

Scottish Hospitals Inquiry

Witness Statement of

Theresa Smith

WITNESS DETAILS

1. My name is Theresa Smith. I was born on [REDACTED]. I am [REDACTED] years old.
2. I am the mother of Sophia Evangeline Smith. Sophia's date of birth is [REDACTED] March 2017. Sophia died when she was [REDACTED] days old at the Neonatal Intensive Care Unit in the Queen Elizabeth Hospital in Glasgow.
3. I live with my husband, Matthew Smith, and our children, in [REDACTED]. [REDACTED].

OVERVIEW

4. My daughter is Sophia Evangeline Smith. Sophia was born at Paisley Maternity Unit on the [REDACTED] March 2017. A few hours after she was born, Sophia was transferred to the Neonatal Intensive Care Unit ("NICU") in the Maternity hospital in the Queen Elizabeth Hospital ("QEUH") in Glasgow. She was admitted as an in-patient and received treatment in the hospital up until the day she died on [REDACTED] April 2017.
5. During Sophia's admission, Matthew and I were with her every day. We arrived early in the morning and left late, last thing at night. Matthew and I stayed at Ronald MacDonald House. My mother and father looked after our other children at our home in [REDACTED]. I can speak to the experience which Sophia and I had in the hospital.
6. There are some specific events that I would like to mention. Following her death, a post mortem confirmed that one of the causes of her death was MSSA PVL which is a toxic strain of the MRSA infection. I believe that she

acquired that infection from the hospital. I speak about that in more detail later on.

FAMILY BACKGROUND

7. I live with my husband, Matthew Smith and [REDACTED] children in [REDACTED] [REDACTED]. In March this year Matthew and I will have been together for 23 years.

8. [REDACTED]

9. [REDACTED]

10. [REDACTED]

11. [REDACTED]

12. [REDACTED]

13. [REDACTED]

14. [REDACTED]

15. [REDACTED]

16. [REDACTED]

17. [REDACTED]

18. [REDACTED]

19. [REDACTED]

SEQUENCE OF EVENTS: THE FAMILY'S EXPERIENCE AT THE QEUH

Sophia's Birth: [REDACTED] March 2017

20. The night before I began to think that my time might be near. I kind of had that feeling the night before, and the next day started with the usual niggles and they progressed on through the day. But you're never very sure, particularly with my parity the Braxton Hicks contractions can be quite severe. I've always had this thing where I didn't want to go and it's a false alarm, because how embarrassing would that be when you've been [REDACTED] before. So I waited and early evening came and I said to my husband I'm not sure about this now, I think maybe we're progressing into labour beginning.
21. That evening I was due at a friend's. We meet every Friday night, or we did before COVID. We met every Friday night and it was just a group of girls who would meet. It's just literally round the corner, minutes from the house, I can see it. Matt said to me just go because if this is it and you have the baby you won't get for a while. So I popped round but I was only there about 15 minutes and one of the girls said to me "are you okay?" I said, "No, I'm quite sore". And a wee while passed and she said, "You don't look good". I said, "No, I think I'm having another contraction". By this point my contractions were only ten minutes apart so my friend walked me back round to my house and we got ready to go to the hospital.
22. Matthew drove me to Paisley Maternity Unit and my mother came with us. My father watched the children, as per usual. I went into the hospital and I was labouring and I noticed when I was labouring that the midwife was very interested in the top monitor, and it was out of my view, but because of that I kept turning to look at the top monitor. I knew I was contracting hard at that point, but I asked her why she was interested and she said baby's heart rate seems to be dipping a wee bit, which is what I suspected she was looking for.

She said we really need to get this baby out soon, Theresa. I said, yeah, okay, let's do this. Really I was pushing even when there weren't contractions because they'd already pressed the buzzer and once they've pressed the buzzer you know that there's a problem. Sophia was having some sort of distress and nobody knew at that point exactly why. In those moments I remember the pain being so severe, but I didn't care. I wasn't taking a break from the pushing because I could see the alarm on the faces with her heart rate dipping as it was, and I was just going for it. Sophia was born at seven minutes to midnight on the 11 March 2017.

23. I knew straight away when she was born that something wasn't good because when a baby's born there's usually just a very slight delay, and it's usually the longest seconds of your life, but there's a slight delay and then the newborn cry kicks up. Sophia didn't cry. Rather than take the baby out and put the baby up onto your chest as they usually do, they were rubbing her down, and they moved her to the side. I was trying to get up to see what was going on and I felt the midwife was trying to push me back down. I felt she was trying to take my attention off what was going on at the side of me by getting me to focus on delivering the afterbirth. But at that stage I wasn't interested: was she breathing? Why is there no cry? The staff were working on her at the side, and they said we don't know at the moment. Then Sophia started to breathe but only a little. They let me see her as she passed, and then they took her away.
24. Sophia was admitted to the Special Care Bay Unit ("SCBU") at Paisley Maternity Hospital. I just remember the silence in the delivery room. I don't think the midwife really knew what to say. It was me and my mum and Matthew in the room.
25. Matthew and I have always had an agreement that if I'm incapacitated he was to go and take care of our child if the need ever arose. Thankfully it had never arisen before, but on this occasion it did. Matthew left to go to the SCBU and my mum stayed with me. He came back with some photographs,

but they weren't very nice. The baby had a lot of tubes and things, and she was obviously being very heavily helped with breathing. Once I was cleaned up which takes a wee while, eventually I was put up to the ward, to a private room.

26. Before going up to the ward I insisted on going to see her. The staff said maybe tomorrow would be better, but I wanted to go that night. I couldn't walk, so I was taken in a wheelchair. I was still unsteady on my feet with the pain killers. It is quite scary when you walk in somewhere like that for the first time. When they took the wheelchair into the front of the room there were two babies in the room, and I stood up, because I could walk about, just not that full distance. I stood up and I noticed that one baby had a mass of blond hair and that one baby had a mass of dark hair, so naturally I walked to the baby with the dark hair and the paediatrician came out and said this is not your baby. I looked at the other one and I said, are you sure? He said, yeah, this is your baby. Matthew and I are both very, very dark, and all of our children have jet black hair, but Sophia was white blonde. Lots of white blond curls on the top. So I was quite surprised by that. I said, "What's wrong?" He said, "We don't really know, but she's not breathing well for herself. But she's stable and safe at the moment. We're just going to monitor her, see how she goes, and we're doing some tests." Then I was taken back up to the ward.
27. A few hours later in the very early hours of the morning, Doctor Brian Kelly came to speak to me. He was with someone else who I took to be a junior or a student. They came to the room and said they wanted my permission to transfer Sophia to this brand new hospital that I'd vaguely heard about. It was called the Queen Elizabeth University Hospital. He told me it had cost mega money to build, and it had all the state of the art equipment, computers, this and that, and they really bigged it up - this wonderful new place, a hospital the likes of which hasn't been seen before in this country. They asked me if I would agree to the transfer. I said I would agree to it if it was in her best interests, of course.

28. I agreed to the transfer, and I shouldn't have. It was the biggest mistake of my life. I agreed to something based on what it cost to build, the equipment he said it had, the type of consultants he said it had, all these impressive things. I believe that if I hadn't agreed that Sophia would be alive today. I will regret that conversation till my dying day.
29. Dr Kelly said he had suspicions about pulmonary hypertension and that they had machines that would help Sophia breathe until such time she could do it herself. When a baby is born a signal goes from their brain to their lungs to say "you're now born, breathe for yourself", and sometimes if that signal's delayed it's called PPHN. Really there's nothing you can do for those babies except support them until they realise that themselves. He said that whilst Paisley had the breathing stuff, the QEUH had all this brand new equipment; that it was the best place for the equipment and the specialists that are there. With what happened next, I now realise we should have left her where she was.
30. Dr Kelly is a paediatric consultant, and he works at Paisley Maternity. He was on call that night. I've also seen him in the Queen Elizabeth A&E for children when I was there with my son, [REDACTED].
31. The transfer happened quite quickly. I asked to go with Sophia but the staff said no. For two reasons. One reason was that there's no space in those ambulances. It's not a normal ambulance like you or I would use, these are paediatric ambulances. It's equipped with the most complicated, scary looking machines from the bottom to the top, and the baby is wheeled in an incubator cot. Grips are placed on the cot to make sure that it doesn't move at all, so that it's rigid during the transfer. They've got everything they need for every kind of emergency in there. I watched them put Sophia into the ambulance. The paramedics were great and they assured me that they would take good care of her and that the transfer wasn't long and there would be no traffic on the roads. I'm guessing, but by this time it's roughly about four or five in the morning.

32. The second reason was that despite my protestations they were not for discharging me because actually my uterus was haemorrhaging. [REDACTED] it was particularly dangerous. It ended up I kicked up such a fuss later on that I did my own discharge. They agreed. I signed a piece of paper declaring that I was discharging myself against medical advice. There was a lady consultant on who had mercy on me, and did it.
33. I went back upstairs from seeing all that obviously very upset before my husband came to the hospital. He was at home and I couldn't get through to him at that point. He was fast asleep because it had been a long night, and his phone was charging in another room. So I phoned my father's house and my father let himself into our house with his keys, woke my husband up. Matthew came to get me and we followed on to the Queen Elizabeth University Hospital.
34. As I was being discharged a call came through to the main desk and they apologised that they couldn't put the call into the room; it was a private call. I was a wee bit surprised why I was getting a private call from the main desk. No one told me it was from a doctor. I took this call from a doctor who just introduced herself as Doctor Jennifer. She asked me what my plans were. I said, "Either way, whether I'm officially discharged or not I'm going." The problem was I had cannulas in my arms and wrists and I was giving the midwife a wee bit of a hard time in a nice way because I wanted to leave.
35. I'd already told a white lie to my husband that I'd been discharged with their consent, and he was on his way to collect me. I actually didn't correct that wee white lie until we were in the car half way to the Queen Elizabeth.

Admission to the NICU at Queen Elizabeth University Hospital: 1 April 2017

36. Having never seen the QEUH before, driving in, it is quite striking. It is very big building when you're looking for a tiny baby in that huge place. I actually can't

remember, but I think we either asked somebody or there were people directing where you were looking for. Although I've noted in recent times there's no one there anymore, but that might have been because it was quite new then. I'm not sure.

37. We were at the hospital at about half past six in the morning on the 1 April 2017. Sophia was admitted to ward one in the Neonatal Intensive Care Unit ("NICU"), which attaches onto the Royal Hospital for Children. Although it's supposedly a separate entity in itself. There is a way that you can go up to the NICU from the main unit, so I presume at some point they're joined right at the very back of the Royal Hospital for Children. The NICU has various entrance points and it is a very separate bit from maternity unit.
38. We were brought in a different way, which I took to be a staff entrance. But I'll tell you from mum and dad's point of view. So when Sophia was admitted, in the first minutes up to an hour she was admitted into either room four or five.
39. From a parent's perspective, I can tell you what happened. You enter through the main doors of the NICU; they're steel automatic doors. You press the buzzer and you explain who you are for security purposes. The doors open up, you come in, and then there's a corridor. Right in front of you is a massive desk where the staff such as the consultants and paediatricians stand. I think it's also where the secretaries work. There are some desk assistants who open the doors and do the general stuff; it's a very busy desk. To the right of that desk is room one. If you're in room one, you're in trouble. Then to the left of that desk, and actually where the corner just turns becomes rooms two, three, four, five and up. There was a wee room for parents, with a kitchenette thing off it. Using the bottled water you can make yourself a tea or a coffee. There's two leather sofas and a TV, which has minimal channels on it, and that's pretty much it.
40. When we arrived there was a lot of people around her and we weren't allowed to go in. It's very alarming when you arrive and you know that's your tiny baby

in there and there's so many people around her. If you get that much attention in a medical unit something's very wrong. We were shown to an interview room I don't know if interviews actually happen in them, but they're private rooms for families who are waiting for consultants to come in and speak to them.

41. It was a while before someone came to speak to us, around an hour and a half. Eventually a doctor came in, and it was the same doctor who had called and spoken to me when I was still at Paisley Maternity. She said, "Hi, I'm Doctor Jennifer, I spoke to you on the phone", a very pretty lady, blonde hair, quite heavy makeup, red lipstick, very high heels. I remember thinking how does she walk in those, they were so high. It's the strangest things you notice at the moments where you shouldn't be noticing anything, but I think your senses are very heightened and you absorb everything.
42. She didn't beat about the bush. She said that Sophia was very sick. She had what they thought was persistent pulmonary hypertension of the new born ("PPHN"). This was the theme all the way through, they thought she had PPHN, but they were never sure. She told us that Sophia was fully intubated, the machine was breathing for her. She had been put into a medical coma. It was very hard. More to gauge the severity of it than anything else, than any real desire to have it done, I said to her, "if we were going to christen should we do it now?". But really it was a loaded question in that I was asking where exactly are we going with severity here. And she said "yes, but if you're going to do it you're going to have to go fast because we're going to ECMO". I remember feeling a real stab to the chest.
43. ECMO is extracorporeal membrane oxygenation. She explained what this ECMO machine was, but she also explained to me that they weren't sure by any means that Sophia needed it. ECMO is a procedure that performs a heart and lung bypass. Sophia's breathing was very poor. She was breathing on her own but definitely not anywhere near enough. She was being supplied with oxygen, but her output gases were toxic. What she was exhaling was really

bad. The machine goes in through the jugular. It took the blood out of the baby's body and into the machine. The machine cleaned the blood of the bad gases, oxygenated the blood and pumped it back in to the baby's body via, what looked like it a clear garden hose. It was that thick. You could see the blood pumping around. There's donor blood there if it's required.

44. Doctor Jennifer said that what they were doing with the ECMO was buying time, it was a last roll of the dice . That's how she put it. I understood what she was telling me.

Sophia's baptism: 1 April 2017

45. I said, that we were going to christen her, and asked that Doctor Jennifer give me time. She said, "I can't give you much time." So my husband made the call and asked a very close family friend of ours to come and christen Sophia. He knew already that it was a difficult birth and that we were in trouble. He was there in twenty minutes. I don't know how he did it. He lives in [REDACTED].
46. When the priest arrived I spoke to him in the hallway, I explained what had happened and where we were. Someone came to us and said that if we were going to christen Sophia it had to be now, right now. We walked into the room and the priest asked a nurse for some water. She seemed confused and explained that the hospital only had tap water, not holy water. He said, that was okay and asked for tap water. Strangely the nurse said "I can't give you tap water". We ended up with saline or similar, it's sterilised water that comes in a wee cup thing that you pull the lid off. I remember thinking "it's not that difficult, just get the guy some water". There seemed to be some issue with it, and they eventually said they couldn't give it to us from the tap. The staff were checking to see if anyone had a bottle of water. Eventually she was baptised with this sterilised saline water.
47. We were not told why the staff couldn't give us tap water. [REDACTED].
It was just people jumping over the top of each other "going water, where can

we get water”, shouting over to someone else “have you got a bottle of water?”. I’m thinking, this is a multimillion pound, brand new unit, just get some water, it’s not that difficult. But it seemed beyond the nurses who were there. Other staff were shouting that we needed to hurry this up. I was stressed because someone’s shouting to hurry up and get this done, and someone else is telling you they haven’t got the water. If you’re Christian you can’t baptise without water. Eventually we got the pot of sterile saline water and she was baptised with that really, really quickly. We didn’t even have god parents. They usually ask you a set of questions, will you raise this child in the Christian faith? There was none of that. He just blessed the water, dipped his hand in the water, did the sign of the cross on her and that was it. It was father, son, holy spirit done, go, and she was taken from that room in the NICU to room one in NICU.

48. I was told that Sophia was in room one because that is the highest grade of monitoring. That is where they were going to do the ECMO, because it is then one to one care with a senior staff nurse. A senior staff nurse is important because the level of care from them only happens in that room. The other rooms have staff nurses or band six nurses or bank nurses because there is less severity. In room one each baby has a senior staff nurse whose job is to monitor, they look at the cot with the baby right in front of them. They do that for ten, twelve hours: watching the baby one to one, and the machinery. If the nurse goes on a break, needs the toilet, there has to be a senior staff nurse who comes in and takes over during those lunch breaks, rest breaks, whatever. It can never be a staff nurse or a band six or anyone like that. That’s how it was explained to us. I remember finding comfort in that, but also naturally being alarmed by it too, because for Sophia to be requiring that was alarming.

49. ECMO requires open surgery and the intention was that it happen in a room where at that time there were five other babies all with their senior staff nurse, so there’s five staff. In addition, there was going to be all the people who would normally be in a theatre doing this operation, Mr Davis plus his junior,

plus all the staff, plus Sophia's nurses. That's a hell of a lot of people in one room. They were going to ask the parents of the other children to leave the room, but all these people had just been in the room, and they're not cleaning the room down as they left. So all these people were now mass exodusing this room and I'm thinking well, you've got five sets of parents leaving the room there, it's not a sterile environment, and they're going to do the surgery, but really the odd germ here or there at that time wasn't concerning me because I had bigger matters on my mind, which was her survival. But I did find it strange, and I do find it strange, because to this day they're still doing the ECMOs in that hospital in the same room as other children, their care givers, and where other parents have just been, and that can be five, six sets of parents, five, six sets of care givers, plus the team that are in. So it's not private nor is it a sterile environment.

50. The ECMO never happened at this point. Sophia rallied. That was the word staff used with me. She rallied after the baptism. At that point I remember thinking that we made the right decision delaying the ECMO to allow for Baptism. The staff said she was really fighting back now. She seemed to have realised in herself, and there was no need for ECMO at that point. Honest to god I could have got on my knees and kissed the ground. The relief at that point as Doctor Jennifer had described ECMO as the last roll of the dice, it was a stay of execution. We were still in trouble, but we were fighting. I made a joke to my husband. Sophia was so unlike us with hair colour and, I said, "well, there you go, she's got something of her mother in her, a bit of fire, a bit of fight". I'm not known for letting things pass me without a bit of come back if needed, and only usually with my children. We had a laugh there. But we obviously weren't happy, but we were just relieved.

51. Sophia was still fully ventilated through a tube in her mouth. She was receiving anything between 98 to, at times, 100 per cent oxygen. She was on an oscillator machine: it's a cot that moves. She was in a medically induced coma. There was a wall of machines in her room.

52. A lot of the babies had that level of machinery in each berth in room one. That oscillator I hated because it rattled, and it does appear quite rough. It made a tinny noise. The motion delivers short, but fast shots of air to the lungs. I remember saying and feeling silly for asking, but being concerned about how violent it seemed to be, asking won't it give her brain damage? Because you would never shake a baby, and certainly not continuously in that way. They said, no, it's fully tested, it doesn't do anything like that, and it brings them on faster. So at that point she was on the oscillator, fully ventilated through the mouth, full oxygen, and she was still breathing some pretty bad gases, really quite awful gasses.
53. At that point she wasn't being fed. She was receiving a multi vitamin saline infusion. I believe, through her nose at that stage. Later a couple of days in I was pushing for Sophia to receive breast milk. She began to get very small amounts, four ml an hour.

2 April 2017 to 10 April 2017

54. Me and Matthew stayed at Ronald McDonald's house. We would come over to the hospital very early in the morning at dawn, and would stay until the early hours of the night usually. We went back to Ronald McDonald house, had a shower, a couple of hours' sleep, not very much, and back again.
55. Every day Sophia rallied. In the early days we were getting very regular updates, like every few hours and not once did she take a step back. She was always stepping forward. She was breathing more on her own so we reduced the oxygen. Her gasses observations were not within her case notes, they were kept within a separate blue folder. I totally relied on the numbers in this folder and clung onto them as an indicator as to how she was every day. What she was outputting was as important as what she was intaking. Every four hours or so our consultant would come and say we've tried her on less oxygen, she's met the challenge. We've just done her gasses, and they've

improved again. When they tested her gasses, this was done through a blood test usually.

56. That was the story that continued all the way through until something happened. Something totally out of the blue, and we noted that Sophia was going downhill. But literally we got a day, most, where Sophia was going downhill and she was lost. But up until that point everything had been progression, progression, progression. And it wasn't small steps. It was leaps and bounds of progression.
57. I remember very clearly on day three, and it's embarrassing to say, but I remember just going outside to walk to Ronald McDonald house for the shower and I remember being so full of joy: that we'd all but won. I literally went "yes", to the sky, because she was almost there. She'd almost won. We were so far forward now that there was no question of survival, which had scared the living daylights out of me on day one. We were now at day three and it just wasn't in the arena anymore. I remember being so full of joy at that point that I very nearly somersaulted: then remembered you've just had a baby and you're not 16 anymore.
58. She was still in an induced coma at that time. Staff told me that they were looking to take her out of that, but they didn't want to push her too hard, too fast, as she was coming on so fast herself. They said she's doing all the work. She's doing it all. Let her do it, because she's doing really well, don't jump in and intervene now. Let her do it. She's pulling away saying I don't want this, she's breathing more on her own, she's realising what she's got to do. So whatever's going on let it go because we're going so fast up the hill.
59. On day nine the staff brought her out of the coma. She was coming round, opening her eyes, looking at us. Still moving around in that squirmy way that newborns do, but still quite lethargic. Staff explained that it was going to take time for the drugs to come out of her system. She was having a good look at us. We were laughing at each other and getting as many photos as we could,

she seemed to be weighing us up when we were talking and she was recognising us. The nurses told us to keep talking because there was something that they noticed when we were talking, but particularly when I was talking, she was very calm on the monitors. We were just talking absolute gobbledegook all those days and actually reading stories to her. You would never usually read a newborn stories, right? But just to give me something to say, to keep talking. So she was recognising our voices and she was squirming and she was looking at us, which was great. By that time she was off the oscillator and just in a normal incubator, but still ventilated. By that point her gases had been so good for so long that they weren't taking the gases observations anymore.

60. The big wall of machinery and equipment was all the way down the side of her cot. It just all seemed to come down straight away. There were no more things. To the point that I was phoning home to my parents who were watching the other children saying "oh, the machinery is away, she's doing so well, all the machinery is gone." There was just one machine left and that was the oxygen machine, which was reading down between 12 and 17 per cent by this point. It was minimal oxygen.
61. Days eight and nine we were talking to the senior staff nurse who was taking care of her and we were talking about Easter coming up. I said I don't know how we're going to manage Easter if Sophia's still here, and she said, no, I don't think Sophia will still be here by Easter. We had a conversation about Easter which was a week or two away at that point. She said the only question here about when Sophia goes home, which will be imminent, is whether she will come home with an oxygen tank or not. Initially I thought, an oxygen tank, wow. Bit scary. But she explained to me. It's just a wee tank by their side and it's just got nasal prongs that go in, and it's really just there to support her. But whether she would need that or not hadn't been decided. So there was a chance, it was 50/50, so there was a 50 per cent chance she was coming home without that. The whole idea of it made me nervous. I'm told it's not a big deal, but it still made me nervous.

62. It all went wrong on day ten. She was looking very pale. I started to say to them baby's pale, and they said, oh, no she's not. I said, yeah, her skin tone has changed. She's very white. This kind of went on and on. I went to the parents room for a coffee and came back, and I noticed that one of the machines was back and I said, what's that for? The nurse said, I thought maybe she was struggling a wee bit there so I've put her oxygen up. I think we've pushed her too hard, too fast. So I'm just doing this just to give her a wee bit of rest, to give her a wee bit more oxygen, let her rest a wee bit, because something is tiring her. That was the beginning. That was really the beginning.
63. The previous night I had reservations because the shift had changed, and on the incoming shift the girl that was there was in a different uniform. She was in a blue uniform. So I looked at her badge and it didn't say senior staff nurse, which alarmed me a wee bit. [REDACTED].
64. I hadn't complained about anything the whole way through, and had a good relationship with the ward sister. She was a very nice woman. I stepped out of the room because in room one the consultant's desk and the desk where the staff all congregate is right there. [REDACTED]. They'd taken away the ECMO machine. They'd had that set up for ages. They'd taken all that away because they said they'd had it sitting waiting and it was this big monstrosity of a machine that sort of loomed over the whole room like death, literally, and they had taken all of that away because they said this baby's never going to need this now. There's no possible way she can go back to where she was from where she is now.

65. [REDACTED].

66. [REDACTED].

67. [REDACTED].

I said to Matthew, I'm not going. Eventually he went on ahead of me to Ronald McDonald house, because he was so tired by this point. He was dizzy. He said, I can't stand much longer, the room is spinning. Quite often at the sides of the cots there'll be only one chair, and just because I'd just delivered and he's the man, he would always give me the chair. He said, I can't stand any longer, I'm dizzy. He hadn't eaten, we hadn't slept in so long, which was just a common theme for that fortnight really. He went and I stayed for as long as I could. I remember going outside to call my mother. My mother and father were living in our house at that time, taking care of our other children. My mother would not go to bed until she'd had her evening update from me on how Sophia was doing.

68. I went out of the ward to use my phone. [REDACTED].

I speak differently when talking to my mother and sometimes get embarrassed because there's the Italian and the Italian accent. I went downstairs and I phoned my mum, and I remember that conversation verbatim. I've never made so many mistakes in my life as I made that fortnight, because my mother is usually really good. She gives great advice. She's a very wise woman. I wouldn't say it if she was in the room, but on this occasion I should not have taken her advice. I went downstairs and she said, it's late, I've been waiting for the call, I'm tired. [REDACTED].

69. [REDACTED].

My mother's got this thing with her children, we all need to be put to bed after a bath. It doesn't matter what age we are. I was in my late 30's by then, but I still needed to go and have a wash and go to my bed. She said, "you're overtired, you're overthinking this, go back to the room have a shower, get a couple of hours' sleep and it will be morning before you know it, [REDACTED]. Sophia will be just fine, it's only for one night." I said, "You know what, Mum, you're right". When I had popped outside and the cold air had hit me I'd started to feel really nauseous that I was going to be sick. It was just I was so tired that I was going to vomit. This time it was around midnight, I'd been

going since five that morning on maybe two or three hours' sleep and a lot of coffee. It starts to churn you up after a while.

70. I went back upstairs and I stayed for a while, then I left, and I walked over to Ronald McDonald house. I remember just praying because I just felt so instinctual that something was wrong. I just left, and I remember saying god, just look after her tonight. I got back to the room, had a shower and went to sleep. As soon as I woke up, didn't even go for another shower, I just pulled my clothes straight back on and headed back to the hospital.

11 April 2017 and [REDACTED] April 2017

71. As soon as I woke up. I put my trousers and my shoes on and left. It was early morning. It was after the shift change, which happens at seven o'clock, [REDACTED]. When I arrived, Lorna McSeveney, the senior staff nurse was on duty, she was the senior staff nurse at the time.

72. Sophia seemed okay, [REDACTED].

73. It was the tenth day. Through the course of the day the baby became markedly unwell. I noticed that Sophia was markedly pale and that the machinery was starting to accumulate again. Sophia progressed from pale to ghost white to almost translucent. I kept saying to the nurses: can you get a consultant; can someone check her over; can you get someone; can you get someone. [REDACTED]. I had this horrible feeling in my stomach. The staff had started to up her oxygen suggesting that she was struggling a wee bit. [REDACTED]. I was alarmed by the step back.

74. Sophia was a full term baby. She wasn't premature, and she wasn't suffering from any other complications really other than this breathing thing. She should not have had a step back. For it to be passed off as normal, she was the biggest baby in this ward and she'd never had a step back. Through the

course of that day I watched the oxygen they were giving her go back up, and everything she'd worked hard for seemed to be coming back down.

75. Sophia's bed backed onto the back exterior of the consultant's desk.
[REDACTED]
76. Around 4:30pm [REDACTED], one of the consultant paediatricians [REDACTED] came in. He took one look at her and said I'm going to have to scope her, you can stay or you can step out. For those procedures I would try and step out because I can't watch that.
77. Matthew and I were taken to one of the interview rooms. That was the beginning of the end. We waited there for quite some time. We were told to wait until someone came to see us. Nobody came. A few times we stuck our heads out the door; looking around, waiting. We were trying to let them see us, looking for an answer and nobody came. It was hours. Eventually we went to the desk. The staff said we could go in to the room to see Sophia and that is what we did.
78. [REDACTED] told us that they had scoped Sophia and that there was quite a lot of blood. He said, they were scanning her lungs because he thought she was having a lung haemorrhage. I asked what that meant. He showed me a chart, like an x-ray picture and told me that one of Sophia's lungs had deflated. I said, "okay, so how do we re-inflate it?". He said, you can't. I looked at him and said, "well, what do you mean you can't re-inflate it? If something deflates you can re-inflate it". He said, "no, I can't." That's the point where I thought is he telling me she's going to die?
79. He just said he didn't have the answers that he didn't know why it was happening. It had gone from we're taking her home soon to suddenly being back in the same position that we were on day one. Sophia had been put back into a medical coma and all the machinery started to build up again, like

bricks against the wall. It was all building and building up again as the hours were passing.

80. With those machines, it's scary. There's wires that come off and they connect to the baby. Naturally with that kind of thing there's a lot of beeping. Now, to this day I still have an issue with beeping. To this day I can't take my kids to McDonald's because the machines in McDonald's beep. Normal people don't notice this, but I'm not normal anymore, not after what happened. The machine beep in the hospital was the same sound. Sophia's machine always used to go off and although I knew it was only a low battery it would scare me. The machines going back was not a good sign, and that wall of machinery was beginning to build up quickly again.

81. I found out later that there was a considerable delay before Sophia was put on the ECMO machine. I continually questioned what the delay going to ECMO was. We had been called many hours previously at Ronald McDonald House by Karen the Senior Staff Nurse at about 1am. She had said 'we're going to ECMO. [REDACTED] is on this way'. [REDACTED] was already in the NICU when I arrived. I saw him in the corridor when I was buzzed through the security door. It was now well past daybreak and we were still waiting for the ECMO procedure to happen. I queried the delay over and over again. At one point a nurse told me that they were waiting for [REDACTED] which I thought must be a mistake because he had arrived before I did. We had acknowledged each other in the corridor. Eventually a lady doctor, [REDACTED] came to see us and told us that Sophia's ECMO procedure had finally been done. I asked her why it took so long to get started and she told us that she had a difference of opinion to the other medics as to whether ECMO was worthwhile. [REDACTED] told us she had called a staff meeting over it, that meeting had finally been decided by vote.

[REDACTED]

82. It didn't look good when we went back in to see her. The day before, there was a baby in the same room as Sophia, and she had died. It was very

present in our minds. This is all played out in front of you because the families and another five babies are all jammed in this room. There's no curtains, there's no privacy.

83. We waited. And that was it. We waited. I queried what the machines were, I was told one's dopamine, one's midazolam - which she had all been given on day one. I was horrified because her battle was won and now we seemed to be starting it again. It was only a day or so previously we had been discussing homecoming. At no point when I was querying the machines did anyone say she's on antibiotics or we've put her on antibiotics. I later found out that she was given antibiotics and I will speak about that later on.
84. The machines were explained to me as oxygen, midazolam, dopamine, other general stuff to keep her asleep, to keep her calm. Morphine for pain. There was the vitamin water to keep her hydrated. I think they had stopped giving her the breast milk at that point. I asked about her gasses and nobody said anything, just that some blood work had been taken. I got that answer a few times but never a proper response. Then when I did get an answer I was told her gasses were phenomenally bad: we had gone from her requiring 12 per cent oxygen with them not even taking blood work because her gasses were so good, to her gasses now being so bad they were taking it constantly.
85. On the [REDACTED] April 2017 Sophia died in my arms at twenty minutes to five in the evening. This was the first time I had ever held her in my arms. We were taken into a room after she passed. The staff had gone to ECMO in the end and after her death she had to go through another surgery to have the ECMO machine removed from her neck. She was taken away for that. When she was dying in my arms she was still connected to the machine, so there was a lot of blood. The blood was passing between her and the ECMO machine. It was still doing its job although she was dying, and when she died. There was a lot of blood through her nose and mouth. It was spilling onto the floor, and I remember my mother slipping in the blood. They were trying to mop it up with these horrible hard hand tissues. [REDACTED].

86. We were shown into a wee room and it was a bad room to be in. You went in through a door and had a wee Moses basket, and it was dark and it had fairy lights. It had a name, this room, but I can't remember it. It was a strange wee room. You came in through one door, and then to the side bit was another door and there was something behind there, and for some reason I thought it was a kitchen, because it had fridges. I was later to understand that those weren't fridges. When the door was open you could see that there were fridges and a lot of stainless steel worktops, but I didn't realise at that point what that was. It was a really bad place to put the room that's supposed to comfort grieving parents, adjoining on to the room where the fridges for the bodies are, and that you could see the fridges from the room.

87. We just sat there in stunned silence. There was the three of us: me, Matthew and my mum, who'd all been present in the room when Sophia died. My dad arrived at the NICU 20 minutes later by which time we had been shown to the strange nursery room. We held her for a while, but they said she had to go to surgery to remove the ECMO pipe from her jugular

88. [REDACTED]

89. [REDACTED]

90. [REDACTED]

91. [REDACTED]

Sophia didn't have down syndrome. Sophia had mosaic down syndrome, which is quite different actually, despite the name. We knew and had been told that she was "physically and structurally sound" because the staff repeated this exact phrase over and over again. They knew there was no brain damage because she'd had multiple scans. We knew that her eyes were slightly more oval. Mosaic down syndrome tends to be more characteristically as in facially, and maybe some balance issues. There is a spectrum for the

condition and Sophia would have been on the milder end of the spectrum. Sophia might have had trouble with her balance, she might have walked later than other babies, mild developmental delays that kind of thing. But it certainly wasn't the worrying diagnosis of down syndrome at its fullest. It was a much more minor thing in the grand scheme of things to be diagnosed with.

[REDACTED]

92. [REDACTED]

93. [REDACTED]

94. [REDACTED]

95. I don't live in a fairy tale world, quite far from it. I understand that people with down syndrome or mosaic down syndrome like Sophia, can die of complications of that genetic disease or illness and the extra gene. I understand that complications can happen and that they may die, but my daughter didn't have a complication of that. [REDACTED]

96. [REDACTED]

97. [REDACTED]

98. [REDACTED]

99. [REDACTED]

100. [REDACTED]

101. [REDACTED]

102. [REDACTED]

The post-mortem – April 2017

106. The post-mortem was performed and we were told when it was done. We were told to send a private ambulance from our funeral director to collect her from the hospital. It did take a wee while. Eventually we were able to send a private ambulance to bring Sophia home to [REDACTED], and then we went ahead and organised her funeral.

107. It's worth mentioning that the only way they could sway me into the whole post-mortem thing was by agreeing that it would be a limited post-mortem. It was explained to me by [REDACTED] as an incision that would begin at her breastbone and end above her navel. When Sophia came down in the private ambulance it was late into the evening and our funeral director, P B Wright, called and said "we feel it would be best if you didn't come tonight, if you waited till tomorrow, there are some things we have to do". They actually spoke to my father who was trying to arrange the funeral to take the pressure off us a wee bit. My dad thought it was a bit weird, but he agreed.

108. Then the next day we went to the funeral director. The lady at the reception desk went to get the manager, Kenneth. We were shown to this room, it was weirdly like a living room and we waited for Kenneth to come. He came in and he sat down, he introduced himself [REDACTED].

109. [REDACTED].

110. [REDACTED].

111. [REDACTED].

112. [REDACTED].

113. I was quite broken for some time after it. And then after a while we buried her. It had been many weeks. We still didn't have the post-mortem result. I had

initially been told it was ten days to two weeks. Now, whether they had got that wrong or not I don't know. I started calling the hospital. I had no contact details for anyone, so I quite literally just googled the number to get through to the desk at NICU ward one. [REDACTED].

114. [REDACTED].

115. [REDACTED].

116. I hounded down the secretary a bit more and eventually got a date after all the hassle. I got a date to go in to the hospital and get the post mortem results.

[REDACTED].

My child had been dead less than, probably less than two months. Matthew and I went to get the results and we had to go to the NICU unit. I said that we didn't want to go there as it was too much. They said, so where else in the hospital do you know? I said, well, I know there's a wee quiet place, it's like a chapel but it's for everyone. I think they actually call it the chapel, there's signs that say the chapel, but it's for all faiths. It's got mats for Muslims, it's got a cross for Christians, it's got everything. It is at the very back of the Royal Hospital for Children, and it also had rooms. We agreed to meet there. On that day we were there first, Matthew and I. [REDACTED] attended with [REDACTED], the ECMO man and so did [REDACTED]. She was the nurse who had been with Sophia on the last day, she was there at our request because she'd been so good with us.

117. We sat down and I just remember [REDACTED] holding the post-mortem report. I put my hand out thinking he was going to give us all a copy so we could go through it, and he said, no, this is mine. I didn't say anything. Then he gave us the results. He said she had MRSA, MSSA PVL. I said, sorry, can you explain this, can you explain that. He explained it. I said, so are you telling me the baby's died of MRSA from the hospital? And he said, yes, that's what I'm telling you. I was sitting there trying to get my head through this and I could

feel Matthew kind of stiffening up beside me because he was realising the same thing that I was realising. [REDACTED].

118. We had a bit of conversation about how apparently they never know where these things come from and no one else has died of this. They said we were the only ones. That it's never been heard of: there's no problem in this big fancy hospital of ours, no one else has died of this. We've never heard of anyone else dying of this, nothing like this has ever happened in this hospital before, you're the only ones, you're an isolated case. I said, do you need to tell anyone, do you need to do anything about this? He told me no, because Sophia was an isolated case, that it's never happened before, it will probably never happen again in his career. I read all those same sentences verbatim. I read them verbatim in the *Daily Record* newspaper about another mother talking about the death of her child and she had been told her child was the only one that had passed away from an infection at the hospital; that this is isolated; nothing like this has ever happened here before. There's no problem with infection control here, nothing like this will probably ever happen again. It's such a lightning strike was the phrase he used. I felt like such a fool when I read that in the paper because I had believed him, and we had believed him. Because you don't know: you can identify that they're arrogant and you can identify that they have very little people skills, but you still have this level of respect where you think well, they're the doctors, they're the consultants, they're geniuses in their fields. They're telling us that we're the only ones, that there's no infection control problem here, that it was bad luck, it was a lightning strike, bolt from the blue, has never happened, would never happen again. You believe them until you start reading it in the papers that they've told every other family that too.

119. At the end of the meeting, I asked for my copy of the post-mortem and [REDACTED] told me oh no, I don't have a copy for you. I said, well, we'll just take that copy, the one in his hands. He said, no, this copy's in blue. It was printed on blue paper. I said, so? He said, that's a medical copy. I said, is it different from the main one then? He said, no, they're all the same, but we

print the medical ones on blue paper. I don't really care what colour the paper is. So I said, that's okay, that doesn't bother me. He said, no, no.

[REDACTED]

He eventually acquiesced that yes, he'll get me a copy. I wouldn't have left the meeting had I known I was going to wait another six months or so for a copy and that I was going to have to go through the whole badgering thing again to get it.

120. [REDACTED]

We left and the copy was not provided. Then I started phoning the hospital for my copy when I realised it wasn't coming.

The post-mortem report

121. Months and months later I did get a copy of the post mortem. I can't remember the date but it was months later.

[REDACTED]

Matthew and I went along because we wanted a copy of this, and because we didn't know any better. We were just doing what they told us to do, and we were jumping through their hoops just to get a copy. We arrived at the hospital. The counsellors office was next to [REDACTED] office; they're pretty much side by side.

122. [REDACTED]

123. [REDACTED]

124. [REDACTED]

125. [REDACTED]

126. [REDACTED]

127. After that meeting the hospital staff stonewalled every phone call, every letter, every email, every communication that I sent to them asking for a full rundown of how our child got this infection. [REDACTED]. Even if, as we thought we were at the time, we were the only ones. I kept thinking the hospital must know possible sources of how she got this infection. In order for me to move on with my grief I have to accept that she's dead and what she died from. I cannot accept that when I don't know the full story of how she got the infection. I can't accept what I don't know.
128. I wrote begging letters to the hospital asking them to help us, to help my husband and I and our family move on. I asked them to please just take the time to explain some things to us. They blanked everything. I sent recorded delivery letters, emails, I made phone calls.
129. We weren't phoning up crying like a pair of nutcases. We explained that we are two intelligent, professional people. We can understand more than you think and we have questions. We asked them to please give us another meeting to answer them. In terms of the grief and the devastation to our family we need to accept what's happened and can't accept it because we don't understand why it happened. Every request that I directed to the hospital was stonewalled.
130. There was a lot of detail in the post mortem report.
[REDACTED].
131. The post-mortem categorically says all the way through, and in particularly in its summing up and its last paragraph, that Sophia's fatality was because of the MSSA PVL infection, which, having taken that on board, it ate her insides. It literally ate her from the insides out, and gave her overwhelming pneumonia and sepsis as a result of that infection. It's pretty damning actually and that's why it begs the question why can't the death certificate be changed retrospectively? The correct cause of death should be recorded.

132. Once I received my copy of the report I bombarded the hospital for another meeting about the results. I didn't get it.

Correspondence with the SPSO – 2018

133. In 2018 I wrote to the Scottish Public Services Ombudsman ("SPSO"). I complained about the care and treatment of my daughter, which ended in a fatality and that that fatality was a hospital acquired infection called MSSA PVL which is a branch of the MRSA. I said that I have severe misgivings about what had happened and I wanted it looked into. The SPSO ignored me. I wrote back again and they ignored it too. I wrote back again and eventually submitted another request online so that I could have proof that I'd sent it.

134. I got a letter back months later saying the SPSO were very sorry for the delay, they were short staffed and that they'd get back to you when they could. I thought, wow, talk about blasé given that I'm not complaining that my wee granny got a rotten soup for her lunch. I'm complaining that my daughter is dead from a hospital acquired infection. Anyway, time passes, I was still waiting then I received another letter which for the second time said very sorry for the delay, they were short staffed and that they'd get back to you when they could. I'm thinking, seriously, don't you have a list of priorities or anything? Does a death or fatality in your hospital not come under priorities? I started phoning them. Nobody could tell me anything. I was emailing them and never got a response.

135. Eventually my husband was getting really upset. He wasn't in a good place at the time, and he was trying to work and he was trying to be a dad to the [REDACTED] other children and trying to hold me up by the scruff of the neck. He got through to someone, admittedly probably because he's a bit more forceful by nature. They said, hold the line. He held the line, and he came back on the line a while later and said, oh yeah, we emailed you that ages ago. Matthew said, well, stay on the line with me. He went into our emails and there was nothing. There was nothing in the inbox, nothing in the junk, absolutely

nothing. Matthew had done a lot of techy stuff at work, if there was something there, he was the man that was going to find it and it wasn't there. He asked them to send it again which they did. He hung up once he received the email.

136. It is the most informal letter I have ever seen given the nature of the topic. It goes something like this. Dear Sir, sorry for your loss of "Sophie". Her name was Sophia. Something about you've complained about the care of "Sophie", we have spoken to [REDACTED] who sees no reason why you would be complaining, and therefore that's the end of the matter, thank you for contacting us. Now, they went to the man that I was complaining about who when we asked how did this happen? His response was bad luck. Bad luck. Are you for real? You don't say bad luck to people when you've just told them that their daughter died because you gave them an infection. When we pushed [REDACTED], known as ECMO man, he said oh, thank you for your maturity today, we weren't sure if we were going to have you swinging at us, as in punching them because they just told us that she died of a hospital infection. They were informal, they didn't give a shit they were delivering this blow to parents, very blasé, very full of themselves and refused to give me a copy of the post-mortem document. They told me that I wasn't intelligent enough to understand it and therefore it would just pickle my brain to read it.

137. I have my own thoughts about how Sophia might have contracted the infection. I've looked into this myself and tried to study this infection, given how fast it took hold I understand that it is a very quick thing; it takes hold very quickly. I'm not medical, but I had some lengthy conversations with some friends in the field and they feel that that would have had to have been introduced to her arterial line to have taken hold so fast. I am not entirely sure what Sophia's arterial line was being used for.

138. I also wrote and asked for the blue folder that recorded Sophia's gases when she was in hospital. The blue folder has mysteriously gone missing and I have applied for it many times. I wrote a letter to the freedom of information people and requested that blue folder under the Freedom of Information Act and any

other emails, documentation, letters or anything regarding or pertaining to my daughter, Sophia Smith. They responded telling me there was no Sophia Smith with this CHI number, that she had never existed. She did exist. I didn't dream two weeks of hell. It was the correct CHI number. That was another stonewall and another kick in the teeth from another body that was supposed to be neutral, or at least law serving.

[REDACTED]

139. [REDACTED]

140. [REDACTED]

141. [REDACTED]

142. [REDACTED]

143. [REDACTED]

144. [REDACTED]

145. [REDACTED]

146. [REDACTED]

147. [REDACTED]

148. [REDACTED]

149. [REDACTED]

150. [REDACTED]

151. [REDACTED]

152. [REDACTED]

153. [REDACTED]

154. [REDACTED]

155. [REDACTED]

156. [REDACTED]

INFECTION PREVENTION CONTROL ON THE WARD

157. Outside the double doors to the ward is a hand pump to do your hands with the surgical spirit. You go in and you go down the wee corridor, and Sophia was in the room to the right. Just outside the door of room one there are pegs, and you take off your outer garments: your jacket, your coat, any heavy jumpers, anything like that, and you hang them there. Then you go in and there's like a big pig trough, but it's waist high. You can do your hands with soap and you can also do them with a surgical soap. You're supposed to do it right to the elbow. Staff show you this on the first day, they tell you how it should be. At Sophia's station there was hand gel there if you wanted to use that as well. I was absolutely scrupulous. We both were. Even though we weren't allowed to touch Sophia. Only the staff were allowed to touch Sophia. I was only ever allowed to touch Sophia twice. Once to change her nappy and again when she passed away.

158. That was a bit of a bugbear for me. While a lot of the staff were really nice, I mean really exceptionally nice, they were allowed to touch Sophia and I wasn't. One of the nurses used to stroke her hair and do this thing with her wee curl at the top, and that was lovely. I would have liked to do that, and I was spotless but I wasn't allowed to do it. But the nurse was and she didn't have gloves on, and she would walk over to other stations, to other babies and other bits and maybe help them with something and then come back and not wash her hands. I used to think how is she cleaner than me, why can't I pat my baby's head?
159. It sounds really petty, but when you've just had that wee baby you're desperate. I honestly thought that I was cleaner than her, because I wasn't touching other babies or other stations or other equipment or any equipment, and they're touching the equipment all the time. They were allowed to touch her and I wasn't, so that made me sad. I know now that it wasn't good infection control either.
160. The other things that would happen was there was a wee fridge and all the breast milk was kept in that fridge, people would come in and out of that room to go into that fridge. They wouldn't wash their hands at the trough, they would just walk straight in, open the fridge, put in or take out, and go back out again.
161. On our first day on the ward, staff told us that mobile phones carry so many germs: that there's more germs on a mobile phone than on a toilet seat. That horrified me. I kept my mobile usage in the room with Sophia to a minimum. My phone was usually away or it was in my jacket pocket in my jacket outside the room.
162. The thing about the mobile phone, it came back on me twofold, because as a result now I don't have many photographs of Sophia, whereas other families were snapping away quite happily. I only have a few.
- [REDACTED]

163. Another thing I noticed was that not everyone was taking their outerwear off and putting it on the pegs. Sometimes they were pulled up for it by a member of staff. More often than not they weren't. Sometimes those visitors washed their hands, sometimes they didn't, but again they weren't going to Sophia's bay so it was none of my business.

OBSERVATIONS ABOUT THE HOSPITAL BUILDING

164. It was an uncomfortable building. We were there April 2017, it was spring and it just wasn't pleasant. For example, we'd be walking over or walking back to Ronald McDonald and the smell would turn your stomach, especially first thing in the morning. There was no wind and it was good weather. There was one particular area between the hospital and Ronald McDonald house that we had to walk past and it was just thick, stagnant water. It stunk to the heavens. That was really bad. I hated coming out in the morning and I have a really weak stomach. You could smell it everywhere, but there was a particular area which looked like a bit of a canal or what it's supposed to be, but it stunk like raw sewage, really, really strong. On days when it was clear and dry and there was no wind the smell was so bad. Then you'd get inside the hospital and you could still smell it from the inside, but it was kind of worse in there, because once you got inside you weren't just coping with the smell, you were coping with the heat, because it was so hot in there.

165. The temperature in the building was hot. I was glad that Sophia was naked because I often wondered why she didn't have a temperature. It was just horrible. In the early part of my life I grew up abroad and in those kind of temperatures you would have air conditioning, especially in a hospital. It was so warm in that hospital, I'd be sitting there and the sweat would just be pouring down my face and my top would be stuck to me at the back and it would be stuck at the front. It was hot and it was smelly. I tried to sit there through it because I was there for the baby, not there for my comfort. Quite often I would go to the bathroom or the parents' room and just splash some

water on my face and hands. I knew not to drink the tap water because staff had told me not to drink the water, but I would go and just splash it on my face, splash it on my neck, splash it down the front. Particularly when you've just delivered a baby and your chest is swollen and you're leaking breast milk and there's all this sweat and hormones. I was surprised that they didn't have air conditioning actually. But then, as my husband pointed out, it's probably not something that would be used that often in Scotland. The staff would mention to me in passing that it was roasting, but I didn't have any proper conversations with any staff members about it.

166. I know they don't open windows in hospitals, I know that's an absolute thing, but in those kind of subtropical temperatures you'd think they would at least open a window so that you don't die of stifling air in there. But they don't. You're just expected to sit there in the heat. Apparently some of the other rooms had fans which were used for really bad days, when it got really hot, but none of the fans were in Sophia's room. The staff were whinging that some of the other rooms had fans and we didn't.

167. We were not to drink the tap water on the ward. Initially we were not told anything about the water. I described the corridor in the ward where there are rooms in a straight line and there's the desk. In front of the desk on the other side of the wall there was pallets of water piled high. Every time I walked past a staff member asked me "do you want a drink of water?" I remember us laughing, Matthew and I, it's like being in Sauchiehall Street when they're unveiling a new flavour of Coke or something and there's somebody jumping out at you trying to give you a free sample. It was like that. Everywhere you went they were trying to throw bottles of water at you, and they had a sign on the taps in the parents' room, "not suitable for drinking", "use the bottled water even if you're boiling the kettle". We got used to doing that.

168. I was never told why I couldn't drink the water and I don't know that it bothered me that much at that point to ask. No one ever explained why. There was tonnes of free bottles of water for your convenience. I don't think I ever

said, "well, why not?". I just presumed there was some sort of Scottish Water thing happening or something like that, I suppose. At the time my mind was elsewhere; it wasn't on the water.

169. The place was dirty. They've got all these really high risk ill people in the hospital building, and they're obviously getting paid a lot of money, it just baffles me why the place has to be so rotten. There's always bird shit everywhere, litter everywhere. For all the wages they're paying out surely they can afford to pay somebody to go in with a jet washer and just clean the swings at the play park; clean the car park areas; especially if you just walk out to come out of the car park, there's just bird shit everywhere. It doesn't look very nice for Glasgow. And when you couple it with the smell it's just not a good overall experience, is it? I saw the odd dead bird kicking about on the walkway between the car park and the NICU.

170. When we were in the NICU the electricity would go out, I knew when it was going to happen because the lights would flicker. The first time it happened I nearly died of panic because the lights were flickering and the staff in Sophia's room seemed panicked about something. There was always at least six senior staff nurses in the room, there might be students with them: it was a busy room, there were lots of people. When the lights flickered they all started panicking about something amongst themselves and they were talking, next thing someone's shouting "you go and do that" and "you go and do that". I asked a nurse what was happening, and she said, the electricity's about to go out. I replied "what?". This was on day one or day two, and Sophia was on 98 per cent oxygen; if the electricity went out how's my baby going to breathe? I posed that question, and she said, "don't worry, we've usually got generators that kick on within seconds of the electricity going out, the generator will kick on and none of these machines will actually go down, but there's usually a couple of seconds delay." In my mind I was thinking, "well, how many seconds, because my baby's not going to be able to breathe for those seconds". I asked the nurse why everyone was panicking if the generators are going to kick in anyway?. There was real panic going on at this point. She

told me it was because they thought the generators were faulty and staff didn't know if they were going to kick on. I nearly died on my feet because my baby needed help to just to breathe, not just for medication, but just to breathe; she was fully ventilated and she needed that oxygen.

171. Anyway, the generators were ready and they did kick on, and the panic was over. I was told that it had been an issue when they thought the generators were faulty. I noticed when the staff came back into the room only some of them washed their hands again. The others just walked back in. And I don't know where they'd been or if they'd touched anything, but they just walked back in; nobody's wearing gloves or an apron. I noticed it particularly on that day with the generators, when there was a mass exodus from the room, and then they all came back and only a few people washed their hands.

172. The lights flickered all the time. It was often; so much so that we got used to it and we didn't respond so much anymore. It didn't panic me the way it had on that first day because I got used to it. Sophia was receiving less and less oxygen, and also because I had the comfort now of knowing that there were generators that were going to kick on, and despite the fears, that those generators they thought were actually working.

Nappy procedure: Water

173. It was a bit of a bugbear for me that I knew I was washing my hands scrupulously but I wasn't allowed to touch the baby, and the nurses all did. One day one of the nicer ones said to me, would you like to do the baby's cares. That's what they called changing her nappy and swab her eyes. I said, oh, yeah, okay, fine. I was given some water in a pot to change the baby's nappy and swab her eyes. You would never swab a baby's eyes - you would maybe do her bum, but you would certainly never swab her eyes with water that wasn't boiled and cooled first. So I queried this, and she was a bit huffy about it and chucked a packet of these water wipe things at me, which I'd never seen before.

174. I changed the baby's nappy, and it was difficult with all the lines.

[REDACTED]

175. The staff gave me water out of the tap. But my theory on this is, if that water's not good enough for me to drink it's not good enough to go on my baby's bum. I was glad at that point that she was getting pain relief and she was asleep because had she been awake I think that's the kind of thing that a newborn would scream their head off about. But again, they said that her nappy is changed regularly every three to four hours.

[REDACTED]

PHYSICAL EFFECTS

Infection and Antibiotics

176. When Sophia was transferred from Paisley Maternity Hospital to the Queen Elizabeth she was swabbed for any infection. I was told that it was protocol when I asked at the time. It was explained that it wasn't because the staff thought she had an infection, it was because it's in keeping with good medical practice to swab if they've come from another hospital. If they've come from home they don't get a swab, but because she had been born at Paisley maternity hospital and had been there for a few hours she was swabbed on arrival for any infections. That swab was clear, but despite that swab being clear they still put her on three days of antibiotics. It was told at the time that they do that just in case. It's a just in case safety net, in case there's any bugs brewing or anything like that. They kill it there and then. After the three days she was taken off them and she had another swab for an infection and that was clear too.

177. We did an interview with STV, because we weren't getting anywhere. It was stonewall after stonewall after stonewall and just jumping hoops and hitting our heads against a brick wall and you don't deserve an answer and go on

and live your life and you have other children attitude where we weren't getting any answers about Sophia's death from the MSSA. We did an interview with STV and after our interview the NHS board was given the right to reply. A doctor called [REDACTED] spoke on behalf of the board. We said our bit, and he agreed to an interview at the very last minute, so it was about to air, and he said he wanted to talk.

[REDACTED]

178. In terms of her medication, she was given antibiotics when she arrived from Paisley. She had the antibiotics for the first three days. She was also on morphine for pain. She was on dopamine to keep her asleep. She was on something else along with the dopamine and that was all for sleeping; to keep her in the induced coma.

179. To my knowledge at the time she did not have any more antibiotics, but we found out after she died that when she had started to decline the staff had put her on a course of antibiotics. At no point had they ever told us they were doing it. I asked the question at the post-mortem results meeting with [REDACTED]. They told me that when they suspected infection, they acted upon it with antibiotics. I asked that why when we continually asked what's wrong, why she was declining and why so fast, that the staff kept assuring us that nothing was wrong with the child. Why did they say it that was just a wee step back and that they all do it? [REDACTED].

180. [REDACTED] said during that meeting that Sophia had been given an antibiotic. [REDACTED].

I'm dumbfounded that they can put a child on medication without asking the parents.

EMOTIONAL EFFECTS

Impact on the Smith family

181. It devastated the family. People use that word casually. When I say it devastated my family, I mean it destroyed us. Life falls into before Sophia and after Sophia. As a family unit we still are solid, but we were a very strong chain and one of the links is broken.

182. I very rarely praise myself actually, but I think if it wasn't for the hard work that Matthew and I put in at the time we could have been looking at a very different situation with our eldest children. Matthew and I put our own grief aside.

183. After Sophia's death, I had [REDACTED] children at home who were absolutely devastated beyond belief, so much so that we needed external help. We weren't in a good place ourselves. I said at the time I didn't care what people say, my kids need grief counselling. [REDACTED].

184. We broke: souls broke, hearts broke. We had some very broken older siblings, because they were going down a path that was almost unrecoverable, and thankfully by the grace of god we managed to pull it back and they're all doing very well now academically, socially. They're doing okay. But there's always Sophia bubbling under the surface. Because we're that kind of family. If the dynamic with one is out, the rest suffer. We're just a very close knit family, and Sophia was already very accepted as one of us since I was pregnant. I'm very lucky that by the grace of god we managed to pull back what could have been a very disastrous situation on more fronts than losing Sophia.

Impact on the witness

185. In terms of me, I would say life falls into before I was broken and after I was broken. There's two parts there. I'm a totally different person now to the one I

was before. Quite honestly I don't think I've genuinely laughed in four years. People would say, "oh, you're so funny". Even to this day, people maybe even say that I'm quick to quip or make a joke. People talk about heart break but they don't talk about soul break. And people are very good at saying "oh, but look at [REDACTED] the other ones you've got". Like that makes a difference. My answer to that is, have you got one? Yeah. Have you got two? Yeah. Choose one that you can live without.

[REDACTED]
186. [REDACTED].

COMMUNICATION

187. Communication was okay. We would always have to ask. The nurses weren't too bad. The nurses would tell you the general chitchat stuff and they would try and be quite upbeat. They would say oh, she's been a pest today, when we all knew she couldn't be a pest because she was in a medical coma. But they'd say oh, she's been pest today and we couldn't get her cannula in, that sort of thing. But that's all just sort of geared to make you feel better, make you feel like the situation is almost normalised. In terms of from the consultants it's very, very poor. You need to chase them down, you need to hound them down, and when you do get their attention they let you know that they're the demigod and you're bothering them. The bugbear for me was that a particular doctor, his name was [REDACTED], nice enough guy, but he kept telling us oh, we don't know what's wrong with Sophia, but it doesn't matter because she's walking her way out of the woods anyway, and he just kept repeating that phrase, we don't really know what's wrong or what's caused the pulmonary hypertension, but she's walking her way out of the woods, and then that became she's walked her way out of the woods. That was pretty much all he ever said to us.

188. That later became their comments in the days to come. The staff told me that they were not entirely sure what was wrong with her but it didn't matter because she was getting better. I found mind blowing with the equipment that they had, the expertise that they had. If someone comes into my place of work and I don't know, I find out. I realise it's a different scenario but they were scanning every part of her. They kept telling us at that point that they knew from scans, brain scans, body scans, every kind of scan you can imagine, every kind of x-ray, that Sophia was "physically and structurally sound". This quote was oft repeated by the staff. There was a slight thickening of an artery around her heart, and they thought that that was making the PPHN worse. There was no atrioventricular septal defect (AVSD) hole or anything like that.

189. It was like they think that theirs is the only profession in the world where intelligence is required and therefore as mere mortals, us parents, we don't have the capacity to understand anything at their level, and I find that quite offensive. But again that was prevalent all the way through Sophia, and when I was there again with [REDACTED] it was the same situation. They haven't changed anything. We were so significantly uncomfortable that we requested that as soon as [REDACTED] was fit to travel that she was transferred to Paisley, and that's what happened.

190. I couldn't risk it on two counts. I couldn't risk that they'd kill another child of mine with their dirty infections. I had just had a ten week premature delivery of a baby. They put me in the room beside where my previous baby had died. They didn't give a shit that it was traumatising for us. We had to walk past that room five, six, seven, eight, nine times a day. We told them and they said, yeah, we know. We said we find it quite hard to walk past, and we were basically told that's your problem. One of the staff who I knew very well, she'd taken care of Sophia, I walked past the first time and said hello to her and she just glared at me. Second time I walked past I said hello, she looked me up and down and made it very clear that she knew exactly who I was. There was another member of staff who came up to us when we were sitting at the cot side and we were sitting there trying to be unnoticeable, trying to be almost

wallflower, and she said, “oh, it is you, isn’t it, last time I saw you was on the news.” That was a very pointed remark from someone that we thought was pretty decent until that point. There was just a lot of things like that. I mean, as I’m lying awake waiting to go out on a general anaesthetic I was terrified. I was terrified to be in that hospital to begin with.

191. I was in the QEUH for a lung scan that day and while I was there they thought I’d gone into labour. Despite my protestations to be sent back to Paisley they said no there’s a maternity unit here, we’re not sure we’ve got time for that, we’re going to go ahead here. I was devastated. I was frightened and devastated. What didn’t help was as I was lying in the operating theatre, I was crying and I was flat on my back and the guy who I took to be the consultant who was going to do the operation came in and he said, where did this patient come from? Then he said, never mind, I already know, she’s already suing us or something like that. Then I was put out on the general anaesthetic. I was absolutely terrified when I woke up. Is my baby alive, where is she? These people hate us, will they take care of us? Will they fulfil their duty of care to my child? And I’m sorry to say I didn’t have faith that they would.

192. We got a mixed bag of treatment upstairs from staff who obviously didn’t like what we’d had to say in the media about our previous experience there, and they let us know it. At the earliest opportunity I made sure I was discharged and I got [REDACTED] transferred to Paisley. For nine days we had to sit in the room beside the room that our daughter died in, and we had to pass that room a million times a day to go to the toilet, to get in and out of the building, everything. It was horrible, and it was the beginning of a breakdown for my husband. I was suitably ill at the time that I was in intensive care and much of the time I was asleep because I had sepsis. The operation had gone a bit wrong and they gave me sepsis. You couldn’t make it up, could you? One of the things they gave my daughter, they gave me. I had sepsis, so I was quite ill, but my husband obviously was well.

193. He wasn't allowed any support coming in and out of the unit because of COVID, which I understand. But he was up there by himself, constantly passing this room. You can see through the window, the bed or the cot that Sophia was in. ■■■ was born on ■■■. It is now 16 June and my husband has not been able to return to work. He's now been diagnosed with post-traumatic stress disorder from seeing and being outside that room again. He started to have nightmares where he's screaming out. He's on all kinds of medication. It was the last straw for him. I remember reading that losing a child in the way that we lost a child, that there is a scoring system whereby trauma is scored and it was akin to soldiers in World War II. That was the only thing that came close to it. Putting Matthew back in that position, back outside that room, back geographically where he was when we could have had her somewhere else put him back in that battlefield. That was coupled with his concern that ■■■ wasn't going to be treated well because of who we were and his mental health just suddenly went downhill.
194. ■■■ was born in ■■■ and I didn't see any change in attitude amongst the staff, whether that be nurses or doctors, in the three years since we'd been there previously. I didn't see any changes in the hygiene practices either.
195. Right across from ■■■ room in the NICU, we could look out of the door and right into the nursery room where we were taken after Sophia had died. It was pretty horrible to sit and look onto, that room as well holds some horrendous memories for us because that was the room we were taken to after she died and ■■■ asked us all the stuff about signing the death certificate. It was also the room that the following day when we came back to the hospital to hold the baby, just to hold her, we were taken into that room again. It's kind of weird.

OUTCOME

196. Matthew and I spoke to the police. The police did a series of interviews with us down at Osprey House in Inchinnan. We had asked for a fatal accident

inquiry. Out of the blue two detectives came to our front door during lockdown. They were two nice guys. They explained they wanted us to come in and give statements. They were very obliging.

197. I think Matthew's interview was over a period of a couple of weeks, but mine actually went on for six weeks: probably, because I can talk the hind legs off a donkey. Matthew's one of these people that just gets straight to each bullet point.

198. It was hard, and I must say we've been through a lot of hard things. In my mind I have a DVD that plays, and it just plays over and over and over again, and I had to vocalise that DVD over six weeks; and it is emotionally quite breaking. I did it because I thought I'm doing it for the greater good, because other people that we've mentioned in these statements, they will be spoken to, they'll be interviewed, and it might further our request for a fatal accident inquiry. But actually what happened was we gave our interviews, COVID was a thing, it got put on ice and it's never come off ice. It was an awful lot to put us through that trauma to not take it any further.

199. I was told eventually by the Procurator Fiscal after hounding them that it's on ice and is probably not going to come off ice for quite some time; that it will be seven to ten years before we find out if our request for fatal accident inquiry is actually going to happen. Bear in mind we've already waited four; which is a long time. But that's okay because I'm not going anywhere. I really think that's the game that everyone's playing here. If they put us through enough trauma, if they put us through enough harrowing hoops, we will end up mentally and emotionally broken and say we can't do this anymore. And we will walk away. I'll just keep on waiting, because I'm not going to go to my grave thinking I didn't do my best to get justice for Sophia. Ultimately Matthew and I, we're playing a lose, lose game, because we can't win. This is a David and Goliath battle, and David's not going to win, Goliath is. That's clear from the outset, with or without these assurances that the public inquiry will be neutral. But also because the prize we want is not one that we can have.

CONCLUDING REMARKS

200. The hospital is not fit for purpose. [REDACTED] even passing there, I look up and see that building and I just feel like I want to throw up. In my opinion, if I was the boss of the world, I'd put a bomb under it and bring the whole lot down and start again on another site.

201. [REDACTED].

202. I do have ongoing concerns about patient safety and care at that hospital. More importantly, I'm really concerned about [REDACTED]'s care. She still has appointments at the RHC in Glasgow. [REDACTED] was ten weeks early, and it's good paediatric practice that every three months they have appointments to check how they're getting on; weight, height. Because she was premature to that extent, they check everything extra: eyesight and hearing, problems with mobility, later to walk. Although [REDACTED]'s doing really well and I have no concerns about her; we've kind of been lucky. I say lucky in inverted commas, in that there was COVID and there was lockdown at her first appointment, so it was done remotely in our house, using a laptop screen. Paediatric care is centralised so I can't take [REDACTED] to Paisley Hospital, I have to go to the Royal Hospital for Children for her to have these check-ups, and she has one every 12 weeks. [REDACTED].

203. Also, let's be honest, nothing's changing up there; how many other families have suffered like mine? How many other families are going to suffer like mine? Here's an example, in 2015, that's two years before Sophia was admitted there, people were telling the hospital, their own employed people were telling them, according to Dispatches on TV, that there were problems in the hospital with infection and poor infection control. I watched that on television programme, and the hospital management were told that this was the case 2015. In 2017 they'd still done nothing about it, and as a result my

daughter is dead. To my knowledge they've still done nothing, and it's now 2021.

204. How many more families like mine have to suffer before they put their hands up and say dear god, we've made a huge mistake in the past, let's fix this? My fear is that they're going to come out with the let's fix this bit and then do a nice big whitewash and that's it: fixed. They will think that they have restored public confidence and everything's okay; but they're going to ignore what's gone before and not make that right. It is not just a case of "let's fix it". Give people like me the respect to admit what's happened. Don't then do the size of the scale of damage that you've caused to other families whilst just whitewashing and trying to say "oh, you know what, it's okay, we've got public confidence instilled again, everyone can vote SNP again". No. Fix the past. Fix the now, and then we all move on. But I don't think that's going to happen. With or without this public inquiry I don't think it's going to happen.

205. I'm proud to call Sophia my daughter. She was a tiny warrior. She battled hard against the breathing problems that had put her in that hospital. For someone so small, she was fierce. She had won her fight. We had won the fight. It was a short lived victory. The cesspit that is QEUH is solely responsible for my daughter's death. Sophia was polluted with an overwhelmingly lethal infection that literally ate her little body from the insides out. A disgusting waste of a beautiful life. Everything she was and everything she would have been. We had dubbed her 'Our warrior Princess' but that infection was just too big, too strong, too much. I think that QEUH and the Health Board should hang their heads in shame. They killed my daughter. They've lied. And they've tried every underhanded trick in the book to cover it up, to make us go away. I can't do that. I was Sophia's mother. I still am Sophia's mother. She will always be an intrinsic part of me and I will continue to fight for her justice. It's all I can do for her now. I will miss her every day of my life. There will always be a Sophia shaped hole in everything I do. I never knew that pain like this was humanly possible. They didn't just kill Sophia, they killed me too.

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