



SCOTTISH HOSPITALS INQUIRY

**Hearings Commencing
20 September 2021**

Day 7
Wednesday 29 September
Afternoon Session

C O N T E N T S

	Pages
<u>Ferguson, Ms Sharon</u>	
Examined by Mr Duncan	1-75

12:15

THE CHAIR: Good afternoon, Ms Ferguson.

THE WITNESS: Good afternoon.

THE CHAIR: As you know, you're about to be asked a number of questions by Mr Duncan. Have you had the opportunity of --

THE WITNESS: Yes, I've met him, yes.

THE CHAIR: -- of meeting him? Good.

THE WITNESS: Thank you .

THE CHAIR: We'll break for lunch, and your evidence will be both before lunch and after lunch. We normally break at about one, although -- since we're starting fairly close to one -- I'll leave it to Mr Duncan to fix the time to take the break. But if for any reason whatsoever you want to take a break -- as I say, for whatever reason -- just give us an indication and we'll do that. Now, I think you're willing to take the oath?

THE WITNESS: Yes.

Ms Sharon Ferguson

(Sworn)

Examined by Mr Duncan

THE CHAIR: Thank you very much, Ms Ferguson. Now, Mr

Duncan.

MR DUNCAN: Thank you, my Lord. Good afternoon, again, Ms Ferguson.

A Afternoon.

Q We usually begin with some formal questions so, if you'll forgive me, I'll just trot through those. Can I have you confirm first of all that you are Sharon Ferguson and that you live with your two children, I think, in Dumfriesshire, is that right?

A That's right, yes.

Q Yes. And you're here to give evidence about your younger child, your son who was diagnosed with leukaemia when he was eight years old?

A Eight-year-old, yes.

Q And he's now how old?

A 12.

Q And I think he's actually with us in the building today, is that right?

A Yes, he is. Yes.

Q And we can see from your statement that he was treated at the Royal Hospital for Children and Queen Elizabeth Hospital in Glasgow between September 2017 and March 2020, is that right?

A Yes.

Q We've got your detailed statement, and you're content that that

is part of your evidence to the Scottish Hospitals Inquiry, is that right?

A That's right.

Q Thank you. But you've agreed to come along today and answer some more questions, is that right?

A Yes.

Q I think you've got your statement next to you, is that right?

A I have, yes.

Q Well, if you need to consult it at any point, just do so, and if there's bits you want me to go to, you just tell me. But what I'm going to do is just try and walk you through a timeline of your son's treatment, and we'll stop at various points and then we'll come back and ask some other things at the end. Let's begin by understanding who this is all about, apart from you. Your son, I think, was in primary four when he was diagnosed.

A Yes. He'd started primary four, yes.

Q What sort of things was he into then?

A You name it: climbing trees, computers, out on his bike, running about with his friends. He was such a happy-go-lucky, you know --

Q Yes.

A Loud and proud, only way to describe him.

Q Loud and proud.

A Loud and proud, yes.

Q Okay, I want to now move into taking you through the story of his diagnosis and his treatment now. As I say, a lot of it we've got in your statement already, so I'll try and avoid repeating it and I'll just walk you through it, if I might. I think we can see that it was at September 2017 --

A Yes.

Q -- he was diagnosed, and was that at the DGRI?

A Yes.

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

A Basically, [REDACTED] started the school week as normal, had a few purple spots on his legs, was fit and well, eating, drinking, you name it. Just started complaining as the week went on. He was feeling a bit tired, but me being a typical mum saying, "Look, you've been off for the summer holidays, you've run around all summer, you're back to sitting in a classroom, you'll be fine."

The Thursday, he come home from school upset. Said he didn't want to go to school because everybody said he had chickenpox. I said, "Right, I'm not going to phone the doctors 'cause they won't see us. I'll take you down the pharmacist the next day."

So, we got off Friday morning, went to the pharmacist and she said, "Take him straight to the doctors." I laughed and went, "Yes." And she went, "No, I'm going to phone them and tell them you're coming." So, we did.

We went to the doctors. We saw Dr Proudfoot, who phoned Dumfries Hospital. Used all these big fancy words that we didn't understand, to be told we were to go straight to Dumfries for a blood test. So, never thought anything of it.

We went to Dumfries, got there, had bloods. [REDACTED], being [REDACTED], was sitting on a spinney chair, playing with his iPad, loud and proud, thinking, "We shouldn't be here. There's nothing wrong with him." To hear everybody in the background talking.

Then some student doctors came along to look at his spots, which I thought was spots, but it was a rash, to be taken to, as we call it, the "Room of Doom", to be told that [REDACTED] had cancer and he was being transferred to Glasgow.

Q And that was by ambulance, is that right?

A Yes.

Q And just to try and get some dates into that, I think it was around about the 8th of September.

A September the 8th, yes.

Q And it was a Friday.

A It was a Friday, yes.

Q And are we right in understanding that [REDACTED] was admitted to Ward 2A in Glasgow that very night, is that right?

A That very night, yes.

Q Yes. And I think there was a central line fitted the following Tuesday, is that right?

A Yes.

Q Yes. To begin treatment. And I think we can see from your statement, it's paragraph 17 for anybody who wants the reference, at that point, you get confirmation of the diagnosis and he's going to be put onto a pretty high dose of chemotherapy, is that right?

A Yes.

Q Just pausing there, Ms Ferguson. We'll go through the story of treatment in more detail. How did [REDACTED] cope with his chemo?

A To begin with, he coped okay. Accepted this was happening. Again, he was only a little boy. You tried to explain. I didn't know how long we were going to be there. We got told we will be there for a few weeks, which was fine. He accepted that, but he just reverted into his iPad and his phone. Didn't really leave his room 'cause there was nowhere for him to

go. So, he just--

Q Okay. We'll go through it in a bit more detail.

A Yes.

Q So, what I'm going to do is I'm going to break it up into particular bits of the timeline, and I'm going to start, I think, with really the early period: September to December 2017. So, just to get an overview of things, I think we can see from your statement that, as you've said, he was admitted to Ward 2A and, apart from a few days on Ward 3C, I think he was on 2A --

A The majority of time.

Q Yes, right up until the 20th of December, I think.

A Yes.

Q Yes. And just to try and understand another aspect of this, where were you at this point? Did you stay with him the whole time?

A I didn't stay with him the whole time because I had another child at home that was sitting exams.

Q Yes.

A So, my mum was helping out. If I needed to be home, I would go home, but if I didn't need to be home, I stayed in the hospital.

Q So, either you or your mum would stay with [REDACTED].

A Yes.

Q Yes. And if we then try and think, again, just about this initial experience. I want to really try and get an impression of your experience and your description, even, of Ward 2A. So, what I want to do, first of all, is just try and get a description from you. I think in your statement, you say that to begin with, at least, you describe it as "lovely".

A It was lovely. Yes. As you say, I described it as it was shaped like half a moon, if that makes sense.

Q Yes.

A We were always at the top end of the ward, which was the Teenage Cancer Trust side, but we were just outside the Teenage Cancer Trust.

Q Yes.

A You'd go through the ward if you needed to leave, or you could take the shortcut, which was the door on the right.

Q Yes.

A As you say, it had a kitchen. It wasn't the best, but it was enough. It had a fridge. You could have some time out if you needed to be on your own. There's a playroom, as I say, which -- [REDACTED] wasn't into going into a playroom to play with little toys. He wanted to be stuck to his

Xbox; that was his thing. But there was nowhere for him to go, so we got given an Xbox, which, to me, was pointless because there was no WiFi. The WiFi was rubbish, so [REDACTED] just didn't bother playing with it, he just lived on his iPad and his phone. Yes.

Q Yes. Okay. I think, as you say, there was a playroom, but there was also a room for the teenagers. So, was [REDACTED] somewhere between the two effectively?

A Yes. We always said they didn't cater for the eight- to twelve-year-olds. They were missed out.

Q You mentioned also the parents' kitchen, what was your impression of that?

A It was just a small space with a couple of chairs and sofa and a table. You had your fridge, you had your microwave, you had cupboards to store your food in, which was great because try feeding a steroid child, who doesn't know what they want to eat three o'clock in the morning. At half past three, they're wanting a pot noodle, or they're wanting a pack of ham.

Q Yes.

A So, you just had to make sure you had everything available.

Q Yes. And was the

parents' kitchen always available to you?

Q Not all the time, no. Sometimes you would go down and just see it would be full of people, or if we'd been put in source, we couldn't access it. We had to get the nurses or other parents to go and access the stuff from the kitchen.

Q Well, that's very helpful, Ms Ferguson, 'cause the next thing I was going to go on to do was to ask you some questions about your experience on Ward 2A at this stage, and you've mentioned being "in source" in your statement, and it's paragraphs 27 and 31. In your statement, you say that [REDACTED] tended to be in source quite a lot.

A Yes.

Q Now, what is being in source, as far as you recall it?

A source was basically, [REDACTED] was carrying some sort of infection that could infect other children, 'cause the majority of them are neutropenic, which was fine, you accepted that. But sometimes your yellow sign would go on your door, and it'd be there for weeks. And you're like, "But he can't still have an infection." Or, "It's just another bowel infection. Don't worry about it. It's clearing up," and you're like, "Well, come on."

But when you're in source, you couldn't access the ward, but we could go downstairs into the atrium, which I could never understand because if he's infectious, we're leaving the ward to go sit downstairs with a couple of hundred people.

Q Yes. And what was the impact on [REDACTED] of being in source?

A Hated it. Hated it. It got to a stage where he struggled with his mobility because he lay in bed with his legs crossed, either sit in the chair and he walked to the bathroom. That was it; that was his exercise. And eventually he had to be given a wheelchair because he couldn't walk anywhere.

Q Yes. I think that there's a -- You make a comment in your statement, it's at paragraph 28, where you talk about for [REDACTED], it was a lonely place.

A It was. It was. It was lonely. He was a little boy, who thought we were going to hospital for bloods, to be taken away and not return home for three months. And he'd left his friends. If that makes sense, he just made a good friendship group to be pulled away from them, and there was no way of keeping in contact with them because he didn't have an Xbox or a PlayStation, which -

- that's how they spoke if they weren't outside playing.

And he was lonely, and he was getting angrier and angrier because -- We always had our room near the Teenage Cancer Trust games room, so he would sit and watch everybody that was older interact in those rooms, and he was sitting there lonely. Yes.

Q You've told us what it was like for [REDACTED], but what was it like for you or your mum, being in a room with a child who was in source?

A It was hard. Again, 'cause sometimes you just wanted to talk to someone. You just wanted to open the door and have a blether for 10 minutes down at the kitchen or at the end of the corridor, but you couldn't. You're stuck in your cell. I was lucky I had a good group of friends that you just text away, but that wasn't the same. You wanted human contact.

Q Okay. Now, what I want to do is just have you tell us a few things about aspects of [REDACTED]'s treatment. Again, just over this initial period of September to December 2017. Now, there's a background issue that you mentioned in your statement, I'm not going to go into with you. And without going into details, I think we can see from your statement

that in about October 2017, you noticed an issue on ██████'s skin developing. And I think, again without going into the details, you thought you knew why that was happening, but the nurses had a different theory, is that right?

A Yes.

Q Yes. And I think it's fairly obvious from your statement, Ms Ferguson, that relations between you and the nurses deteriorated, is that right?

A With some of them, yes.

Q Yes.

A It did, yes.

Q And also between ██████ and some of the nurses, is that right?

A Yes.

Q Yes. Now, what I do want to ask you about is, again so we can understand the detail of the timeline. 23rd of October 2017, ██████ required treatment for his lungs, and you understood there to be an issue with fungus, is that right? That's paragraph 21, for those wishing the reference.

And then I think, jumping a month forward, the 22nd of November, a chest infection, but again, I think you understood it to be the same thing, is that right?

A The nurses said, "It looks

like the fungus is growing," but we were always told it was chemo fungus. It was part of having chemo that they were prone to getting lung infections. So, you just agreed with what they said because we didn't know any better.

Q Yes. And just for those taking notes, that's paragraph 44 of the statement. Now, I think, as you've already indicated, ██████ was discharged on the 20th of December 2017. How did he feel about that?

A Oh, great. Couldn't get him out the door quick enough. He was waiting all day with his bags packed. But when you get discharged, it's not an early discharge. It's always a tea-time discharge by the time they sort medicines and bits and pieces out. So, as soon as they said go, he was gone.

Q And I think we can see from your statement, in fact, it's paragraph 48 that by this stage, he was actually in remission, is that right?

A Yes.

Q So, he was doing well?

A He was doing great, yes.

Q But I think you also tell us that you've subsequently found out that before he was discharged, he was tested positive for something called "Enterobacter"?

A Enterobacter, yes.

Q Okay. Now, just moving forward, then, again, just trying to get the timeline for us. If we look at the end of December 2017/January 2018, I think we can see from your statement that there were temperature spikes, returns to hospital on the 26th and the 27th of December, is that right?

A 26th, we had to come back because he was having a lumbar puncture. But when we got there, he'd spiked a temperature. But ██████ could do this, he could spike a temperature, and nothing would happen. It would be one temperature. We just learned that was ██████. But they always had to be cautious, but I think because it was over Christmastime, he was due a lumbar puncture, his counts weren't great so, they decided to send us home, not to do his lumbar puncture.

So, he went home that day, which he was happy about, because you got to go home and play with his toys, his Xbox, whatever. So the next morning, he's sitting, munching his breakfast, and we get a phone call from day care to say, "You need to get back to hospital now. Professor Gibson wants his lumbar puncture done. She's annoyed that you've been sent home."

So, I don't drive because I'm ██████

. So again, you think -- Luckily, I had friends and people on standby to get us there. So, "Look, he's eating his breakfast. I'm not going to snatch it out of his hand because he'll end up being in a bad mood, we'll be there as soon as we can." And we travelled back up and yes.

Q And then you were sent back home after that, is that right?

A Yes. That's right, yes.

Q However, I think we can see that ██████ was admitted again at the beginning of January, is that right? And that was again back to Ward 2A?

A Yes.

Q Now, in your statement, and its paragraph 54, you say that your recollection is that you were in Room 10, and I think you've got a recollection of an issue with that room.

A Yes, some people said it was too hot, other people said it was too cold. ██████'s a hot potato. Doesn't really feel the cold, and for him to say, "Mum, this room's really cold." It's not like him. Again, I walk about with a little t-shirt on, and I noticed it was getting colder and colder, and I was having to put cardigan on, and I thought, "This is not right." ██████'s lying there with a duvet on, a couple blankets, a dressing gown and slippers. No, this is not him. So, they

kept saying, "Look, no, no. The temperature's fine."

Then, just one day a doctor said, "No, this room is really cold. Something's not right." So, I don't know who it was, engineer or whatever come to look at, said nothing was wrong. The next day another said there was an issue with the pipes being frozen. So, we were moved out the room and put into another room.

Q Had anyone tried adjusting the temperature?

A I was told by the engineer that the temperature gauge on the wall was just for decoration; it doesn't work.

Q Right. I think we can see from your statement that eventually [REDACTED] was discharged, I think, on the 26th of January, and he was discharged to something called Marion House.

A Yes.

Q And you tell us a bit about that in your statement, at paragraph 55, but I wonder if you might want to say something just now about it.

A Marion House is a home from home, run by CLIC Sargent. It was a godsend because you didn't have to keep everything in your room at the hospital. You just kept enough clothes that you thought you need,

enough toys, consoles, whatever. You met families, and it was lovely 'cause you could go and relax. [REDACTED] loved to go there because he could actually eat food that he wanted, not, as he called it "microwave stale food". And he loves -- his thing's food.

Q I think you described it as a "home from home".

A Home from home, yes.

Q I think you say in your statement it offered peace and quiet. And, as you say, fresh food, is that right?

A Fresh food. Yes. You were left alone. If you wanted to talk to people, you spoke to people. If you just wanted to hide in your room, hide in your room.

Q Okay. But I think he was readmitted to 2A for some more chemo, is that right?

A Yes.

Q Okay. I want to move on a bit, then. And we'll go to February to May 2018. And again, just dealing with some of the key steps. We'll come back and look at some of it in some detail later. I think we can see from your statement, it's paragraph 57, that in February 2018 [REDACTED] had some sort of operation, I think, to remove fluid from his lungs, would that be right?

A Yes.

Q And I think you now understand, but didn't know at the time, that this was something to do with something called aspergillus?

A Aspergillus, whatever, yes.

Q I'll go with your pronunciation, it's more likely to be correct than mine. But you understand that to be some sort of mould.

A Yes. It comes from, how she put it, damp environments.

Q And again, without going into the details, we can see from the timeline that there was a recurrence of the issue with ██████'s skin around this time, is that right?

A Yes.

Q Now, I think I understand that ██████ was discharged from the Children's Hospital on the 5th of April 2018, paragraph 65. You want to check that?

A Yes, please. He probably was, but I don't remember all --

Q I should perhaps have said at the start, the dates are not actually critical to this, it's just --

A Yes. No, that's fine.

Q And I think he then goes into outpatient care until, I think, it's the 10th of May, and again, that would be

with you staying in Marion House.

A Yes.

Q Now, an issue arises on the 11th of May, and I think it's your mum who's taking a shot of being with ██████, is that right? You want to walk us through that? It's at paragraph 68.

A Sorry. Yes, basically, that week ██████ was going in day care every day. We were there from nine, sometimes we didn't get out 'til five, 'cause ██████ had an issue holding his salt, so he would need potassium and magnesium infusions, get his bloods checked, and then if we needed more, we got more. And basically, he wasn't himself. He was just sleeping all the time. And that's not ██████.

Everybody knows if ██████'s not attached to his phone or his iPad or eating, there's something not right. If he wants to go to sleep and ignore the world -- you knew something was coming. Mama tried to get the doctors to listen, but they just kept, "No, his counts are fine, his bloods are fine." But something's going on. Something's not right with him.

The Friday, he left and was told by a nurse that, "Look, if you're really worried about him, just get him back in here, he shouldn't be going home." But, I didn't think nothing of it. We went to CLIC -- Or sorry, Marion

House. And the Monday, mum took him to day care again. He hadn't moved all weekend, he'd just slept. He'd wake up, get his medicines, go back to sleep. But he was having lots of stomach problems and lots of bowel movements.

Monday afternoon, my mum phoned me upset, saying, "Look, you're going to have to get up here. These clowns are not listening. I've had enough. Something is not right. He's pasty. He's waxy looking." So, I got a friend to bring me up the road, got there and you could tell he wasn't well. I just said, "Look, I'm going next door to 2A to get someone to come and have a look at him." Luckily, Jane, ANP, was on. She come and looked at him and said, "Right, I'll be back in a minute. I'm going to go and get the Prof." So, Prof come through, straight away she wanted ultrasound, chest X-rays. And within 10 minutes ██████ started rigoring, slipping into septic shock.

Q Now, we've had a bit of evidence about -- Did you pronounce it "rigoring"?

A Rigoring.

Q Rigoring. Yes. What is rigoring?

A It's basically, ██████'s body struggling to cope with what's going

on, the infection. So, his body's starting to shake to say, "Look, something's not right. Get it sorted." So, they just pumped lots of fluids into him. Just try and stop the rigoring.

Q And did they also give him antibiotics at this point?

A Yes.

Q And I understand from your statement that he did actually start to perk up?

A Yes, as soon as they flushed his body. It was a quick turnaround, if that makes sense. Yes.

Q Yes. Now, do you have a recollection of any of the doctors making any comment to you about what had happened?

A A doctor had come in 'cause we got admitted to the ward later that night. We just seemed to wait for a room for ages, but it doesn't matter. The nurses at day care stayed to look after ██████ until there was a room available. We went into the ward. He was kept an eye on all night. The next morning, a doctor come in and says, "Oh my God. That enterobacter's got a lot to answer for. It's just another bowel infection."

Q So, doctor comes in and says, "The enterobacter's got a lot to answer for."

A Yes. He give us such a

fright, yes.

Q What did you understand the doctor to be indicating when there was reference to something called “eneterobacter”?

A I didn't really think anything. Maybe that's me being quite naive. Again, they just blamed everything on a bowel infection. I didn't Google anything because, you start Googling things, your brain starts to work overtime.

Q So, your recollection is that in addition to a reference to enterobacter, there must have been some indication that it was something to do with a bowel infection?

A Yes.

Q Moving on then -- Or rather, before we do, did [REDACTED] continue to improve at that point?

A He did, yes. It was really quick. Yes.

Q Yes. Moving on, then, to the timeline again and I'll take us to the summer of 2018. And in fact, if we just go all the way through, then, to April 2019, we'll pick up some of the key events along the way. I think we can see that from July 2018, [REDACTED] goes to attending day care five days a week from Marion House, is that right?

A Yes.

Q And then this gradually

reduces, is that right?

A Reduces, yes.

Q Until eventually outpatient. And where would that be?

A We went home round about the 20th of August, and clinic was on a Tuesday. So, we'd attend clinic every Tuesday.

Q And that would be where, sorry?

A That's at Glasgow Hospital, yes.

Q Yes. And is that on the ground floor? Or --

A Yes.

Q Yes. And how did you feel at this point, as regards how things were going?

A Well, great because we were home. We're slowly getting back to normal, whatever normal is.

Q Are you starting to think that things might be going in the right direction?

A Yes, that's it. Yes. We're moving away from all the craziness. Yes.

Q Now, in your statement, it's at paragraph 74, for those who wish the reference, you indicate that in September 2018 you became aware that the Schiehallion Unit was, in fact, closing and being moved. How did you find out?

A Word of mouth, Facebook.

Q How did you feel at that point about --

A About time. It's exactly what I said: "about time". The place should've been closed down a long time ago.

Q Right. I'm going to come back later and ask you a bit about that, about why you feel that way. But we'll move on just now with the timeline. Now, if we go into the following year, then, and we start to think about the period from April to August 2019, I think at some point, paragraph 75 of your statement, Ms Ferguson, we can see that [REDACTED] required go back for a lumbar puncture, is that right?

A Yes. His normal 12-week lumbar puncture. Yes.

Q Now, in your statement, you say that -- Well, sorry, just to take a step back. I think, again, you were staying in Marion House, is that right?

A We were, yes.

Q And on this occasion, you were with him?

A I was with him, yes.

Q Yes. You say in your statement that there was just something not right about [REDACTED] after that.

A It was weird. How

should I put it? The Monday, we left to come to Glasgow, and it was like he was on a high. I was having to scrape him off the ceiling. It's like, "What you so excited?" "I'm not, Mum. I just don't know why I'm up here." Like, "Are you OK?" "Aye, I'm fine. I'm fine. I'm fine."

And the Tuesday, we waltzed into the hospital to get our normal checks, and he started -- By then, [REDACTED] couldn't hear. [REDACTED] was interacting with a doctor, and I won't say that he didn't like, but they just never seemed to get on, if that makes sense. And we're all looking each other going, "What's going on? These pair are having a great laugh. Something's not right." Laughing it off.

He went for his lumbar puncture. He was last on the list that day. We went back to Marion House. He wasn't feeling the greatest because who does after a lumbar puncture? He went to bed really early, woke up the next day, just said, "Mum, my head's really, really sore." I says, "Right. Okay, we'll give you some paracetamol." As the day went on, I said, "Look, we're going to stay at, darling. Something's not right with you. I'm not happy. What's one more night?" So, I said to the ladies, "Look, we're having the room for another

night, is that okay?" They said, "That's fine."

Again, that night, his temperature was just sitting borderline. He was sitting at 37.8. I said, "Look, I'm not giving you paracetamol. Just get yourself the way to bed." The next morning, I woke him up. Well, he just freaked. He just told me to get the curtains, started screaming, didn't like the light, had a temperature. So, I give him the paracetamol, phoned the hospital when day care opened to say, "Look, [REDACTED]'s not wanting to move his head, doesn't like the light. Something's not right with him." "Bring him over."

So, we got there, antibiotics is ready. Start giving them and he sat, curled up, in the chair all day, if that makes sense, in a wee ball with his teddy. Just didn't want to move his head. They were going to put on another ward, which was 3C, because there was no beds. I says, "Look, if we don't need a bed, why are you putting us on another ward? Why can't we just go back to Marion House? I'm not stupid. I can bring him back if he deteriorates."

They agreed to that, gave him some Oramorph for the pain. But just as we were about to leave, [REDACTED] spikes a temperature, lo and behold.

He's good at that. So, they said, "No, he's got to stay." Then, Professor Gibson come along and said, "He's going nowhere. We need an emergency CT scan. He had an abnormal lumbar puncture on Tuesday" -- which can happen -- "and we need a lumbar puncture tomorrow." So, that was it. We were staying on the ward. We got an emergency CT scan. They started him with fluids and IV steroids, just to cover the bases.

And the next morning, they tried to do a lumbar puncture awake, but without success. So, [REDACTED] went to theatre that afternoon and then, at 5 o'clock, Professor Gibson come and took me to the Room of Doom, as we call it, and we was told that he'd relapsed with CNS disease.

Q That must have been fairly devastating.

A It was. It was a kick in the stomach 'cause he was just getting back to his normal self. Mixing with his friends again. We'd just been given the go ahead for him to get his cochlear implant surgery done. And then "poof", everything's put on hold again. You're back to square one. Yes.

Q And he was started on chemo immediately.

A Yes.

Q And admitted as an inpatient to Ward 6A.

A Yes.

Q In the adult hospital. I think we can see from the timeline that, there was a new central line fitted, I think, on the 29th of April, would that be about right?

A Yes.

Q His old one had been taken out because he was in remission and treatment was stopped.

A Yes. Didn't really need it anymore.

Q Yes. I think we can see from your statement, Ms Ferguson, that he kept spiking temperatures over May and into June, and I think in your statement, it's at paragraph 80, you tell us that on the 1st of June, the way you put it is that he was looking really unwell.

A He was. He was, again, pasty looking, he just wasn't himself, he wasn't interested in anything. His belly was just getting bigger and bigger. And it's like, "What's going on? Something's not right?" And, as you say, again, we were told eventually that he'd had haemophagocytosis, or HLH.

Q Yes. And I think you indicate that about this time, I think it was actually on the 9th of June, you

had a conversation with Professor Gibson about where things were, is that right?

A That's right. Yes. I was at home because he -- He wasn't settled, but I needed to go home because my son was sitting his exams, and I couldn't abandon him. So, my mum had come to take over. I'd went home for two days, and Mum phoned me on the Sunday morning, saying, "Look, you've got to get back up here. Professor Gibson's coming down." She'd been away at a family wedding. She was coming to see me, and I thought, "Oh, okay. What's going on?" She says, "I don't know." She says, "Nobody's not telling me anything, but you've just got to get here by lunchtime."

So, I did. I got up the road. Professor Gibson come and said -- took us to the Room of Doom, said things weren't looking good. Next 48 hours, just we really need to keep an eye on him and hopefully can turn things around.

Q Right.

A Yes.

Q And I think there was a conversation also with another doctor at this point, Dr Shazi (?), is it?

A Yes.

Q And did Dr Shazi say

something similar?

A Yes, she just said, "We're really, really worried about him." It sounds a bit crazy, but more people were coming to see him, if that made sense.

Q Do you mean more doctors?

A More doctors, more nurses were popping in and a couple were getting upset, and reality kicked in, if that makes -- "Am I going to lose him?" Yes.

Q Eventually, what happened?

A Again, [REDACTED] does this really well. He just turns it around. Yes. Few days later, he just starts -- You notice an improvement. It's like, "Okay, what's going on?" And he just starts to slowly get better. Thinking, "You devil, you have us all on tenterhooks waiting", but this is [REDACTED]. He doesn't do things easy.

Q And at about this time, were you told what it was that had been going on here?

Q Just that, basically, his immune system started attacking his organs, which can happen in some immunosuppressive people.

A Now, if we look at paragraph 82, Ms Ferguson, you indicate that he developed -- The way

you put it is that between the 18th of June and the 23rd of June, he developed a bug in his blood.

A Yes.

Q What do you mean by that?

A Just again, nurses, "Oh, he's got a bug in his blood. They're growing something. We'll keep you up to date with what it is when the results come in." But you never really got told. It was just, "Well, what is it? Is it Enterobacter again?" We were starting to hear about *Stenotrophomonas* floating about the ward again. And it was like, "Well, is it that?" They just, "Ah, it's just -- Don't worry about it, it'll be fine?"

Q Yes.

A Yes. And then his line had to be removed.

Q So, are we to understand from what you're saying at paragraph 82 that there was an indication at this point that there was an infection in his line?

A Yes.

Q And the line was removed.

A Yes.

Q And I think we can see from the very next paragraph, in fact, that there was a new line fitted on the 9th of July, is that right?

A Yes.

Q How was his temperature by this stage, as far as you can recall?

A It's fine. It's back to normal. Yes.

Q Right. And I think you indicate -- If we just wind forward a bit into August, and you talk about that at paragraph 84, looks like there was another issue with his temperature, is that right?

A Yes. [REDACTED] being [REDACTED]. We come over -- [REDACTED] had to get injections in his thighs every day. It was to do with the HLH. So, we were out on pass. So, [REDACTED] wheeled himself into the ward on Saturday morning, as he does, shouted at Maxine, the nurse, saying, "Right, Maxine, get my bloods done and get my injection. I'm outta here. I want my steak and ale pie for my dinner." Again, food orientated. And she laughs, she went, "All right. I'll get them sorted."

So, he went to his room. We waited. She come and done his injection, then Marie, the phlebotomist, come and took his blood. She just walked out the door, and he just went really grey and started -- I says, "Are you all right?" "I just don't feel well, Mummy. I really don't feel well. Give me a blanket." So, I got him a blanket,

went to the door and I said, "Maxine, look, [REDACTED]'s rigoring." Well, the next minute, everybody's in the room. It was full of lots of different people.

Q Yes. And I think you indicate that, in fact, he was suffering septic shock, is that right?

A Yes.

Q And again, his line was removed, is that right?

A Eventually, yes. We went to intensive care 'cause they couldn't control his blood pressure. So, he had to get a medicine in intensive care. Still wasn't managing to get on top of it. So, it was agreed through the night that they would take his line out.

Q Okay. So, I think you indicate that that was on the 4th of August.

A Yes.

Q And did he recover quite soon after that?

A Oh gosh, yes. Everything just picked up soon as the line went.

Q And then, just thinking about how he did -- I'm going to go on and ask some more questions about this event. Just thinking about how he did, I think he continued to get treatment as an outpatient after that, and again, staying at Marion House, is

that right?

A Yes.

Q Yes. And I think eventually, he was admitted again on the 20th of August, and he got another new line, is that right?

A Yes.

Q And his treatment continued.

A Yes.

Q Can we assume that his treatment was paused every time that a line was removed, is that right?

A Yes.

Q Okay. Let's just go back very slightly, then, to the incident at the beginning of August. Now, you mentioned that the line was taken away for testing, is that right?

A Yes.

Q It's a paragraph 86. And you mentioned that you, after that, had a discussion with Professor Gibson and somebody you call "Theresa", is that right?

A Yes, who used to be a microbiologist there. Yes.

Q Right. Can you remember what they said to you?

A Just basically said they were growing something in his line, and it was *Stenotrophomonas*.

Q What explanation, if any, did you get as to --

A Nothing, really. Nothing. I said, "What is it?" And they just said, "Oh, it's just a bug." I went, "But is it from the water? Is it from the--," and they went, "Well, we don't know." Because [REDACTED] had been going out on pass, he could have picked this bug up anywhere. I laughed and I went, "Really? Don't access his line outside the hospital." We were only going out for the night. We weren't getting any treatment at Marion House. We were going out, having something to eat, having a bath, going back to the hospital the next day.

And she said, "Well, we don't know exactly if it's come from the environment or not. We're assuming, and other people are saying, it could be 'cause we were out on pass," and I just said, "That's a lot of rubbish." But I just kept my opinions to myself because that's what you did.

Q Do you have a good recollection of this conversation or was it just one of a number of conversations, with all the stress going on?

A I didn't actually have many conversations, if that makes sense.

Q Right.

A That was the only one that ever told me was -- That's the only

environmental bug they told me about. I was never told about that Enterobacter was an environmental bug. I was never told nothing.

Q Yes. I think you indicate that they were actually further meetings about this shortly after that, is that right?

A Yes. 'Cause I was annoyed. I thought, "Well, what's going on? This ward is supposed to be safe, but how come my son's had more issues being in this ward than he ever had when he was in 2A?"

Q Staying with where we were, roughly, in your statement, I think it was at paragraph 87, you indicate there were further meetings, and did those involve other parents as well?

A Yes. There was a meeting. We were asked if we would attend a meeting, if we wanted, to just ask some questions, but if you were in source, you couldn't. Luckily, it was the one time we weren't in source, so I could go. And people were getting annoyed because the truth wasn't being told. It was some new parents. Well, I was an old parent, and I said, "Look," I says, "I'm just getting fed up with this." I says, "It's not your son that was lying in intensive care a week or two ago." I says, "It was my son." I

says, "Watching my son die in front of me." I says, "That's disgusting." I says, "Just be honest." I says, "If there's a problem, this is all we want to hear." I says, "We don't want the lies." "No, no. There's nothing wrong with the hospital. There's nothing wrong with the environment. We're just here to answer questions."

But, they didn't really answer any questions. New parents were asking, "Well, what is wrong?" And they were saying, "Look, the environment is fine." Then people started asking about prophylactic antibiotics, and, "It's just to protect you from--" But if there's nothing wrong with the environment, why do they need protecting?

Q Yes.

A And then we got told it was part of the treatment plan, which we've all realised is the biggest load of rubbish ever 'cause it's not part of the treatment plan. Nobody else up and down the country takes antibiotics.

Q Okay. What will now be probably after lunch, I was going to ask you some questions about some of the concerns that you had about the hospital. I think it's fairly obvious from what you're saying that by this stage, if not before, you certainly did have some concerns.

A Oh, yes.

Q Yes. And you've just seen █████ go through what he went through and felt you were entitled to some answers, is that fair?

A Yes. Exactly, yes.

Q Right. I'm going to ask you just about one further matter before we break. It's really just to take a pause from the timeline. You've already indicated that █████ had now been admitted to Ward 6A, and it might be appropriate, then, just to get some of your impressions of that ward. You talk about it at paragraphs 89 and 90. I mean, would it be fair to say that you considered there was really a lack of facilities on that ward?

A Yes, there was nowhere for anyone to go. You couldn't make a coffee. You couldn't have five minutes' escape. If you walked out your door, "Where you going?" "Want to stretch--" "No. Get back in your room." You weren't allowed -- It was almost as if they didn't want you to talk to other parents.

And then, when I questioned the layout of the ward, because the ward was at the beginning and day care was at the back -- Why? It should be the other way around. Should day care not be at the front because there's a lot of coming and going? So,

you're watching all these family members, and sometimes it was a day out for them, it would be Mum, Dad and the four kids all come traipsing through the ward. Yet, that was acceptable. It was like, "Well, we can't even walk around the ward, but these people have got freedom to walk around."

And you could tell staff was stressed. They'd had enough. They were done in, just like, well, I was done in as well because we'd done it the first time around, and we're doing it again. And they were still lying. They still wouldn't -- All I ever wanted was the truth, and they wouldn't give you it.

And even going for bedding was a mission, if that made sense. "Where you going, Sharon?" "I'm going to get █████ some clean sheets. Been sick on his bed." "Oh, we'll get you them. Don't worry. Get yourself back in your room." They didn't want you to communicate with anyone.

Q And did you have some issues about the cleanliness on Ward 6A? I think you talk about this at paragraph 145.

A Yes. 2A and 6A were exactly the same: disgusting. You wouldn't let your pet pig live in there. █████ has mentioned it, as well. Infection control come into our room one day,

and cared more about a little bit of dust that was sitting on a box then the vomit and the faeces that was sitting on my son's bedrail that I'd been asking for a new bed for two weeks, 'cause we had an old bed that didn't have the plastic around the bedrail.

So, (inaudible) tell what it was. It was all stuck in the bedrail, but they wouldn't give us a new bed until this lovely lady came in and picked up on one little piece of dust. So, when I pointed out the bed, the bed was changed within 10 minutes.

Q And as far as you can recall, was that 2A or 6A?

A That was 6A. And again, the kids walked on the floor. Now, like before, [REDACTED] had nowhere to go. He walked from his bed to the toilet. Within 15 minutes of walking on the floor, his feet were filthy.

Q I think the last thing I'll ask you about before lunch, in relation to 6A, you mentioned in your statement that at one stage you saw portable filters being brought onto the ward, is that right?

A Yes. Big, noisy HEPA filters to try and keep the air clean.

Q What did you think about that?

A Well, again, when you asked the question, "What are these

for?" "It's just to purify the air." "Why are we purifying the air?" "Oh, it's just to keep the environment safe." But in one hand, you're saying the environment safe, and in the next hand you're saying it's not. What is the truth? And I asked a few times to speak to people, but I basically never got to speak to -- I was dismissed. It's almost, "Oh, just go away, Sharon, and be quiet."

Q Thank you, Ms Ferguson. My Lord, I am about to move on to a different chapter, so this might be a convenient point.

THE CHAIR: Yes. That's just after one o'clock. Could I ask you to come back for two to resume your evidence? Perhaps Ms Ferguson could be allowed to go for lunch.

A Very much.

THE CHAIR: We'll sit again at two.

13:05

(The luncheon adjournment)

14:00

THE CHAIR: Good afternoon, Ms Ferguson.

THE WITNESS: Good afternoon.

THE CHAIR: I think we're ready to resume. Mr Duncan.

MR DUNCAN: Thank you, my

Lord. Good afternoon, again, Ms Ferguson.

THE WITNESS: Good afternoon.

MR DUNCAN: I think on the timeline we had reached August 2019, and I'm just going to complete the timeline and take you onto September. I think, for those who wish, the reference is paragraph 96 and onwards of Ms Ferguson's statement. I think we can see that [REDACTED] had a bone marrow transplant in September, is that right?

A Yes. It was, yes.

Q And was that successful?

A Yes, brilliant.

Q Yes, and he was discharged to Marion House and to day care again, is that right?

A Yes.

Q I think we can see that there was a setback. There was a spinal fracture.

A Yes.

Q And then I think we can see -- it's at paragraph 102 -- that in November, there was another line infection, is that right?

A Yes.

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

A We were just sitting in day care, like you say. We were staying at Marion House and, again,

just spiked a temperature and we got kept in and, again, told it was another line infection. So, again, line was removed.

Q Yes.

A Yes.

Q You tell us about paragraph 102, and was it explained to you that he had contracted something called Acinetobacter?

A We call it Acinetobacter, sorry.

Q I'll call it that then. But that was the explanation you were given?

A Yes.

Q And his line had to come out?

A Had to come out, yes.

Q Yes. I think he was discharged again to Marion House and then home, is that right?

A We went home for a while and just -- We were in and out of Marion House just for appointments and sign language classes and bits and pieces, yes.

Q Yes, and I think chemo stopped altogether in March 2020, is that right?

A Yes. His IV chemo, yes.

Q Yes. And is it just check-ups now or is he still continuing with medication?

A He's not on nothing drastic, just a few medicines. He's had his last lumbar puncture, so, yes, just check-ups to keep an eye on him, yes.

Q Good. Okay. That really completes the timeline, and what I want to do now is go on and deal with two things. The first thing I want to deal with is various issues that you've raised to do with the hospital, and I'll deal with those in two parts. The first part is that you raised a number of issues concerned with the water supply in the hospital. To help you, if I tell you I'm not terribly concerned about identifying particular dates or anything of that nature, I just want to get a general impression.

Now, one of the issues we've already touched on today -- you've told us about it, I'm not going to ask you about it -- the issue with ██████'s skin. What I'm going to ask you about is you say that when you were on Ward 2A, there were signs not to drink the water.

A There were signs basically telling us not to wash our hands -- you know, to make sure you wash your hands or run the water for two minutes before we brushed our teeth or had a shower, and then signs went up eventually saying, "Don't drink the water".

Q Okay. And were you

provided with bottled water at any point?

A Yes.

Q I think you also indicate that you saw filters being put on taps, is that right?

A Yes.

Q Can you remember which ward you were in when that happened?

A 2A.

Q You indicate that you saw drains being checked, is that right?

A Drains -- It seemed to be on a Monday, you'd get something poured down it or some people would come in and shine a torch down it and maybe take a swab.

Q Right.

A Yes.

Q As you confirmed this morning or earlier today, there was a period where ██████ was in Ward 2C.

A Yes.

Q That was in October in the first year of his admission, and I think you indicate in your statement that you had bottled water there.

A Yes. We had bottled water there as well, yes.

Q Do you have a recollection of any of the nurses on that ward saying anything about that?

A No, they just -- We went on the ward, as you say. The first thing we said, "Look, you know, do we drink the water here, you know, or do we get bottled water?" And one nurse said to me, "No, you get bottled water because we wouldn't give immunosuppressive kids the water." And then you just left it at that.

Q And, just thinking about the issues we've just mentioned -- well, you've just mentioned -- did you have any concerns about any of that?

A It was nothing I didn't already know. I'd tried to approach management about it. I had a meeting with a manager who basically told us it was all in our heads about the water. There was nothing wrong with it. Even when my son was complaining about his skin, he said, "No, there's nothing wrong with it. Stop being paranoid." Then, two weeks later, they rolled up with these portable sinks and telling us not to wash with it, not to brush your teeth with it; "don't touch the water".

Q Can you remember which ward you were on when you had that meeting?

A That was 2A.

Q Can you remember who it was you had the meeting with?

A Yes.

Q Who was it?

A Jamie Redfern.

Q You indicate at one stage -- this is paragraph 64 of your statement -- that a nurse asked if you had leaked something to the media, is that correct?

A Yes, she was -- She just come barging in the room and said, "Did you leak it to the papers?" I said, "What are you talking about?" And she went, "About the water and everything." I said, "No, I didn't." I said, "I'd be honest if I'd leaked it to the paper." I said, "Why would I go behind your back?" And she just went, "Are you sure it's not you?" I went, "No, it's not." So, she just walked out and slammed the door.

Q Moving on, I want to ask you about the second issue to do with water, and that's to do with the shower, and I'm talking in particular about the flooding of the shower.

A Mm-hmm.

Q Paragraph 107, you mention that. Now, did you yourself experience the shower flooding?

A Yes. Yes, you had to make sure you put towels at the door, so it didn't go sprawling through the bedroom.

Q And which ward were you on when that happened?

A 2A.

Q And did you ever experience it in Ward 6A?

A No, because I wouldn't use the -- I would refuse to use the shower.

Q Right. Did you ever actually experience it flooding into the room or did you prevent that?

A The first two times, yes, it -- Yes, 'cause you didn't know. You just put the shower on, you were having your shower, and next minute, you turn around and it was like, "Whoa!" You know, it's just gone.

Q Yes. And in your statement at paragraph 140, you indicate that you saw a video that someone had taken of this?

A Yes, the flip flops floating out the bathroom into the bedroom.

Q Right.

A Yes.

Q You've actually seen that video?

A I've seen that, yes.

Q Who took -- I'm not going to ask you for a name, but was that a video that was taken by another parent?

A Yes.

Q You mention a number of other issues in your statement apart from water, which you've spoken a bit already today about cleanliness, but

you also indicate that at some stage you became aware of a new method of cleaning being used, is that right?

A Yes, they were using this HPV or mist stuff in the room to try and kill bugs apparently, so you were moved rooms every day.

Q I think you describe it as hydrogen peroxide.

A Yes.

Q Which ward?

A That was 2A.

Q Thank you, and how did you understand or come to understand that it was hydrogen peroxide?

A They were giving -- Again, you got a piece of paper shoved under your door or handed to you, whatever. That was the method of letting you know information on the ward. They didn't come and tell you. They just give you a piece of paper. "Here you go. Read that."

Q In relation to the operation that we were speaking about just now, this cleaning operation, can you remember what the piece of paper said?

A Not off the top of my head. I do have a copy of it.

Q Can you remember the gist of what it said?

A It just basically said they're trying a new process of

cleaning and that we might have to move rooms. It can last 24 hours to clean the room and just -- Basically, don't get settled 'cause you'd just be moved here, there and everywhere.

Q Yes. You mention that on one occasion you were aware of I think what you describe as "black stuff" coming out of a vent.

A Yes, it was weird. Again, it was Room 10. Me and [REDACTED] were just trying to fill our day in, so we were playing I Spy and messing around and, just out of nowhere, this black stuff just fell on his bed. And he's like, "What's this?" You know, "I don't know, darling." So, when the nurse came in, I mentioned it, and soon as I mentioned it, that was it, we were gone. We needed to move into another room.

Q Was it a large amount of stuff or a small amount of stuff?

A I don't -- I couldn't really say. You know, it was noticeable. It was just all over his covers, yes.

Q You mention that you were aware of a window or windows falling out of the hospital.

A Yes. As you say, a window fell out and then another window just cracked.

Q Were you there when that happened?

A Yes.

Q And you mention, at paragraph 142, that you were aware of a smell. Can you tell us a bit about that?

A That was just the sewage works. You know, it was regular. You got used to the smell. We used to jokingly say it was two o'clock in the afternoon, two o'clock in the morning, the smell would just -- sometimes more, but also the cleaning stuff left your room with a smell as well, so you just got used to not a very nice smell in the hospital.

Q Okay. Now, just pausing there, thinking about all of the things that you've just mentioned, how did those make you feel?

A Uncomfortable. You didn't want to be there. At every chance, you were trying to get out the door. At some points, I'd just say, "Look, do we really need to be here? Can we not go to day care?" And they're like, "No, no, you need to be here. You've got to have IV chemo and things like that, so you've got to be here." It's like, "Well, I don't really want to be" but he knew he had to be here, so we just put up with it.

Q Now, I want to go on and ask you about another matter which you deal with in quite a bit of detail.

I'm going to deal with it in two parts.

A Okay.

Q First of all, I want to just understand what preventative medication you now understand [REDACTED] to have been on, and then, secondly, I want to go on and understand your evidence in relation to the effect that you think that has had upon [REDACTED].

A Yes.

Q So let's take it in those stages. I think your understanding -- we can see from your statement, it's paragraph 129 -- that [REDACTED] was put onto, is it Posaconazole?

A Posaconazole.

Q Thank you, and that was from September 2017 to August or September 2018, is that right?

A It was probably a bit longer than August. I don't know exactly the date when he come off it, but it was about August/September time when I questioned the medicine at clinic.

Q Okay, but your recollection is something in the order of a year?

A Yes.

Q And were you told that he was on that?

A Yes, I was told he was going on Posaconazole because he'd had the fungus in his lungs, and it was

just to protect his lungs. Wasn't told it was to protect him from the environment, just to protect his lungs.

Q Okay. And you also say in your statement that in March 2018 -- this is paragraph 130 -- you were advised that [REDACTED] was to be put onto something referred to as "Cipro".

A Cipro, yes.

Q What was the explanation for that?

A It was to protect him from the environment.

Q And who did you get that explanation from?

A It was just one of the nurses. You know, doctors would come and examine the kids, then they'd leave, and then they'd just -- You know, I was on the ball with [REDACTED]'s medicine, so I knew if there was something new introduced, and I just said, "What's that tablet for?" And she went, "Oh, that's Cipro. That's to protect him from the environment."

Q And --

A And I went, "What d'you mean? Why is he taking something to protect him from a building that's supposed to be safe?"

Q And are you saying your recollection is that it was a nurse who told you that?

A Yes. And then I did ask

a doctor, I can't remember who it was, but I did mention it, and they just said, "It's a preventative antibiotic. It's nothing to worry about. It's just to keep them safe."

Q Safe from what?

A You tell me. I tried to ask, but they just -- All we got, "No, the environment's safe. It's just a preventative."

Q And in your statement, Ms Ferguson, what you say at paragraph 130 is that Professor Gibson told you that all the kids were going to be started on prophylactic antibiotics --

A Yes.

Q -- Cipro, to protect them from the environment.

A Yes.

Q Is that the conversation you're referring to?

A No, that's another one.

Q Right.

A Yes.

Q So did this come after the conversations that you've just mentioned?

A Yes.

Q And are you indicating that Professor Gibson did give you an explanation?

A She just said that all children were going on it just to protect

them from the environment, and she was my son's consultant, so I just trusted her with anything to do with my son.

Q Now, going a wee bit further forward in time, you indicate at paragraph 150 -- if you want to have a look at it, by all means, do so -- that on the 7th of June, you received another piece of paper, and I think you indicate it advised you of two things, is that right?

A Yes.

Q One was something to do with cleaning chilled beams, is that right?

A Yes.

Q And the other thing was something to do with antibiotics, is that right?

A Yes.

Q Is that also a piece of paper that you still have?

A Yes, sure. I've still got both of them, yes.

Q Right, and it's your recollection that on that single piece of paper, they told you these two things?

A Yes.

Q Yes. And then, I think, finally, just on the question of antibiotics or preventative medication: is it also your understanding that at some point [REDACTED] was put on

something called Gentamicin?

A Gentamicin.

Q Gentamicin.

A Yes, ██████ -- in, was it February or March? -- had an issue with his lungs and he took really, really not well, so he was put on a couple of different antibiotics and Gentamicin to try and bring his temperature down. He was -- I don't know how long he was on it. It just seemed to be he was on it forever, and then, as you say, he come off it because he started to improve so -- But, you know, a lot of strong antibiotics.

Q Yes, I think in terms of the timeline on that, I think I have, according to your statement at least, going onto that in around about February 2018, would that be right?

A Yes.

Q Paragraph 58. Now, I want to move on then to the second bit of this, which is the effect you perceive on ██████.

A Mm-hmm.

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

A Basically, nobody knew ██████ carries a dodgy gene, which comes from my mum's side of the family, which anything ototoxic can affect his hearing. Because he'd been on Gentamicin for such a long time, that is

one of those drugs that can and did -- It took part of his hearing, but the hospital didn't believe us.

I kept saying, "Look, something's not right, you know. ██████ can hear you down the corridor talking about him, but he's not even hearing me in the bathroom." And, "Oh, no, because he wears his headphones all the time, stop worrying about it." You know, it just got dismissed. I left -- His teacher was saying, "Look, he's struggling with his half-an-hour class. He's going, 'What? What? What?'"

So I planted a few seeds, I'd go to the bathroom and say, "██████, your counts are really good, Prof's not in this weekend, we'll have Domino's pizza, she'll never know." Any child, you know, "Yes! Let's have pizza!" I done it where he'd been good, we'll get him some iTunes -- he didn't flinch. So I just kept pushing it.

A junior doctor did have a look in his ears and said it looked like that he's maybe had an underlying ear infection, but they didn't pick up on it because he was on all the antibiotics for his chest, but he would send him for a hearing test. So, we did. We went away for a hearing test to be told he'd lost 52 per cent of his hearing.

Q And, just pausing there, are we to understand that that was

around about April 2018?

A Yes. 2018, yes.

Q That's paragraph 66.

And when you mention the genetic issue --

A We didn't know straightaway.

Q Yes.

A It was -- How should I put it? It was quite a while later that Professor Gibson had come and said that, basically, they'd done some tests and sent it away to Dundee, who sent it to Manchester, and it's come back that ██████'s got this gene so certain -- you know, all or certain ototoxic medicine will take his hearing.

Q And, to begin with, do we understand from your statement that the thinking was that it was the Gentamicin that was doing this?

A Yes, 'cause he'd had -- he'd been on the chemo for quite a long -- other drugs for, you know -- But the Gentamicin just seemed to do the damage, yes.

Q Yes, but that was stopped, is that right?

A Yes.

Q Do we understand from your statement that, nevertheless, ██████'s hearing continued to deteriorate?

A Yes, we just noticed it just kept declining and we couldn't

understand why. He was at home with his hearing aids on and they just weren't picking up anything. So, again, you're thinking, "Oh, God, is it because he's a boy and he doesn't want listen?"

So I just come to his appointment at clinic, and it was Dr Jacob at the time, and said, "Look. Not being daft, but all these medicines ██████'s on, except for the Posaconazole, is the ones he's had since day one." I said, "Why is he still on Posaconazole if he's not in the hospital?" He says, "Well, no, he doesn't really need to be on it anymore." So, we took him off the Posaconazole and his hearing just plateaued. It just stayed the same, so I just -- maybe I'm wrong -- I put two and two together and just come to the conclusion that the Posaconazole was still -- it was taking some of his hearing, yes.

Q Did you have any discussion with Professor Gibson or anybody else about whether there is a possible link?

A It wasn't until we were readmitted in 2019 that they wanted to put ██████ back on Posaconazole, and I said no and was asked why, and I said, "Because the tiny little bit hearing he's got" -- I said it wasn't very much, you know, I said, but I wanted him to

keep that. And they said, "What do you mean?" I said, "Well, as far as I'm aware" -- So I discussed it with a pharmacist who had done (inaudible) and said anything that's got "azole" in it taken long term will make anybody's hearing decline a little bit. So, I just refused, yes.

Q Moving on, then, just to actually think, then, about [REDACTED]'s hearing, you describe it as "plateauing". Has it recovered at all?

A No. [REDACTED]'s hearing will never recover.

Q Yes. What is the extent of his hearing loss?

A [REDACTED] is now profoundly deaf.

Q And, even during the process that you've described, were you aware that it affected his ability to communicate, like when he was in the hospital, for example?

A He could communicate fine, but we couldn't communicate with him.

Q Yes. I think you indicated that he had sign language lessons, is that right?

A Again, I had -- I was asking for some help when we went in the second time and we were told -- Gosh, a play worker tried to help us, we had theatre porters who were

getting more annoyed because Schiehallion were just ignoring him, were just ignoring the fact that he was deaf. They didn't see it being a problem.

This were a day we'd went away for a hearing test at 8.30 in the morning, come back to be told it was totally gone. And it didn't matter who would've walked in that door behind me, I would've screamed and shouted at anybody, and it just so happened to be a junior doctor and I just ripped into him, and I just said, "I've had enough." I said, "There's no way you're making my son suffer like you have done." I said, "You're ignoring him." I said, "Nobody talks to him, nobody asks his opinion." I said, "How would you feel if you were lying in bed," I said, "and somebody just grabbed you like a piece of meat?" And he went, "Well, I wouldn't." I said, "Well, that's what you're doing to him." I said, "You speak to me." I said, "You don't speak to him." I said, "Not one of you see this as being a problem."

And then [REDACTED], being [REDACTED], just blurted it out, you know, "But, Mum, if I couldn't speak English, they'd bring in an interpreter, but because I'm deaf, they don't care." And the doctor went away.

A nurse come in and said that the

doctor had said I'd just lost my temper with him, and she'd said, "Well, we've been trying." And nurses had been trying to get us help, but nobody wanted to help us. And I thought, "This is supposed to be the super hospital. Why can not one person come and ..." He's not the only deaf person in the super hospital. Why did nobody care? And he was, for two years, he was stuck in his own little world, and nobody spoke to him.

Q And how is he now?

A He's got his cochlear implant surgery, which, again, I had to push for because after transplant, you're more susceptible to infections and things like that. They wanted them to wait a year, and I just said no. I said he'd been in isolation for two years. He couldn't wait another year. He was moving into secondary school. He needed this surgery to start moving on. So they agreed to let him have the surgery, which we did August last year and he's now got his cochlear implants.

Q How would you assess the impact of [REDACTED]'s hearing loss upon him?

A A big impact. He was lonely, he was angry, he was -- He was labelled rude and ignorant. How would you feel if a doctor walked in to

examine you and you can't hear him, but then, "He's very rude today, isn't he? He didn't even speak." But you didn't speak to him. You spoke to me.

Q What about now? How would you assess the impact of his hearing upon him now?

A His mood's up and down. He has got upset quite a few times and said, "I wish I'd never got this stupid surgery." I'm like, "Why?" "Because it was safer being deaf." And I said, "What do you mean by that, darling?" He says, "Well, now I hear what people say about me." He says, "And going back to that place," he says, "I don't like it." He says, "Because" -- Again, they've got better 'cause [REDACTED]'s had a meeting with Professor Gibson, and [REDACTED] had said, basically, people wearing the masks is no good. People need to remove their mask to speak to him or wear a visor if they're worried.

Q Now, I want to go on now, Ms Ferguson, and ask really about a couple of final things.

A Mm-hmm.

Q The first thing is to just try and have your reflections on the impact of all of what you've described on you. Before I do that, maybe I could ask you this question: I think we can see from your statement that [REDACTED] was included in something called the

Case Note Review --

A Yes.

Q -- and there's a section in your statement about that, and I wonder if I might just have Ms Berechi(?) share that with us, please, on the screen, page 177.

A Mm-hmm.

Q And the particular paragraphs I'm interested in, Ms Ferguson, are paragraphs 170 and 171. I wonder if I might have you just read those two. Would that be okay?

A Yes, sure. 170, 171, sorry?

Q Yes.

A Yes.

"The report says that the first episode of Enterobacter cloacae was possibly related to the hospital environment and that the second episode occurred with the same organism although the type and results are not available. They said that a lot of the rooms weren't tested, only some of them were tested."

It's just disappeared.

Q Can we go back to where we were, please?

MS VERRECHIA: Sorry.

THE WITNESS: No, you're fine.

A

"They also said that the impact

of the Enterobacter infection was severe based on how long [REDACTED] had to stay in hospital."

Q Can I just pause you there, please, Ms Ferguson?

A Mm-hmm.

Q You said that a lot of the rooms weren't tested. What do you mean by that?

A Only certain rooms were tested and --

Q Tested for what, sorry?

A Just tested to see if there were any bugs in the drains and [REDACTED] - our room was never tested.

Q Are you indicating -- You're not talking about testing by the Case Note Review team. You're talking about testing by the Health Board, is that right?

A Yes, board, yes.

Q By the hospital, yes?

A Yes.

Q Sorry, could you go onto 171 now?

A

"I know they'll never say it has definitely come from the hospital but they have said it's a possibility the stenotrophomonas infection was related to the hospital and that the possibility was quite strong and that [REDACTED] had been an in-patient for the

three months prior and that a couple of other kids were diagnosed with stentrophomonas around about that same time.”

Q Thank you. Now, thinking about what's written there and thinking about, in other words, what you now know, thinking about the other issues that you've described about ██████'s time in the hospital, have you got any reflections on all of that that you would like to share with us?

A It just -- How should I put it? It wasn't -- It's not an environment you wanted to be in. You didn't get the answers you wanted. We were in there with our kids because they had cancer. That's what we wanted to focus on, was getting them better, not all the other issues that were going to make them sick. And worrying about things, like the food, the cleanliness of the water, was the water safe? You know, everything. You just -- The air. Who builds a hospital with no windows to open or air conditioning that doesn't work, but you can't have a fan when your son's running a temperature and the room's boiling? It was a sad place to be. The nurses and the play workers tried to make it fun, but they were struggling as well. Everybody was struggling. These poor people

were having to lie to us every day. Not management, because they wouldn't come near us, and not something I would want to repeat ever again. I wouldn't put anybody through that.

Q And the things that you've just described, what impact have they had on you?

A Emotionally, physically, everything, it's -- I'm exhausted. You know, I've got PTSD, I don't sleep properly. We get so anxious when we have to go. You dread every blood test 'cause you're like, "Please, don't be anything. We don't want to be readmitted." There's a few times ██████'s pleaded with me not to phone the hospital when he's took a temperature 'cause he doesn't want to go back. We have to -- We plan it when we have to go to Glasgow because it's like, "Right, it's okay. We're just going to be in and out. We're not going to be staying." "Are you promising?" I'm like, "I promise. We're just in, get our bloods checked, get out." He'd rather go to a local hospital, but he understands why he can't until Professor Gibson says it's time to move on.

Q Thank you, Ms Ferguson. Now, I think you have something further that you would like to say. You have something you

would like to read, is that right?

A Yes, this is from [REDACTED] himself. He would love to have done the statement himself, but he might not be so polite. But this is his words:

“Management is a joke. They couldn't care less about any impatient in the hospital. They think it's fine to lie and hide behind their office doors and leave the nurses and doctors to take the anger from patients and parents. If the building, water and air conditioning was fine, why did I have to take Cipro and Posaconazole? They say the environment was safe -- what a joke. Also, how dare management say they never ever told us not to touch the water? Yes, they did. We couldn't even have a shower or brush our teeth. I had to go to Marion House to have a shower. You try not having a hot wash for weeks and having to stay

locked in your cell.

Miserable.

We were deprived of a basic human right of clean air, clean water and fresh food. We got none of that. Then the filters on the taps, (inaudible) solution poured down the drains once a week and then the HEPA filters to clean the air. Yes, your environment is really safe -- no, it ain't.

I had an issue with my skin on and off for nine months, but no one cared. They made me feel as if I was dirty. Even a nurse blamed us for bringing the germs onto the ward. Every time I used the water, my skin flared up. I told them when you wash your hands and showered, you felt like something was crawling on your skin and would scratch and scratch. So, a couple of times, we were kicked off to 2C.

The rooms were dirty.

My mum had to clean the room a few times a week as the cleaning stuff they used was rubbish. My mum has pictures on her phone of the floor cloths after she cleaned the floor. It wasn't the cleaner's fault. They tried their best with the rubbish products they had, and it stunk of sweaty socks.

Management would hide in their office and leave all the staff to take the flak from the kids and the parents. Also, no one cared about us. The 8- to 12-year-olds, they wanted somewhere to go and hang out but got told, "No, we will close the playroom for one hour a day." What a lot of good that is. I was isolated and lonely. They kept us in source most of the time to stop my mum asking questions.

Matters were made worse when I started to lose my hearing, and no

one believed us. They just told us I was wearing my headphones. Then I took a drug called Gentamicin as I had Aspergillus in my lungs, then Posaconazole took the rest. Some nurses tried to help but couldn't get anywhere. The theatre porters were trying to help as well. Even a cardiac anaesthetist had tried to help us, but the cancer doctors didn't care. It was easier for them to leave me in silence, and that's what hurts the most. I could communicate with them, but they couldn't with me. Yes, they gave me a whiteboard, but only so many people could be bothered to write on it. Yes, I started to learn sign language, but the staff weren't, so what was the point?

Only a play worker could sign, and I think it would be beneficial for the hospital to help fund

this lady to keep improving on her sign language skills so at least someone can help if another deaf child would come onto the ward.

Maybe if staff weren't so busy trying to deal with all the hospital issues, then maybe they could have had more time to help and support me. Management need to be honest and stop hiding and admit they had lied and messed up. It's not their kids' lives they're messing with. It's other parents. I will never, ever touch the water and get very scared, and my anxiety is through the roof. I hate having to come up to Glasgow, but I understand why. I have faith in the doctors and the nurses and everyone else, but just not infection control because they just lie. [REDACTED]."

MR DUNCAN: Thank you, Ms Ferguson. My Lord, those are all the

questions for Ms Ferguson and that would conclude her evidence.

THE CHAIR: Thank you, Ms Ferguson. Thank you for coming and thank you for giving your evidence as well as, of course, your witness statement, which is part of your evidence to the Inquiry. But that's now finished and you're free to go. Thank you.

THE WITNESS: Thank you very much.

(The witness withdrew)

THE CHAIR: Now, that's the evidence for the day, Mr Duncan?

MR DUNCAN: It is, my Lord.

THE CHAIR: And we should be able to sit again at 10 o'clock tomorrow?

MR DUNCAN: Indeed.

THE CHAIR: Yes. I think, again, two witnesses.

MR DUNCAN: We have two witnesses tomorrow.

THE CHAIR: Two witnesses. Well, we shall adjourn and we'll see each other tomorrow at 10 o'clock, all being well.

(End of Afternoon Session)

