SCOTTISH HOSPITALS INQUIRY

Hearings Commencing
20 September 2021

Day 12
Wednesday 6 October 2021
Morning Session

CONTENTS

MR DUNCAN: Could I ask Mrs Stirrat to say something, please? Because so far we've not been able to see her on the screen and we've only just been able to see you.

THE WITNESS: Yes. Can you hear me now?

MR DUNCAN: Yes, we can see you-- Well, we could. Could you say something else, please, Mrs Stirrat?

THE WITNESS: Yes. Good morning. Can you hear me?

MR DUNCAN: Yes, I think it appears to be working. I think we can proceed, my Lord.

THE CHAIR: Right, I will now administer the oath to Mrs Stirrat but perhaps, by way of preliminary, I should say to those who are in the hearing room my apologies for complicating the proceedings this morning. I think it's probably been explained to you that I have been in contact recently with somebody who has tested positive for COVID, and I'm still waiting for the result of my PCR test. But if I can now, if it were, turn to you, Mrs Stirrat, can I ask you to raise your right hand and repeat these words after me?

Stirrat, Mrs Karen
(Sworn)
Examined by Mr Duncan

THE CHAIR: Thank you very much, Mrs Stirrat. Now, Mr Duncan.

A Thank you.

MR DUNCAN: Thank you, my Lord. Mrs Stirrat, are you able to hear me and see me?

A Yes, I can hear you. I can see you too.

Q And I can now see you. We usually start with some formal questions, and if you'll bear with me, I'll do that just now. Could you confirm that you are Karen Stirrat and that you live with your husband and your three children in ?

A Yes.

Q And you've joined us here, albeit remotely, this morning to give evidence, I think, about your son, who is presently five years old.

A Yes, that's correct.

Q And he was three years old when he was diagnosed with cancer, and he received treatment at the Royal Hospital for Children and the Queen Elizabeth University Hospital. Would that be from about February 2019?

A Yes.

Q Thank you. And we've obviously got a detailed statement from you, Mrs Stirrat, and am I right in understanding that you're content that

that forms part of your evidence to the Scottish Hospitals Inquiry?

A Yes.

Q Thank you. Now, can I just clarify that you have a copy of your statement to hand?

A Yes, I do.

Q Good. If at any point you want to have a look at it to jog your memory or to check anything, just indicate and please do so. Is that okay?

A Yes, that's fine.

Q Now, as you've just confirmed, principally we're here to talk about events beginning in about February 2019, and I'll come onto that in a minute. But I think we can see towards the beginning of your statement that you've also told us quite a bit about experiences you had before that in the neonatal ward in 2016.

A Yes.

Q We've got your detailed evidence on that, and unless you wish to say more just now about it, I was going to move on to the events in 2019, subject to two points that I want to ask you about, is that okay?

A Yes, that's fine.

Q Okay. There are two things that you do raise in your statement about the events in 2016 that might be relevant to the Terms of

Reference that the Inquiry has. Am I right in understanding that when you were on the neonatal ward in 2016, you saw signs that said something about the water supply?

A Yes, so the signs were on the taps just as you enter neonatal because you had to wash your hands to see the babies, and on them we were told that you weren't allowed to drink the water. It was for hand-washing purposes.

Q And did you think anything of that at the time?

A I didn't because we were new to the hospital, so I just thought that that was kind of the norm, just to have those things.

Q And I think you also go on to say something, and it’s at paragraph 21 of your statement - it might be worth just having a look at it, Mrs Stirrat - you say something about subsequently discovering that babies should have been washed in bottled water because there were septic tanks?

A Yes, that’s correct.

Q Could you tell us a wee bit about that, please?

A So that didn't come to light until we started doing some of our own research when it came to light, obviously, that there were issues within the hospital water, and we got that information from leaked documents that Anas Sarwar had. We looked through those and it was from the water reports, and it stipulated that they had to find out about these tanks previously in round about 2015, and the advice had been - I think that was round about 2016 - the advice was that the children should be using bottled water to wash them in. Basically, that's where we got that information from.

Q Thank you. Now, if we move on a wee bit from 2016, going to move towards thinking about your son's illness and his treatment, one of the things that we've been doing in everybody's evidence was to get a better understanding of who these stories are really about. And so, before we start to look at the history of treatment, I wonder if you could just tell us a bit about your son.

A Yes, certainly. So [redacted] was diagnosed at three years old. He is a triplet. He was born at 27 weeks. His sisters are [redacted] and [redacted]. They had quite a rough time going through neonatal, but [redacted] seemed to be the more stronger one out of the three. Never had any issues until he was diagnosed at the age of three. He doesn't let him stop him doing

anything. He's pretty much very strong-willed and rules the roost in our house. Happy little boy, just loves playing with his sisters and just being a kind, little, sensitive person, really. Just really very much a happy little boy. Just struggled a little with not being allowed to go to like play groups and things like that with, obviously, being diagnosed. When he was first diagnosed, he hadn't been allowed to do any preschool stuff either because of being premature, so it took him a little while just to basically settle himself and be a normal little boy, and then that got very quickly taken away from him just because he was diagnosed.

Q What sort of things is he into? What does he like doing?

A He's very competitive. He loves his computer, loves board games, loves to just-- basically has to win at everything, but he's a very kind, considerate, little soul too with that. Him and [redacted] are very much alike in terms of they're more twins, I would say, than triplets. [redacted]'s very mature to him, so [redacted] kind of goes with his sisters along the lines of that. But he loves some outdoor fun as well, loves going out and visiting his friends, his cousins. Obviously, with being diagnosed, he couldn't have a lot of little friends and wasn't allowed to go to parties and things, so he just took that in his stride. But, at the same time, you know, I was a wee bit unhappy for him. In terms of going to the hospital and stuff, he's a bit fearful of the hospital. But obviously just being round that kind of environment all the time's kind of done that as well. But, generally speaking, he is a kind little boy who just loves to be with his family, really.

Q Okay. And am I right in understanding that the three of them have just started school?

A Yes, they just started school in August, so that's a time we never thought we would see. Just basically last year he was given palliative care and he's now on a trial drug and he's excelled, and we just found out on Monday that his recent scan's stable again. So that's been such happy news this week.

Q Good to hear, Mrs Stirrat. Thank you for that. I'm going to go on now and ask you a bit about his illness and his treatment. At this end, or it might just be my hearing, the connection is not that brilliant. Could I maybe ask you just to speak quite slowly to make sure that everybody who's listening to this is able to hear it properly?

A Yes.

Q If we go to February 2019 and, just to try and get an overview of things, am I right in understanding from your statement, Mrs Stirrat, that you felt that [redacted] wasn't quite himself and, I think, was he being sick and a bit dehydrated? Is that right?

A Yes. Yes, so, basically, it started off with what we thought was just a viral. One day, he just was sick. He came home from soft play and we just thought he's just caught a viral. Next day, my mum had came 'cause he'd been sick over like 12 hours of that period constantly, like every half hour. My mum said he looked very dehydrated, maybe take him to the doctors. So we took him up to the doctors and the doctor, again, said the same as us, "Yes, think he's dehydrated, possibly viral." But did say that if things progressed any worse or he didn't eat or drink over the weekend to take him to A&E, so he gave us a letter just to take him up. However, that evening, it was a Thursday evening, [redacted] came home and started complaining of a headache. Being three years old, my parents kept saying, you know, "That's not normal. He shouldn't have a headache. He's only three." The next day, we decided we would take him up to A&E, so my husband took him to A&E where he was seen.

Q And, eventually, I think, referred to neurology, is that right?

A Yes.

Q Yes, and is that when Mr or Dr O'Kane arrives?

A Yes. So what happened was he was taken to A&E and they had basically said again it was viral. But over the course of two to three days, we were continually, you know, speaking with A&E saying things weren't right. They had also said, "Did you give him Nurofen?" And I said, "Well, no, you gave me Calpol," and they said, "Well, give him Nurofen 'cause that's for a headache." So we said, "Right, okay." So we went away and did that and that was the Saturday. He was still writhing around during the night, and then on the Sunday, I just thought, "I need to take him over." Something just kind of clicked with me at that point.

So when we arrived at A&E, we were taken into another room because we'd previously been in, but, again, we were told, "No, it's viral. There's nothing wrong." And, you know, at that point, I knew something wasn't right and said, "No, we need something done. We need to look at

him. We need to get a scan or something," and I said I wasn't leaving till they did, and they reluctantly agreed and phoned neonatal-- sorry, neurology, and neurology said, "Yes, do a scan just to be on the safe side." And then that's when it was kind of flagged up that [redacted] had what was, in fact, a mass at that point in his head and was haemorrhaging, and that was when Dr O'Kane arrived on the scene.

Q Okay, we'll come onto that in a minute. And how was [redacted] at this point?

A When he arrived in A&E, he was very lethargic, really in himself. He was lying in the pram, wasn't kind of corresponding at all. We were just left for a few minutes in A&E in the main corridor and then we were taken to the CDU. At that point, things started to kind of deteriorate pretty quickly for [redacted]. He just really wasn't responding. They did put fluids and things on him, and then what happened was, obviously, when they did do the scan, we went down just normal on a wee chair pushed along, and within half an hour, I was called back and told that [redacted] was basically, the symptoms that he had-- At that point, the fluids started getting pushed through, so [redacted] was getting a bit better in himself. But obviously they were saying, “We need to get an emergency scan done now to find out exactly what we’re gonna have to do with surgery.”

Q And that was an MRI scan, is that right?

A Yes.

Q And am I right in understanding you went with him into the scanning machine, is that right?

A Yes, because they said they couldn’t sedate him because of the state that he was basically in, and him obviously being too little, they wouldn’t put him through the machine himself. So they said to me, “If you can lie in the machine with him, Mum, then we might get a better picture of it.” But we also had a crash team on standby, just because they were saying that he might not even make it into the scanner because, at this point, things were pretty serious because his tumour was actually haemorrhaging at that point, and it was starting to bleed.

Q Yes. So the scan showed a large mass, i.e. a tumour, and I think, as you’ve just said, it was already starting to bleed----

A Yes.

Q -- and [redacted], at that point, was deteriorating, is that right?

A Mm-hmm.

Q Then, I think we see from your statement that he was admitted immediately after that to surgery, and it was quite lengthy surgery, is that right?

A Yes. So he was in surgery for eight hours to get a (inaudible) of his head.

Q And then, I think, into the paediatric intensive care unit for a spell and then Ward 3A, is that right?

A Yes.

Q And that was while they and you awaited the results of a biopsy of the tumour, would that be right?

A Yes, we were told we would have to wait 10 days for the biopsy to come back.

Q Yes. And how did [redacted] cope in the period immediately after the operation?

A He was obviously pretty tired. I think at that point they were giving him morphine and then went down to paracetamol. Within kind of three days, [redacted] started to come round himself and, you know, being [redacted] again, and within the week was up and walking, which even the people on the ward were so surprised at just how resilient he actually was. In our own heads, I think we were just kind of thinking, “Maybe this has just been a bad bump or something and it's not anything to do with cancer. Of course, it can’t be cancer,” you know. I think that's what we were kind of trying to think. But obviously that wasn't the case.

Q Yes, we'll come onto that in a minute. But, at this point, when he goes to Ward 3A, were you feeling fairly hopeful that it would be okay?

A Yes. Yes, I think so, because he'd just come out of intensive care and he'd done really well in intensive care because obviously he'd get up and about within the three days, up to neurology. So we were hoping things were going to be good.

Q Yes. I would like to ask you a wee bit about Ward 3A. I think in your statement, paragraph 34, you describe it as "such a good place".

A It really was, yes. You know, we just got-- we went into neurology and it just basically felt kid-friendly. You know, the walls were bright and colourful, there was a little kind of like soft play area for kids who, you know, have behavioural issues and maybe like physio and things like that, so sensory and things. So it was just really welcoming. There was a toy room. There was just so much for the kids to do that, you know, we didn't feel like they were missing out, really.

Q Yes. I think in your statement you talk about the sensory room. Is that the soft play room that you've just talked about?

A Yes.

Q Yes, and was that something that [redacted] liked?

A Yes, he really enjoyed it and, just before [redacted] was diagnosed, we had been getting a test for processing disorder issues with [redacted], so this really helped him too at that point. It also helped him 'cause at this point I think he'd been off his legs for about ten days at that point, so his leg muscles were pretty weak. So in the sensory room, he was able to try and get up on his feet. And he wouldn't necessarily talk to the physios. He was a bit shy and that. But as soon as they walked out the door, he'd be up doing the thing. So they kind of caught him a couple of times off guard, so that was quite funny.

Q And did you see any improvement in [redacted] over this period?

A Definitely yes, because he had the opportunity just to be able to use his legs, walk around and do the things that he would normally do at home or at play group. And he would go into the wee, like-- It was like a sort of nursery setting, the play area, and there would be lots of different things to do. You know, kids could watch the TV, they could play their games, jigsaws and things, all the stuff that he was missing. So I think that kind of helped him along a wee bit because he could do that with his sisters when they came to visit as well.

Q Yes, and are you indicating that there was, in addition to the sensory room, there was a play area as well?

A Yes. There was a play area, a toy room as well, just down the (overspeaking)----

Q And, I mean, it helped him along. Did it help you at all?

A Yes, definitely, because it made him have time away from the room. So he was able to walk up and down the corridor and talk to other wee boys and girls on the ward as well, which, for us, as parents, we could speak to the other parents that were in the ward and get to know what they were in for and things like that. And I think most of the people in neurology tend to be long-term patients, so for them, it was good to have a wee bit of feedback on how they had been in the ward, etc. as well.

Q What facilities were there for parents on the ward?

A Well, they actually had a little kitchen just off [redacted]'s room, so you were able to get in there and make some toast, you could get bottles of

water, you could heat food up just down the corridor. It was in another corridor but it wasn't far from the actual ward itself, and in there it was like a family setting. So they had like tables and chairs and things and you could sit there and have a meal with the kids, and I think at that point, I remember it being a Sunday, we'd actually just got like a roast chicken from like Morrison's or something and we'd all sat and had a Sunday meal together, which was just nice because we'd had-- you know, the kids were really upheaval at that point and they didn't know what was going on. Mum and Dad were at the hospital and the girls were kind of elsewhere. So, for us, as a family, it was nice just to be able to sit and be a family again. So the facilities were really good. You know, you could store things in the fridge, so you could bring stuff in, snacks and things as well, which was really helpful.

Q Yes, and you indicate in your statement that you had a very high level of trust in the staff at this point. Would that be fair?

A Yes. Nothing was too much trouble for the staff and they got to really know the child. You weren't just kind of like a number. You know, they took their time with the kids and they really invested in you and not-- You know, “Do you need more blankets? Do you need more towels?” Just simple things that you always kind of take for granted, I suppose, in some ways. They were just-- You know, they were on the ball with medication. They knew exactly what everything was and when he was to get it and, “Don’t you worry, Mum and Dad, ‘cause we’re on that,” and they would be there when they should be and things. Mealtimes weren’t an issue either and if you wanted to leave, they would let you leave and things and, you know, communication was key and it definitely worked in the ward.

Q Now, moving on a little in time to March 2019, I think you're still in the neurology unit when you receive the outcome of the biopsy, is that right?

A Yes, that’s correct.

Q And am I right in understanding that, almost simultaneously, you get that news and you're introduced to an oncologist, is that right?

A Yes, yes.

Q And can we detect in your statement that you have some concern about the way that was handled?

A Yes, so we had to wait that day and there was a bit of a time lapse on when they should have arrived for the results. It was two o’clock in the afternoon and when they arrived it was Dr O’Kane and Dr Sastry. Obviously, I knew who Dr O’Kane was ‘cause we’d met him from [redacted]’s surgery, but I didn’t know who Dr Sastry was. He just said, “This is my oncologist,” and I just thought I don’t need to know any more ‘cause he sort of told me.

Q Yes, and you were given the diagnosis at that point, is that right?

A Uh-huh.

Q Do you want to tell us a wee bit about that?

A So we were basically just sat down and told that [redacted] had a cancerous tumour, and basically it was a rare and aggressive type of tumour. At that point, it kind of floored me. I think, at that point, I kind of shut down, Andrew was trying to take everything in, and we were told that he had to get treated very quickly. We were also told that, had it have been 10 years previous, then he’d have just been sent home because there were no treatments back then. However, they did have one sort of indication. They'd been on the phone to various different hospitals within the UK and abroad to find out the right call for treatment, and we were told that we would have chemotherapy followed by radio or proton beam therapy, which would, if it was the proton, would have to be done in America.

Q Yes. That's helpful, thank you. I think in your statement you indicate that one of the things that they'd done before they came to see you was that they'd had discussions with doctors in the UK, and I think in your statement you say it was in America as well that they spoke to other doctors. And you're indicating that already at this stage they were thinking about treatment in America, would that be right?

A Well, from what we were told, it would have to be on a trial board. So it would go to a trial board and they would decide what the best course of action was. From what I remember, I think it may have been a couple weeks down the line that we got told exactly what the case would be and what would happen in terms of the proton therapy.

Q And so was the plan to start chemo in the meantime anyway? Is that right?

A Yes, chemo definitely had to start straight away. So we were told, actually, it would be, you know, a couple of weeks down the line. We were discharged that day 'cause the first thing they said was, "Is there anything we can help you with? Any more questions?" I said, "When can we go home?" They said, "I think you go home just now, and we'll put a plan in place," so we just left.

So our initial thoughts were that it would only be maybe a matter of a week or two we'd be in this sort of world. However, that sort of got changed. When we were home, we got a phone call just the following day saying that [redacted] had to be brought in within the day, basically, because treatment would have to start a lot quicker based on the information they had been provided from other hospitals.

Q Yes, okay. And I think we can see that, in fact, [redacted] was taken in very soon after that and, I think, admitted to Ward 6A in the adult hospital, is that right?

A Yes. Yes.

Q And I'm going to ask you some questions about that in a minute. Am I right in understanding that the day after he was admitted, he was given surgery and he was given a central line, or a Hickman line, and a nasal gastric tube, is that right?

A Yes, uh-huh.

Q Those two things happened at the same time, is that right?

A Yes. From what I remember, the nasal gastric tube was put in when he was in theatre so that he wouldn't be alerted to it.

Q Yes. Now just----

A That was on my side of things----

Q Sorry, I interrupted you.

A It’s all right.

Q I was gonna ask you, just while we're on the subject of the central line, maybe deal with this point, just at this stage: am I right in understanding from your statement that at some stage you had some concerns about the plaster that covered his line and secured it to his skin?

A Yes, that was after he had it in a couple of days, we had the issue with the plaster. [redacted] was asking to have a bath. He was a bit scared, and we’d just got one of the kind of kid’s baby baths, so I said, “Can we just use the showerhead and fill it with bath water and just give him a bath ‘cause he's never had a shower?” And they said, “That's fine.” So we got him bathed and, obviously, I didn’t know how to deal with the central line. I didn’t know what the dressing needed

done and it got a bit wet, so he got a bit frightened, and we called a nurse in who said she would change it for us, the dressing.

And then when she took the plaster off, she needed to put another plaster over it, but [redacted] wasn’t fully dry, so the area was quite wet, and my sister was in the room and she had experience of being in the hospital previously and she kind of stepped in and said to them, “Are you gonna put that plaster over wet skin? You’ve just put it over the top of it. You know, that would be causing bacteria.” And she was a bit startled, the nurse, because she just-- I think she was kind of like, “You’ve kind of spoke to me out of place,” sort of thing, and she kind of just ripped the plaster off [redacted], which then [redacted] was hysterically crying. And then my sister dabbed him down, she cut another one on top of that, which, you know, at that point, that was our first sort of bad experience and sort of traumatised [redacted] from then onwards when it came to doing anything with his Hickman line.

Q Okay, thank you. Now, I’m going to ask you some questions about your impression of Ward 6A, but I think what I would like to do before that is ask you what you had been told before you went to Ward 6A.

A So on the day we were told about [redacted]'s diagnosis, obviously we asked the question about infections, etc., and we were told that the best protocol would probably be to take the kids out of nursery settings, e.g. the play group that they'd just started, purely because our kids didn't have an immune system due to not being allowed to go to nursery, etc., beforehand from being premature, so they didn't build anything up. So they felt that if [redacted] caught something off them, you know, it would be most likely they would bring a lot of infections in. So I was quite upset.

I said, "You know, he's just started play group. I don't want this to be a big upset for him. He's just settled in play group." And they said, "Don't worry. When he goes into the ward, the ward is usually really good. It's got play leaders. It's basically like a nursery or a play group setting. They'll do so much things. There's a toy room, it's very bright, it's very kid-friendly." So it kind of put me a wee bit at ease and then I started to sort of sell that to [redacted] because I had to go back and tell the three of them that, "You can't go to play group anymore and this is why, and obviously don't worry because this new ward is gonna be nice and it's gonna be really fresh like the neurology ward, and it'll be very kid-friendly and you'll have happy things to do."

Q And how did [redacted] react to that?

A He was more happy when I told him that he was gonna be able to go and do all these things. He was more excited 'cause he just wanted to know what toys they had, really, so he was a bit more at ease, I think, because he thought-- You know, we tried to make it a fun factor 'cause we knew that we were in this for the long haul, so we tried to make it fun and just express that a bit more in terms of the toys and things. So he was quite happy to go along with that at that point.

Q Okay. And when you arrived at Ward 6A, against the background of what you'd been told, what did you think?

A At first, I actually thought was I on the right ward because there was not any indication that it was a child's ward. The rooms were pretty dull, the main foyer where you came in was very dark and not airy, there were no kid-friendly pictures. It was just eerie.

Q Was there any playroom?

A Well, we got ourselves

settled in the room and I asked where the playroom was, and the nurse looked at me like I was some sort of clown and said, "That's it there," and kind of pointed to a plastic table and chairs with a pack of crayons. And I just was like, "No, we've been in neurology and they've got a playroom, they've got toys"-- Sorry, this just upsets me, this day. I said, "They've got toys, they have things. I've sold my child this. I've told him all these things are here." She said, "I'm so sorry, we don't have a playroom. This is it." And she said, "I can go and see if I can get you some colouring-ins and things for him. Would that help?" And I just was taken aback, and I just said, "Right, okay." That was that.

Q And what was the effect on [redacted]?

A He was upset. You know, he then started to kind of distrust us and what we were saying 'cause we'd sold this to him for so long, trying to jazz him up a bit about things. And, at that point, he was just really, I think, disappointed. For a wee boy, he just looked like-- You know, he was sat in that bed and he was just like-- That's the expression. I can't even describe it, to be fair, 'cause, you know, at that age, [redacted] can't describe how he feels, but he kept asking, "When can we go to the toys, Mummy?" And then he was referring back to where he'd been previously and he was saying, "Can we go to the soft play? Can we go over to the soft play?" And I'm thinking, "No, we can't do that because we're not in that ward anymore," but it's very hard to describe that to a three-year-old because a three-year-old doesn't understand. They're just thinking, "Mummy's told me this, but now it's not happening."

Q And, eventually, did you do something to try and help out with making sure that he did have something to entertain him?

A Yes, so I think, once we got our thoughts together, it was kind of like we need to make this as fun as possible. So our family and friends started rallying round and bringing gifts in and really spoiling [redacted] so that that side of things was taken away, and we really got him on board with that and he was always grateful that he would come in with a new toy every time he was in hospital.

And we just took it from that that he had his own little kind of treasure chest at home that he played with. We actually requested mats as well. So the floors were pretty dirty and we just felt like-- I don't know if I'm-- Sorry, I don't know if I'm going too ahead with this, if you want me to chat about this at the moment.

Q No, fire away.

A So we basically had-- [redacted] was in a cot, so when [redacted] had his first lot of chemo, the chemo drivers, the battery packs weren't working. They weren't very good at all, so they would cut out after like 20 minutes/half an hour. You couldn't-- They had the old-fashioned Yorkhill signs on them so we knew they were old, and [redacted] was basically tied to the chemo driver for three to four days at a time, so you couldn't walk around the ward and stretch your legs, etc. So my initial thought was we'll get one of these blue mats and we'll put him on that 'cause it just reached the bed and the cables of the machine. So he was able to sit on that, plus the floor was pretty dirty so it meant that we could actually sit him on something that was safe and clean.

But, quite often, when we would come in, they would say that there wasn't any mats available, they didn't know where any was. And then, one day, we walked down a corridor, there's a bathroom just as you walk in the door in the corridor of the ward, and we noticed that all the mats had been stored in there. So I think it was Andrew or myself - I can't remember who, sorry - who pulled them aside and said, "Look, there's mats in there." So they kind of sighed and got us one out and gave it a little clean, but we kind of scrubbed it again ourselves, and then they knew, going forward, that every time we came in, we would ask for those mats and the minute they tried to say there wasn't any, I'd say, "They're in that cupboard." So they'd got to the stage where they would start getting them out as soon as we came in 'cause they knew that, obviously, we knew where they were stored. So it meant that [redacted] had somewhere to play with his sisters and they could sit down and play with building bricks and stuff and just do stuff like that.

Q Thank you, that's helpful. Just in relation to what you said about the battery packs, are we to understand that the equipment that [redacted] was connected to in his room was plugged in?

A Yes.

Q But if you needed to leave the room, you obviously needed to leave with his equipment and there were batteries that they could, in theory, run on while that happened, is that right?

A Yes, uh-huh.

Q But the batteries in your experience didn't last long enough. Is that what you're indicating?

A No. No, I don't know if they were faulty or if they just didn't have charge, but I'd assume they were faulty. And we did bring that up at a later date as well with the meeting with Jeane Freeman, who said it would be resolved but it never was.

Q And when you indicated that you saw signs that said Yorkhill, where were they?

A Yes, on the actual machines themselves, they still say Yorkhill on them.

Q Did [redacted] experience temperature spikes much when he was on the ward?

A Yes. So when he first started on the chemo, he started to have temperature spikes and it got to a stage where he would have his chemo, go home, spike a temperature, come back, and it was just sort of that process all the time. And, from that, we were just told, "Oh, it's just part of chemo. That's what happens and then you just bring him back in."

Q Okay. And, just thinking again back to your impressions of Ward 6A, when you were in [redacted]'s room, were you able to look out the window?

A No, because the first room we got, the blinds weren't working so the room didn't-- the blinds

didn't open at all. So we were then given that news that there was no play area and then having no blind to look out, it just sort of made it a bit bleak.

Q A bit?

A Bleak.

Q And can you confirm whether [redacted] was isolated in his room much when he was on Ward 6A?

A Yes, there were occasions where [redacted] would be brought back in from having a temperature spike and they would give him antibiotics and say that he would be put in isolation, just because they didn't know what he had.

But there was never any communication once they took the cultures from him 'cause you would have to wait a few days to find out what was actually going on. But we never really ever got any answers, so it was just, "Oh yes, he can come out of isolation now." But, on one occasion, we were told that after three or four days that he could be out of isolation, and then the nurse was off shift and [redacted] had been going up and down the corridor, and then a few days later the same nurse came back and said, "Why is he out of isolation?" And I said, "'Cause he's allowed," and then I was told he was to go back in again. But nobody ever clarified why or anything what came from that, so we were just sort of left in limbo. And then, with everything else going on, it was just one other thing on the list that, at that point, to us, it was just part of chemo because that was the norm.

Q Now, just thinking about all of what you've said so far about Ward 6A and about his room, can you recall an exchange with any of the nurses about the room?

A In terms of…?

Q I think in your statement you say you recall one of the nurses making a comment about what it was like.

A Yes, so what happened was when [redacted] was stuck on the chemo machine, he was in his cot so he couldn't move. This is before we'd discovered that he actually could have the mats down. And there was a period of time where he was connected to the device, and it was about 12 hours and he wasn't disconnected because there was no one that disconnect him. They kept saying they would come back, but the chemo was finished and he was still there, you know, still connected. And eventually, you know, I kind of let rip and I was saying, "He's been lying there with that on his machine for 12 hours and nothing's happening." "Okay, we'll get him disconnected," and they did disconnect him, and the nurse made a joke and said, "Look at him, it's like a wee jail in there." And I thought, "She cannot be serious. She's actually making a joke of this!" And I don't know, on her part, if it was, you know, uncomfortable situation knowing that this was wrong or if she genuinely was making a joke. I just-- I don't know. At the time, I just thought, "I can't believe I'm hearing this. This is not funny." And they did disconnect him.

But, at the very same time, we had physio come out the following day to check [redacted]'s legs because [redacted] had been in the bed for so long, due to not having the battery packs and moving around. So they checked his legs to see how they were and how he was moving around because his legs were already having poor muscle tone, due to obviously being off them for so long previously.

Q Now, moving on a wee bit in time to April 2019, and I'm thinking now I'm going to try and just think about the period April 2019 to December 2019, are we right in understanding that in early April the discussion about America that there had been returned, and there was a plan or there was a suggestion of taking [redacted] to Florida for therapy, is that right?

A Yes, that’s correct. It was Jacksonville we were told to go to, which is in Florida.

Q Right, and for those who want the references in Mrs Stirrat’s statement, it’s paragraph 62 onwards, more or less. And I think we can see that on the 22nd of April [redacted] was discharged and travelled to Florida for, did you describe it as proton beam therapy?

A Yes, that's correct.

Q Now, I think it's clear from your statement that you had some concerns about the arrangements that were made for all of that. Is that something you want to go into just now or are you quite content just to leave us with what you’ve got in your statement about that?

A No, I think I'm quite content with what’s in the statement.

Q And I think we can see that-- Were you in Florida for about eight weeks?

A Yes, that’s right.

Q Yes, and we can see that you came back to Scotland on the 19th of June, I think, and then back to 6A for more chemo, is that right?

A Yes.

Q Okay, that’s helpful.

That gets us the kind of timeline on that bit of it. Just to move into some of the detail then: so the chemo that [redacted] went back onto, am I right in understanding that that was not chemo that he had when he was in Florida?

A Yes, he had that chemo when he-- It was his first chemo when he first started the protocol in the UK. But when we went over there, he was due to have it again. He had to get three different chemos and they said he couldn’t have it, which we didn’t know anything about so we were like, “Why can’t he have it? He has to have this.” But they said it wouldn’t work with the proton, something to do with the toxicity, I think, of it, so they then had to phone over to the UK and have that discussion.

The next planned stage was that we can try him with the other two chemos while he’s there, and when he came home, the missed chemos would be caught up with when he reached the UK.

Q Okay, and was the plan that he would be a day patient, but in effect, he became an inpatient in 6A, is that right?

A Throughout the treatment, he would be an inpatient for various cycles, but would also be a day patient at some points because the more cycles that went on, the sicker [redacted] got, so he would constantly need blood and platelet transfusions.

And it got to the stage, because of the waiting times when we were getting these transfusions, and when he arrived we'd have quite a long wait to get them as well, what would happen is we would be coming in early morning then leaving late on at night, and then the next day he would be back in again to get another one. So, you know, we sort of made the joke of we might as well bring our beds here because we literally are-- and it's quite cruel on [redacted] that he's being taken home for a couple of hours absolutely knackered and then told we're going back in in the morning again.

Q Yes. I'm grateful for that because it's something I should've asked you earlier, which was who stayed with [redacted] when he was on the ward?

A Andrew did a lot of the overnight stays. I did an odd one 'cause I had the girls home. But I did all the day patient visits and any visits in between that for other departments, etc.

Q Thank you. Now, something I want to ask a bit about in relation to this stage of things is [redacted]'s eating and drinking. When he was in

Florida, was he fed using a nasogastric tube?

A Not at all. He was eating freely of his own accord, happy to eat more or less everything. There would be a couple of days, he'd maybe have an off day. But the majority of the time, he loved his food in Florida.

Q Yes. But he wasn't having chemotherapy when he was in Florida, is that right?

A No, he was still having chemotherapy, just wasn't having the strongest dose of the chemo. So, he had the other two chemos over there.

Q And when he went back onto 6A, how was he fed when he was on 6A?

A Mainly via nasogastric tube.

Q Yes. In your statement, you refer to something called bolus feeding.

A Yes, that's the milk that they use. So, they basically put it through on a syringe or a driver for the milk, and it feeds him through that.

Q Through the nasogastric tube?

A Yes.

Q What was your understanding of why he was being fed that way in Glasgow?

A Well, when we first came

into the hospital, the very first day, when he was admitted back in February 2019, in Schiehallion or 6A, we were told that he was to get a nasogastric tube, but we didn't know anything about that. Nobody had told us, so we were just about to fit it. We were like, “What?”

Q I'm sorry, you were a bit-- Sorry, Mrs Stirrat, could I ask you to maybe just slow down a wee bit? I don't think the connection’s that great.

A Yes, it keeps disappearing on me. So, can you hear me now?

Q Yes. So, is my voice disappearing at times?

A Yes. A little.

Q Okay.

A So, in February ‘19, when we went into the Schiehallion the first time, we were told that [redacted] was getting a nasogastric tube, but nobody had told us previously to this. We had his protocol of chemo, etc., but nobody told us that he was going to get this NG tube fitted. So, I'd ask the question and they told me that kids just get these because they can't eat. They just don't eat with treatment. So, at the time, I’d said, “Well, can you give him the benefit of the doubt? Because he’s a good eater, he loves his food. If he doesn't eat, fair. Well, we'll just give him the tube.” But at the point, they said, “Oh (break in audio)----

Q Mrs Stirrat, your screen is frozen.

A Sorry, you’ve disappeared.

Q Can I stop you there, Mrs Stirrat?

A Yes.

Q Are you able to hear me?

A Yes, I can hear you, but your-- Yes. Your screen’s back again.

Q You disappeared as well. I'm just going to keep talking just now. You tell me when I reappear. Any sign there?

A Yes, you’re back. Yes, you're back.

Q Okay. You want to just go back over what you were just saying?

A Yes. So, I just start at the beginning again?

Q That might be the best.

A Okay. So, in 20-- Sorry, in February, when he was diagnosed, we were given a protocol of everything that would be happening and what he'd be getting done, etc. We were told about the Hickman line going in. But on the day that we came in to get that fitted, we were also told that [redacted] had to have an NG tube fitted, but there was no explanation what that was. So, at the time I said, "We weren't told this. Why is he getting this done?" We had a little bit of indication of what NG was because they'd had one when they were premature.

And they says, "Oh, because when kids are on chemo, they just don't eat. So, this is just part of the agenda of what's going to happen next." And I'd said, "Look, can we give him the benefit of the doubt because he does like his food? I think that we should let him decide whether he's gonna eat or not." And they said, "Well, we can put on the notes that mum's not happy." And I said, "That's not really the case. I've just been told this news." And I was quite taken aback that it was just put on me and he was just to get it done there and then.

With [redacted] I was very worried that he would be very upset that this had to go in while he was awake 'cause he was only three. So, they kind of reluctantly agreed and said, "I suppose we could speak and see if they can get it done while he's getting his Hickman line fitted." And that was the agreement, that he would get this tube in while his Hickman line was fitted.

Q Okay. When he was in the Glasgow hospital, was there any point when he was not being fed using the nasogastric tube?

A They would provide food on a daily basis. So, it would be either a hit or miss whether [redacted] would want it or not. At the time, I think a lot of it was to do with the standard of food that [redacted] was being provided. So, he wouldn't actually want the food that they provided, but wouldnnecessarily-- (Inaudible) the food that we provided him.

Q What was the food that was being provided?

A Chicken nuggets, fish fingers, pizza. But a lot of things were there-- was no nutrition in them. They were reheated, like they were really hard, and sometimes you couldn't even cut the things up because they were so solid. And they just were disgusting, basically. I wouldn't give it to a dog, is my description of it. It wasn't nice at all. We did complain on a couple of facts, and we were told that this is the dietary menu that's been given.

And then at one point, myself and Andrew spoke to the dietician, who then said that there was actually other menus that are available. But there are more menus, and it basically comes down to your dietary requirements, which they eventually provided, but again, it was a hit or a miss as to whether you were allowed it, depending on what staff member came along and took the menu that day. So, some days they would say that, “Yes, you could get that menu,” but other days they would say, “No, you’re not allowed that menu.”

Q I think we know that eventually, in I think October 2019, treatment finishes, is that right?

A Yes. So, he finished his chemotherapy at that point.

Q Yes. And I think his Hickman line was eventually removed in December of that year, is that right?

A Yes.

Q So, if we move forward in time, the next bit in the timeline, and we pick up the story in, I think, March 2020. I think we can see he had a scan then, and it was all clear, is that right?

A Yes. Yes.

Q But can you recall, not long after that, in May 2020 you began to see a change in his behaviour, is that right?

A Yes. So, he became more aggressive and constantly wanting food, but not in a good way. It's as if he didn't have a cut off. The only way I could describe it was a bit like a Duracell bunny. It was constantly like that. And I just thought, “Something's not right.” It just didn’t sit well with me. I knew my own son and I'd been told previously changes in mood swings, etc., could be a reoccurrence of his tumour. So, we did look out for those sorts of things.

Q And was he due to have another scan?

A Yes. So, he was due the scan in May. I think it was the end of May. So, when I phoned up to raise my concerns, which is, I think, the beginning of May, I was told that it was an on-call doctor and he said, “I'll speak to the team and see what they say.” And he phones me back and said, “You’ve just to monitor the situation, he’s due a scan anyway soon, so that’ll resolve things then.”

I was a bit taken aback by that answer, considering that [redacted]’s tumour is a very rare and aggressive one. So, if [redacted] does relapse, with this type of cancer, you only have days, not weeks or months, because it just haemorrhages and that’s you. Basically, that's what happened the first time around as well. We were told that if we hadn't have stood our ground that day in A&E, [redacted] wouldn't be here because he would have haemorrhaged and died that night. So, this was all in the back of my head when we raised concerns.

Q Okay. And eventually he did have a scan, is that right?

A Yes. It was delayed due to COVID. So, a lot of protocols and things were a bit delayed. So, by the time we had raised our concerns, and [redacted] getting scanned and results, it was four and a half weeks down the line.

Q Now, I think we can see from your statement, and for those who want the references, I think we're picking up the story from around about paragraph 71, we can see that I think you have some concerns about the way that the scan was done, is that right?

A Yes, that's correct. So, the night before, we had been on the Schiehallion group page on Facebook and had also heard from the hospital staff that Schiehallion patients, because of the new protocols that were going around, patients weren't allowed to be put to theatre and put to sleep with their parents; they would have to stay in the wards. But because of Schiehallion patients and their experience of having so many anaesthetics, etc., they were allowing the parents to go down to the rooms.

So, when we arrived that following morning for his scan, I had said, "I'll need to go down with [redacted] because [redacted]'s quite agitated and things when he gets put to sleep. And they said, "You can't do that, Mum." And I said, "Well, why not? Because we're Schiehallion." And they said, "No, that's not the case. He's going into the MRI scan room and he's not going straight to theatre, so it'll be different again." So, I said, "Well, he won't sit there. He'll be too upset. It'll not work. You can't put him to sleep with that because he just won't sit for it." She said, "Don't worry. We'll give him a mild sedative," and she said - this was the anaesthetic - "We'll give him a mild sedative and he'll be fine." So, she initiated this to the nurse. At that point, I think it was like ten past nine and he was to go down for 9.30. They'd said, "Give him the anaesthetic just now, and basically, that'll how be how--" The sedative, sorry. "And that'll be him ready to go down."

Ten, 15 minutes went by. Nothing had been given to [redacted] yet, and they were just taking him round. So, a couple minutes before they took him, the girl came in with two little capfuls of drugs and said, "Just get him to swallow this down," which was hard enough because [redacted] was one of these kind of kids that doesn't like swallowing medicine in the first instance. So, got him to do it, and was pleasantly surprised he did do it. And just as he went to take the second one he was drinking, she said, “Oh, that's the ketamine going in.” And I was like, “Sorry, what?” Because I hadn't been told this. And I don't know, something in my own head thought, “Need to keep an eye on him here because this isn’t right.”

The next minute, [redacted] started to sway. So, I put him up onto my legs and all I can describe was horrific because he was paralysed, and I mean paralysed. He couldn't swallow. He was choking. I could hear a (mimics choking sound) noise and his eyes were just blurred. Couldn’t move. And he was lying on me, and I keep hearing this funny noise, and a nurse came in and I said to her, “He's not right. There's something ….” And she went: “Oh, it's okay,” she said, “It'll just be because he's paralysed, and he can't swallow properly.” And I was just like, “What?” And then he was very quickly taken away, put on the bed and took down to the theatre-- Or the scanner machine.

So, I couldn't believe what I'd just seen. I was just a bit taken aback and things happened very quickly. Looking back now, I think my initial thought was, “They gave him two drugs because she should have gave him the sedative right away, and because she didn't give him it right away, it wouldn't have worked in time because it takes a wee while to work. So, instead of just giving him the one, we've just given him the ketamine as well, because that will mean he’ll be paralysed enough to go down.

Q Okay, thank you. I want to take you back to the very start of that answer. You mentioned the Schiehallion group page on Facebook.

A Yes.

Q We've had a bit of evidence over the past three weeks or so about Facebook pages, and I think we're starting to understand that there were different pages. When you refer to the Schiehallion group page, who’s that for? Is that just for the patients and families, or is that the hospital as well?

A There's two. So, there's one just for patients and families, and there's another one that the hospital opened up and they basically put communication through as well sometimes on that one.

Q Which one was this?

A I can't be 100 per cent certain, but I think it may have just been the family one. But then I do remember seeing bits from the hospital as well. So, I don't know if it was on both, so I can't be 100 per cent certain on that.

Q But is it your recollection, then, that there was discussion on the Facebook page among parents about how scans would be dealt with for Schiehallion patients, is that right?

A Yes, basically because a parent had been in the day before, and that was her experience and what she was told from the staff. So, that’s (break in audio) we're told. And then when-- I think I'd been on the phone that day in regards to it and they’d clarified on the phone as well that yes, that would be the case. Things would go ahead that way.

Q And who’d you been on the phone to? Can you recall?

A Just day care, but I don't know who it was I spoke to and anything.

Q Anyway, so as you've described it, the scan proceeded and was it then just a case of waiting for the result, is that right?

A Yes. So, when they brought him back up the stair to the room, they said, “Oh, he was quite feisty when he was coming round,” but it was like a different child they were describing because [redacted] was still pretty much out of it at that point, and they had to lift him onto the bed. So, when they lifted him onto the bed, he started to come around a little and they said, “Right, Mum, just feed him and get him home.”

So, I started to feed him, but it was like he was there one minute and gone the next. As if the medicine hadn't worn off on him and like he would forget to swallow and then start choking. And I said to the nurse, she said, “Oh, he’s fine.” I said, “No, he's not.” I said, “I'm not feeding him anymore. This is dangerous.” So, I stopped feeding him, and we had to wait a good hour or so for [redacted] to start eventually being him, but it just didn't look like [redacted]. He was quite drained and they said, “Oh, yes, Mum, he’s eating now, so you can go home.” And sent us home with no aftercare.

At that point, we were in the middle of COVID times. So, I felt it was very -- it was very important. I phoned my mum because I just felt like she would know, out of anybody, whether Caled was good or not, because she always knew with [redacted]. So, she said, “I'll come and see him.” And she came and she said, “No.” She said, “There's something not right with him. Phone the hospital back and tell them that he's not right.” So, I did phone them. At that point, Calev had fell asleep and they said, “Let him have his sleep, and if he does waking up and he's still the same, then bring him back to us." But he did waking up a good couple of hours later, and he was all right in himself. I think it was just about forward.

But from my own experience in my family that work in the medical industry, they had said that, given the ketamine, he should have been given a leaflet and should have been told that there was aftereffects of having this drug. And also, at the time, she was saying, "I don't understand why he's been given that, because you usually give that to patients that maybe had a car accident, are on the road and had something wrong with them serious. You wouldn't normally give that to a patient that's put in a scanner."

So, that kind of highlighted the effect that that was quite bad. And I phoned day care and said I wanted to make a complaint about that. And Dr Sastry, [redacted]'s oncologist, phoned me back and said that he would investigate into that. And I didn't hear anything back until the day that [redacted] was going in for surgery from the anaesthetic team, which I felt was a disrespectful, to be fair.

Q I think, if we go back to a stage when [redacted] is back home, am I right in understanding from your statement that on the 1st of June, your husband took a call from the hospital that they wanted you to go there urgently, is that right?

A Yes. So, they phoned up, and it was nine o'clock in the morning and they said to Andrew, "Sorry for phoning so late." As soon as they said, "Sorry for phoning so late." It's nine o'clock in the morning, what do you mean late? That was a bit strange. So, we knew that, obviously, given the fact that we thought that he was relapsing that we knew at this point, yes, it possibly is a relapse.

Q Yes. And I mean, there's a lot in your statement about this chapter of events. And I think it'd be fair to say you have concerns about the discussions that took place about the treatment options, is that right?

A Yes.

Q Yes. Now, I'm not proposing to go through all of that. We've got your very detailed account on that already. But I think initially you were told that it would only be palliative care that would be offered, but eventually, and partly through your own researches, there were discussions about going on to a trial, is that right?

A Yes.

Q And is that eventually, what, in fact, was agreed?

A Yes, it was. Through my own discussions.

Q And I think, as you've just indicated, [redacted] was operated on again and a further tumour was removed, is that right?

A Yes.

Q Yes. And I think he then went onto a further chemotherapy, and would that be the chemotherapy that was part of this trial, is that right?

A Yes. So, initially we were told that after the surgery, he would be going onto the chemotherapy, the new drug that he's on at the moment.

Q And is he----

A However-- Sorry.

Q No, you go. Sorry.

A However, that was our initial treatment plan. But two weeks after the surgery, when we were just initially thinking that [redacted] would start this chemo, we were given a call and told that the Beatson wanted to meet with us, which we found was a bit of a strange thing because the Beatson were one of the teams who had said, basically, this wasn't going to happen; there was nothing. There was no other options available. And we went

up to a meeting, and they then granted six weeks of radiotherapy, which we were taken aback. We'd just been told that they couldn't do anything and now we're given this option of six weeks of radiotherapy as a direct result of how well the surgery went. And then we were given the new trial chemo drug on the 1st October last year.

Q Yes, and I think [redacted] also had, was it six weeks of radiotherapy, as well?

A Six weeks of that.

Q Now, I want to move on a little to an event that occurred in December 2020, and initially began,

I think, with a sore ear. Do you want to tell us a bit about that?

A Yes. So, [redacted] started complaining just occasionally. He'd had a wee bit of a cold and was at nursery at that point, so we thought he's just caught a bug again. He was putting a jumper over his head, he'd complain of a sore ear, but nothing majorly that would indicate that he had anything big wrong. A week down the line, we phoned the GP. GP said, "I think it's just an ear infection." No, sorry. "I think it's congestion, possibly from the cold. All right, just keep an eye on him." A couple of days later, he just wasn't really happy, and I thought, "Best phoning day care because day care are more-- they know [redacted]'s situation than the GP." They said, "Yes, I think you should just take him over just to be on the safe side and get him have a looked at."

So, Andrew took him over to the day care and day care looked in his ear and said it was (inaudible) green. They'd said, "Never seen anything like this before, so we'll need to send him down to Ear, Nose and Throat."

So, Andrew went downstairs to Ear, Nose and Throat, and again they looked in his ear, seen the (inaudible) was green. Again, they don't know what it was, had asked if he'd put anything in his in his ear, which to that (inaudible) he said, "No, he's not that kind of kid who would do that." And he definitely was saying himself he hadn't done anything. They had thought that [redacted] had just had a scan, and it was possible contrast that had leaked through into the ear. They said there was a bone in his head that, possibly from the re-sectioning had done previously, had maybe shifted and that that would be the problem. But they proceeded to say that he would need a scan to that effect to find out, but at the time said, "We don't want to do a scan until his next scan's due at the end of January. So, in the meantime, go home, make sure that if there's any fluid leaking (inaudible) and get him straight up to A&E. He may spike temperatures due to this."

So, when Andrew took him home, there was no medicines or anything like that. This was a Tuesday. And I said to Andrew, "I'm not waiting. That's a ticking time bomb. It's the same side of his head from these previous problems." So, I phoned up and said, "Look, I'm not happy." No, sorry. I hadn't phoned at that point. Andrew took him in on the Thursday to day care, and I said, "If you don't say anything, I'm going to say something. I'll give them a phone."

He went in and he said to them, and day care said, "What are you talking about? We thought you'd just been sent home." So, there was no paperwork had been followed through from ENT to the day care team. So, they said, "We'll get on the top of this and we'll chase them up and find out what's actually going on, and they'd say that Mum's not happy. We want this seen a lot quicker." From the Thursday to the following Monday, the day care were trying to get in contact.

And the Monday morning, [redacted] got up and was going to nursery and, at this point, [redacted] wasn't eating very well. And we always know something's wrong with [redacted]. If he doesn't eat, that tends to be the case. And, at that morning we were told to keep stretching his stomach with back on the NG feeds. So, he spat out his NG tube and we thought, “Oh, right, it's just ‘cause we're stretching his tummy. He's been sick because there's too food going in.” So, the nursery had taken him in.

And then that morning, we got a phone call about lunchtime, saying that had spiked a temperature. I think it was 39.2. And they said, “Can you bring him up to--” They said, “Can you come and collect him?” So, (break in audio) collect him, and Andrew took him over and I phoned day care ahead. So, they said, “You need to go to A&E. We know probably what’s going on, but obviously with COVID protocols, it’ll need to be A&E, but we'll let them know because we have a room ahead for you.”

So, Andrew went into A&E. Sorry, it wasn't Andrew, it was myself. It was myself at that point. I took him to A&E. I went into A&E and by the time we got to A&E, [redacted]’s temperature had shot up again. I think it was 39.8. Even a normal child, you would be giving them medicine. But we waited two hours of medicine. He couldn't swallow medicine because he had spat the NG out, and all his medicines were going through that. And [redacted] wouldn't swallow medicines in the first instance. So, we had said that right away. They said, “We'll get a line put into him,” and we waited. There was nobody there to put a line in, and my mum kept phoning me, saying, “You need to get him treated, why’s he still sitting there?” He was in this room.

At this point, he was getting delirious, he was just away, and I think it was the practitioner from the Schiehallion Ward came down. She looked at him and said, “What's going on?” And I said, “They've not given me anything.” She said, “We don't have 20 minutes to wait. He needs to get medicine right now.” And I said, “Well, he won't swallow medicine.” And at this point, he couldn't even open his eyes. There was no way he was going to swallow medicine. So, eventually they got a line into him and gave him the Calpol, I think it was.

Q Sorry to interrupt. Sorry to interrupt. Was the line using a cannula?

A Yes.

Q Sorry. Please continue.

A So, they took him and they said, “He's probably got a viral.” And I said, “Listen, he's not got a viral. This is to do with his ear. I know it's to do with his ear. We've already been told these things might happen.” So, they took him-- I think it was 3C or 2C, I’m not 100 per cent. It was a COVID ward, anyway, because I remember all the signs around the door. I obviously wasn't happy about that either, being the kind of patient [redacted] was, that he was getting put in this ward. I kept saying to them at the same time, “I've got doubts about this. There’s something seriously wrong.” And they kept saying, “It's fine. It's fine.” And then, got us settled in the room, [redacted] has fluids put on.

At that point, he started to get a wee bit more alert again. And then fell asleep. So, the nurse came in from Schiehallion and said, “Mum was saying that she is obviously worried about him.” They said, “Yes, but we've got a plan in place.” This was the ward staff. And she said, “Right, okay.” So, that was that. And then I proceeded to go home ‘cause Andrew was going to take over. I'd literally just walked in the door, I think it was quarter to seven at night, and I got a phone call from Wendy from Schiehallion, and she said, “Where are you, Mum?” And I could hear the panic in her voice and she said, “You need to get straight back here.” And I said, “What's going on?” She said, “It’s your boy.” She said, “He's not

very good.” And I just said, “Is it sepsis?” And she said, “We think so.”

So, I came in and there was just a crash team around him. There was a lot of stuff going on. People were trying to look for things that weren’t in the right cupboards. They were trying to get him down to a scan team, they were going to intubate him. It was all just-- I remember my legs just going away from it and having to-- They sat me in a chair, and all this stuff, looking around, I'm thinking, “I’ve just left him literally an hour ago, you're telling me he was fine. I knew he wasn’t fine. I kept saying that and nobody would listen.”

And then, at this point, he was just totally gone. They said that his heartrate had went through the roof, and they couldn't control it, and they didn't know what was going on. So, then, eventually got him down in the scanner. They had phoned ENT to see what had been happening, because at this point, they still didn't have any of the paperwork that they should have had from the previous week. So, they were only going on what we were saying, but they couldn't get hold of anyone from ENT. So, they said they were going to just intubate him and take him into the scanner to find out what was going on. I think when they tried to intubate, [redacted] was startled a little, so they said they didn't want to do that to him.

So, the just left him to see how he would be, and they took him into the scanner. And there was a lot of toing and froing about things. And I was saying, “Based on my previous experience, I only want to speak to Dr Roddy. ‘Cause Roddy knows his job and Roddy will tell us the truth, and I just want him.” So, he was off and his senior person had came in, said, “I've been on the phone to Roddy, and he said this, that, the next thing,” which kept me in check and knew that he was looking after things at his side.

So, they took him in for the scan anyway, came back out and said, “Yes.” The fold at this point, was kind of bulging at the top of his head above his ears, so you could actually see where it had spread. They then said the whole day that after -- They’d plowed him with every antibiotic possible at this point. They said the following day they were going to, basically, do a lumbar puncture, because they thought it with meningitis. And I asked at the time what meningitis it was, and they said it would have stemmed from the ear. So----

Q Sorry, I didn't catch you there. It was a what from his ear?

A It would have stemmed from the ear, the meningitis. So, when it was confirmed that it was meningitis, the consultants said, “Yes, it would have stemmed from the ear.”

The following day, another consultant came in, I said, “Look, I've heard it’s came from his ear, and that's because it wasn't treated, etc.” And then, he proceeded to tell me that, “No, it couldn't quite possibly be that. We can't confirm that.” I then turned around and said, “Well, what kind of meningitis is it? Did he get it from playgroup? Did he get it from the environment outside?” And he said, “No, he couldn’t have got it from that?” I said, “So, what are you hiding?” I said, “’Cause I’ve been told one story and you're now trying to cover tracks of a doctor who was discharged, [redacted], who shouldn't have,” and he just was startled.

And at that point, I lost it and I said, “I suggest you just walk out of this room right now.” Because to me it felt like they were trying to cover their tracks because the consultant the day before had confirmed to me what had been said and what their thoughts were. And then this person’s now telling me a completely different story.

Then Schiehallion team came

down and it was two new girls that I'd never met before, two new doctors, and I let rip. At this point, [redacted] was off his trial drug because they were then phoning the trial company because there was no backup with the drug. They didn't know enough. So, they were phoning, finding out whether the drug would've had played part in it, which came back and said, "No, it's not the drug." 'Cause I was saying, you're taking [redacted] off a drug. You're now fixing a problem with another problem, and now we might have a relapse on our hands because he's not on his drug. So, I was obviously going through the roof, as you can imagine.

So, the Schiehallion team then stopped when I was talking and said, "Sorry. You mean to say [redacted] was sent home at that initial appointment at ENT with no antibiotic?" I said, "He was given nothing." And she said, "Nothing at all?" And I said, "No. Nothing. He was sent home and told he were waiting a scan." She said, "Well, that shouldn't have happened." And she said, "I'll get to the bottom of that." But nothing ever came out of that either.

Q Thank you very much. Now, I'm going to move on. I'll have you talk about different things that (break in audio) given us through the complete history of [redacted]'s treatment,

and you brought us up to date, of course, at the very start of your evidence. What I want to ask you about now are a number of other questions about issues to do with the hospital that you identify in your statement. And the first of these issues is issues to do with the safety of the water supply. You've already told us a bit about what you saw on the neonatal ward.

What I want to ask you about now is your experiences on Ward 6A and 3A. And I think the first thing, probably, I want to ask you is: did you see any signs in those wards about whether it was safe to drink the water or not?

A Yes. There were signs on the sinks. That was the very first thing we noticed when we went into 6A was there was a sign saying, "Hand wash only." Not to drink it. Again, it just stuck in my mind from being in neonatal and seeing the same thing. So, again, at that point, I just thought, this is kind of the norm.

Q Yes. Did you see filters on the taps?

A I can't officially remember right back at the beginning if there was filters. I think maybe there was at that point filters on the taps, not on the showers.

Q When you were on Ward 3A, were you provided with bottled water?

A Yes. There was bottled water readily available. It was in the fridge and you could help yourself to it.

Q Yes. And what about sick-- Sorry. I interrupted you.

A That's what we'd use to make up diluting juices and things like that, as well with the bottled water, and the same in 6A. If you asked for diluting juice, they would come along with the bottled water and then we would fill it up from that. But sometimes you were waiting a long time and by the time they would come along with it, [redacted] wouldn't want it anymore, so we started bringing him our own water so that we didn't have to wait for staff members getting it for us.

Q Yes. What discussions or communication was there with any of the staff about the water?

A There wasn't any. Literally. We were just literally told what's on the sink, basically, went and you didn't have-- You just used the bottled water. "Ask if you want any water, we can get it for you?" But there was no discussion as to why that was the case or anything like that.

Q Do you have any recollection of a discussion with Dr Sastry about issues to do with the water?

A Yes. So, that was basically when the reports had been coming through, saying that the water was fine at that point. This is when [redacted] was put on the second medicine and at that point they were saying that the water was safe and was wholesome. And we kept asking the question, "If the water is safe, and we know that [redacted] has been put on this medication because of the water issues, then why is he still on this medicine?" But at the board meetings that we attended, nobody would give us the answer. And it was the Chair of the Board then tried to blame it on miscommunication, you would have to speak to your doctor, which we knew was total rubbish.

And then I had online phone call-- Sorry, just a phone call from Dr Sastry. And I said to him, "Obviously at this point, we've been in the media, I need to know what's going on and why he's still in this medicine if you're deeming the water is working and fine." And he turned around and said to me that the reason why [redacted] was still on the medicine was, although the filters were on the taps and it was deemed safe and fit for purpose, they didn't know if the moisture in the air or the cracks in the walls, or any water from here was safe, and that was why [redacted] was still on medicine.

And at that point I said to him, “All these families are in the same situation. They don't understand why their child's on this medication, and now I've been given this additional answer. What do I do with that?” And he said, “You do what you see fit.” So, then I let other parents and families know that, that although the board were telling us this, this was why our children were still on this medication.

Q Yes. Thank you for that. Now, in your statement, you do tell us about a meeting with Jeane Freeman, and there's a meeting also with the Health Board. And are you indicating, therefore, that the discussion with Dr Sastry was after that meeting was the Health Board.

A Yes.

Q And I'm going to ask you in a minute about preventative medication. Is that what Dr Sastry was referring to in that conversation with you?

A Yes. Yes.

Q Yes. Now, can you recall whether, among the parents, possibly in the in the Facebook group, for example, there was any discussion about issues to do with the water?

A I think everyone was on the same belief of, we were just told to take this medication, and obviously there was issues with the water. There was a parent who said that her kid had contracted an infection, and at that point, we don't know what an infection was. But then it came back that obviously it was because of the water. And that’s when we were then given all the preventative medications.

Q Thank you. Now, still on the subject of water, just moving on to a slightly different aspect of that. I’m going to ask you some questions about the showers. Did you ever see any signs that told you anything about how you were supposed to use the showers?

A Yes. So, there's a sign that’s still currently on it. It says to run them five to ten minutes every day, but it doesn't tell you who's to run them or if it should us or the staff that run them.

Q Right. Is there any explanation? Or did you ever receive any explanation for why you needed to do this?

A No. In my own thoughts, it was that you can get bacteria from showers from not running them, all the times they’re not in use, but now looking came back, I think, well, that wouldn’t make sense ‘cause the rooms are always in use, so therefore, the showers are in use. But there was never any explanation from the hospital themselves.

Q Did you ever experience any issues or concerns to do with the showers?

A Showers were a nightmare. You couldn't leave them on for any length of time because the floors weren't lowered enough, so the water would come out over the circle, where it should go in the drain. So, you'd quite often have flooding and have to put towels in a circle shape so that-- Give it a bit of a sandbank, as it were, so that the water didn't come out of the shower room. And I also think it was quite a bit of a hazard, in terms of slipping on things. I didn't feel they were particularly could use the-- You always were very cautious when you were in the shower that you could only be in for two minutes, in case anything was to happen and the water was to go everywhere.

Q And to be clear, in terms of who was taking a shower, was it just you? Or I think you indicated earlier that [redacted]-- Did he have a shower or did he not have a shower?

A He would use the shower, but we would fill it up into a bath so that the water-- We'd just take the handles and fill the bath water up because he was just too little to stand. And I think, as well, for myself, with him having a head injury, it was more safety because of the water and how far out it would come in the room. So, it was more about at least I can control where the water is for him.

Q Yes. And did you ever have any concerns about [redacted] using that water for his bath?

A I did once things started to become apparent, but at the beginning, no. But in hindsight now, just seeing all the evidence that's been given from other parents, it's now put me on the course of [redacted] had skin issues. At the time, we were told it was eczema from the staff. And when I've seen other patients describe it, and what they had been told, I'm now thinking the whole nines of, "I don't think it was eczema, because when he stopped being an inpatient, the flareup thing didn't happen." This wasn't a flareup, this was permanently, every time he was in. And then when he stopped going in, he didn't have this anymore.

And having eczema myself, I know that that's not the case, and it wouldn't necessarily go away. They didn't prescribe any creams either. It was (inaudible) care bath stuff for sensitive skin, and said, “Just use that.” Which I'm thinking now, “If it was eczema, why didn't give me any cream for it? That makes no sense.”

Q Thank you. Now, I think another thing that you mentioned in your statement to do with water, is you say that you saw maintenance people putting stuff down the drains, is that right?

A Yes. So, they would just walk in your room. Sometimes they didn't even chat, which, you're saying you’ve got an immunocompromised child in the room, I felt wasn't really good. They didn't have any protective clothing on; they’d just come in their work stuff. And so, “Oh, we're just going into the toilet, in the bathroom.” And then they would stick some sort of fluid down the drain. And then, there was never any explanation, they would just walk back out again, and that would be them.

Q Did they just walk straight into the room?

A Uh-huh. There was quite often occasions where they would just walk in and they hadn't even knocked. But I feel as well, you don't know what's going on in that room. You don't know what that child has, or what protocols are, and they just would go in. So, I didn't feel that was good either.

Q Thank you. Now, I want to ask you about something else now, and it's preventative medicine. I think we know from your statement that [redacted] was on something called Posaconazole, is that right?

A Yes, that’s correct.

Q Were you told about that when he went onto that particular medication?

A No. Well, that was the second one. Sorry, I mix the two up, so I think Ciproflaxin was the first one that he was put on, his chemo, and Posaconazole was his second one.

So, what happened was we got a phone call and we’re told to arrive at the hospital. We had seen in the media that was things going on and there was issues with the water, etc. So, we sort of knew something was happening. We were taken into day care and sat down, and it was literally read off a statement - what was to happen, and [redacted] was to get this medicine and would have to take it so many times a day. There is no explanation as to why; there is no communication of whether we had any choices in the matter, it was just told we were to do that. And when I asked the question, “What is it we are treating and why?” They were told that they couldn't disclose it, and the person in question, who’s provided the medicine, the doctor brought and said, “I only wish the people upstairs would come down and tell yous because my hands are tied.” At that point, you know, we'd already been lied to previously with the medicine he’d been on, and we were now being lied to again - or not disclosing the information.

I remember, at that point, someone from the lunch team came in and provided soup for [redacted] and, you know, obviously I don't know what we’re dealing with and I said to them, “Well, I'm not giving him that soup because, you know, I don't know what we're treating here. For all I know, it could be in there.” And the doctor said, “You're well within your rights because I wouldn't either.”

Q And did there come a point where, well, you needed to speak to the media about these matters?

A Yes, I think because we were not getting any answers and, you know, people would ask the question. And I think it was when we’d been to the meetings, and we were getting told the water is fine. And [redacted] was then told that we had to go downstairs for a scan.

So, we arrived at the scan room,

which is down in the ground floor. [redacted] dropped his dummy out on the floor - and, at that point, you know, I was taking in my own cutlery and plates and everything because we just couldn't trust the environment we were in, so I wouldn't have washed his dummy under the tap anyway - but when I lifted the dummy, the scan lady said, “Don't wash that under the water.” And I just was taken aback, I said, “Well, what do you mean? They’re saying the water’s fine now.” And she said, “Eh…” and went, “… too much chloride in it.” And I was like, “What?!” So, I just left it there because I thought, “I'm not going to get into this because she looks as if she's a bit startled, and I don't think she really knows what she's talking about.” So, I just kind of went, “Right, okay, I wasn't going to wash it anyway. There’s a spare one.” And then at that point, I thought “If she's telling not to wash that in the water, there's obviously a reason, and I'm not getting any answers from anywhere that I've been.” And I thought it’s about time that we tried to get the answers ourself because this was my son's life and this was affecting him.

And I also think as well, when we were given that medication, we were also told that we were allowed to take [redacted] down to the toilets in the ground floor and that he shouldn't wash his hands in the toilet or do the toilet in there and neither should we if we had [redacted] with us. And I said “Well, why?” And all she could tell me was “In case there's any splash back from the flushing of the toilet or the washing of the hands.” I then later found out, at a later date, that the parents who were using the clinics downstairs hadn't been notified of this, and then found out, at that point, the reason why we had been notified was because [redacted] had a central line in and they didn't - which then brought me to the fact that you know, we were being treated with this medication because this bacteria was down to the central line. It was (inaudible) the central line, and that's how we got our information.

Q Thank you. I want to move on to some other matters, and you've already touched on them to some extent, and these are issues to do with communication. And the first thing I want to ask you about is the meeting with Jeane Freeman in September 2019; I think you were at that meeting, is that right?

A Uh-huh.

Q Do you have a recollection of the meeting?

A Yes.

Q Do you want to tell us what was discussed and what your impressions were?

A So, I think at the time, you know, all the families were quite upset finding things out in the media, and this was just to be, basically, clarification of what went wrong and what was going to happen next. At that meeting, there was quite a lot of people, and all of the families kind of had their say in what their, you know, problems and issues with the hospital where. Jeane Freeman herself came across as being very helpful at the time, wanted to listen to the families, and we were told that she would look into all the issues that were raised at the meeting and would then come back to us with the answers.

At that point, we brought up about the battery packs, the lack of facilities, no kitchen, nothing for the kids to do, all the dietary requirements - everything was kind of brought into that meeting. And you know, at that point, I’d said about our finding out about the medication in America that we'd been lied to as well so, everything, you know. She sort of acted like she was surprised at some of the things we were saying but, now, in hindsight, it was just basically to mask what she already knew.

Q And I think you mentioned earlier that, subsequent to that, there was a meeting with the health board, is that right?

A Yes. So, that was taking place in the hospital.

Q It took place in the hospital. And what was discussed? Sorry, let me take a step back-- Who was present at that meeting as far as you can recall?

A So, I know there was a patient liaison person who is on the board, and there was a facilities manager, and various other different doctors who were part of the team, as in the health trust.

Q Can you remember what was discussed at the meeting?

A I think a lot of it was to do with the building works and what was actually happening with them. And, at that point, I think it was because there was so much media attention, it was basically trying to go over that and basically try and reassure the families that things had been put in place and, you know, things would be dealt with. But my reaction to it was they didn't give us any information, didn't divulge anything at all.

I think it was Jennifer Haynes I sat with, and I explained that, you know, I'd raised all these concerns and still no one had come back to me from the previous meeting. And she then sat and took all the notes down and said that "I will come back to you because that's my job; and they wouldn't want to, you know, upset yous with all this reaction, and we will get to the bottom of the matter and come back to you." But nobody ever did come back to me properly at all.

Q Yes, did you raise any particular concerns at this meeting?

A Yes, at this meeting, this is when we were talking about the second medication that they were on. So, I think it was the chair of the meeting - I can't remember his name - and I said to him, you know, "Why is my son still on this medication if yous are saying that, you know, the water is wholesome and fit for purpose?" And he was startled, and he then tried to blame it on miscommunication and individual cases, and "You will need to speak to your doctor." And I said, "Well, that's lies because he's just told me that he's on it for a reason." And then he just kind of went, "Duh-duh--" and turned off to something else.

Q Yes. And then, as you've explained subsequently, you had that discussion with Dr Sastry, is that right?

A Uh-huh.

Q Thank you.

A Now I'm trying to work out if it was before or after - I'm sure it was after.

Q Thank you. Now, I want to move on really, towards the conclusion of your evidence, Mrs Stirrat. And I want to ask you some questions about impact. I mean, to what extent have the problems that you've described with the hospital environment-- what extent of the impacted upon you or upon your husband or upon [redacted]?

A We don't trust the hospital. You know, when we first went into the hospital, we had a lot of faith in them, and we trusted everything was going to be above board. You know, nobody prepares you for having a sick child, let alone, you know, who's having to go through such gruelling treatment. I think for us, it's a bit of panic stations when we go into the hospital now. You never know what's going to happen, and you can't fully comprehend whether what they're saying is going to be truthful or it's going to be something else that's made up. I think once you lost the trust, it's very hard to get it back.

[redacted] is pretty much terrified of the hospital now. For him, it's really hard because he doesn't want to speak to anyone in the hospital. He pretty much cowers away from people, and I don't know if that's just an onset of seeing our reactions to what's happened in the hospital or it's just his way of coping with things. I feel that a lot of, you know, the lies and things could have been avoided if they'd just been truthful. They may not have, you know, the answers and things, but at least, you know, there would have been a bit of trust there that they were forthcoming with events. I think, for us, the biggest thing that stood out really was being lied to in a foreign hospital, finding out that you had a dirty hospital with dirty water. You know, finding out that your son was on a medication that he should not have been on - that, right away, made us distrust the hospital, and then having no explanation as to why when we came back to the UK.

You know, the trust is gone, and I just feel like, for us, as a family, going forward, as much as we have to visit that hospital on a regular basis, if there was another hospital alongside that that we could go to, we would very much be there. I just feel that, for us and other families, that hospital should not be there. It shouldn't be where it is because it's very much wrong.

Q Thank you, Mrs Stirrat. Now, I don't have any further questions for you. Is there anything further you want to say before you conclude your evidence today?

A I think, really, just based on the facts of everything that's going on in the hospital, I really do feel for the staff because the staff have had to make so many harsh and rash choices and, for them, you know, the pressure has been really bad on them. I feel that, overall the staff would go above and beyond. In quite a lot of the cases they will do what they can, but I feel that, for them, the pressure is really, really a lot; and I feel that they need support as well as the families that have gone through this, ‘cause I feel that a lot of them aren’t coping as well as they could, and it's due to the environment that they have been provided with to work in.

MR DUNCAN: Thank you, Mrs Stirrat. My Lord, those are all the questions for Mrs Stirrat, and that would therefore conclude her evidence.

THE CHAIR: Yes, thank you very much, Mr Duncan. I take it you can hear me now.

THE WITNESS: Yes.

MR DUNCAN: Yes, we can, my Lord.

THE CHAIR: Yes, yep. Well, Mrs Stirrat, again, can I repeat my

apology for the delay in beginning this morning. But, quite frankly, thanks to our technical people, not thanks to the legal team-- Thanks to the technical people, we've been able to make a connection. Thanks to the legal team, we've been able to go through your evidence in a way that I've certainly found it easy to follow with the benefit of your witness statement. So, can I say thank you very much for your attendance and thank you very much for providing a witness statement, which will now, of course, be part of all the evidence which the inquiry will be considering. So, thank you very much, indeed.

THE WITNESS: Thank you.

(The witness withdrew)

THE CHAIR: Turning to Mr Duncan: that is the business for today, as I understand it, Mr Duncan?

MR DUNCAN: That's correct, my Lord. We have two witnesses tomorrow, the first at 10am and the second witness is in the afternoon, and she will be connecting remotely. Neither witness is likely to be terribly long, but I understand that there is no way of bringing the later witness forward. So, we will probably have a bit of a break in the morning, I would imagine, and then reconvene in the afternoon.

THE CHAIR: Thank you, Mr Duncan. For the benefit of legal representatives, I hope to have the result of a PCR test and, of course, I hope that it will be a negative result. I don't know whether or not that may be the case. If I do get a result later today and it is negative, we will proceed as we would have planned to proceed with a hearing in person in the morning and convening in the hearing room with the witness remotely in the afternoon. However, it may be that we will have to adopt something close to this method tomorrow, depending on the results of my test.

So, I thank everyone involved in achieving what appears, from my perspective, to have been a successful morning's hearing of evidence; that has required the technical team, the legal team, but it also required a degree of patience on the part of legal representatives - so can I recognise that and apologise to them for the delay. But we will see each other, all being well, tomorrow at 10 o'clock. Thank you very much.

(End of Morning Session)