that maybe things have changed in the 30 years since my daughter went through it. Looking back now, I think there was maybe something wrong with the room [redacted] was in but they didn't tell us that.

23. After the transplant rooms, you had rooms to the side where you took the toilet and things, yucky things, like bedpans. And then there was the laundry room and after that there was the desk where nurses sat. When was well enough she actually sat with the nurses at night. There was a wee nurses bit outside [redacted]'s room too. It was a wee box thing that came in front of her room. We never went past this because that was the teenage area.

24. There were bedrooms on both sides of the ward and because of the layout of the hospital building, rooms on one side of the ward would have a view looking into the atrium, and the rooms on the other side of the ward would have an outside view; you would look out and see people coming in and out of the hospital entrance. The outside view was better. Kids with leukaemia and tumours do spend quite a lot of time in their bed. You're there with them 24/7 whether you're sleeping or not, in case they wake up. So it was good to have something to look out to.

25. If you were on the other side, then you were looking out to the outside doors and could see people coming in and out and you could see the car park. There was a smell on that side, a sewage smell. I thought that it would be really bad in the height of summer but I got used to it if I'm being honest. I don't know where this smell was coming from. You couldn't open the windows in the rooms so I don't know if it was coming from outside or from inside.

26. I never really passed [redacted]'s door. One time I took her up to the teenage area as she was desperate to see what the teenagers had. They had

everything that she didn’t. They had their computers and everything all set out and they had a great big room to be in. I took her up to see it but that’s the only time I was up there. Most of the time we were in [redacted]’s room. I can’t recall any of the numbers of the rooms that [redacted] was in.

**Facilities**

27. There was a playroom on the same side as the transplant rooms. I always felt that they didn’t actually accommodate [redacted]’s age. They accommodated for younger ones, up to maybe seven years old, in the wee playroom. They had their play lady and their wee arts and crafts things. Things that the younger ones could do. But nothing that [redacted] would want to do. She was nine, she was nearly ten. I don’t think they’ve accommodated for that age group, from your eight-year-old to your 13-year-old. They had the teenage unit and I know that money had been raised and that’s why they had the teenage bit.

28. To me, eight to 13 is quite a difficult age and it should maybe have been accommodated; that’s the scared age. Up to the age of seven, the mum, gran, papa, they’re the ones that know everything. Then they get to 13 and think they know everything. You then have your eight to 13 year olds where something big has happened to them and they’re taken away from their family and friends. They’re taken away from school and they’re scared. Schiehallion really didn’t accommodate them. So the parents try and deal with the kids. We could with [redacted], she would listen. She would take it all in. But there should have been more things there for her and people going in to speak to her more about what was happening. To me, that is a really, really hard age. It was a fantastic hospital but they hadn’t thought about this middle age group. That’s quite a scary thing they’re going through. You could see it in [redacted]’s eyes that she was scared.

29. There wasn’t much for her to do, so we entertained [redacted]. We played monopoly and other games. We watched films. We asked if we could have a PlayStation and we got one so I went out and bought her some games for it. She had her iPad which she was on quite a lot. We could sit up until

midnight playing monopoly. It was her game. She loved monopoly. Everything worked in the room: the TV and the Wi-Fi.

30. We never wandered up and down the ward. It wasn't quite like Yorkhill where they would go out and play in the corridors. Some of the kids did go up and down on the wee toys. I saw this in Yorkhill hospital and RHC but I saw this more frequently at Yorkhill. I agree that it's best to have kids in their own rooms but I also think if they're well enough and they've not got an infection then they should have had another bit to mingle and play in.

31. To be honest, you didn't really mix and see everybody that was in the rooms in ward 2A. The old Yorkhill had a sitting room. Parents would maybe sit in there, and they had a wee kitchen as well. So you could go and make yourself a cup of tea if somebody else was in visiting [redacted] and you could sit in the sitting room. In ward 2A they only had a kitchen area that wasn't really that big. It did have a couch in it but it was a bit wee if somebody was in using the microwave and the fridges. There wasn't anywhere else to go in the ward. You could go downstairs to the canteen but that was away from the ward and away from [redacted] for too long.

32. The kitchen area would have been okay if you'd had another bit to go and sit. Some families came in to see their kids and they would quite like to sit together and eat. If they were there, then that was the room taken up and there was no room for anyone else. I'm not knocking anyone for this as this is what they wanted to do. It did mean that, if someone was in to see and you were trying to disappear from a while, you couldn't sit in the kitchen and watch other people eating so you just had to wander around the ground floor.

### Staffing

33. The nursing staff were lovely on ward 2A. I actually can't say anything about the nursing staff. [redacted] loved some of them, and she had her favourites. They had a way of working with her. They actually got the gist

of her. They knew how much pain she could handle and when she wasn't able to take anymore.

34. [redacted] was getting laser treatment on her mouth ulcers because it was really, really bad and it was incredibly painful. She was feeling really crap. I spoke to the doctor who was doing the laser treatment, and told her that if she had a dog she should talk to [redacted] about that and she would have a friend for life. The doctor did this and she was fantastic. After that they would always talk about the dog. It was just the simple things like this that could make it so much easier because [redacted] actually trusted her then.

### Protocols

35. There were special protocols in place if [redacted] was in the transplant room that I have already described, and, as far as I know there were protocols in place for infections more generally on the ward. There was always supposed to be barrier nursing if there's infection. But obviously nurses go in and out rooms. That's a hard one to call, to be honest with you, because while you're coming in and out of rooms you don't actually see if the nurses have gone and scrubbed. They'll come and wash their hands but you don't know if they're dealing with somebody else that's maybe had another infection. It wasn't as good as Yorkhill. No one had any masks on, and the cleaners and nurses would come in and out of the rooms. No one was wearing gowns. That was the main difference we saw between Yorkhill and the new hospital. The first month [redacted] was in Yorkhill, everybody was gowning up. We didn't see this as much at the new place.

### [redacted]'s Initial Treatment: January 2017 – June 2017

36. [redacted] had chemo again and they did bone marrow tests throughout her chemo. It was maybe April, when the doctors said that [redacted] would need a transplant as the leukaemia just wasn't going into remission the way they were hoping.

37. When we were told in the April that [redacted] would need a transplant, the doctors started the process of looking for a donor and they found a really,

really good match. She was getting the transplant on 15 June 2017 and she started her conditioning for her transplant on 4 June 2017. This happens two weeks before the transplant because it floors you. The chemo is so severe that it takes away all your immunity. [redacted] also had to get radium treatment at that point too so she was sent over to the Beatson for that from the Schiehallion. She went there twice a day for about ten days for this treatment. She would get picked up in a taxi and taken between Schiehallion and the Beatson. [redacted] had to go to the Beatson Hospital for radiotherapy treatment. They did not have the facilities for this at the new hospital. The Beatson Hospital is another adult's hospital in Glasgow. It is a 20 minute taxi drive from QEUH.

38. [redacted]'s transplant was on 15 June 2017. She had done really well and fought all the way. She had a sore mouth because of the treatment and struggled with eating though. These are all the normal things that we've gone through before with both [redacted] and my daughter and it was always a battle to get them to eat and drink things. My daughter never had a feeding tube, but [redacted] did. [redacted] didn't want the feeding tube; she didn't like it. She was just like every other child. They fight these things.

39. [redacted] was quite poorly for a couple of weeks because she had no immunity but Kimberly did everything by the book. [redacted] was showered. Her bed was changed daily. Kimberly took in her own bedding. It was all brand new and was done the way it should have been done. The only thing they really used was the hospital sheets and a couple of pillow cases. Everything else, she took in herself. She made sure everything was super clean. We had to go and buy new shoes; you had to change your shoes before you went in her transplant room. We kept ones that we could wear in the room. We made sure we had everything as you weren't allowed to wear your outdoor things into a transplant room.

40. [redacted]'s transplant seemed to be working and some of her levels were coming up really well. This included her blood levels and white cell count. We started to go out for a wee while because her levels were improved. I

can't recall how long after her transplant she was allowed out of her room. It started off we just went round the hospital grounds and I took her round the back bit where there was a wee park where she could see her mum drive out of the multi-storey car park to wave to her as she left the hospital. Then we could go to Braehead Shopping Centre and then she was getting home for two hours. Everything was positive. Her eating and drinking still wasn't good but everything else was positive. We went on holiday expecting [redacted] to be home by the time we got back but obviously that wasn't the case.

### [redacted]'s admission and time in PICU: July 2017 – 31 August 2017

41. We were away on holiday in July 2017 and Kimberly told us when we were away that [redacted] had been saying for a couple of days that her Hickman line was sore. She wasn't really one for complaining so I think the doctors should have listened to that. They did eventually say that they were taking her down to theatre to take the line out. Kimberly phoned to say that she was going down to theatre and they were going to check her tummy at the same time because she'd had quite a bit of diarrhoea. Then she phoned us to tell us that the line was out and [redacted] had gone into septic shock.

42. I think it was a septic shower that the doctors called it but we had spoken to [redacted] and she sounded okay. By the time we came back from our holidays, I went straight in to see [redacted] and her breathing was not good then. Her colour was not good. She did not have a lot of energy. She was lethargic. She had no line in. She had the one cannula in her hand but not what she normally had. She normally had a line in her chest. It could be put on either side of the chest. I think it's called a Hickman Line, that's what it was called when my daughter had one. So it sticks in my head that it was a Hickman Line and that had been taken out.

43. I asked Kimberly when the Hickman line would be getting put back in and Kimberly said that will maybe be a week or two before they can put it back in. I can always remember when my other daughter was in, if they took the line out from one side because there was an infection, they had to put it in

the other side so it went straight back in. That wasn't happening and I thought maybe things are different now and obviously our trust was in the doctors. So I thought it was fine. [redacted] just had her cannula in her hand at this point.

44. At this point [redacted] just kept going downhill. I remember thinking she should be in ICU and I think she went too late. I might be wrong but I thought she should have been in ICU. The Schiehallion staff would come into [redacted]'s room to take her blood pressure and I would say to them she was poorly They were sending requests for ICU doctors who were coming up, but nobody was doing anything about getting a line in her and giving her more antibiotics, or whatever she needed. I didn't say anything to the doctors as you just trust that they are making the right decisions, but things just went from bad to worse. [redacted] did not have a Hickman line in. The patients get all of their medication through their Hickman line. She only had a cannula. A cannula can break down the vein more easily. When that happens, another cannula has to be inserted into another vein. It is not pleasant for the patient having to have multiple cannulas. All of the kids get Hickman lines for cancer treatment. Once the Hickman line is in it does not come out again, unless it gets infected. They don't need to get jags when they have a Hickman line in like they do with a cannula. They go to theatre for a Hickman line to be fitted. With a cannula they just apply some cream to the skin before it is fitted. A cannula is not as secure as a Hickman line.

45. Eventually [redacted] was admitted to PICU early August 2017. I think her dad was with her when it happened and a nurse or doctor had come into the room and had seen [redacted] going to the toilet and her lips were blue and that was when the decision was made that she had to go to PICU. That had been happening quite a few times. [redacted] had been struggling to get to the toilet and walk back. Her chest was sore as she was really struggling to breath, and she was having to have oxygen on her when she was sleeping. That's why I think they were too late in moving [redacted] into PICU.

46. Once [redacted] was in PICU things just deteriorated and she was on a ventilator within a couple of days. Kimberly wasn't actually there when the doctors came to tell me and [redacted]'s dad that they wanted to ventilate her. We had to phone Kimberly and tell her to come straightaway so she could spend some time with [redacted] before they put her to sleep.

47. I told [redacted], that she was being put to sleep as all her veins were gone and it would be easier for her when they would be putting in the cannula so that she wouldn't feel it. She did not know she was being ventilated. Only her mum and dad and me got to speak to her before she was put to sleep. It was just heart-breaking. She never got to speak to her brother or any other members of the family. She was sedated from that point until she passed away.

48. That day, we asked how long she would be ventilated for because she wasn't able to communicate in any way and we were told by the doctors that they weren't sure, maybe a few days. Then she was on all these other different machines, one that shook her all the time. She was on one that I think is called an ECMO machine and then there's one that's trying to hoover all the infection and mucus out. It's a very deep suction and they're put on a board thing and it just shakes and rattles all the time. The physios were coming in too. She was also on a kidney dialysis machine. They were trying different things.

49. The nurses kept saying to us, "She'll be fine." They said that the ECMO machine was wonderful and that everybody's that's on it, comes out of it. They're the doctors. They're the professionals and we were emotionally involved. You don't always see the bigger picture. You just think she'll be okay. We were being given hope that she would pull through. Looking back the doctors were probably admitting that things might not go the way we were all hoping but no one ever said that at the time.

50. [redacted] had been on the ECMO machine for the maximum number of days. There's only so long you can go on that. I think it's 21 days. Staff were

talking about giving her a heart transplant down south but she would never have been able to go anywhere for a heart transplant. I don't even know why staff were saying that but they did try to take her off the ECMO. There's something I think they do before she would be off it altogether so they tried to take her off it for a couple of hours and I think she did actually manage to breathe, but the mucus in her lungs just kept coming back. The doctors tried absolutely everything but none of it worked. Every part of her body was failing.

51. At one point, Derek and Kimberly were called into a side room with Professor Gibson and a consultant. They told Derek and Kimberly that was a very sick girl. We all knew that though. I think this was later on in the August when [redacted] was still in PICU.

52. We tried to go to the hospital as often as possible but we also had to ensure [redacted] was looked after. I stayed with Kimberly a couple of times as she wasn't really leaving the hospital at all at this point. After she had been ventilated, [redacted] was sedated the whole time until she passed away, but there was always someone with her and we kept talking to her.

53. On the night that [redacted] passed away, Kimberly had come home for her tea and was going to go straight back in. [redacted]'s dad was with [redacted]. He phoned to say they think there's a bleed on [redacted]'s brain. I think she actually died at that point if I'm being totally honest. Me, Kimberly and [redacted]'s dad headed back in.

54. Her aunty on her dad's side drove up from Leicester to see her but she didn't make it in time. We'd gone in and so had her other gran and papa so we could say bye. The specialist doctor to turn off the machine was supposed to come, I think around midnight, but we were told by another doctor who was present, that there was an emergency which is understandable. It was three o'clock in the morning when the specialist doctor we had never met before, came in and turned the machine off. I

think [redacted] was away earlier than that, but once the machine was turned off she just passed away.

55. We had no idea what the infection was that cause [redacted] to become unwell. We knew that it was from her line, but we were never told what it was and there was never any indication that it was related to the water in the hospital. Nobody said anything about what had caused the infection.

**COMMUNICATION: GENERAL**

56. The day after [redacted] went down to PICU, I came up to Schiehallion to get her slippers. When I said to the nurse that I was there to get [redacted]'s slippers she told me that [redacted]'s room had been emptied and her stuff was in a store cupboard. I couldn't believe it. I thought it was strange and heartless as she had only just left the ward. No one on the ward had come down and told us that is what was happening and they didn't give us a reason why that was done. It is like they had already decided she wasn't coming back to the ward. I just think it was a bit heartless the way it was handled.

57. When [redacted] passed away we weren't told anything about why she had passed. The doctor who came in to switch off the machine didn't tell us anything and we had never met them before.

58. We weren't there when [redacted]'s death certificate was being issued. It was her mum and dad. They had to go back to the hospital the day after [redacted] passed away and Derek took Kimberly in. We were just functioning. We weren't taking anything in. We did see the death certificate but I don't know when we saw it and I didn't know what it said. They were all big words to me. I couldn't have told you what any of the infections were. Nobody has ever said it was from the water or anything. When we read it, we just thought she had an awful lot of infections.

59. As far as we are aware, there weren't any meetings with anyone from the Schiehallion just after [redacted] died. Usually Kimberly would tell us if there was anything but I can't remember her saying that she was going to meet with

anybody until Professor Gibson and an outreach nurse from the Schiehallion came out but that was a while after [redacted] had died. I think it was a few months later as I was back at work, possibly February 2018. I had to get time off my work to be with Kimberly for the meeting with Professor Gibson. During this meeting, Kimberly did ask about the stenotrophomonas infection but it was brushed away as a hearsay question. She was asking about this infection because it was on the death certificate, I can’t remember exactly what she said, but I know that Professor Gibson brushed it aside. It wasn’t answered. Professor Gibson didn’t elaborate on any of the questions. She was just asking things like, “How are you coping?” I can’t remember fully what was said but Kimberly was trying to find out what that infection was and we didn’t get any answers. I expected more from the meeting, even after all those months. The big question is why were her parents not told face-to face what the infection was and how [redacted] got it? We didn’t know about some of the information at the time but the infection actually started before [redacted] got her line out. I did not find this out until I read this in the independent case note review report. The report was prepared by a consultant who reviewed ’s medical records. Then she had the septic shower. I can’t believe that it has actually gone on and they hadn’t told us. Why not tell us? They’re always going to say it was an infection. We didn’t know what kind of infection [redacted] had. We knew it obviously had to be a line infection or something to do with the line as when it was removed, that’s when she started to go downhill. Nobody said anything about what caused it.

60. With her experience of dealing with [redacted], Kimberly was very good with medics. I don’t know how she managed to remember all the medicines and infections and what the doctors were doing to [redacted]. She was always on the ball with everything and that is how I know that Kimberly didn’t get an answer to her questions as she would have said something at that meeting.

61. Until this actually came out in the papers, we had no idea at all about the water and it hit us like a ton of bricks. After the meeting in February 2018

the next thing I was aware of was when Kimberly phoned me at work saying it was in the papers. Anas Sarwar had gotten in touch with her and told her about these whistle blowers. Kimberly said it was a water infection that [redacted] had. This was November 2019 so a lot of time had passed. It just brought absolutely everything back and then we were worse than what we actually started with; all of a sudden, we realised [redacted] could be here. It brought up so many emotions, we were so angry and disappointed with the hospital. At this point there was no name in the papers but Kimberly knew it was [redacted]. She just instinctively knew it was [redacted] they were talking about when they said a child had died. She knew instantly. It is thanks to the whistle-blowers that this was all brought to everyone's attention because they don't want to live with the feeling that they're letting something go. It's understandable but I wish they'd done it earlier.

62. Between August 2017 and then this all coming out in November 2019, we were not contacted about the circumstances of [redacted]'s death, but we did have some communication from the hospital regarding a memorial service that we were invited to. Karen, the outreach nurse from Schiehallion, and some of the nurses from the Schiehallion were the ones that would get up and speak so I think it's through them that we got the invites. I can't say for sure though but we did get an invitation. At the service, they had the children's names up on a screen and you go and set off balloons and light candles. [redacted]'s name was on the screen with all the other kids who had died. Kimberly and I always tried to go. When this all came out in November 2019, we weren't asked to attend again. We weren't invited to anything. This was very disappointing as well. I don't think it's a coincidence that we weren't invited after all this came out in the press. I know that the children's names go up on the screen for at least five years and there were families there whose kids had died several years ago and they were still invited even though their kid's names weren't up on the screen.

63. I found out about the Schiehallion ward being shut through Kimberly. She called me and let me know that the ward had closed. I think there was a

Facebook group because she kept in touch with some of the parents so that's probably how she found out but I'm not 100 percent sure. When we heard about it we thought things were getting worse in the hospital and we worried about the kids there that needed treatment and wondered what was going to happen to them. I didn't know the reason for the ward being shut.

64. When I heard about the ward being closed, I had my suspicions that this maybe had something to do with [redacted]. We were also hearing about the infections from the pigeon droppings too and when we started to put things together and form a picture of what was happening; we realised things weren't working in that hospital. We started to think; "Why all of a sudden are they closing and not opening up again?". There must have been problems. There must have been a big problem.

65. We didn't receive any direct communication from the hospital but we weren't really expecting it anyway as it would be to the parents, not the grandparents. We sat in on things with Kimberly if she was having to make statements, or talking to reporters, or if she went to Edinburgh, but we never spoke to the press or anyone else, we were just there for support. Derek went with Kimberly to a meeting at Holyrood, I think with Anas Sarwar, but he was just there to support her. We sat in a few times with her when the reporters spoke to her. When she did that documentary with Lisa Summers and the other one that came out, we only sat in. We weren't asked anything. We were just there to support her.

66. I do remember that maybe the Chief Executive at the hospital did contact Kimberly and gave her the opportunity to speak to them if she wished to. Her attitude was that it was too little too late and that it should have happened before all of the information came out in the press. I don't know when this was.

## ISSUES WITH THE BUILDING

67. Derek wasn't really in the hospital as much as I was as we also had [redacted]'s brother to look after so that Kimberly could be at the hospital and he did most of that. Sometimes I would drive to the hospital and we would swap over [redacted]'s brother and Kimberly would come home. At the weekends, Derek would be at home looking after [redacted]'s brother until I would go to the hospital and let Kimberly or [redacted]'s dad leave. Kimberly would then come home to look after her son. We had a wee rota. So I was at the hospital more than Derek.

68. The building was brand new and it was immaculate. I did notice that there was always some work being done on ward 2A. They were always fixing things like the doors: the doors coming into the ward and things. It's a new build, so you're always going to get wee problems and wee things that have got to be sorted. So I didn't really give it any thought.

69. One of the times the wee kitchen area was closed because there was an infection somewhere in the ward. I can't remember what the infection was but the only thing we were allowed to do was go in and get water from the wee machine which was connected to the taps. It was like a filter of some sort.

70. I never noticed anything in relation to the water in the ward. [redacted]'s dad always said he thought there was something but I don't know if Kimberly actually thought about the water. I think she read it and googled it later on but [redacted]'s dad thought there was something, even at the time. He had noticed they changed the shower heads. They didn't do it when I was there but her dad said that the showerheads in [redacted]'s room had been replaced two or three times and that there had been workmen in the room. He's a tradesman himself so was more suspicious of these things but nothing like that was done when I was there. We don't know if it's something they had to do routinely. We never saw this; we were just there to look after [redacted]. The only time we left the room was to go to the toilets, they had a toilet in the room but I preferred to go out as she was using that toilet. We would maybe go and get a drink or something to eat for ourselves but most of our

time was spent in [redacted]'s room. I even slept in the room. You were basically in the room 24/7 other than being up and down the stairs to get something from M&S or the soup place.

## EMOTIONAL IMPACT ON [redacted]'S FAMILY

71. Part of me thinks, "*hats off to the whistle-blowers*". But I wish they had done it at the beginning, in 2017 not 2019 when the grieving process had already started. We were trying to get through every day as it was. I almost feel it would have been better if they had just kept quiet because it brought so many emotions back. We are so angry and disappointed in the hospital. We've known Dr Gibson for over 30 years. I'm not wanting to believe that she knew any of this. It was just devastating. Every time it came up, every time it was on television, you saw pictures, it was in the papers, your heart just broke even more. You get a tightness in your chest. You don't want that sadness or pure anger. Because we just want her here and that's never gone away. Even though now we know that can't happen, it's just still something you want. We've all been robbed of [redacted].

72. Derek doesn't think the hospital should have opened when it did. They seem to want everything now up and running and they're not doing the right tests. It's a case of we want this built, we want this running, open. I wouldn't take my child to the hospital. I don't feel it's safe. We have a family member due an operation there and I'm terrified.

73. The grieving process, when it started in 2017, was bad enough. We supported Kimberly every way we could. She's our daughter so we're trying to do this, support her and grieve all over again. That's what has happened, the grieving process has started again and it brings it back every time we talk about what happened to [redacted]. It's not that we don't talk about [redacted]. We talk about her like she's still with us but it's stories of [redacted], happy stories, before she passed away.

## CONCLUDING COMMENTS

74. We've not had any communication from the hospital. There should have been communication. The hospital should have been open and transparent. I wish they'd told us right from the beginning all about the infection and not kept it to themselves. At the end of the day, they've got to live with this. We're living through it but they've got to live with it for the rest of their lives. Somebody has made a big mistake. Someone's passed something that they shouldn't have passed. Somebody's not checked things that they should have checked before that hospital opened.

75. We don't want this to happen to any other family; for somebody else to die, and then two years down the line it's exactly the same thing, where there are whistle-blowers revealing more problems and it's all back to where it was. There's loads of families out there that are probably terrified to take their kids to the hospital now. Personally, if I was watching the news and listened to this, I would be petrified to take my child there. People need the hospitals and unfortunately children still get ill and they still get cancer. The need to be reassured that everything is all right and nothing is going to happen to them. I know that can't be guaranteed because nobody can guarantee tomorrow but they shouldn't be losing someone through something like this.

76. We hope one day we'll get the truth. I think the Health Board have just crossed their fingers and are hoping for the best. It's not been the best for us. I think they've all known that there were issues and they've just kept going and hoped it would maybe clear itself.

77. [redacted] is no longer here. That's the main thing. She should be here. The hospital building was at fault. That's it as far as I'm concerned. She should be here with us now.

78. 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.