

Scottish Hospitals Inquiry

Witness Statement of

Lynndah Allison

WITNESS DETAILS

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

OVERVIEW

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

WITNESS STATEMENT OF LYNNDAH ALLISON

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

FAMILY BACKGROUND

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

SEQUENCE OF EVENTS

Diagnosis and Experience in RHSC Edinburgh: September – November 2017

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

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

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

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

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

Experience in RHC: November 2016

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

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

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

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

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

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

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

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

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

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

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

Ongoing treatment at Edinburgh Sick Kids: February – April 2017

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

WATER: EVENTS INVOLVING WATER SYSTEM

Water incidents in RHC

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

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

POTENTIAL INFECTIONS

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

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

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

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

OTHER ISSUES RELATING TO HOSPITAL BUILDING

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

CLEANLINESS

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

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

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

Overall emotional impact on witness

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

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

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

COMMUNICATION: GENERAL

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

Facebook Group

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

CONCLUDING COMMENTS

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

WITNESS STATEMENT OF LYNNDAAH ALLISON

A34547515