**Scottish Hospitals Inquiry**

Witness Statement of

Lynn Kearns

## WITNESS DETAILS

1. My name is Lynn Kearns. I was born on [redacted]. I am [redacted] years old. I work as an [redacted].

2. I am the mother of [redacted]. [redacted]'s date of birth is [redacted]. He is 15 years old.

3. I live with my husband, [redacted], and my two children, [redacted] and [redacted], in [redacted].

## OVERVIEW

4. My son is [redacted]. In December 2017, when [redacted] was 11 years old, he had some blood tests which raised the suspicion that he had leukaemia and, after further tests, in January 2018 he was diagnosed with Aplastic Anaemia, a rare blood disorder. [redacted] was treated in the Royal Hospital for Children (RHC) between December 2017 and March 2018 when he finished his treatment. He attended the hospital as an inpatient and as an outpatient. He still attends the Haematology Clinic as an outpatient every 2 months and has his bloods checked monthly.

5. [redacted] spent time in wards 2A and 2B of the RHC which are known as the Schiehallion Unit. This is the oncology unit. My husband [redacted] and I were with [redacted] throughout his admissions and I can speak of or about the experience [redacted] and I had on these wards.

6. I will come on to talk about some specific events in the hospital which affected our experience. There were issues with the water throughout [redacted]'s

time in the Schiehallion Unit that significantly impacted [redacted]'s experience and there were also issues with other amenities like the air conditioning in the rooms and the facilities in the ward.

## FAMILY BACKGROUND

7. I live with my husband [redacted] and our children, [redacted] and his sister [redacted], at our family home in [redacted]. [redacted] is [redacted] years younger than [redacted] and they are very close.

8. [redacted] is a very mature boy. He loves sports and was in [redacted] Running Club. He liked playing football and his passion in the summer of 2017 was scootering. He was always down at the skate park doing his flips and tricks on his scooter and he was very good at it. He actually made a scooter himself with a foam base that let him practice some of his stunts on a trampoline to save him getting hurt if he fell. [redacted] often had bumps and bruises because of all of his activities like his scootering and his football.

9. Other than when he was an in-patient in the hospital, [redacted] rarely missed school. He loves school, maybe apart from Primary 7, when he didn't like his teacher so much, but he was very sporty, was in the Scouts and loved doing different things like canoeing and climbing. He had been looking forward to the Primary 7 School Camp for many years, but sadly he had to miss it because of his treatment.

## EVENTS LEADING TO [redacted]'S INITIAL VISITS TO HIS DOCTOR – NOVEMBER/DECEMBER 2017

10. One day in November 2017, [redacted] was at school, when he banged into a glass door and gave himself a very sore bump on his head. After this, he complained about headaches and alarm bells started to ring for me. He

was still going to school but with his other bruises that I'd just put down to his physical activities, I thought I'd get him checked out just in case and I took him to the doctor.

11. The doctor suggested it was probably just a virus and said we should give it a week or so and see how he was. But [redacted] still had the bruises after this time and I also noticed that he had some little rashes which I now know are called petechiae, to do with the blood and which can be a sign of leukaemia. I took [redacted] back to the doctor and they said they'd arrange blood tests. We had also noticed that [redacted]'s pallor was very yellowy, with black circles under his eyes.

12. [redacted] was continuing his running and scootering and was still very active, but he mentioned a few times that he was getting breathless, which was not like him. We didn't read too much into it but my husband took him to the doctor for the blood tests on Monday 4 December 2017. I remember the date as my [redacted] was the day before and we had all done a charity Santa Dash [redacted]. [redacted] had been a bit reluctant to do the Santa Dash because he hadn't been feeling great, but he managed the run ok.

13. So the day after the Santa Dash, [redacted] took [redacted] back to the doctor for the blood test appointment. They struggled to get blood from [redacted] but put it down to how cold and frosty the weather was that day. I understand that it can be more difficult to take blood if the body is cold. They said that [redacted] should pop [redacted] over to the Sick Kids hospital where they'd be able to take the blood more easily.

## <u>INITIAL CONTACT WITH THE RHC– DECEMBER 2017</u>

14. [redacted] took [redacted] to the RHC straight from the doctor on 4 December 2017. [redacted] phoned me at my work to say that they were giving [redacted] a

really good MOT but that [redacted] was quite happy and playing on his iPad. Then [redacted] phoned me when I was at the gym that lunchtime and said I should head to the hospital as they thought [redacted] might have leukaemia.

15. I shot over to the hospital and remember dumping my car outside A&E as I wasn't familiar with the hospital. [redacted] was in a room in A&E with [redacted]. They took me into another wee room with a Consultant, and she said "We're 90% certain it's leukaemia". We didn't want to worry [redacted] so I was trying to stay upbeat but he knew there was something wrong and we told him he had to be admitted as there was something wrong with his bloods. We didn't say what it was, just that he'd need to get some tests.

16. I have since found a letter that says [redacted]'s platelets on admission were at 5, which is virtually zero, his neutrophils, which fight infection, were at 0.2 and his haemoglobin was at 50 when it should be up at 200 or that kind of level.

17. We were moved to the Oncology Ward, 2A, which is part of the Schiehallion Unit. Ward 2A is a long corridor, in a kind of U shape, with individual rooms off the corridor at both sides. The nurses' station was at the far end as you entered the ward. There were some rooms behind the nurses' station as well. [redacted] was put into an individual room near the entrance. Of course [redacted], not being silly, saw some of the kids in the ward with no hair and said "Mum, is this the cancer ward?" I said it was and he said "Have I got cancer, am I going to die?" We reassured him as best we could and I know that the success rate for treating children's leukaemia these days is amazing.

18. [redacted] and I were taken into a room on our own and told that the next day [redacted] would go for a bone marrow biopsy. By this point [redacted] was getting blood and platelets transfusions and he had been fitted with a cannula.

19. That was an awful night. [redacted] was in tears thinking he was going to die, I was in tears and it was tough.

20. The next morning, 5 December 2017, the surgeons gave [redacted] the bone marrow biopsy. This was done under general anaesthetic. In the late afternoon, [redacted] and I were taken into another room again, where the staff told us that it wasn't leukaemia, that the bone marrow had no abnormal cells to indicate leukaemia and that basically it was empty, which was strange and not something they had seen before. [redacted] was not diagnosed with Aplastic Anaemia at that time. Apparently a diagnosis of Aplastic Anaemia (which was eventually diagnosed) is pretty rare and it was seven years previously that they had last treated it in Glasgow, so it wasn't mentioned at this time. This was another issue for us, as we were never quite sure how [redacted]'s treatment would go. The hospital had Professor Gibson as the big specialist for leukaemia, but they didn't have a specialist on [redacted]'s condition.

21. [redacted] got his transfusions but the staff couldn't do much more as they still didn't really know what they were treating at that stage. The transfusions were to increase [redacted]'s platelets. With his blood count back up, [redacted]'s consultant ,Dr Chalmers, decided there was no need to keep [redacted] in, so he was discharged on Wednesday 6 December 2017, two days after the admission.

22. After this, [redacted] was being monitored to check the level of his platelets, so we were back at the hospital every couple of days, in Ward 2B, day care, for bloods to be taken and twice weekly blood transfusions. I counted more than 100 visits to the hospital in total.

23. That continued until 23 December 2017 when [redacted] took [redacted] over to the hospital for a routine transfusion but [redacted] had a temperature spike, which the nurses always took very seriously because the spike could

indicate infection and [redacted]'s condition left him less able to fight infection. The hospital decided to keep him in because of this, which was a blow because we'd been hoping for as normal a Christmas as possible, as much for [redacted]'s sister [redacted], and it wasn't clear how long he'd be in. So they pumped [redacted] full of antibiotics, I can't recall which ones, and at 5pm on Christmas Eve he was released as his temperature had come down again. But the poor soul was pretty much zonked on Christmas Day with the effects of the antibiotics and because he wouldn't have slept properly in hospital.

## DIAGNOSIS OF APLASTIC ANAEMIA – JANUARY 2018

24. Between Christmas and New Year, we were back and forward to ward 2B for the usual blood and platelet transfusions every couple of days, Dr Chalmers, the consultant, started other tests as they needed to know the cause of [redacted]'s condition and I remember Dr Chalmers mentioning Aplastic Anaemia. Of course I was straight on to the web when I got home to find out what this was and I saw that it's potentially life threatening, not directly from the condition but because the body can't fight any infections it picks up. I discovered there was an Aplastic Anaemia Trust that gave lots of information. After various other blood tests, and analyses carried out in a different part of the UK, they eventually confirmed the diagnosis of Aplastic Anaemia in mid-January 2018.

25. When we got the diagnosis, we were told by Dr Chalmers that the treatment is either a bone marrow transplant or ATG therapy. A bone marrow transplant should be a cure as you are completely replacing the cells in the bone marrow. ATG is anti-thymocyte globulin and it's just a treatment that suppresses the immunity to allow [redacted]'s own bone marrow cells to work for themselves again. There's two different types of ATG, one which is taken from rabbits and the preferred type now seems to be from horses. We joke with [redacted] now that he is part horse.

26. The nurses took blood samples from [redacted] but she was only [redacted] at the time and she howled when she was getting the blood taken. Unfortunately she wasn't a match and although [redacted] was on the bone marrow waiting list, there was no sign of a match there either so we decided to go down the ATG route. We were told that this was a very expensive treatment, around £20k. Dr Chalmers told us it would take a while to confirm the timing, both because of the cost and as it would take some time to source the treatment. That's why it took until 19 February 2018 to be told the hospital had the ATG and [redacted] could come in for treatment.

27. Ahead of the treatment, we took [redacted] to the hospital on 13 February 2018 for his usual transfusion and then again on 14 February 2018 to have his central line fitted. This was the Hickman line that remained in place until 5 December 2018. I was told the line would go into [redacted]'s chest during a general anaesthetic, and that it would be important to keep it clean to avoid infection going straight into [redacted]'s bloodstream. It looked like two long plastic tubes, maybe ten inches long, with different coloured caps. It went in just above [redacted]'s right nipple and it was kept in place with a dressing. We were told by Dr Chalmers that the Hickman line was the easiest way of getting the medication and transfusions into [redacted]. It would save him the pain of the injections each time, though we were conscious of the increased risk of infection around the entry point of the line into [redacted]'s chest. [redacted] was discharged after the line was fitted and we had to be taught how to clean the dressings around the line to save the nurses coming out to our house each time, though a nurse would come out each week to flush the line. The outreach nurses who came from the hospital were specifically from the Schiehallion Unit and they were great in coming out to help us with [redacted] after he had been discharged. They even visited him at school to try and avoid any disruption to his routine.

28. The ATG treatment was due to start on 19 February 2018, but after we turned up at the hospital that morning and after completing all the necessary paperwork for [redacted] to be admitted, it was discovered that the wrong ATG medication had been received in the hospital and treatment was unable to proceed.

29. We were sent home and advised that it may be a couple of weeks before treatment could begin as the medication was bespoke and had to be sourced from England. [redacted] was really upset about this as he had mentally prepared himself for treatment and it was now back to waiting for an admission date. I understand that it was the rabbit version of the ATG, rather than the horse type, that had arrived. I'm not sure if this was because the wrong item was ordered or the wrong one sent, it wasn't clear. I guess that the error wasn't discovered until they were taking the medication from the fridge in the pharmacy that morning but Dr Chalmers, the consultant, was clear that the horse variant had a better chance of success for [redacted] so we were better to wait and she said that the delay wouldn't cause a problem. However, this did mean that the Hickman line wouldn't have been fitted so early, so [redacted] had it in for a few more weeks than necessary and it meant some continued transfusions until the ATG treatment could start, which ended up being on 7 March 2018.

## ADMISSION FOR ATG TREATMENT – 7-27 MARCH 2018

30. I can't recall how much notice we got that the ATG treatment could begin but it wasn't long before [redacted] was admitted on 7 March 2018. He went into Room 13, Ward 2A. Room 13 was a single room with TV, though the TV and blinds didn't work. There was also a pull down bed for parents to use if they stayed over, which was reasonably ok.

31. We immediately noticed that there were bottles of spring water at the sides of the sink in the bathroom and we were advised by the nursing staff that

these were to be used for everything including, washing and cleaning teeth, as bacteria had been detected in the water supply. I was not given any information about what this bacteria was. The water supply was still on as the taps in the sink in the room and the bathroom still worked. This obviously meant no hot water for washing was available. Showers were out of bounds. We weren't told how long the situation would last but we judged by the numbers of pallets of water in the corridor that it wouldn't just be a couple of days.

32. The room was clean but although fitted with a state of the art TV, it did not work. We had numerous attempts from various members of staff (play-staff, auxiliaries, porters) but despite them all trying, no-one could get it to work. So [redacted] couldn't use the TV. I'd have liked to use it too and other family members, like when [redacted] was sleeping, so it was frustrating it never worked and none of the staff seemed able to fix it.

33. The temperature was also an issue. It was often far too warm. There was a temperature controller in the room but it didn't change anything. We were told that the temperature was controlled centrally but it didn't seem to make sense to then put controllers in rooms that didn't actually do anything.

34. [redacted]'s treatment started on 8 March 2018. This immunotherapy was in the form of a solution infused to [redacted] through a drip connected to the Hickman line over a long period; around 12 hours. This was the horse version of the ATG which would trigger [redacted]'s own bone marrow to start producing cells again. He was in Room 13 at this time and was not in isolation, but he had to be monitored constantly during this period by nursing staff as there could have been side effects or an allergic reaction and obviously he was attached to the drip the whole time. This was all so difficult for a young boy.

35. We also discovered that the facilities on the ward for [redacted]'s age group were poor. The "playroom" was really for much younger children, up to age 10, I would estimate. We asked if he could access the Teenage Cancer Trust (TCT) Room but were told no. [redacted] was in that unfortunate age group, where he was too old for the play room but not old enough for the TCT room.

36. They did allow him to sneak into the TCT room briefly just before Christmas when it was very quiet on the ward. It was amazing but it did make it a bit worse because it gave [redacted] a taste of what he was missing out on. The TCT room had a huge TV with PlayStation and X-box, pool table, juke box and comfy chairs where parents and patients could socialise. [redacted] was only a few weeks away from his 12th birthday, which I think is the age they can use the TCT room, so this made it really hard for him. Three weeks without any entertainment just made the time drag out for [redacted]. So basically he was stuck in his room the whole time as the playroom was really for people younger than him, although he did go the atrium once or twice. Since then I know that fundraising has taken place by two previous patients to make a room for those who fall within this age group. This would have been a huge boost for [redacted], particularly since there was no working TV in his room. The charity work the two girls are doing is amazing.

37. I was really grateful when the Les Hoey Bellshill Charity got [redacted] a Nintendo Switch which helped him pass the time. He also watched the whole series of Stranger Things on his iPad. Public Wi-Fi in the wards was really bad and I heard lots of parents complaining about it. [redacted].

38. On 9 March 2018, [redacted] reacted to the treatment and presented with seizures, which are a known side-effect. He was sedated, intubated and transferred to the Paediatric Intensive Care Unit (PICU). He was given a

CT scan but it was thought after review by a neurological consultant that these were functional seizures brought on by the stress of hospital admission and treatment. These seizures can be controlled with reassurance and mindfulness and they don't necessarily require medical treatment. [redacted] still has the seizures to this day but we manage these ourselves, for example using the cognitive behavioural therapy techniques recommended to us by the psychology department.

39. It was agreed to stop the ATG treatment due to the seizures. Dr Chalmers and the Neurology staff didn't know what was causing the seizures but they didn't want to risk continuing in case it was the medication. The drawback of stopping was that the two days of ATG already given wouldn't have worked by this point so it would mean treatment having to restart at the beginning. The only other option was to wait again for a bone marrow donor but there was no guarantee how long this would take. This meant that the four days' worth of treatment that was planned needed to restart and the two days already given were effectively lost.

40. Dr Chalmers put [redacted] on a tiny dose of diazepam, a muscle relaxant, and they decided to keep him on this when they began the treatment again as it was more important to continue the ATG treatment even if this meant additional medication to calm the seizures.

41. On Saturday 10 March 2018 [redacted] was back in room 13, Ward 2A, after his brief transfer to PICU on the Friday. He had his endotracheal (I think that's what is called) tube removed, however, this was a harrowing event and also left him with vomit on his face. The first thing he wanted to do was have a proper wash or shower and freshen up. This was impossible due to the lack of hot water and showering facilities being out of bounds.

42. [redacted] spent the whole day in bed feeling dirty and sweaty, just wanting a good wash. This was a ridiculous situation, washing is one of the most basic of facilities that should be available, not least in a hospital.

43. We just had to use baby wipes to try to clean [redacted]. The nurses gave us wipes and I'd taken my own, but wipes just don't do the job. The staff were very nice about it and apologetic. I think they were actually embarrassed about the situation. The nurses didn't have any idea how long it would last and we asked Dr Chalmers about moving to another room or even a different ward that wasn't affected by the water issues. We were told the other areas were full. We even suggested moving back to the old Yorkhill but were told this wasn't possible. I asked on numerous occasions why patients had not been moved but was advised there was no room to move anyone to. Being in a single room, I never spoke with any other parents, so have no idea how other parents were managing to get their children washed.

44. [redacted] was fed up and upset – he felt really dirty and just wanted home. [redacted] and I were lucky as we could go home for a proper wash but poor [redacted]had no options but to remain unclean.

45. Sunday 11 March 2018 was Mother's Day. It was quite a nice day as they offered mothers a massage in the ward and gave us a wee bag of chocolates. I had an aromatherapy neck and shoulder massage from a girl who was giving free treatments. It was in a wee separate room she was working from and it was free of charge. They also gave [redacted] chocolate eggs at Easter time. These were really nice touches but I just wished they'd managed to get right the basics, such as hot running water, TVs that worked and decent food. [redacted] also had lots of family visitors that day, which helped break up the day.

46. On Monday 12 March 2018, we were pretty much in limbo with no treatment being provided although Dr Chalmers was in constant discussion with us and it was agreed that treatment would be restarted as soon as the ATG therapy could be obtained. They had to order it and I have mentioned the budgetary issues. I think Dr Chalmers had to make a case because they'd already paid for one lot of this expensive ATG and the treatment had to restart from the beginning again because of the pause when [redacted] had his seizures. I think Dr Chalmers mentioned the cost of the treatment and I probably googled it too.

47. During this time there was still no facility for a proper wash and there was no information about what was being done to resolve the situation. So finally, with [redacted] getting more and more upset about the situation, I asked if there was some way that he could have a wash.

48. I was provided with a basin of water, which I took a picture of and have provided it to the Inquiry [**Picture LK/01 – at Appendix 1**]. The water had been warmed, but I don't know if it was from the tap or bottled water. My 11 year old son, just hitting puberty, had to stand in the bathroom on a towel and I had to use a plastic cup to try and wash him. It was literally a case of me scooping up the water and pouring it over him. [redacted] was at the age where changes were happening and he was becoming more conscious about his body, so standing naked while his mum washed him was humiliating for him.

49. I asked for a gel of some sort to help with the washing and an auxiliary provided some baby wipes and an aerosol. I sprayed the contents on[redacted]'s back and discovered that it was actually "Emollient", a dry oil moisturiser and not a shower gel. I can't recall if I spoke to the auxiliary; I was probably so fed up I just got on with it

50. Portable sink units were installed in the ward at 4.30am on Tuesday 13 March 2018. Again, I have provided a picture of this to the Inquiry [**Picture LK/02 – at Appendix 2**]. I think these were put in all the rooms, certainly [redacted]’s. We were now advised by the nurses not to use the sinks in the bathrooms at all, only the portable sinks that had been provided, and a letter would be provided to all in-patients. We weren’t given any particular information about the portable sinks. We also received a letter advising us to speak to an auxiliary if parents wished a shower and they could be provided with a taxi to go to Marion House, the CLIC Sargent place. I have provided a picture of the letter to the Inquiry [**Picture LK/03 – at Appendix 3**]. This is the accommodation for parents and families who did not live near the hospital. We never actually did this so I can’t say where it is. It’s fine if you had more than one parent on the ward but most parents take turns at staying with their children. Certainly I would not have wanted to leave [redacted] for a period of time to go and have a shower in another location. My husband and I had been taking turns at staying overnight so at least when we returned home, which was only a 20 minutes’ drive from hospital, we were able to shower and clean our teeth properly.

51. On Friday 16 March 2018, we got a letter advising that the water would be shut off again. I can’t recall when it had been turned off previously but I think it was only for a short period, maybe a couple of hours. I don’t have a copy but I think it came from the Health Board. I can’t remember when it had been shut off previously but I have an email where I told a friend that it was being shut off for the second time. At this point, parents were advised to go to another ward to use the toilet. With [redacted] experiencing seizures, even leaving him on his own to go to the parents’ kitchen to make a coffee made me nervous so having to leave the ward to use the toilet was unacceptable. I think the easiest other toilets to get to were on the ground floor, so this is where I went and the round trip probably took about five minutes. [redacted] was advised to use a bed pan if he needed the toilet and he was shocked by this and understandably, as a young boy, refused to

do it. Of course he eventually had no choice and he just had to do it. I emptied the bed pan in the sluice area at the other side of the nurses' station as asking the staff to do it would just have added to [redacted]'s embarrassment. He got so agitated by all of this, I think it was one of the reasons that the staff agreed to allow us home the next day on the day pass. I believe that staff were also having to leave the ward to use the toilet.

52. Speaking to other parents there, I remember those with babies saying how ridiculous it was when they couldn't even bathe the babies. Given all the concerns about infections, not being able to wash properly was just not right. All the patients on that ward would have been particularly susceptible to infection, given the medical conditions that put them there.

53. All of this sent me over the edge and I actually contacted the Daily Record about the situation. I didn't see any point in an internal complaint. I wanted people to know what was happening as I just couldn't understand how it was being allowed, especially in a state of the art hospital. It wasn't until I read the newspaper article that I discovered that some children had actually contracted infections which could have been due to the contaminated water supply. I'd asked that my name wasn't included in the article but my story was covered.

54. Dr Chalmers advised me that [redacted] was to receive a course of antibiotics as a preventative measure to ensure he did not catch an infection due to the water situation. I can't recall precisely what the antibiotics were. By this time it seemed common knowledge that there was some kind of bacterial infection, people all seemed to know about it. I can't recall if this was from nursing staff talking about it. It has to be remembered that throughout this period [redacted]'s immune system was seriously compromised and his neutrophils which fight infection were often almost at zero.

55. On Saturday 17 March 2018, we were allowed home on a “day pass” which allowed [redacted] to get a shower and some proper food. During our stay the food in the hospital had been appalling, poor quality, little choice and only just edible. When [redacted] was an in-patient, everything seemed to come with chips and it was pizza, chicken nuggets, all processed and no salad options. I thought the food choices were really poor and hardly healthy options. I do think they have improved this since [redacted] was in, but I was really surprised at how poor it was at the time. My husband discussed this with a hospital manager on a later visit and I believe it is much improved now although offering something other than toast made from cheap white bread would be an improvement.

56. We spent the day as a family 10 pin bowling, eating at the World Buffet and walking in park. [redacted] got a proper wash and shower he was able to sleep in his own bed.

57. On Sunday 18 March 2018, we returned to Room 13, Ward 2A to have treatment restarted the next day. [redacted] wasn’t happy about going back in. Having had such a nice day, he didn’t like the idea of being stuck back in a hospital room, with the water problems, no TV, poor food, etc. We didn’t know how long it would take but knew it would be a while. We understood that we’d be in for at least another week after the treatment had completed.

58. [redacted]’s treatment restarted successfully Monday 19 March 2018. The length of treatment was determined by the rate of infusion, which they could adjust, increasing or decreasing the flow. Sometimes [redacted]’s blood transfusions would be up to five hours, sometimes much shorter. We understood that the ATG treatment would be for up to four days, though it ended up being three.

59. [redacted]'s treatment was completed on Wednesday 21 March 2018 and the after-treatment started, which involved steroids and anti-rejection drugs being prescribed. [redacted] had to stay on the steroids for two weeks and he was then put on to ciclosporin, an immune suppressant that he only finished taking in May 2021. He was still on this because I think it's his own immune system attacking the bone marrow cells. Side effects of ciclosporine are excessive hair growth, not so bad for a boy of his age. The steroids had also made his face bloated and increased his appetite so we had to be careful with his diet. [redacted] has a good sense of humour and his sister joked he had hamster cheeks after the steroids. Fortunately, these side effects were temporary and [redacted] soon returned to normal.

60. On Thursday 22 March 2018, [redacted] was finally able to have a shower. The nurses didn't explain why this was now possible but we just assumed that the water problems were sorted. I recall that the water was only good for washing, not drinking, but I can't recall the conversations. The design of the bathrooms we discovered was quite strange in that it was like a wet room, obviously for wheelchair access, but the water flooded into the bedroom so a cleaner had to be sought quickly to mop up this up. Water did not go down the plughole quickly and the floor wasn't angled away from room. I spoke to a nurse and they got a cleaner to come in with a mop. They were fairly quick. I can't recall asking if this was a common problem with using the bathrooms.

61. [redacted]'s treatment was successful and he was discharged on Tuesday 27 March 2018. He continued to get his transfusions until May 2018 while his system adjusted. We went back to ward 2B, as an out-patient, twice a week to begin with and then it was once a week. [redacted] is now in remission.

62. I understood that [redacted] should have seen a teacher while in the hospital but this didn't happen until just before his discharge. There is a teacher in

the Schiehallion ward and I think that the ward are supposed to send them details of new in-patients and what class they were in. But it didn't happen and I asked if [redacted] should have had a teacher. It seemed that it hadn't been put in place on [redacted]'s arrival but he did see the teacher two or three times before he left hospital. I remember the first time as [redacted] and I had both had a bad night, with little sleep because of everything going on and the noise from the machines. The teacher arrived at 8 o'clock in the morning, when neither of us were are our best. Having a teacher throughout his stay would have helped break up the time for [redacted]. They did have clowns that came round but they really weren't suitable for [redacted]'s age. [redacted] hated that and he just tended to ignore them.

## IMPACT OF ISSUES WITH THE HOSPITAL ENVIRONMENT

63. The problems with the ward's water supply impacted [redacted] and me, both in relation to the difficulties created for [redacted] being able to wash and shower and also regarding the toilets, where [redacted] had to use bed pans and I had to go to the toilets on another floor.

64. We saw the external filters that were also fitted to the taps. They were white, soft plastic, bulbous things. Sometimes the workmen took the whole sink unit/faucet off though I'm not sure what they were doing.

65. In addition to the obvious concerns about keeping [redacted] clean and safe, and the talk about bacteria being present in the water, the humiliation for [redacted] and the overall inconvenience cannot be overstated. The situation was simply unacceptable.

66. Throughout our time in the ward, there was a constant procession of workmen coming into the bathroom, often when [redacted] was asleep or on treatment. I recall them checking the water in the bathroom sink with a dipstick and advising me "There's still bacteria" as they told me not to use

the sink. It was the workmen themselves who were confirming to me that there was still bacteria. I think this was also in letters from the hospital though I don't have copies. As well as the noise being disruptive, mentions of bacteria were really worrying given that [redacted] was immune-compromised. I was not happy to hear this and we just couldn't understand how this was happening and how the problems couldn't be fixed. My husband is an engineer and couldn't work out why it was so difficult.

67. The various works that were being done, mostly in connection with the water, could be noisy and disruptive, but I can understand why they were necessary if they knew there was bacteria.

68. Because of the water issues, there were challenges with personal cleanliness. Other than that, I think room 13, where [redacted] was, was clean enough. I have been less impressed with the cleanliness of the toilets, even during recent visits, including when I saw bins overflowing in a toilet in the adult's hospital.

69. [redacted]'s room was usually too hot. It wasn't helped by the fact that the blinds didn't work and although there was little sun when [redacted] was in, I can't imagine how bad it would have been had it been sunny. It just seemed strange that there seemed to be a temperature controller in the room, yet it seemed to have been disabled, I presume because it was all being controlled centrally. I wasn't sure of the point of the controller.

70. It was just really frustrating that the TV in [redacted]'s room didn't work and no-one was able to fix it. What made it worse was that he was at that in-between age where he was too old for the kids' play room but too young to use the TCT room so he was just in limbo. It all meant that his three weeks as an in-patient felt even longer than it was.

## EMOTIONAL IMPACT ON [redacted].

71. Having the line fitted meant lots of limitations for [redacted]. He had to be careful not to bump it, dressings were changed twice a week, it was flushed once a week and of course it needed to be kept dry so swimming was not possible. He couldn't do any contact sports at school or gym or running. The line would be obvious through his shirt and there was a period when some girls at school were making really cruel comments, like calling him "Cancer boy". Happily, his pals were very supportive.

72. [redacted] had never had any seizures before 9 March 2018 and they did do a CT scan and tested him with the thing that had all the electrodes on his head. Nothing untoward was shown, which is why they put it all down to the stress of everything, the combination of being in hospital for a serious condition while having to endure the issues in the ward, like the water, lack of TV, poor food etc.

73. In November 2018, the CLIC Sargent social worker referred us to the Paediatric Clinical Psychology Service (PCPS) as they thought that [redacted] would benefit from their service. CLIC Sargent are a charity that allocates you a social worker who supports families and helps with applying for allowances, etc. Lesley Anne Gillan was the social worker who helped [redacted]. She was great, really first class. [redacted] had some issues that we were concerned about, for example where he would [redacted]. He used the PCPS service about 8 times, going every couple of weeks, so two or three months in total. The girl gave him coping techniques as they thought his seizures were stress related and kind of panic attacks. Dr Jo Skeldon dealt with [redacted] and she was really helpful. He was discharged when they were happy he was ok. Discussions centred on what he had been through and his worries about the future. He can sometimes [redacted] when he winds down and things tick over in his mind.

74. As I have said, [redacted] really struggled to deal with all of the problems that were over and above the serious medical challenges that he had to fight. Not being able to use the TCT facilities when he didn't even have a working TV in his room made the stay so much more difficult for him, but I know the lack of basic washing facilities and the need to use bedpans really caused distress. [redacted] didn't need this humiliation on top of what he was going through and I know this didn't help with his stress levels and the seizure type incidents which he was experiencing. In a way, I think that not even trying to wash [redacted] using the basin of water might have been better as it would have saved both him and me this really distressing experience.

## OVERALL EMOTIONAL IMPACT ON WITNESS

75. I was off work with family-related stress from when [redacted] first went to A&E in December 2017. I was signed off work for around seven months. I couldn't cope with [redacted] being off, the uncertainly of his condition and it was all too much to be able to be at work at that time. My work were really good and understanding about it.

76. It still resurrects occasionally and I was myself diagnosed with [redacted]in 2019 when I was off work for three months, so my mental health hasn't been ideal over the last few years. I got the all clear [redacted] but still have to undergo regular check-ups.

77. The whole experience was horrendous, not only is being in hospital with your child who is seriously ill exceptionally stressful but to not have basic washing and cleaning facilities was a disgrace. However, what could we do, you want the best for your child and presume that the clinical and hospital management know what they are doing.

78. However the worry that people were going to catch something was always top of my mind too, especially after hearing about how other people had been affected and the Hickman line had been mentioned. The children were so vulnerable to serious infections, particularly when [redacted] and presumably all the children on the ward have little or no immune systems.

79. When I think back, the problems at the hospital just exacerbated what was already a horrible situation, having to deal with [redacted]'s condition. It made the whole experience so many times worse, when on top of the worries about [redacted], we had to endure the added stress of fears about the water supply and the risks of infection. Things like broken TVs and poor food we could just about tolerate but the potentially dangerous water situation really added to our stress as it was completely outside our control and it seemed to go on for so long.

80. Both [redacted] and I don't think we will ever stop thinking about it. It's not an experience we'd ever want to repeat and I think it will live with us for ever.

81. I joked with [redacted] that every time he took [redacted] to the hospital there's a problem so I tend to do most of that stuff. He was still working and was usually looking after [redacted] when I was at the hospital with [redacted].

## OVERALL EMOTIONAL IMPACT ON FAMILY MEMBERS

82. [redacted] is very close to [redacted]. She missed him a lot and would come home from hospital and sleep in one of his T shirts. She was devastated when she wasn't a match for a bone marrow transplant and we joked about how she could have said she had saved his life.

83. We only took [redacted] to the hospital every couple of days. It wasn't a nice place for children and I was worried about the danger of infections and the issues with the toilets. We're wary even now of these things and even before Covid we felt that the toilets could do with a good clean and a couple of months ago I took a picture of an overflowing bin in one of the toilets in the adults' hospital outside the door to the Schiehallion.

## HEALTHCARE ASSOCIATED INFECTIONS

84. Fortunately, [redacted] has not picked up any Healthcare Associated Infections during his time in the hospital. As I have previously mentioned, he did receive a course of antibiotics as a preventative measure to ensure he did not catch an infection due to the water situation. I can't recall precisely what they were.

## COMMUNICATION

85. The communication around the water problems was really non-existent, other than a few letters about being told not to use the taps or the toilets. It was not acceptable but we just got on with it. In fairness, I think the staff were in the dark too and, as I mentioned, they were also affected by the likes of having to go to toilets that were further away so it didn't make their jobs any easier. The staff were great and it was clear that the problems were out their control.

## COMPLAINTS

86. We never raised any formal complaints. To be honest, we had enough going on at the time. It was through exasperation that I contacted the Daily Record to highlight my experience. I wanted to remain anonymous but I

felt that the problems should be exposed to help others using the hospital in future.

87. [redacted] did speak to one of the hospital managers around December 2019 when [redacted] was in for a biopsy and basically sounded off about various issues, mainly about the quality of food, broken TVs and general poor facilities for [redacted]'s age. He didn't mention water as it was so long ago but it looks like it's still not sorted because ward 2A is still not open after all this time. [redacted] thinks that the manager took notes, he had a clipboard, but we didn't seek specific feedback. I think the food situation has certainly improved, judging from my recent visits. When [redacted] was in, everything seemed to come with chips and it was pizza, chicken nuggets, all processed and no salad options.

## OVERSIGHT BOARD / CASE NOTE REVIEW / REPRESENTATIVE GROUPS

88. [redacted] was not part of the Case Note Review and we are not part of any representative groups.

89. I am not part of any representative groups, though I'm on the Schiehallion Facebook page and I've been keeping up to date through that. Sometimes it is helpful but I don't go in to it a great deal.

## CONCLUDING COMMENTS

90. Throughout the stay, the nursing staff were always professional and I know that they were affected too particularly when the water was shut off and even they had to go elsewhere to use the toilet facilities. The staff didn't seem to know, particularly about water problems and I think they were kept in the dark until there were letters from hospital management. We got particularly friendly with a couple of staff who were inconvenienced

too by the water problems and having to use other toilets. I know they were unhappy about it all too but they just had to make the best of the situation.

91. I can’t understand why ward 2A is still closed. I suspect that the staff aren’t happy but it will be difficult to build up confidence in it when it opens again, after the problems of the past. I think there should be more publicity about the current situation, as no one seems to know what’s happening and when 2A will reopen, including the staff.

92. Even now, I am surprised at lack of security to get in wards in the hospital. There’s the buzzer but no one ever asks who is there and you are just let in. Even in the last couple of weeks, with the Covid restrictions, it’s easy to get in the wards without anyone checking who you are.

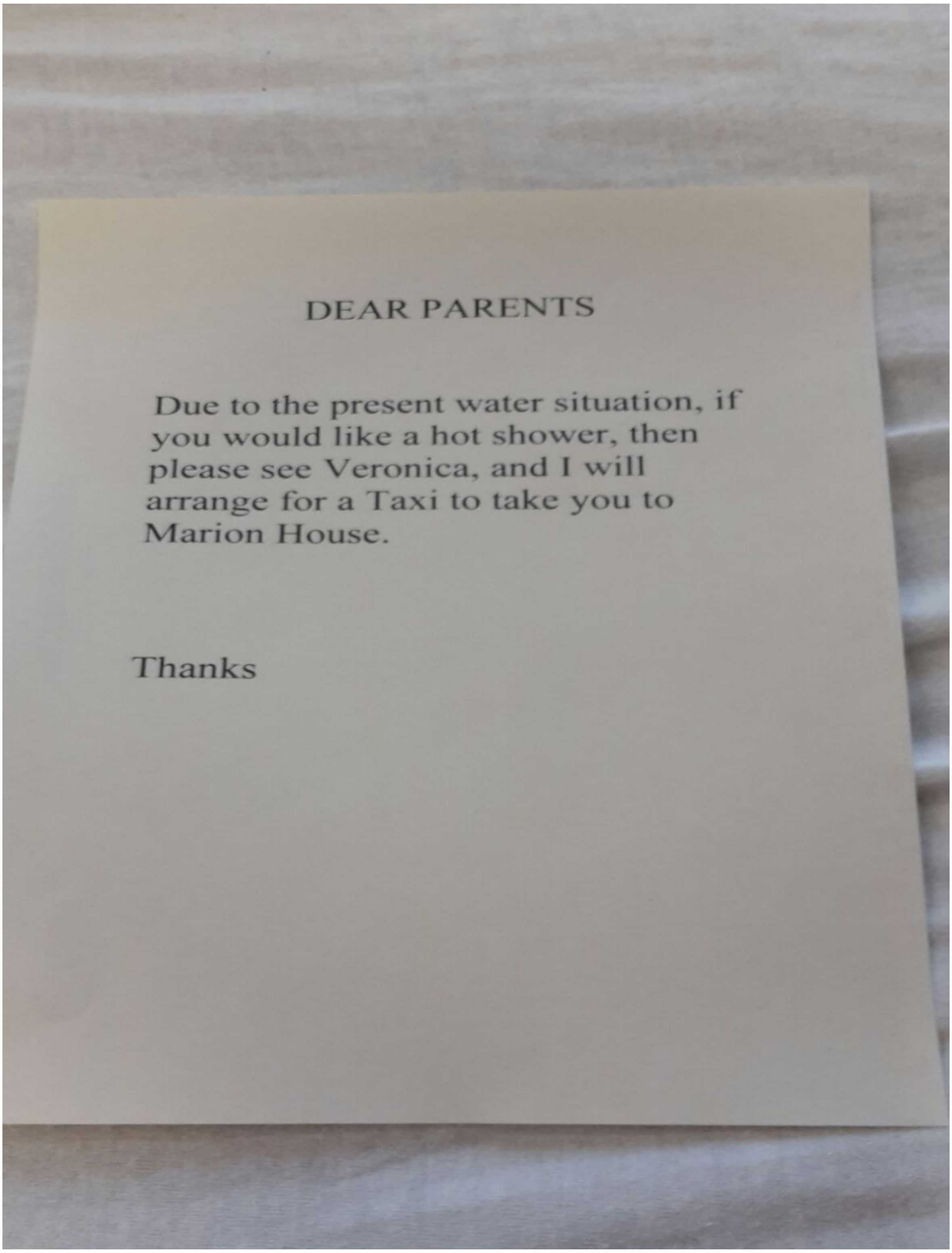
93. Though [redacted] has not been an inpatient there, we had to visit Ninewells in Dundee. It was the Easter just after [redacted]’s treatment and we were at our caravan near Crieff when [redacted] came out with terrible petechiae. We were told that Ninewells was the nearest hospital with a children’s Oncology Department. We were amazed at the facilities there, with rooms that were like suites, with bed and couch and kitchen for family, large TVs and it was hugely impressive. [redacted] said he’d like to be there if he ever needs treatment again.

94. 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.

**LK/01 - Appendix 1**

**LK/02 - Appendix 2**

**LK/03 - Appendix 3**



DEAR PARENTS

Due to the present water situation, if you would like a hot shower, then please see Veronica, and I will arrange for a Taxi to take you to Marion House.

Thanks