

## Scottish Hospital Inquiry

Witness Statement of

**Karen Stirrat**

### WITNESS DETAILS

1. My name is Karen Stirrat. I was born on [REDACTED]. I am [REDACTED] years old. I am [REDACTED].
2. I am the mother of [REDACTED]. [REDACTED]'s date of birth is [REDACTED] and he is 5 years old.
3. I live with my husband, Andrew and our three children, [REDACTED], and [REDACTED] in [REDACTED], [REDACTED].

### OVERVIEW

4. My son is [REDACTED]. [REDACTED] was diagnosed with Atypical Teratoid Rhabdoid Tumour (ATRT) in February 2019 when he was 3 years old. [REDACTED] was treated at the Royal Hospital for Children (RHC) and Queen Elizabeth University Hospital (QEUI) from February 2019 and is still undergoing treatment presently. He attended both hospitals as an in-patient and an out-patient regularly for over two years. [REDACTED] is still under the care of Oncology and attends the QEUI for treatment.
5. I have provided the Inquiry with a timeline which my solicitor helped me to create, showing the dates in which [REDACTED] attended hospital and the wards where he was treated. The timeline is attached to this statement at appendix 1 (**KS/01**) and I confirm it is accurate to the best of my recollection.

Witness Statement of Karen Stirrat

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6. ██████████ spent time in wards 3A which is the Neurology ward, and 3C of the RHC, and wards 1C, which is the surgical ward and 1A of the RHC. ██████████ also spent time wards 6A and 4B of the QEUH. Ward 6A is classed as the Schiehallion Unit where kids with cancer are treated. We never got to visit the Schiehallion Unit when it was in the RHC as it was closed when ██████████ was going through his treatment. Andrew and I took turns in staying with ██████████ as we had our other two children to look after too. I can speak to the experience which ██████████ and I had on these wards.
7. There are some specific events that I would like to mention. ██████████ relapsed in June 2020 and we had to fight to get him treatment otherwise he was just going to get palliative care. There were issues with the water supply throughout ██████████'s time at the QEUH. I found out that ██████████ was prescribed preventative antibiotics in March 2019 which were because of the water supply. There were other issues with the construction of the hospital and the communication around these, when ██████████ was in the hospital which, in my view, impacted his experience. I will come on to talk about these events in more detail. My family has had an earlier experience with the neonatal unit at this hospital in January 2016.

### **FAMILY BACKGROUND**

8. I live with my husband Andrew and our three children in ██████████. ██████████ is one of triplets which includes his two sisters, and ██████████. They are all 5 years old.
9. ██████████ is really close with his family. He had a close bond with ██████████ before he was ill and they used to gang up on ██████████. Those two are very much alike, more like twins. When they all attended the nursery, the staff suggested splitting ██████████ away from them. They were

all kept in the same bubble but [REDACTED] wasn't with them all the time so he has a really good bond with [REDACTED] now.

[REDACTED] and [REDACTED] have been [REDACTED]'s crutch. They help him and he helps them when he can. [REDACTED] and his sisters are due to start [REDACTED] school in [REDACTED] on 17 August this year. As they already attend the nursery there, some of the school staff already know them which is good.

10. [REDACTED] doesn't have many friends out-with his family because with illnesses going around and [REDACTED] going through treatment, we've had to keep him away from a lot of that. The situation with Covid hasn't helped. He has his cousins that he plays with. The older ones have been showing him how to use a play station and an X-box but I still think he's too young for that. There's [REDACTED] kids, including our three, [REDACTED] so they're all really close together. He enjoys going out and seeing his cousins and playing with them, so he's going to have no trouble making friends. [REDACTED] has been brought up in the house with mainly girls so it's good to see him doing boy things instead of just sitting with his sisters playing with dolls.
11. [REDACTED] loves playing games and is very competitive. He doesn't like to lose at anything. Every night I come in from work and I'll sit and play board games with him. [REDACTED] loves the outdoors and he's learning how to ride a bike now which is great to see because when he was going through his treatment, he couldn't do anything like that. He loves the trampoline too and it's been really good watching him build up those skills. [REDACTED] would rather be outdoors than indoors. We're quite an outdoor family and try to get out every day.
12. [REDACTED] has always been a happy wee boy. He loves to run around and just be a normal child. He doesn't let anything defy him at all. Nothing defines him with his illness, he's just on the go all the time. He's just had so much

strength and courage throughout. Looking at him, you would never think he was ill. It's amazing to see how incredible he actually is.

### **FAMILY'S EXPERIENCE IN THE NEONATAL WARD AT QEUH: 2016**

13. [REDACTED], [REDACTED] and [REDACTED] were born at 27 weeks so they were 13 weeks early. Due to this, we had to stay in the hospital with them for 13 weeks.
14. There was a lot of miscommunication with the nurses in Neonatal. There would be times when a new nurse would take over the triplets' care and she wouldn't know the other nurse's shift so you would have to update her.
15. At one point, when [REDACTED] was just a couple of weeks old, she was overfed after staff had missed her feed. Instead of owning up, the staff member decided just to feed her subsequent food so [REDACTED] ended up with quite a lot of food in her tummy. [REDACTED] was really ill after this and had to be put back on the ventilator. Before this incident, she had been doing really well. It was only because we picked up on it that staff apologised and explained they missed the feed and had tried to spread it out and give her more. They should have just told us they missed the feed. To this day, [REDACTED] still doesn't eat very well. We don't know if it's down to that or not but the fact she had been doing really well then a of sudden went back the way, we wonder if it's been down to that. If I've asked anyone later on about it, I've just been told it's due to her prematurity.
16. One day when we popped in, [REDACTED] had an antibiotic in her arm. When we asked staff why she was on the antibiotic. They would just tell you that [REDACTED]'s infection markers were up so we think she's got something. They would never clarify what she actually had. Having three

premature babies, you were busy enough so you just go the stage where you started accepting everything staff were telling you.

17. There were also a lot of times where things were missed or they wouldn't listen to you as the parents. Staff would bring you bottles for feeding your babies and then requested that you purchased some. They would then change the bottles to the cheaper ones and tell you it was because they worked better as they were faster flowing but the babies would be choking and vomiting the feed back up. If you raised this, the nurses would just blame the babies' age. From personal experience and through speaking to other parents though, it was said quite a lot to parents. Nurses would say it was tried and tested methods they were using. They never wanted to do anything new to see if it would help.
18. One day when we walked into the ward, we saw that [REDACTED] had poo in her incubator. Rather than clean the incubator and put it away for it to be properly cleaned, staff just wiped it down with a wipe which wasn't even antibacterial and then just put [REDACTED] back in the same incubator. I was sat there thinking to myself, why have I just accepted that? I was sitting with a baby on me at the time so I wasn't going to be arguing about anything. I was really upset about that though. I went home that night and phoned the Charge Nurse. I told her I wasn't happy about what had happened. She told me that there had been numerous complaints about that same staff member from other parents. I had already heard from other parents that the staff member had been leaving their babies in nappies for over twelve hours at a time and their babies were soaking. We didn't see that staff member after that so we don't know what happened to her.
19. On another occasion, we came in and if I remember correctly it was [REDACTED]'s incubator this time where there was a dirty poo nappy left in with her. All her clothes had been put in the same bag and popped into her drawer rather than separating them out. If the clothes were soiled and had to go in the bin then fair enough but they put them all together in

██████████'s incubator. That was really upsetting to see. Things should be clean, especially around premature babies.

### **Water: Neonatal ward – 2016 to 2017**

20. I noticed signs in the Neonatal ward stating not to drink the water but as it was the first time we'd ever had anything to do with a hospital, I thought it was normal so didn't take much notice of it.
21. When we were in the Neonatal Unit, we had been using the water. It wasn't until all the issues with the water came to light in 2019, when ██████████ was being treated for ATRT, that we found out that Neonatal staff should have been washing the babies in bottled water because there were septic tanks there already. We carried out our own research and found out from Anas Sarwar, MSP, that there was paper work stating that because there were septic tanks there, bottled water was to be used on babies. We didn't know this had been going on when we were in Neonatal in 2016.
22. A year after the kids had been patients, I started working for BLISS, the premature children's charity, in the Neonatal ward. Not once did I see any of the kids being washed in bottled water at that stage either. This should have been happening though. These kids could have picked up an infection because they weren't using bottled water.

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

#### **Admission to hospital: February 2019**

23. ██████████ had been violently sick over 12 hours and he just wasn't himself. Every half hour he was just being sick and I didn't think it was right. Being premature and not having a strong immune system, he hadn't actually been to any kind of preschool things previously and he had just started

playgroup. I thought he had maybe just caught a bug but I was alert; I'm aware of children being sick, but not like that. We left him overnight and hoped that things would be better in the morning. The next morning though, was quite lethargic and I thought it was just because he'd been sick so much. We left him until that evening and my mum came to visit. She had a look at him and said that he doesn't look right so get him checked at the GP. Andrew and my mum took [REDACTED] to the GP. The GP thought it was viral and that he was also dehydrated due to being sick so much. The GP gave us a letter in case we had to take [REDACTED] to A&E over the weekend if he deteriorated or didn't eat or drink anything.

24. Later that evening, [REDACTED] started complaining of a sore head. My mum and dad said to me that headaches shouldn't really be happening at that age as he's too young. I had been trying not to go back to the GP as they did tell me it was viral and I was hoping that was all it was. The next day though, which I think was Friday 22 February 2019, I thought something still wasn't right with and that we needed to get him checked. Andrew took him up to A&E with the letter from the GP. A&E were very busy that night so [REDACTED] was assessed in the plaster room. The doctor that assessed him said it was viral and sent them home with calpol. [REDACTED] doesn't like taking calpol though and just spits it out so the fact he wasn't getting any better, I thought it was maybe because he hadn't had enough calpol. At this point though, I thought it was strange the other two children hadn't been showing any symptoms. Usually when you have children and one of them catches something, they all get it.
25. On the Saturday afternoon, [REDACTED] still wasn't any better so I called A&E again. I told them my husband had been in the night before with but that [REDACTED] was still complaining of a sore head and I was worried. The staff member I spoke to just asked if I had given him Nurofen as that's for headaches. I told her we had only been prescribed calpol and she said to give Nurofen and he should be fine with that. I took [REDACTED] out in his buggy

later on, hoping the fresh air would help but he was just lying there, not himself at all.

26. During the Saturday night, [REDACTED] was writhing in bed shouting, "My head, my head". I let him sleep for a couple of hours to see how he was. Early Sunday morning, I dropped the girls off at my mums and took [REDACTED] back to A&E in the RHC. I just knew something wasn't right with him. The consultant at A&E was able to fast track us as [REDACTED] had been in before. She didn't think it was viral and [REDACTED] had no other symptoms bar the headache from the Thursday night now. I told the consultant I wasn't moving until something was done with [REDACTED]. She said she supposed she could call Neurology. We were moved down to Neurology in the RHC so could get a scan.
27. The on-call surgeon, Roddy O'Kane, was called in to treat [REDACTED]. I was told by Roddy at this point that they didn't know what they were dealing with so he wanted to do an emergency CAT scan and MRI on [REDACTED] but they didn't have time to sedate him as it had to be done very quickly. I was asked to go into the machine with him. [REDACTED] was delirious at this point. Staff had started pumping fluids through him so when he got in to the machine, he was starting to be a wee bit more awake than he was previously. He knew something wasn't right but he was just a wee baby. I heard someone saying they'll have to bring the crash team in because they didn't know if anything would happen to [REDACTED] in the MRI machine. As it was a Sunday, all the staff were leaving to go home. I was saying to them, "You have to stay, we have to get this scan done, you have to come back", and thankfully the staff did come back. In the space of half an hour, they had [REDACTED] in a room and were telling me that he had large mass on his brain which was beginning to bleed and that they had to get him into theatre as soon as possible.

**[REDACTED]'s initial treatment: February 2019**



28. Roddy took [REDACTED] into theatre and he was in there for eight hours. Thankfully he didn't need the crash team. He managed to get the scan done then too. [REDACTED] was in the theatre for the 8 hours and then he was put in to intensive care in the RHC for three days I think. They brought round after surgery and were happy with his progress in ICU at that point. He was going to be admitted to the Neurology unit, ward 3A until we found out further information as a biopsy had been taken.
29. Roddy was very forthcoming with information. I think it was Andrew he had spoken to initially as I had to go home for the girls. Andrew was better at understanding things as at this point, I had been awake for 36 hours. Roddy spoke to Andrew within a few hours of [REDACTED]'s surgery. He told Andrew that things had gone well but he would discuss it in more detail with us both later on. I went back up to the hospital with our parents a few hours later and Roddy spoke to us all. He showed us the X-rays and what he'd seen. He said that we were lucky we didn't go home that evening. If I hadn't have stood my ground and refused to leave until something was done for [REDACTED], then wouldn't have been here in the morning. At that point, the mass had started to haemorrhage and bleed. If we'd gone home, it would have been a full blown haemorrhage and he wouldn't have made it.
30. We were told it could be up to ten days before the result of the biopsy were back. Roddy had said the mass was very significant in size for such a wee person but that he wasn't sure what it was.
31. For the three days that [REDACTED] was in ICU, he was on pain relief. I think it was maybe morphine to begin with then I think he came off that and was given paracetamol. Within a couple of days, [REDACTED] was back to wanting food and being his normal self again, which was so nice to see. Staff couldn't believe how well he was doing considering he had just had major surgery. We were told that [REDACTED] might get bruising on his face over the next few days but this didn't happen until we moved to the Neurology ward.

32. I'm very fortunate in that I stood my ground the night [REDACTED] was first operated on. The doctor we initially saw was very nice but she was willing to send us home without doing anything further for [REDACTED]. Once it was realised that [REDACTED]'s situation was serious, she promised to come up and see how [REDACTED] was doing after his operation. She never did though. It felt as if some of the staff that night were over compensating with promising to visit him because they knew they had messed up. If they had done their jobs correctly in the first instance, I wouldn't have had to fight to get his scan. If I had just gone home, I dread to think what the alternative would be.

### **Experience on Neurology ward RHC; February 2019**

33. After spending three days in ICU of the RHC, [REDACTED] was moved to the Neurology ward. I think this was ward 3A.
34. The ward was so accommodating and it looked like a children's ward. It had nice things on the walls, there was a playroom for the kids to play in and there was even a sensory room. In the sensory room, there were three balls and a soft slide that was to help children get back on their feet after operations. It was this room that got [REDACTED] back on his feet. He was only three years old and he had been in his bed for a week with being ill so when he saw the sensory room, that was him, he would go and play in it which was so nice to see. The playroom was good too, there was always someone around that you could speak to or another child that [REDACTED] could play with. Apart from the facial disfigurement from the surgery, [REDACTED] was back to his normal self.
35. Physios would come in and they were very good in the way they worked; each of them knew what the other one was doing. They were really helpful and they were checking how [REDACTED]'s legs and things were doing after the surgery.

36. The Neurology ward was such a good place. It had parent facilities and a staff room. There was as much there for staff as there was for the kids and their families. You could put things in the fridge on the ward, you could store things and take food in. You could go and help yourself to things too, before Covid, and if you wanted to make toast for the kids or anything like that, you could. There was also a microwave outside the ward and a seating area so families could go and sit there. We had the girls up a couple of times so they could sit down with [REDACTED] and have a meal. It was good that we could sit down as a family and do that. I think this also helped [REDACTED] recover as he was able to do normal things. You were able to do all the general things that you should be able to do.
37. I would say that the Neurology ward was a nice ward. All the staff know all the children and because a lot of them are on the ward long term, the staff take the time to get to know the children and take an interest in them. Everything was really on the ball in that ward, there were no big issues and I trusted all the staff in there 100%. The ward was a sort of circle shape. There were quite a few small nursing stations through-out it and there was a larger one in the central part of the ward which was just across from the big bathroom. At that point in time, they had the big baths that you could use. The only slight issue I had in this ward was that I never saw anyone cleaning the bathroom.
38. I can't remember which room we were in on the Neurology ward but it was just past one of the nurses' stations. There was a TV in the room, I can't remember if it worked or not but there was nothing about the layout of the room that looked off to me. The only thing that I would say was that it was just basic chairs in the room, not the fold back ones. There was also a bathroom adjacent to your room with a shower in it. I think there was also a small wardrobe and a unit too.

39. [REDACTED] had been on the Neurology ward for ten days when he was discharged on 6 March 2019. It was on this day that we first met Dr Sastry, who would be [REDACTED]'s oncology consultant going forward.

**[REDACTED]'s discharge from neurology: 6 March 2019**

40. We had been waiting on [REDACTED]'s biopsy results and knew we would get them on the Wednesday that [REDACTED] was discharged which was 6 March 2019. The results didn't arrive until the afternoon. The surgeon, Roddy came in with another doctor, who was Dr Sastry. Roddy introduced Dr Sastry as [REDACTED]'s oncologist. At this point, I didn't need to know any results as he had virtually just told me by introducing an oncologist. They sat us down and told us that they'd found a really aggressive brain tumour and that it was quite severe. I asked Dr Sastry what the outcome would be but he didn't want to say. I told him I'm direct and prefer straight to the point answers so I know what we were dealing with. Dr Sastry said less than 50%. I was floored. I didn't expect him to say that. I was thinking it would maybe be 70-80%. He said he didn't want us to dwell on that fact as [REDACTED] is in the higher bracket of the 50%. He said that some kids have complex needs that don't go in their favour but that [REDACTED] had nothing like that and he was a well, healthy boy. I asked if it was because he was an IVF baby or if it was because he was premature and he said no. It was just bad luck. I thought, how much bad luck can one family get. It took us so long to have the triplets. They were originally quadruplets but I lost one early on and now this.
41. When we went in to get [REDACTED]'s results on 6 March 2019 and Roddy had introduced his oncologist, I picked Roddy up on this later in the day. I can't fault Roddy but at the time I said to him, when you introduced Dr Sastry, I knew before you said anything else what we were up against. He said he was going to change the way he introduced the oncology doctors in future.

42. Andrew sat and took everything in. I was sitting trembling. I was trying to hold it together for my son who was still there sitting listening to all of this. He was only 3 years old but he knew something wasn't right when he saw our reaction.
43. We were given a timetable of the treatment plan for [REDACTED] by Dr Sastry and Roddy but I couldn't take it in at that point. Andrew was really good here as he knew what we were up against. They asked us if we had any questions but I just wanted to get out of that room and go home. They told us they had been on the phone to all the UK hospitals and America too about [REDACTED]'s tumour as it was so rare and treatment options. America were more advanced so they'd already given Dr Sastry and Roddy information and advice but they were still waiting on other bits and pieces being confirmed. Dr Sastry and Roddy said they would tell us in due course and keep us updated.
44. [REDACTED] had been himself over the previous ten days. I remember being on the phone to my mum the day before that telling her we could get devastating news and be told [REDACTED] had cancer but at the time, I didn't think it was that. We were asked if we had any questions and I asked if we could go home. I just wanted out of that room. We left and were told that [REDACTED] would have to come back to the hospital for chemotherapy but we thought we would have a couple of weeks before that started. A couple of weeks as a family where we could do things together.

#### **[REDACTED]'s admission to ward 6A: March 2019**

45. Initially we were told by Dr Sastry that [REDACTED] would have to come back to the hospital within the week to get his Hickman line fitted with the plan to start chemotherapy in the next couple of weeks. We had only been home for a couple of days and then received a phone call from the hospital to take back up to the QEUH the next day. This was possibly 8 March 2019. I was told to go to ward 6A on arrival. I did think it was strange telling me to go to ward 6A but I didn't know the Schiehallion ward had been moved. I think it was a male

nurse that called us. I remember as there was only one male nurse and he introduced himself when I entered ward 6A as the person who had called me. We had previously been told by Dr Sastry and Roddy O'Kane on 6 March 2019, that [REDACTED] would be getting treated in the Schiehallion ward. We were told it has a nice new play area, like a nursery facility. I was told would have good fun there.

46. I was quite glad when I heard about everything they had in the Schiehallion ward as it meant [REDACTED] wouldn't be missing out. [REDACTED], and [REDACTED] had only started play group six weeks before this all happened as they were premature and the girls had been on oxygen so we weren't allowed them at playgroups and things until they had built up their immune systems. We were told by the hospital staff that we would need to take and [REDACTED] out of playgroup due to risk of infection to [REDACTED]. [REDACTED] had only just started to settle at play group too so I thought at least he was getting something on the ward that he could do.
47. There was confusion when we first arrived on ward 6A; it was as if they didn't know what to do with [REDACTED]. We thought with the way things were explained in the phone call, that [REDACTED] would be starting treatment that day as staff at the QEUH had been told by doctors at other hospitals that [REDACTED]'s condition was too serious to be left. However, it wasn't until the next day that things were put in place for him. Nobody seemed to know what was happening and I was just told I would need to speak to my doctor. I didn't see the point of us going in that day and we could have had another day at home. I don't think the staff knew what they were doing. We were getting bombarded with things at this point but we weren't really taking anything in. The communication at this stage wasn't that good. Nobody knew what the other one was doing.
48. We were asked some basic questions about [REDACTED]'s medical history by a nurse. I had a discussion with the nurse about [REDACTED] being fitted

with an NG tube as we weren't told about that. I asked why [REDACTED] was getting it and what it was for. The nurse said that kids don't eat when they're having treatment. I asked if we could give [REDACTED] the benefit of the doubt and see if he wanted to eat first and then give him the tube if he didn't but they were hesitant and kept saying that they thought I just needed to let get the tube fitted. I was thinking, this is going to get forced in him when he's awake, which I was against, and I told them they can't do that to him as he's only a child. The staff said they could put notes in to say, "Mum wasn't happy", but it wasn't about being happy. It was the fact that they had only just told me all of this and I was upset. I think in the end, staff said [REDACTED] could get the NG tube fitted when he was in surgery getting his line fitted which I thought was better than trying to insert it when he was awake. I was told afterwards what the feeding tube was for and how it would help [REDACTED] but only because I was asking questions. I was worried that [REDACTED] would pull the NG tube out as he didn't like the feeling of certain things on his skin. The staff just kept saying it would be okay. Staff do this every day and it's just a job to them. I think they forgot that as parents, it was all new to us and not something we were used to seeing.

#### **Experience on ward 6A: March 2019 - April 2019**

49. The day after we were admitted to ward 6A, which was maybe 9 March 2019, had his Hickman line and NG tube fitted in surgery under a general anaesthetic. Staff didn't go into detail about the Hickman line. All they said was that it was for giving him chemo. Staff said they could give us a booklet that would tell us a bit more about what it's like. I don't recall staff giving me any other information about the Hickman line just that when they put the chemo in, they said they were pushing it through the line. I think the day [REDACTED] got the Hickman line in, someone came down and said how they were going to do it but no further details were given. To this day, my knowledge of the Hickman line is still the same. It was at this point that the nurse said they were going to get the dietician in to speak to us about the NG tube and [REDACTED]'s milk. I asked what an

NG tube was. Obviously I had a rough idea what they were because the kids had them when they were babies in neonatal. The nurse said all the kids get fitted with an NG tube when they start treatment. I'm not 100% sure but I think had chemotherapy in his spine at this time. He would have had a lumbar puncture carried out too at this point. Staff do try and do everything like this at the same time so they don't have to take kids into surgery more than they have to.

50. I gave [REDACTED] a bath a day to two after his Hickman line was fitted. The nurse was changing the plaster and putting a clean one on over his dressing and the Hickman line. My sister was with me at this point and she has previous experience at the hospital so she pulled the nurse up for putting the plaster on 's wet skin. She asked the nurse if she was trying to cause an infection as she had just put the plaster over wet skin. The nurse was quite startled so rather than peel the plaster off [REDACTED], she just yanked it off him. [REDACTED] was crying horrifically at this point and after that, he was very, very fearful of his Hickman line and would have to be pinned down to get it cleaned. I'd been too scared to say anything that time as it was all new to me and we hadn't been in the hospital that long so I was glad my sister was there.
51. The room he was in at first was right up the back end of the ward, nearer Day Care. I think the room number was in the twenties. I found out the area they were using as the Schiehallion Ward is the adult unit that used to be the cancer ward. Initially both wards 6A and 6B were adult cancer wards but they had amalgamated into one as the new children's ward. Nobody ever told us that though, they just told us where the cancer ward was. It was only when we spoke to other parents that we realised this wasn't the original Scheihallion ward.
52. I had been telling [REDACTED] about the playroom, even on the way into the ward, I had been talking to him about it but when we walked in the ward, it was just grey. There were no bright colours or friendliness and it was very narrow. It looked boring. Once we were settled in, I asked one of the staff where the



playroom was and she looked at me like I was a clown. She asked me what playroom and I explained I had been told there was a playroom that could go and play in. She turned around and said, "Oh, that's the playroom there", pointing to a plastic table with two little plastic chairs and a packet of crayons. The thought of it was hurtful. Out of everything, even now, that was really, really upsetting for me; I remember having to go back and tell there was no playroom. How are you supposed to sit there and tell a child that everything you had previously been told was wrong and therefore you had told him about stuff that wasn't there? Looking back, I realise that when they were first telling me about the playroom, they were describing what the Schiehallion used to have. [REDACTED] was crying when I told him there was no playroom. As we were going to be in there for so long, I was wondering what I was going to do with him. At that point, I decided I needed to make it fun for and bring our own stuff in. People started rallying round and buying him gifts and things to take in to the hospital. Coming from neurology where it was so fun and friendly, he was expecting the same where he went. To go from that into nothing, where it was like a jail, was disappointing.

53. I mentioned to staff that I had some food to put in the fridge. They told me they didn't have a fridge and that there were no parent facilities on the ward. They didn't even have anything for making a cup of tea. They said they would make me cups of tea and bring them to me. There was also nowhere to sit so you couldn't speak to other families.
54. I was overwhelmed at what we had walked in to. Within the space of an hour of us being in the building, we had found out there were no children's facilities, no parents facilities, nowhere to sit. We couldn't even look out the window as the blind was broken.
55. [REDACTED] was stuck in his bed attached to a chemotherapy machine for three of four days as the battery pack didn't work. He was still in a cot at this point and he was stuck there. At one point, they had him hooked on to a

machine for 12 hours because there was nobody there to detach it even though he was finished his treatment. One of the nurses came in and joked that it was like a wee jail. I thought she can't be serious, she was actually joking about this; had been hooked up to that machine for so long but I couldn't say anything to her as I wouldn't be able to stop and it was early days in the hospital. [REDACTED] was in his cot for so long a physiotherapist had to visit him.

56. During [REDACTED]'s admission, he kept spiking a temperature so he was put in an isolation room which was a normal room but extra measures were taken; staff would gown up and there would be a sign on the door saying to contact staff before entering. In general terms, if you've got a bug you might be put in there depending on how serious it is. Staff put a note on the door about the isolation and staff are supposed to wear gowns when they come in. I'm sure at one point we were told he had an infection. There was a note put on the room door saying that nobody was allowed in. We were in there for three or four days as they were waiting on blood cultures coming back. Usually you get put in to isolation if your child has caught a bug so that they don't spread it to other children. [REDACTED] would get put on antibiotics but we were never told what they were or what infection they were treating. If you asked any of the nurses, you were sometimes just told it was because of the chemotherapy. It didn't make sense to isolate [REDACTED] if it was that.
57. Sometimes, if the children have a temperature they're put into isolation and there's a protocol that's followed. Whenever [REDACTED] was put into isolation, there was a sign that got put on our door saying nobody was allowed in the room and we assumed that when isolation was over, someone would come and tell us. On one occasion, after being in isolation for three or four days, [REDACTED] was allowed to go out and play on the ward. The nurse that had originally put us in isolation was off and it was another nurse that told us [REDACTED] could leave his room. However, when the other nurse came back on duty, she said [REDACTED] had to go back into isolation and shouldn't have been allowed out. I asked why he was put in isolation in the first place but I never got any answer. They always

said they would go and get someone else to speak to you then they disappeared. Nobody would come and speak to you.

58. [REDACTED] was given fluids after his chemotherapy and the doctor had said to the nurse for him to be taken off them. He was connected to chemo and fluids but he had the fluids for an extra 24 hours. The nurse hadn't taken them off when the doctor had told them to. I think it was Dr Sastry that asked the nurses why [REDACTED] was still on them as he told them to take it off [REDACTED] the day before. The nurses told me to watch for swelling as he shouldn't have had so much fluid. They said they would investigate why this happened but nobody ever came back to me about it. There was no apology either.
59. It would sometimes be different staff that dealt with [REDACTED]. There were student nurses there too but they weren't allowed to administer anything so you would be going back and forward with things and sometimes miscommunication became an issue. Some of the nurses gave you the impression they didn't even want to be there as they took no interest in [REDACTED] and a lot of the nurses were leaving too. I think there was a lot of bank staff there which didn't help and I think some of the nurses were leaving due to the stress they were under due to everything that was happening. Around Christmas time 2020 when was at the hospital with the meningitis, one of the nurses that had originally dealt with [REDACTED] when he was first diagnosed asked me why we were back at the hospital. I told her what had happened to [REDACTED] and she said that nobody had told her anything and that things have been kept from her. She said half the nurses had left because of the stress; it had been one things after the other then the water situation and the lies and now with Covid, everything was being blamed on that. There was also a lot of scare mongering about the Inquiry. Sometimes you would hear things but the they didn't want to discuss it any further. I had also noticed the changeover in staff. There were a few familiar faces but a lot of the staff were new. Medications were sometimes missed, or under-dosed or overdosed as [REDACTED]'s records weren't filled in correctly so you had to be on the ball with his medication. The records not

being filled in correctly meant that the next person to come in and see had no idea what had been given by the last person.

60. There was nothing really for [REDACTED] to do when he was in the ward so I managed to get one of the blue play mats for him to play on. You were able to attach the medicine for the chemotherapy drivers and there would be just enough room for him to sit on the floor on one of those mats, which was better than sitting in his bed all the time. When we first came into the ward though, staff would often tell us that there were no mats available or they didn't know where they were. One day when I was walking through the ward, I noticed that the mats were being stored in a make shift bathroom at the front of the main entrance to the ward. There were quite a few mats in there. The nurses knew that every time Andrew and I came in the ward that we would ask for one of those mats so [REDACTED] could play with building bricks and just be a normal child for a while.

### **[REDACTED]'s Proton Beam Therapy and readmission to QEUH on return to Glasgow from Florida**

#### **April 2017 – October 2019**

61. [REDACTED] had been in ward 6A at the QEUH for about six weeks as his blood counts weren't at acceptable levels for him travelling to Florida. [REDACTED] was getting blood and platelet transfusions as this point until his blood counts came up to an acceptable level. Proton Beam Therapy was thought to be the better of the two radiotherapies. It has more of a direct hit rather than shooting everywhere, was how it as described to us. Proton Beam Therapy would hit less cells so wouldn't impact [REDACTED] as much with his development so it would be better for him. We were told that his case had to go in front of a panel who made the decision as to whether he would get the treatment.

62. Earlier in April 2019, there had been talk of [REDACTED] going to Florida for Proton Beam Therapy. We were told by one of the outreach nurses that the Board had agreed to him going but that it would be at least a six week wait for him. The outreach nurse however, then told us that we were going that week. She said she had told them in the meeting to make sure they spoke to us about going but nobody had. Bearing in mind, we had another two children to try and sort childcare out for too, telling us last minute wasn't ideal. There was miscommunication round [REDACTED]'s trip to Florida; at first we were told that [REDACTED] would be going with one parent then we were told it would be with two parents. They then told us that all three of our children should go due to them being so young but that they wouldn't pay for them. Initially it was one parent they paid for and we were to raise funds for the rest of the family. I was then told to take [REDACTED]'s grandparents to help with the other kids when we were over there. All of this was miscommunicated to us. The communication around Florida wasn't good at all neither was the duty of care carried out before we were sent over.
63. On 22 April 2019, [REDACTED] was discharged from the QEUH and sent to Florida for Proton Beam Therapy straight from the hospital. [REDACTED] was just out of hospital and was seriously ill. We had to triple dose his medication to get him to Florida. The journey out there was an absolute nightmare. We had to liaise with three different airports that hadn't been informed that there was an immune-compromised child on the flights and as [REDACTED] had an NG tube fitted, we had to cart two massive trunks of milk with us which was a nightmare. We had to take the milk with us as staff at the QEUH didn't know if they had the same suppliers in Florida and if the milk connectors would fit [REDACTED]'s NG tube. I can't remember if [REDACTED]'s NG tube fell out or not but the doctors in Florida decided that as he was able to eat and drink, they didn't need it put back in for the milk feeds. They had facilities at this hospital that enabled [REDACTED] to eat and drink easily. [REDACTED] used the NG tube for some of the medications but because he was doing so well with his eating and drinking, he didn't need it for that. We were originally meant to

be in Florida for 12 weeks but ended up only staying for eight; there was a mask that was designed for kids and that took two weeks to make but as was sedated, he didn't need the mask. That and the combination of him eating and drinking meant we could leave after the eight weeks as he finished his treatment quicker.

64. There were a few things that happened en route to Florida and when we first arrived there that I know aren't part of the Inquiry but I'd like to mention them. We had to get three connecting flights and the airlines hadn't been told that was immunocompromised. The accommodation in Florida was dirty and builders had only just left before we arrived. We had paid extra to upgrade and it wasn't how it was described to us. Florida hadn't received [REDACTED]'s notes from the QEUH either. We were told by staff in ward 6A that all of [REDACTED]'s notes would be sent over before we arrived. There was also an issue with the positioning of [REDACTED]'s NG tube as they didn't scan him to see if it was in the right place. We didn't have much time as the trip was brought forward and we had to organise things last minute and still fundraise.
65. We had to do a lot of the organising for the trip to Florida ourselves. We were given a list of approved hotels from the Florida Hospital that we could book and we had a contact, Coral Brady, from the hospital finance team in Glasgow. Coral was organising the flights and everything for us but I had to chase up things. We had to organise all the insurance and I had to tell the company [REDACTED]'s circumstances which I think I shouldn't have had to do, I think this should have been the hospital that did this. Things were bedlam on the ward and I was having to phone insurance companies and the hospitals. I was told I would have to pay the insurance out of my own pocket and they would pay it back to me. I had to organise the car and the house we were staying in too. Everything was left to the last minute. I think they also could have flown us out a few hours later; it was Easter Monday and the cost of flights had sky rocketed. I know that [REDACTED] had to go but a few hours wouldn't have made much difference. We had to find more money to pay for the flights. We

were also told to get our faces in the paper to raise the money as we had to go now so that was quite hard too. We were told we would have special assistance on the flights but when we got there, there was nothing in place for us. We had to organise transport from the hospital too. I think we phoned the taxi and the hospital paid for it. We shouldn't have had to deal with all of that, we should have had it all organised for us so we could just focus on going with [REDACTED].

66. We got home on the Wednesday which I think was maybe 19 June 2019. It was a long flight and as [REDACTED] wasn't due his next batch of chemotherapy straight away, I asked the staff in Glasgow if we could spend a couple of days at home and they agreed. We went back to ward 6A on the Friday of that week and [REDACTED] started his chemotherapy again. When he was in Florida, couldn't get the stronger doses of chemotherapy so the two lots that he missed, were administered back to back. It's the chemo which I think was called DOX. [REDACTED] was really sick when he had that before. I don't know if he wasn't given it at the same time as the Proton Beam Therapy because they didn't mix but he couldn't miss them as they were the most serious ones in treating him. They had to give him them every two instead of every three days.
67. At this point, [REDACTED] was an in-patient for his chemotherapy. He would have five or six days at a time in the hospital then he would have two or three days off. As time went on, the more time he spent as an in-patient. It got to the stage that although he was only meant to be in as a day patient, he ended up being an in-patient or he would get to the stage where the day that he was off he would come would have to go back in because he was so sick and he needed so many blood and platelet transfusions. I said to staff jokingly one day that I would have been as well bringing my bed to the hospital as we were going home very late in the evening and coming back very early the next morning. It was cruel on [REDACTED] as he wasn't getting any time at home.
68. As there were no parents' facilities on ward 6A for me storing food for

██████████, the nurse put ██████████ back on the bolus feeds, which are milk feeds. I was angry at this and burst out crying so I had to walk out but I had to stand in the corridor and cry as there was nowhere else for me to go. ██████████ had been doing really well with his eating and drinking in Florida and had been progressing because of that. It was like being in a jail. I don't think he should have had to go without proper food because the hospital had nowhere for me to store it.

69. ██████████'s admissions continued in this pattern from June 2019 to October 2019. I think it was the middle of October that ██████████ finished his treatment. He still had his Hickman line in at this point as he was due a scan so many weeks after his treatment ended. He was due to get his line removed the week before Christmas but it was brought forward a few weeks for several reasons, including me asking questions about the medications he was on. We were originally told there was a waiting list to get the lines out and Dr Sastry had said it would likely be Christmas time it was removed. When I was asking more questions, we were then told ██████████ could have his line out. I knew other families who had kids that had finished treatment but had to wait until after Christmas to get their lines out.

#### **SEQUENCE OF EVENTS FROM MAY 2020 UNTIL PRESENT DAY (2021)**

70. ██████████ had a scan in March 2020 which was clear. However, in May 2020 his behaviour had started to change. He became aggressive, eating constantly and just wasn't himself. I called the Schiehallion Unit and spoke to one of the nurses. I explained the changes in ██████████'s behaviour and that I was worried. Previously, Roddy, the surgeon who initially operated on ██████████, had said if we noticed any changes in ██████████ like this, to phone the Schiehallion Unit. The nurse told me she would get someone to call me back. It was the on-call doctor that phoned me back. He asked how was and I explained the situation to him. He said that he would speak to Dr



Sastry but as [REDACTED] had a scan due, just to monitor him until then. The scan however, was delayed due to Covid so [REDACTED] got his scan four and a half weeks after that call.

71. On the day of the scan, we were called in by the staff. Due to Covid protocols, we were told that children could no longer have family members with them when they were put to sleep for the scan. But the day before, someone had shared a post on Facebook stating that wasn't the case and the families who were part of the Schiehallion Unit were allowed into the scan with them as the children had been through so much already. [REDACTED] had already had between 40 and 50 anaesthetics by this point so he knew the process but he needed someone there with him for reassurance. I knew he wouldn't sit still for the staff if one of us wasn't there with him. As the scan was being performed in another ward, 1C I think, we weren't treated as Schiehallion patients at all. I was told by staff that they would give [REDACTED] a mild sedative before they took him away. At about 9am the doctor said to the nurse that [REDACTED] would be going down for his scan at about 9:30am so to give him the sedative now. The nurse disappeared though and didn't come back until 9:20am. She gave me something which I had to force [REDACTED] to take then informed me it was ketamine. She didn't tell me the impact this would have on [REDACTED] and he started swaying. I had to hold him up. It was horrible. I couldn't believe what I was seeing. It was as if [REDACTED] was paralysed from the mouth down and he was making this horrible gargling noise. When one of the other staff members asked if [REDACTED] was okay, that nurse said he was fine and had just had his sedative. Staff took [REDACTED] down for his scan and I was allowed down with him but not into the scan room. When they brought back up, one of the staff said after he had come round he was feisty and was fighting against them. He's never usually like that. He couldn't get out the bed when he was given back to me so I was confused as to how he could've been feisty during the scan.

72. After a while, [REDACTED] had started to come round and staff told me to feed him something. I gave him some food and [REDACTED] started choking. One minute he would be with you then the next he would be away on another planet. It was as if the sedative hadn't worn off. I told staff I was worried as usually he comes round very quickly and is on his feet and out the door within half an hour.
73. I believe [REDACTED] shouldn't have been given the ketamine and had that nurse done her job properly, he could have had his usual sedative. Nobody had told me about any of the side effects with this one. We took him home after about an hour but he still wasn't right at home. I had to call the Schiehallion Unit and explain what had happened to them. They said to put [REDACTED] to bed and see how he is when he wakes up. Thankfully when he did wake up, he was fine.
74. On the morning of 1 June 2020, Andrew took a call from the Schiehallion Unit. We were told to take [REDACTED] straight up to the hospital as staff were reviewing the scans at 12:00pm. I knew something was wrong as before had that scan, they asked if we were okay for them to phone us with any results. Once we were at the hospital, we were met with Roddy and Dr Sastry who told us that [REDACTED] had relapsed.
75. When we were initially told on 1 June 2020 that [REDACTED] had relapsed, we were told by Roddy, Dr Sastry and the charge nurse, Angela, that had a mass again in an adjacent area from his previous mass and that there were three other spots. I asked what the plan would be and they said they were sorry, but it would just be palliative care, there was nothing else they could do. I argued the point as I'd done research and I was on a Facebook page for other ATRT families so I knew there were other treatments available. None of the three of them were very forthcoming with information. They offered to get the scans to show me but I found it very odd that they had all just come out of a meeting where they were discussing the scans, yet none of them had any

paperwork on them. I asked about Alisertib, which was a drug I had found out about from a Facebook group I'm a member of, and Dr Sastry told me it was something they couldn't afford on the NHS. I was shocked at this. He shouldn't have been saying these things. I begged if there was anything they could do. Roddy was sitting with his back against the chair at this point as if he didn't want to be in the room with us. He had always been forthcoming with us so this wasn't like him at all. I asked him outright what his opinion as a surgeon was and he replied that he could operate. Dr Sastry glared at Roddy, it was as if he thought Roddy was undermining him.

76. After we had spoken to Dr Sastry and Roddy, we were sent home. Dr Sastry had dropped this bomb shell then we were told there was no palliative care team or follow up in place at the moment. We were told that [REDACTED] would get a weakness down his side and he would have seizures and when it got to this point, we were to email the hospital and let them know. There was no support for us at all and no real explanation. I said I wanted a second opinion and Dr Sastry replied to say that everyone in the room had agreed, even the Beatson Team had agreed that nothing else could be done. I was devastated. We went home and tried to get our heads round what we had been told.
77. On the Friday of that week, which I think was 7 June 2020, after what we had been told on the Monday, Andrew said he thought there was something up with Roddy and that I should phone him. I did phone Roddy and his secretary got him to call me back. I said to Roddy that he once said if we had any questions, we were to contact him and I wanted to know what the hell was going on. I said to him, "You told us you could operate and the rest of them are telling me they're not going to do a thing, it doesn't make sense to me." He replied that if it was his child, he would fight tooth and nail for him and if we could get him the medication, he would operate on [REDACTED]. He gave me his secretary's email address and phone number and had told his secretary to let our calls through.

78. After I had the chat with Roddy on the Friday, we were trying to find medications that could help. I had put a request up on Facebook asking if anyone else was in a similar position and a parent replied on the Saturday telling me about a drug called tazemetostat. She said her child was on it and they were based in the UK, Manchester. I managed to get hold of the oncologist, Dr Kilday at Manchester hospital for children on the following Wednesday. Dr Kilday had then started to email Dr Sastry and was waiting for him to return paperwork. Dr Kilday even offered to fill in all the paper work for Dr Sastry just to sign it but Dr Kilday had nothing back from Dr Sastry and asked me what was going on. I was really surprised at Doctor Sastry not helping as he sat on the Board that dealt with trials. I let Roddy know what had been going on and it was decided that he would liaise with Dr Kilday as he had previously trained with him. Roddy took it out of Dr Sastry's hands and sent the scans to Dr Kilday. Roddy wasn't bothered about the consequences for himself at this point. I don't know if he could have gotten into trouble by doing all of this for us.
79. Round about 9 or 10 June 2020, [REDACTED] was at home and his headaches were being treated by morphine but the dosage was only half of what it should have been. He was on this for two or three days when he had to be readmitted to ward 6A. No member of staff ever apologised or explained this.
80. [REDACTED] was back in hospital due to headaches and he was still on morphine for them. Dr Sastry was in the room and he said that should be allowed to make memories and I thought, memories? I said to Dr Sastry, "Are you for real? He's lying in a hospital bed not even able to speak. Is this his memories?" Dr Sastry never really said anything after that. I think he knew how I felt about it. He said that he had been in touch with the trial company and hopefully they would come back to him. Hopefully. The word hopefully wasn't helping me. He knows with ATRTs you only have days, not months or even weeks. You have days before that haemorrhage and that's it. I was asking him to get me the answers but he was dragging his feet on it. [REDACTED] was initially admitted to ward 6A then was transferred to ward 3A shortly after being

admitted as he was going to be Roddy's patient and the nurses there were more trained than the oncology nurses as it was the brain they were dealing with. It was decided [REDACTED] would stay on that ward until after his surgery.

81. The outreach team hadn't been in touch with us either. There was no other direct communication with the hospital. I think it was me that made contact with outreach team first and told them what was going on. They weren't even aware of the situation. They knew we were getting bad news but they didn't know where we were with the situation. The outreach nurse said to me that we needed to get the ball rolling now and I explained I was trying to do that but nobody was listening to me.
82. Coincidentally, Florida phoned at that time to see how [REDACTED] was doing. They said that they never hear how the patients are doing as Glasgow send them over then never update them but they needed information about patients' progress for their research. I explained to them what we'd just been told by Roddy and Dr Sastry. Florida said they would be on board with us too.
83. I later asked Roddy what had happened at the meeting on 7 June 2020 that he attended before speaking to us. We had a call to bring [REDACTED] to the hospital with us but to then be told in front of your child there was nothing that could be done didn't make sense. Roddy told me off the record that he had looked at the scans on the Thursday and Friday of week before and had the plan in place for what he felt he could do so he knew he could treat at that point. He knew he could take away the mass but he didn't know the oncology side of it. He was under the impression he was going to be operating on [REDACTED] that day which is why we were asked to bring him with us. He knew oncology would have to give [REDACTED] some form of treatment but Dr Sastry had said there wasn't any. The Board then unanimously agreed with Dr Sastry. The Beatson Centre had advised the Board that as had been given Proton Beam Therapy, it was too soon to do more treatment on him so they felt from their side, they couldn't do anything either. Roddy was

annoyed as the Board had blocked him doing his job. He apologised for his body language when he later spoke to us. I said in reply to Roddy, "Don't you dare apologise because if it hadn't been for your body language, and the way you reacted in the meeting with us, and then telling us you could operate, I would never have known anything was wrong. I would have just gone with what was said about the palliative care. You effectively saved my son".

84. We were told that there were three shadows on the scan and Roddy told us that one of the spots was crossing a certain ventricle which was a risk. The first time Roddy operated on ██████████ in 2019 when he was first diagnosed, he went in not knowing what he was dealing with at all as it was all so sudden so potentially ██████████ could have died at that point. There was no time to think and discuss what to do the previous time, Roddy just had to act so this time round, it was pretty much the same thing but there was slightly more time to think about it. Dr Sastry however, was thinking along the lines of the team could operate but it risked leaving ██████████ in a vegetative state. He didn't say this but that was impression I was getting from him. The team could operate on ██████████ and still lose him. I wasn't happy with that. Roddy then informed us all that the other shadows in the scan could just be scarring from ██████████'s initial operation so they might not be anything to worry about. I was annoyed at this as we were originally told the three spots were cancerous and now we were being told they were shadows that might not be. Was this to throw us off the scent and make things look worse than they actually were? This is how I was feeling at that point. I'd lost all trust in Dr Sastry now too. I didn't want him to be with us. He should have been fighting my corner.

85. At some point when we were in Florida, the Christie, a new centre had opened in Manchester. The Christie did the Proton Beam Therapy like they did in Florida so we could liaise with them now instead of Florida. We had actually been the last family to fly to Florida for ██████████'s treatment. There was a meeting set up with the Christie and various London Doctors. They all unanimously agreed that ██████████ should be given the option of

tazemetostat, which was the trial drug, after having the option of surgery. That was the treatment plan that was agreed on at that meeting. Florida had also been keeping in touch at this point and they were chasing things up at their side. They thought because the second tumour was so near the original one that [REDACTED] had removed, that it sat just outside the area that the Proton Beam Therapy was concentrated on. They thought that's why relapsed as the Proton Beam therapy wasn't strong enough to hit the other cells. Proton Beam Therapy is more direct than radiotherapy. Radiotherapy would have hit off outside areas too. It wasn't the QEUH that told us all of this, it was Florida and the Christie.

86. Due to the situation with [REDACTED] being so serious in case of haemorrhage and Roddy wanting an electrode team in so they wouldn't hit a certain part of [REDACTED]'s brain that would profoundly affect him. The electrode team pin point how far away from the nerves the surgeon is going. [REDACTED] had a wall and within this there was a vessel that they didn't know if it was debris or the tumour that was pressing against the wall. If they hit the vessel, could have bled out so to minimise the risk, the electrode team would tell Roddy how far down he could go. The operation couldn't be carried out until the Monday, which I think was 15 June 2020, when this team were available. From the Thursday to the Monday, [REDACTED] was kept under close observation and a theatre was kept free in case he deteriorated and the operation had to be done in an emergency. [REDACTED] managed to make it to the Monday though and he had his operation.
87. [REDACTED] was in ICU for a couple of days in the RHC then he was transferred to the Neurology ward which was ward 3A I think, for about six days. I think it was the Saturday that we asked one of the on-call doctors if we could take [REDACTED] home. Roddy was off that weekend so we hadn't had the chance to catch up with him and neither had the on-call doctor. However, the on-call doctor reluctantly agreed to let us take [REDACTED] home due to them all being happy with his progress.

88. We had been home for about two weeks when the outreach team called us to tell us the Beatson Centre wanted to see us. The outreach team, are a team of nurses that act as your point of contact if you're an in-patient or an out-patient and they can take bloods at your home so you don't have to go into the hospital. We already knew that [REDACTED]'s medication from the trial had been approved at this point and we were just waiting on [REDACTED]'s surgery healing so he could start on it. I asked why the Beatson wanted to see us but the outreach nurse said she wasn't 100% sure but thought the Beatson might be offering treatment. We went to see them with the outreach nurse and they said they wanted to offer [REDACTED] six weeks of radiotherapy. I couldn't get my head around this as they had earlier stated they couldn't give anything. They were now telling us that due to how well [REDACTED]'s surgery had gone, they didn't want to give him the trial drugs, they wanted him to have the radiotherapy first.
89. I'm a member of a Facebook page for ATRT so I knew about the trial drug already. There was a wee girl diagnosed with the same thing as [REDACTED] and she relapsed. She had been put on the drug round about the time was going to be getting palliative care. The trial drug was also a big thing in America so we knew that we could ask for it if [REDACTED] relapsed. We didn't know if the drug was available over here though as the wee girl was in Ireland and they're slightly different to us. A parent from Manchester got in touch with me to let me know her child was on it so we then knew the drug was available in Manchester. This is why I was so angry at getting told would just be getting palliative care. I was told by Dr Sastry when he told me about [REDACTED]'s relapse that we couldn't get the drug on the NHS yet I found it was already in Manchester through my own research.
90. [REDACTED] started the radiotherapy at the end of June 2020, possibly the beginning of July and it lasted for six weeks. He was attending the Beatson every day, five days a week for these six weeks and then he was to be seen



over at the QEUH, Ward 6A every Thursday so they could check his bloods and make sure everything was fine with him.

91. I think that three months after [REDACTED]'s surgery, there was another scan performed on him but I can't remember. He started his trial drug on 1 October 2020 and has been on that since. He takes the drug every day, twice a day. Every second Thursday, he has to attend the QEUH to get his bloods checked to make sure he's still on the right path. [REDACTED] gets a scan every eight weeks which the hospital had tried to move to every 12 weeks without consulting with me and this is when I had it out with Dr Sastry regarding the communication and his lack of support when [REDACTED] relapsed.
  
92. In December 2020, [REDACTED] had been complaining about a sore ear which the GP and ourselves had initially thought was maybe congestion as did have a touch of the cold. After a few days, he started complaining a wee bit more so I called outreach and they told me to take him in. Andrew took him in to ward 6A and when they arrived, staff checked [REDACTED]'s ear and there was illuminous green stuff in it which staff said they had never seen before. [REDACTED] was sent down to Ear, Nose and Throat (ENT). ENT had a look at [REDACTED]'s ear and told Andrew they also hadn't seen anything like that before either. They said it was maybe contrast dye from his last scan and it was weeping or it could be the start of an ear infection but they didn't give [REDACTED] any treatment for it. ENT had also mentioned to Andrew that it could be a wee section in his head where the bone had moved to his ear so they were half blaming the surgery [REDACTED] had. Andrew was told that [REDACTED] might possibly get a temperature and if there was any fluid leaking in his ear, it was CSF fluid and to get [REDACTED] straight to A&E. ENT had wanted to do a scan but as this was mid-December and [REDACTED] was already due a scan at the end of January 2021 for his head, it was decided to wait until then and do the scans at the same time.

93. Two days later, which was a Thursday, [REDACTED] was back at ward 6A for his routine bloods and Andrew had asked if there was any information from ENT. The Schiehallion team didn't know anything about what had been said by ENT so they tried to chase it up. Over the weekend, [REDACTED] took a turn for the worst and was getting temperature spikes. I took him to A&E on the Monday and his temperature was 39.8 degrees. Staff in A&E knew [REDACTED] was a Schiehallion patient so they put him in a designated room but he wasn't given any medication at that point either. [REDACTED] had spat his NG tube out at home earlier that morning and didn't take medication very well in his mouth so the staff were trying to get a tube or a cannula into him but they didn't have anything to get the cannula in with and they didn't have any tubes the size needed. This went on for two hours during which time [REDACTED] was becoming lifeless. One of the Schiehallion nurses came down and told the staff they needed to get medicine into [REDACTED] immediately through his mouth. [REDACTED] couldn't even get up at that point so there was no way I could shove medicine in his mouth so I told staff they needed to get a cannula into him now. They did get a cannula into him after this and gave him medicine. [REDACTED] was then admitted to ward 3C but staff kept telling me it was viral. Andrew stayed the night with him and I went home. I got a call from Wendy, the oncologist saying I had to go straight back up to the hospital as there was a crash team around [REDACTED]. She told me [REDACTED]'s heart rate was through the roof and they didn't know what was wrong with him. I asked if they thought it was sepsis and Wendy replied yes.
94. When I arrived at the hospital, [REDACTED] had lines in everywhere and staff were all rushing around looking for packs of medication that were missing and trying to get scans organised. It was hell. We were told they were going to intubate [REDACTED] and take him down to intensive care. When staff had tried to intubate [REDACTED], he responded a little so they kept him awake for the scan whilst another staff member was on the phone to ENT to find out what was going on with him. Due to [REDACTED] being on the trial drug, nobody knew how to deal with him so they suggested calling the trial company.

was pumped full of antibiotics for the next two days and then it was decided by staff that they were going to do a lumbar puncture as they were now thinking it could be meningitis. I was told by the consultant in intensive care that it was meningitis but not the viral type. It was the bacterial one and it had come from an ear infection that was mistreated. The Schiehallion staff had assumed had been sent home from ENT with antibiotics for his ear infection. They didn't know he wasn't given any treatment and he should have been. As he wasn't given anything to treat the ear infection, it had turned into meningitis. Once again, I had to do their job for them. If I had done the usual stuff you were told to do, take him home, give him calpol and take him back if it got any worse, it would have been too late for [REDACTED] again. He was mistreated yet again. I've no trust in them now. Every time the doctors get it wrong. The next day, the ENT doctor came to see me. He was trying to blame [REDACTED]'s surgery but we had already been told it was meningitis. I feel the ENT doctor was trying to cover up the fact he had got it wrong. I told him I already knew it was meningitis caused by the ear infection not being treated. [REDACTED] had already been on antibiotics as part of the safety protocol when he was admitted. He had a lumbar puncture done and it came back with the meningitis and he was already on the right antibiotics to treat it so I think they just upped the dosage. [REDACTED] was meant to stay on the antibiotics for another ten days which would have been over Christmas. We asked if we could take him home and give him the antibiotics there and staff agreed. At home we had to give [REDACTED] and injection of the antibiotics straight into his leg. I think he was on the antibiotics from 16 December 2020 to 31 December 2020. [REDACTED] is still attending ENT and had an appointment in February 2021. They still don't know what the green stuff was that was in his ear but he's due back in six months for another check-up.

95. [REDACTED] still attends the hospital. He takes the trial drug twice a day. Every two weeks, he'll go to the hospital, every second Thursday, to get his bloods checked to make sure that he's still on the same path. [REDACTED] also gets scans every 12 weeks.

Witness Statement of Karen Stirrat

A34194778

**WATER: EVENTS INVOLVING WATER SYSTEMS****Water incidents in QEUH:**

96. I noticed filters on the taps in ward 6A during [REDACTED]'s admissions in 2019, but I can't remember if this was during his first admission in March 2019, and in 2020. They had filters in the bathroom and on the wee hand-wash basin outside, there was a filter on that too. As you came into the room, there was a basin on the right or left hand side depending on which way the room was facing. They had filters over the taps on those basins. I don't remember them being on the taps the first time we were in though.
97. In the bathroom, there was a sign telling you to run the shower for ten to fifteen minutes before using it. You had to watch that the showers didn't flood too. The floor didn't seem to be far enough down. Usually there's a dip for showers like that. Some of the floors weren't level enough the way they should be that's why the water would overflow. My nephew had been in this hospital quite a lot so I had a rough idea of what the rooms were like in the RHC but my sister was telling me about there being sewage coming up through the floor and leaking in to their room when they were in. They had flooding too when they were there so she told me early on I needed to watch the floors as they can be dangerous.
98. I remember we would sometimes get people coming in the room in ward 6A, lifting the drain in the bathroom and putting something down it. It was a bottle of fluid of some sort. I think it was maintenance guys that were coming on as they were in their normal overalls. Thinking back though, from an infection perspective, should they just have been coming in the rooms like that? We didn't ask them.
99. There were signs up saying not to drink the water. I think the signs maybe also said not to put anything down the sinks too but I'm not 100% sure about that.

Witness Statement of Karen Stirrat

A34194778

Staff would give you bottled water, you could just ask for it and they would provide it. They would offer it to you too when you were having a tea or coffee and your dinner. There was bottled water in the fridge in ward 3A of the RHC that you could help yourself to but I didn't think anything of it at the time. The Schiehallion Unit staff in ward 6A were more proactive in offering it to you; even the diluting juice would be made up using the bottled water. I thought it was strange that everything was done with bottled water. We started bringing in our own bottled water though; [REDACTED] liked diluting juice but sometimes you had to wait ages on the nurses getting you some so we brought our own in so we always had it for [REDACTED].

### **Water: communication**

100. Andrew asked one of the cleaners who was responsible for running the shower for the fifteen minutes and he told a staff member would come in every day to do it. We rarely saw anyone though so we ended up doing it ourselves. We knew there must have been a reason for doing this but nobody told us what it was.
101. When you asked the maintenance guys what they were doing with the drains in the bathroom, they just used to tell you they were in checking them even though you'd just seen them pouring fluid down the drains.
102. It was Dr Sastry who told us about the water situation when we were given the certain antibiotic. I think this was round about the August-October 2019, possibly. It was round about the time we had meetings with the Health Secretary. He phoned me and I said to him, "I am not going to sit here and be lied to again. I'm sick of it and I've just had enough now". He then told me that the reason the Health Board were saying the water was fine according to their reports, was that they knew the water in the taps was fine but they weren't sure about the moisture in the air or the cracks in the walls. [REDACTED] was still on the medication because they didn't know the impact this could have on

patients. At that point, it wasn't public knowledge. I asked him what I was supposed to do with this information because these families are in this situation and they don't know that because nobody wants to tell them. When he spoke about it, he told me I can do what I wanted with the information. I asked him what he expected me to do with the information he had given me. He said to me, "You do what you see fit with that information." So it was myself that told all of the families why we were still getting treated with that medicine. Things had started coming out in the media at this point too so I spoke out.

## **HEALTHCARE ASSOCIATED INFECTIONS**

### **HAls: communication**

103. We knew there was some sort of bug in the hospital. It had started appearing in the media. One of the parents in the parents' group had shared it on the group page. She said it was possible that the hospital were treating the children for an infection but she didn't disclose what the infection was even though she said her child had it. Eventually the stuff about the infection came out in the media and what they were treating this child for so we found out what we were up against. I can't remember the name of the infection though.

## **PREVENTATIVE MEDICATION**

104. [REDACTED] was on posaconazole which we found out when he went for treatment in Florida on 22 April 2019. This wasn't actually part of his chemotherapy treatment which we had originally been told about.

105. He was later put on ciprofloxacin in the August 2019, once again as part of the chemotherapy regime.

106. It was Dr Sastry that originally explained to us about the posaconazole and it being part of [REDACTED]'s treatment to protect against infections but the way it was explained, it was as if it was to help if [REDACTED] got a cold or anything that could go into the lungs. We didn't think anything of it at the time.
107. [REDACTED] had to go to Florida for Proton Beam treatment in April 2019. When we arrived at the hospital there, the doctors wanted a list of all his medication. I read them all out but when I got to posaconazole, the two doctors just looked at each other. One then asked why [REDACTED] was on that and I told him it was part of this chemotherapy regime. We had been told this at the start of his initial treatment by the doctors at the QEUH.
108. One of the doctors told me it wasn't part of chemotherapy treatment and he said he was going to call the UK to find out why [REDACTED] was on it. We met Lacey, one of the nurses who was looking after [REDACTED] in America the next day and spoke to her about the posaconazole. She told us that the doctors from the QEUH told her the reason [REDACTED] was on posaconazole wasn't anything to do with his chemotherapy treatment and that he was on it because of the hospital. I asked her what she meant and she told us it's the dirty hospital. It's the dirty water and the building in Glasgow.
109. I didn't understand what they were talking about regarding the dirty hospital. The staff in Florida then told me that UK doctors had advised to take off the posacanazole straight away but the minute we step foot off the plane back in the UK, [REDACTED] would have to start taking the medication again. I phoned my mum to tell her and she said I should phone Glasgow to find out what the hell they were giving [REDACTED]. I had enough to deal with and I decided to deal with it when we got home.
110. When we got home and attended ward 6A, this would have been approximately 21 June 2019. I was met by a nurse who we knew from Day Care and have dealt with quite a lot, who asked me straight away if [REDACTED] was back

on the posaconazole. I asked why he was back on it as I found out in Florida, it's not part of [REDACTED]'s chemotherapy treatment. The nurse seemed a bit startled and said it was because of the building. I said that didn't make any sense and the nurse said she would get someone to speak to me about it. Nobody did come to speak to me though. I asked another nurse, maybe a couple of weeks later why [REDACTED] was on posaconazole as I still wasn't getting answers. I was told this time that it was due to the climate we live in. I told the staff that I had been doing my own research and had found that other hospitals in Scotland weren't using pozaconazole. I had spoken to other parents and my cousin who's an NHS nurse and she did some digging.

111. I was now starting to wonder what other parents had been told. I was a bit fearful of asking other parents as I didn't want to upset the apple cart. If they didn't know already why their child was on this, I may set off fireworks but at the same time, I wanted to know what was going on. I asked a couple of the parents if their children were on the medication and was told yes, it's part of their chemotherapy. I knew this wasn't the case but what was I supposed to do with the information I had?

112. I spoke to one of the other parents about what I had found out and she was trying to get me to talk to the media. I didn't want to be put in that situation though as [REDACTED] was still going through treatment. There was an auxiliary nurse asking me to go to the media too but the final push was when [REDACTED] dropped his dummy on the floor and the nurse told me not to wash it in the water yet the hospital deemed the water safe. I'd had enough of the lies at this point. Something clicked and I decided I was going to talk to the media. One of the other Mums was already going on the TV to speak out and when she asked me again if I'd be willing to speak out, I agreed. We spoke to BBC and STV. This was after a lot of too-ing and fro-ing with the hospital and never getting any answers about the water or the medication. We had previously had media involvement when [REDACTED] was due to go to Florida as we had to fundraise for it so he had quite a big following on his face book page. It had



turned from us needing help to send [REDACTED] to Florida to us needing help to get answers that the hospital weren't giving us. If I remember correctly, I think it was July 2019 that we spoke to the media.

113. In August 2019 I received a call from one of the outreach nurses, asking me to go up the hospital immediately. She said that everyone was being asked to go to the hospital but didn't tell me why. [REDACTED] had the posaconazole stopped and was put on Ciproflaxin. It was Dr Storey that put him on it and it was the first time I had met her. We were sat in a room with her and she was reading off a pamphlet which we were given a copy of. I asked what it was that they were giving [REDACTED]. She said it was Ciproflaxin but didn't say why was being put on it. Obviously I asked what she meant by that and she replied that she only wished she could tell me but the Board weren't letting her tell anyone because it wasn't good for their reputation given that so much stuff had already been in the media about previous infections. I think Doctor Storey had been given the horrible job of giving all the families the news. She was very upset herself that day and quite teary. I think this was maybe because she had been getting it in the neck from families all day. I just wanted to know the truth about what [REDACTED] was being given. We were just told that he was to take this medicine so many times a day. No other explanation was given. It was also round about this time that we found through the parent who had mentioned on Facebook that their child had contracted an infection, that this is what they were treating. Everything about the infections was now coming out in the media. The hospital apologised and said it wouldn't happen again but it kept happening.

114. Doctor Storey also said that [REDACTED] or ourselves were not allowed to use the toilet downstairs. The reason for that was if there was any spray off the sinks or the toilet itself. Andrew can give more details about this.

#### **OTHER ISSUES RELATED TO HOSPITAL CONSTRUCTION**

Witness Statement of Karen Stirrat

A34194778

**Hospital build issues: impact of construction works**

115. I don't think the blinds were fully working and were broken. They never allowed proper daylight in. We raised this with them and asked how we got them fixed. We were told staff had sent a report in and were waiting on it coming back. I asked how long the report would take and I was told that they didn't know, just whenever they get to it, so we were sitting in darkness. I think [REDACTED] ended up with an eye issue from sitting in the dark all the time for three weeks.

116. The rooms were a hit or a miss too. One minute it was really warm, the next minute it was really cold. In the summer months you couldn't breathe as they were so stuffy. We asked staff numerous times if we could have fan but we were told no because it wasn't good enough in the environment the kids were in and therefore it wasn't good to have a fan so you would be left sitting in the heat. This came from infection control. They said we weren't allowed to use the fans. They didn't go into detail but from what was said I think it was to do with the air circulation in the room if we were to use a fan it wouldn't be good for the immune system. They never clarified what they meant by this. They had air filters in the room but not all of them worked, to purify the air but if you used a fan, it wouldn't work. Nurses would complain too as they were sweating working in that environment. There was never a happy medium. You could try and control the heating with the thermostat in the room but it only went down to 17 degrees but 17 degrees didn't feel like 17 degrees. The kids would then spike a temperature but they were just roasting due to the heat in the room. When we were in America I asked how they could tell if it's a temperature spike or just hot because of the room. The staff there told me that they if a child spikes a temperature over there and it was particularly warm, they would leave them for a few hours but still check their temperature. If the child's temperature had come down, they would know it wasn't a spike, they didn't just assume it was a temperature spike due to something else. I tried telling the staff that at QEUH as even the parents were hot and would likely show a temperature but the

response I got was that it's protocol so then your child would be put on antibiotics when they maybe weren't needed.

117. The televisions in the rooms didn't all work either and the battery packs they had for the chemotherapy drivers didn't last long. [REDACTED] would be hooked up to a machine that would drive the medication in to him and the battery pack would go in the back of the machine. This meant that [REDACTED] would be able to hold the pole on his machine and walk up and down the ward. But nine times out of ten, those battery packs wouldn't work or they would run out of charge after twenty minutes, so by the time I would have [REDACTED] out of his bed and doing whatever we needed to do, the battery would have run out. There was also a shortage of the battery packs and not enough to go round the children who were needing them. Some of the packs were obviously older too as they still had the old Yorkhill stickers on them.

118. I remember the windows falling out which was a big thing at the time. The hospital put these railings up and told us that the windows were safe but they had scaffolding round it for numerous months. How can the windows be safe if they've still got scaffolding round them? That makes no sense. Nobody's ever picked up on that either. The windows in Day Care go round in a circle and there's a ledge some of the kids stand on. Our kids can go in to Day Care and lean against the windows and could fall out of them, God forbid.

119. Ward 6A was not set up for long term use. When we came back from America in June 2019 and [REDACTED] had been eating proper food, to come back to ward 6A and not have anywhere to store the foods he was eating was devastating. I was told by the nurses that Infection Control wouldn't allow a fridge. The food the hospital gave you wasn't good. They didn't have any salad or cold meats. It was all things like fish fingers and chicken nuggets that you could stot and bounce off a wall, soggy, freezing chips or congealed macaroni. It wasn't pleasant.

**CLEANLINESS**

120. There was a lot of dust. For example, on the top of the overhead TV stuff, you never really saw anyone coming round cleaning them. You could have thick layers of dust on them as well. There was dust on the floors too. Sometimes you didn't know when the floor in your room had last been mopped, it looked as though it could have been weeks. The cleaners were very nice though and the majority of them tried to speak to the children but there were a few that just didn't want to be there. Their mops were dirty and yet they were still washing the floors with them and then going to the next room and using the same mop. You wondered how many rooms they were doing with that one mop. I thought they should have at least be changing the water. Considering this was supposed to be the 'new' Schiehallion and supposed to be clean, it wasn't.

121. The floor always felt grainy too with dust so I wouldn't let [REDACTED] play on the floor. I asked the nurses if I could have one if the mats for [REDACTED] but they said there weren't any so I informed them they were in the bathroom so they went to get us one. One of them said she would give it a wipe down but it was just a quick skim she gave it. I wasn't happy with this as they had been stored in a bathroom. I got the wipes out and cleaned it myself.

122. Due to the fact there was no parents' kitchen, we had to use the microwave which is down in the main foyer. There was once an infestation of flies that would circle round the microwave, literally. We were told that was where we should cook any meals that we brought in. We weren't supposed to bring meals in however, if parents wanted to, they could cook down there. Then you would have to walk through the main foyer full of people, in to a communal lift and up to your room with this food. It made no sense to me but that's what staff told us to do.

**OVERALL EMOTIONAL IMPACT ON [REDACTED] AND HIS FAMILY**

Witness Statement of Karen Stirrat

A34194778

123. [REDACTED] couldn't wash his hands in bathroom at the hospital so he was obsessed with hand sanitiser, even more so now with Covid. He was behaving that way because of the way I was reacting.
124. I shouldn't have had to go to the media. I had been asked in July 2019 to speak to the media but didn't speak with them as [REDACTED] was in treatment but it got to the point that I was fed up being lied to and I wanted answers. Everybody now knows everything about me and my family now because I've spoken out. Don't get me wrong, I'm grateful to the media for their help when I was ill and all the help I received through it but at the same time, it has a detrimental effect in your day-to-day experience. I was known as the bad woman on the ward for speaking out or at least, that's how I felt.
125. When you take your child to a hospital, you expect them to be safe and to be treated properly. To have to be constantly on your guard and fighting every day while you're going through treatment at the time too, it had a knock on effect. It wasn't good.
126. The thought of having to go back there, leaves us on tender-hooks. It will feel like, here we go again, the cleaning process and bringing your own stuff in to clean with. Bring your own plates and cutlery in for your child because he feels he can't get his hands dirty. That was constantly worrying that you felt things were going to happen in there.

**COMMUNICATION: GENERAL**

127. When the media had started reporting about the hospital, there was a meeting with Jeane Freeman organised. I think this was in the September of 2019. I don't know who organised the meeting but I was told by another parent in a group chat I'm a member of that this meeting was taking place in the Grand Central Hotel in Glasgow. At this meeting, I was one of the more forthcoming parents as a lot of the other parents were shying away. I was really angry with

being lied to about the posaconazole so I raised concerns about this, the treatment, blinds not working, the food that we were getting at the hospital and the miscommunication. I raised the issue of the battery packs not holding charge too and there not being enough of them. I told her that [REDACTED] had physio for his legs as he was stuck in his bed all the time because of this. Jeane Freeman apologised and said she would rectify the situation but it was never rectified. They still didn't have enough battery packs and the ones they did have, still run out of charge.

128. There was a note taker at the meeting who was writing everything down and if I remember correctly, we were given minutes of the meeting at a later date. A lot of the points were included in the minutes and we were told by the people holding the meeting that they would come back with answers. Once again, they never did come back to us. Jeane Freeman during the meeting appeared to be really shocked and appalled about what she was getting told by the parents and I thought at that time she was genuine. The parents felt that maybe something would be done now but looking back, I think I was maybe naïve to believe that. The one positive thing that did come out of that meeting though was we did get a parents kitchen in ward 6A. It was built in a room where there had been a bathroom before but you weren't allowed to use the tap but when it became the kitchen, the tap was fine to use. That didn't make sense to me.

129. There was a second meeting held in the November of 2019 I think and this was with the Health Board. Once again, I think this meeting was organised because of everything that was being reported in the media about the hospital and the Health Board had been forced in to it. The Facilities Manager from the hospital was there and he spoke about the building works, what was going on with wards 2A and 2B and what the progress was. He was trying to reassure us by telling us that works were in place to fix the issues and that they had to get a part for the ventilation system but there was a delay. He said that they were still on target for next year but initially it had supposed to be opened that January but it was postponed to the May 2020. He said we would all be kept informed.

Jennifer Haynes, who I think was one of the Heads of Patient Care, and Fiona McQueen, the Chief Nursing Officer, were at this meeting. Fiona McQueen had been at the first meeting too. There were also various other people at the meeting from the Board. They all said they were focussed on patient centred care and had a communication board set up. I think this is also when I first met Professor White. We were told he was there for us and they were trying to make us feel part of what they were doing to try and resolve things. I did have some contact with Professor White but he was only a point of contact. You could send him questions but he was never going to answer them or if he did, it was in an indirect way. This sounds really bad but if you weren't educated enough, you wouldn't realise that Professor White was answering your questions with another question so he never actually gave a direct response or confirmation to anything. In my opinion, he was just someone that the hospital could say to the media, they have someone in place so the parents had a point of contact and that they were doing their best. They weren't though as I still had questions further down the line.

130. The Chairman from the Board was there too at the meeting in November 2019 and he had been trying to speak to us before the meeting to try to get to know us which I think was a bit twisted as he should have said who he was. He was first to speak at the meeting and appeared quite overcome with emotion until we started asking him questions that he didn't want to answer. Those holding the meeting had started discussing the water reports that the hospital had received and telling us that the initial one was showing that the water was fine but they were awaiting another report. I asked the Chair to confirm if the water was fine and every child was deemed to be fine and he said yes to both. I then asked, "If the water was fine, why was my son still on the preventative medication?" The Chair then tried to blame the doctors saying it was miscommunication stating that the doctors hadn't spoken yet to the people involved. I told him that was rubbish as I had just spoken to [REDACTED]'s doctor and he had confirmed why the children were still on this medication and that it was to do with the cracks and moisture in the walls. I knew the answer

but I wanted the Chair to admit it but he wouldn't tell me the truth. He didn't want to answer me and just told me to take it up with [REDACTED]'s doctor then he changed the subject to something else. They had report after report so if everything was fine, why were they double and triple checking everything? The reports should've been gospel. They shouldn't have needed anyone to check again and get someone else to clarify it.

131. The other parents said to me that I had shot the Chair down as I knew the answers and he knew he was lying to my face. He was trying to blame it on the doctors then wait for the second water report. Two weeks after that meeting where I had questioned the Chair, I received a phone call to advise that would have his central line removed two weeks earlier than planned. I think this was the hospitals way of shooting me down so I couldn't ask any more questions; [REDACTED]'s line was removed so he was no longer on the preventative medication so I would have no need to keep asking questions about it.

132. I found out at these meetings that other parents hadn't been told the same information I was by Dr Storey about keeping away from the downstairs toilets. The other families were still using them because they were going to clinics downstairs. I thought that because they were out-patients at the clinics and we were in-patients, they weren't getting told the same information. Those families had still been using the downstairs toilets but I later found out we were warned about using them because [REDACTED] had a central line in and it was a line issue with the infections and the other kids didn't have a line.

133. Other parents had been told the same information we got at the start about the preventative antibiotics. They were told it was part of the chemotherapy protocol. I found this out after speaking to some of the other parents at these meetings. The only difference was that instead of it being posaconazole, it was a weekly injection into the central line rather than a daily one. I think this was because children aren't meant to be on that type of antibiotic for so long. Some



of these parents had seen me in the media when I spoke out and they asked me what was going on as they were new to this and wanted to know what to expect. I had to tell them to speak to their own doctor as their child had leukaemia which was different to what [REDACTED] had and the protocols may be different. It sounded like they had been fed the exact same script we'd had though. I never wanted to be put in that position. It wasn't my place.

134. I spoke to Jennifer Haynes and told her I had sent emails to Professor White and I that I had asked him what was happening after the previous meeting we had with Jeane Freeman. She said she would chase up the answers for me but she never did. I raised an issue regarding the positioning of [REDACTED]'s feeding tube when he was in America too and it took her months to come back to me about that.
135. I think it was in between these meetings that the parents met and spoke with Monica Lennon and Anas Sawar. I think this was organised by one of the other parents who had initially spoken to them. The BBC were involved and they had contacted us too.
136. I still don't think communication is adequate at the hospital. I'm thankfully not in frontline treatment with [REDACTED] any more so I don't know how adequate the communication is for the people that are in there just now but there are still no follow ups done. [REDACTED] can get his bloods done and staff just send you home after they've done them. You never get any results back. You have to phone the hospital for them. The same happens if you need to ask staff a question. You wait about four or five days for an answer that should be given on the same day. I don't think the communication issues are the staff's fault though. I think they're understaffed and they're not 100% focussed on their job and that's not their fault. I think it could maybe get better if I think the hospital employed reliable staff who are there all the time, not bank staff. They should not rely on students to do their job because there are more students than there

are staff. I'm not saying students shouldn't be there but they should have someone with them that can do the job.

137. Dr Sastry was sent to see us the night before [REDACTED]'s surgery as the outreach nurse knew there was a lot of animosity between us and with him being [REDACTED]'s doctor, he was made to come and talk to us. I had been telling the outreach nurse about the way [REDACTED] had been treated and she said that they can allocate another doctor but that Dr Sastry was the best one for dealing with [REDACTED]'s type of tumour as it's so rare. He didn't know what to say initially. I said to him, "Will we just talk about the elephant in the room?" That's when it all came out about why he acted the way he did. He told me about another family he had organised a trial for but the Board voted against it last minute and that's why he's not keen on trials now. At the time of [REDACTED]'s relapse, Dr Sastry didn't respond to Dr Kilday in Manchester who had offered to help when [REDACTED] relapsed and I felt he wasn't supportive of us at the time. He also told me about the issues he was having and he was quite heated. He said staff were complaining about not having a staff room and the phone didn't work half the time and there was no reception so if they were across the other side of the building, they were having to get back over if something happened. I think he was venting about how he felt about the hospital at this point and I felt bad for him but at the same time, I'm a parent and I'm there for my child.

138. I had an argument with Dr Sastry in March 2021 as I felt he wasn't helping us and the communication was awful. He didn't come to check on [REDACTED] after his surgery and never commented on how well he was doing. Since we had the argument though, things have been a little bit better regarding communication from him. He will now email and if there's ever a time where he can't make a meeting with us, he will let us know and apologise. We got a treatment plan from him too but I worry if [REDACTED] was ever to relapse again and we have to go against the Board, will Dr Sastry stand up for us? I don't feel the right outcome for [REDACTED] would be there if that was to happen again.

gets scans done and I always have to chase the hospital to get the results but I feel due to the way [REDACTED]'s tumour is, they should be calling me with results. I shouldn't have to chase for results. Dr Sastry will ask me now what information I have. He knows I'm on a Facebook group so he checks with me to see what information I've found out from Facebook. It's better than it was before but it's hard to get trust back once something like that happens.

139. I said way back at the beginning, if the hospital had just told us the truth, we wouldn't have liked it, but we would have taken it on the chin and went with it because we didn't have any other option. To blatantly lie consistently to your face, that's just morally wrong. I feel if they just were upfront about anything that was to happen and not have us finding out through a third party. Communication as I said, is key and that's what they need to get it right.

## **COMPLAINTS**

140. I made a few verbal complaints to staff members that were never really resolved. They would always tell me they'll get someone to come and speak to me but nobody ever did. The complaints I'd made would be about things like the fact we couldn't store food for [REDACTED] on ward 6A or that I wasn't told the right information at times. It felt like it was a case of, well that's just how it is.

141. When [REDACTED] was given the ketamine at his scan appointment in May 2020, I complained about it to Dr Sastry. I told him what had happened and that I wasn't happy about it. I had sent an email about it to the doctor who was part of the anaesthetic team that day and to be fair, he did phone me about it. The anaesthetic team tried to call me again two weeks later but [REDACTED] was going in for surgery that day. They also sent me an email saying that they knew it was a bad day to try and speak to me, yet they were still trying to anyway. They said in the email that they didn't know what had happened. I never

followed this up though as we go the results from [REDACTED]'s scan back and we had to concentrate on him.

142. I complained to Dr Sastry in May 2020 about the delay in [REDACTED]'s scan. This was when Covid had hit. Dr Sastry told me he initially had 100 patients he was allowed to scan. That then got dropped to five people then two. He had always put [REDACTED] at the top of his list due to the aggressiveness of his tumour and what he had been through but he found it difficult to choose. It was the Board that made the decision due to Covid. It's awful for a doctor to be told that but I feel Covid has been used as an excuse for so many things. If [REDACTED] had been scanned when he was meant to have been instead of it being delayed, his relapse would have been picked up sooner. I told Dr Sastry I didn't think [REDACTED] was very well and he didn't do anything about it. That angers me as [REDACTED] is a child at the end of the day. I understand we've to protect the NHS but it's these families in the same situation as us that are being compensated. Those children are meant to be our future. I felt at the time they were saving the older generation, which sounds awful but I felt we had been let down. There were already these misconceptions with the department and no clarification and then no communication. Then this on top of what was already a disastrous ward. Nobody knew what was going on or what they were doing and we just slipped through the net. I know of another family who's passed away during this. She relapsed at the same time as [REDACTED] and was told she could get the same treatment, radiotherapy. The family came to me asking what they should do as the doctors wanted to stop her treatment and I told them they had to take it up with the doctors. She just didn't have the strength at that time so waited two weeks and when she came back they told her the child was too sick for the treatment so they stopped it then they came back again and said they should have continued the treatment but by this time, four weeks had passed and it was too late. How many other families have been in this situation? Getting the citation for the Inquiry, it's nerve wracking but when you see the other families and what they're going through, they can't continue

the way they are so I have to do it. I hope it will get better when we're back in our own ward again although I have heard it's delayed again.

143. I sent Jen, the Head of Care, a list of questions about Florida and what had happened around that, especially with [REDACTED]'s NG tube not being positioned correctly. I never got a response from her so I then emailed Professor White who I think passed my email to Jennifer Haynes. After a while I eventually got a response and she answered my questions with another question. She said it wasn't protocol for [REDACTED]'s NG to be checked but I know it was as it's to make sure the tube goes into the right place and doesn't cause an infection. I wrote back to every point she made in the letter but I never received a response from her and to be honest, I didn't chase it after that.
144. On 19 November 2020, I sent a list of questions to Professor White about the water and the medication. By 25 November 2020, there was no reply from Professor White so I tried to contact Lara, Professor White's contact and Jennifer Haynes. I can't remember if it was the minutes from the meeting with the Health Secretary that I received on 7 December 2019 or whether that was the date of the meeting with her but there was still no reply from Professor White or Jennifer Haynes. I sent another email to Jennifer Haynes on 9 December 2019 and received a letter about [REDACTED] on 3 January 2020 from Jennifer Haynes. I think the information about the anti-fungal medication was in this letter. I replied to Jennifer Haynes stating that they had written to me with lies. I called them out on what they had said to me. I got a reply on 31 March 2020 so it took them three months to come back with a reply but by that point, I had caught on to what they were saying. There was no constructive response from them, no answers just lies. I did get the offer to go and meet them if I wished but I was advised by other people, MPs I think, to have everything in written form. I'd been told that if I don't have written communication to take with me to any meetings, they'll just try to bully me and if it's only me and them in the meeting, there's no witnesses. I wasn't interested in having a meeting with them though as they weren't giving me any answers anyway. I knew if I went to

a meeting with them, I was just going to get told a load of crap again so there really wasn't any point.

**OVERSIGHT BOARD / CASE NOTE REVIEW / REPRESENTATIVE GROUPS**

145. I know that a couple of the parents were on the Oversight Board but I just feel like a lot of that was just, information to cover the Oversight Board's own tracks. As much as they were trying to look like they were doing stuff, they weren't giving any answers. Every week you had the same. It got to the stage where after three or four weeks I just thought, what am I reading? All I'm reading is a whole load of flack that is of no relevance to us. You're just making yourself look important. And you put two parents on the page and in this meeting to make it look like we're involved. We're not any further forwards. We're not getting any answers. So is there actually any point to this oversight board? No.
146. That's my opinion on Oversight Board. Other people might have different opinions. Anything that I did get, any correspondence, I was sharing it with Andrew. I didn't even feel like I had to update him because I didn't feel there was anything there to update him with. A whole load of medical jargon and stuff that they would try and make them look important was my opinion.
147. [REDACTED] wasn't part of the Case Note Review. I understand why they were doing it in regards to infections but I don't know obviously infection-wise whether there's anything there for him. [REDACTED] may not have acquired an infection but we're part of this because we were given all these medications because of these infections. Families have been affected because they got an infection but, from our perspective, we've been affected because was given treatments and we'd been lied to and all the rest of it that goes with that. I think [REDACTED] should have been part of that Case Note Review.

Witness Statement of Karen Stirrat

A34194778

It shouldn't just have been deemed on acquired infections. It should have been on the whole thing, like the Public Inquiry, the relevance of it. It shouldn't have just been on infections but the measures taken to prevent the infections too.

148. I know that the Case Note Review was partly done through the hospital, and although they say it's independent, I feel it wasn't fully independent. I feel it was pretty much one sided. I did read parts of it. I can't remember 100% but I think it came out possibly around the time that [REDACTED] was admitted with his relapse. The relevant pages for [REDACTED] were maybe one or two pages of that report. I felt again it was another cover up. I didn't feel that it was truthful. I felt the people who did the review were trying to make out that the parents were lying. They tried to cover up a lot of things in it like the death of a child. They were saying things like, hospital acquired infections possibly have come from other environments. I think that's complete lies. Some of those kids weren't even out of hospital. I don't feel there was any relevance in it.

149. If I remember correctly, there were two reports. The Case Note Review one that was done last year and then the one that came out with the findings this year. Basically the conclusion of that one was that, yes, the parents were telling the truth. Overall what we had been saying previously, they were trying to say was wrong but it was actually true. It's now shown that they did give people medicine and there was a sort of cover up going on, and the lies and things. In some ways you felt relief that you were you weren't these paranoid parents, although as much as they were trying to help, there's people out there who aren't in this situation who would say, oh they just want five minutes of fame. They forget we were living it. We don't need our five minutes of fame. But just to have the clarification there that, you know, what we were saying was true and we weren't idiots that they were trying to make us out to be. At the end of that, much as this has all affected the families, it's those little individuals, those little human beings who are only children who were affected most.

150. I've been involved in a group just this year with Stephanie, from Thompsons. This is all the parents that are on the WhatsApp chat that are represented by Thompsons. I'm also in a Facebook group with some of the families. This group is quite informative. I'm in the WhatsApp group as well and we chat through that so it's good, in terms of communication, because we obviously don't trust the hospital. If anybody does find anything out, they always put in on there. You know that you're going to the answers from them before the answers come from anywhere else.

151. I think some of the parents have been too scared to come forward. Some of the parents that have been affected haven't spoken out, with scaremongering amongst staff and just being treated differently. I certainly felt like that at the beginning when I spoke out, that I was treated differently by some members of staff. They were on their guard with you or would leave you to your own devices because they didn't want to be involved with you. As time has gone on, I've been more public and I think more staff are on your side than not now but I feel a lot of the people on these Facebook pages, including staff, don't want to speak out because they're fearful, which is horrible. I know it's a horrible situation to be in, especially for families who are still going through treatment. I think a lot of the families fear that if their child was to relapse, they worry about how they would be treated. We are one of those families who has been put in that situation. When [REDACTED] relapsed, Andrew straight away said that the Board had gone against us because we spoke out. I understood how Andrew felt as I had my doubts too at that point because of the way we were treated by the doctors and the board when [REDACTED] relapsed and the lack of help they gave us. I can't sit and think about that though because at the end of the day, for my own family's sake and for the sake of the children who died, you would just sit and cry. Some of the other families have asked me how I was treated after speaking out. I was honest with them and said it was hard but it doesn't mean the same thing will happen to them as it's different situations we're all in and different treatments so there's nothing to say the same will happen to their family that happened to mine with [REDACTED].



**CONCLUDING COMMENTS**

152. I have no trust in the hospital at all. The only person I trust is Roddy. Roddy is the only person who would tell you the truth. From an oncology perspective in the Schiehallion, I go in because I have to. If I had another option I'd use it. I hate going in to the hospital to be fair. But I hate going in in case they give me any answers I don't want to hear. At the same time it's not the relapsing side of it, it's the whole lack of back up, nobody in my corner. That's the way I feel. I feel like everyone's against me rather than with me. As much as I had the argument in March 2021 with the oncologist which has cleared the air a bit, I still wouldn't trust him as far as I can throw him. When you've broken somebody's trust like that, you can't get it back. That goes for the whole hospital to be fair.

153. If I had to pick a ward to be in, it would be the Neurology ward. Everything was really on the ball there and there weren't any major issues. As I've said, I only trust Roddy and that's his ward. There were a couple of little things that happened to us down the line in that ward but staff couldn't have done anything about them.

154. The issues are still there in Glasgow. Why is it allowed to operate? If those things happened in any other job, they wouldn't be allowed to operate. Look at Edinburgh, it was shut for similar issues but Glasgow was deemed fit for purpose. I'm still anxious about the water and the building works going on but I do feel a wee bit safer because [REDACTED] doesn't have a central line in now.

155. Regarding the Health Board, they should get rid of it. They always came out with an answer for everything but it was never the truth. How can you regain trust in somebody who's lied so many times? You just can't so I would never trust anything they said. They haven't been doing their job properly which leads

to the rest of the hospital not doing its job properly either. It's not the fault of the staff, it's the Health Board.

156. I requested [REDACTED]'s medical notes but the woman on the phone who I spoke to about them told me I should request the notes for all three children from birth. I was alarmed at this but I did request them all and I've only read the neonatal notes so far. There's a note in [REDACTED]'s when she was getting her tonsils out implying that Daddy was there but he wasn't really there, if that makes sense? [REDACTED] was getting his first round of chemotherapy on the same day [REDACTED] was having her tonsils out and the staff knew that but they wrote stuff in [REDACTED]'s notes about Andrew rather than medical facts.

157. When we had to take [REDACTED] to Florida, we were initially raising funds. The hospital told us that they would initially pay for the flights then we would reimburse them. They did pay for the flights and we had approximately two thousand pounds to pay them. We kept asking them if we could pay the bill. This went on for months. We were begging them to take the money from us and chasing them up about it. It wasn't for the lack of trying on our side that it hasn't been paid. In the September of 2019 though, it all went quiet and nobody spoke to me again about it. It wasn't until I was talking about this the other day though that this all happened around the time things were kicking off at the hospital. I don't know if there's any relevance to this but we never heard back from them about the money we owed so it would make sense if it was related.

158. I believe that the facts stated in this witness statement are true. I understand that this statement may form part of the evidence before the Inquiry and be published on the Inquiry's website.

**Appendix 1 – KS/01 – Timeline**

- 20<sup>th</sup> February 2019 – ██████████ shows signs of being unwell with vomiting and did not seem himself. He attended his GP who advised that ██████████ had a viral illness. His symptoms did not improve.
- Friday 22<sup>nd</sup> February 2019 - Andrew took ██████████ to QEUH for further checks. He was monitored in accident and emergency and the staff concluded that he had a viral illness. He was sent home with calpol.
- 24<sup>th</sup> February 2019 - ██████████ attends A & E at QEUH. There were no beds available so he waited in the plaster room. A CT scan is ordered after Karen demands one (staff wanted to discharge ██████████). Karen and Andrew find out on this day that ██████████ has a “mass” on his brain and that there was a risk it was going to haemorrhage. He is sent for an MRI scan and he then went for an 8-hour brain operation. After this operation he is transferred to ICU for 3 days approx.
- 28<sup>th</sup> February 2019: ██████████ is moved to ward 2C. He remains there for 10 days
- 6<sup>th</sup> March 2019 - ██████████ is introduced to Dr Sastry and discharged home.
- Within the same week of the 6<sup>th</sup> March– ██████████ returned to hospital and had a Hickman line fitted. He was admitted to ward 6A, room number unknown. It was a room at the end of the ward. ██████████ begins his treatment plan around this time (chemotherapy and radiotherapy). During this round of treatment ██████████ was extremely unwell with regular temperature spikes. He was moved into an isolation room and at one point he was told he had an infection. ██████████ was put on Propiconazole at the beginning of his treatment.

Witness Statement of Karen Stirrat

A34194778

- 22<sup>nd</sup> April 2019 – [REDACTED] and the family travel to Florida so he can undergo proton therapy for 8 weeks. This was a particularly difficult journey due to the hospital not communicating with the 3 airports about [REDACTED]'s situation and the route being organised by the NHS without consideration for the family's situation. While he was in Florida it came to light that he had been on propiconazole. The doctors in Florida queried why this was and contacted QEUH. They were told that [REDACTED] was receiving this because the water at the hospital was dirty. Up until then Karen had been told that this medication was part of his chemotherapy (or had that impression).
- 21<sup>st</sup> June 2019 - The family returned to the UK. The moment returned to the UK to QEUH he was put back on Propiconazole. Shortly after returning he also had to undergo strong chemotherapy treatment because he was unable to receive this in America because of the Proton therapy. This meant he went through a period where he was an inpatient for 5 days or so and then a Daycare patient. He was continually in and out the hospital until December.
- December 2019 – [REDACTED] finishes treatment. His central line is removed. Once the line is removed he is able to stop the antibiotics.
- December 2020 – [REDACTED] develops meningitis.
- March 2020 – [REDACTED] has a scan and everything is shown to be clear.
- May 2020 – [REDACTED]'s behaviour changes, he becomes aggressive. At the end of May 2020 he attends for a scan (which was delayed due to covid)
- 1<sup>st</sup> June 2020 – The family are told that [REDACTED] has relapsed. At a meeting on this day with Dr Sastry and Dr Roddy, it is explained that there is

Witness Statement of Karen Stirrat

A34194778

an adjacent brain tumour and 3 more spots beside it. Palliative care is suggested instead of treatment by Dr Sastry. Dr Roddy says he could operate despite this palliative care suggestion. Karen and Andrew research treatment options. They find treatment and Dr Sastry denies that he has heard of this treatment, then tells them that this is not available on the NHS.

- 7<sup>th</sup> June 2020 (approx.) - Karen and Andrew speak with Dr Roddy. They discuss a possible trial treatment. Dr Roddy tells them that before they had met on the 1<sup>st</sup> June a board meeting had been held with Dr Roddy and Dr Sastry. At the meeting Dr Roddy had suggested operating, which was not backed up by the board. The decision was because of cost.
- Mid-June 2020 - After appealing the decision this was overturned and was able to get surgery and receive a trial medication. Had the family not fought for [REDACTED] to receive treatment, (due to the NHS saying it was too expensive) [REDACTED] would have likely not survived.
- [REDACTED] has done well since this point. He has recently had a scan and there was a fear that he had relapsed. It is now confirmed that he has not relapsed. [REDACTED] is still receiving chemotherapy and has a feeding tube.