Scottish Hospitals Inquiry

Witness Statement of

Samantha Ferrier

WITNESS DETAILS

- 1. My name is Samantha Ferrier. I was born on **Example**. I am years old. I am a student psychiatric nurse.
- I am the mother of sectors. was born on sectors and she died on sectors, when she was less than 12 months old.
 I live with my partner, sector, and my other daughter, sector, in sector,

OVERVIEW

- 4. My daughter is **Matrix**. Was born with congenital abnormalities, mainly arthrogryposis, which is joint contractures, and respiratory complications from an undiagnosed genetic mutation. She was born in the Queen Elizabeth University Hospital ("QEUH") maternity unit and was then in the Royal Hospital for Children (RHC) being treated for all of her short life.
- 5. During our time at the QEUH and the RHC, there were a number of issues about the hospital that concerned us while we were there, and I can speak to my experience of these issues.

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FAMILY BACKGROUND

6. I live with my partner and my daughter in Glasgow. It is

years old and we really wanted to give her a wee sister.

- 7. was a very much wanted second child. We planned to have a second child for and would have loved to bring home. As a family we wanted her very, very much. And we loved her, regardless of her disabilities. She was a very curious little thing. She loved to listen to different noises and different sounds. She loved her music. And she knew that we were there because she would reach out and try and grab me with her tiny hand. So she was a thinking, feeling wee child.
- 8. Im had a wee sense of humour as well. She would bite on the catheter in her mouth and it was as if she was playing tug of war with the catheter. She knew that she was hanging on to it with her teeth. She would look at you as if to say, "And what are you going to do about it, mum?"

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

- 9. was born on **Example** in the hospital's maternity unit. It is a separate building and is connected to the main building through a tunnel.
- 10. had breathing problems, among her other medical challenges, which meant her staying in the maternity unit for several months. They tried all different types of procedures to help her breathe but it wasn't happening for

Therefore, the last resort was to give her a tracheostomy which happened around about three months of age.

- 11. The tracheostomy was carried out on the **Exercise**, in the maternity unit. After that, they were monitoring **Exercise** condition and doing all sorts of tests and things.
- 12. Inext surgery was a gastrostomy on . A gastrostomy is where the food gets put directly into the tummy via a tube. A gastrostomy is where they called it a floppy airway and she couldn't really swallow properly so you could never give her a bottle or anything. She also had a cataract removed at this time, to help her sight. Again, these were done in the maternity unit.
- 13. At some point when we were in the maternity unit, maybe around

when was about 4 months old, they told us that the genetic condition that had, although they didn't know what it was, could be terminal. It was Dr Heuchan, who I think was quite a high up neonatal consultant who told us this. There were no timescales mentioned and I guess she was just trying to prepare us for the worst. Dr Heuchan also mentioned a respite place called Robin House that she said could be available if we needed it in the future.

14. The main of the maternity unit until **Sector**, when she moved to ward 3A of the main hospital building. I think that this was just because she was getting a bit older and required a bit more stimulus, so it seemed to make sense to transfer her over to the children's ward over at the RHC. We didn't have any particular concerns about the maternity unit. Our concerns about the building began after we had moved to 3A.

Experience in ward 3A

15. The RHC corridors went round in a semi-circle. This meant that visual and auditory detection of patient buzzers was much more difficult. You couldn't see the end of the corridor and, to me, this presented as a problem because

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the nurses couldn't see what buzzer was flashing because the thing went round in a circular bend. was less than a year old and was placed in her own bedroom without 1:1 nursing observations. If in distress, was clearly too young to manually press her buzzer and she couldn't cry for help. She was essentially 'mute' due to the tracheostomy procedure.

- 16. If you had gone into Ward 3A through the main doors, was about 15 metres in, which might encompass passing about four or five rooms on the left hand side and then the nurses' station. Then she was a further four rooms after that on the left. Apart from the single rooms, the ward had only had one bed bay, which consisted of four patient beds, but was really only in there at the beginning, and then she was always put into one of the single rooms, especially once the infections began. So that meant that she was more or less alone. All of this made us anxious because we had concerns about was safety.
- 17. was in several different single rooms. They were all pretty much the same, so it's hard to remember the numbers, but I think she might have been in rooms 11 or 21 at some point. When she first showed signs of an infection, she went into the room that was opposite the one with a hepa filter in it. I believe that The hepa filter room was a specialised air conditioned/air purifying room.
- 18. We were never really told why was moving rooms. I assumed it was maybe to allow them to go in and do a deep clean. Rooms were cleaned daily, wiping of sinks and floors etc, however, some patients were sensitive to cleaning fluids and easily disrupted, so deep cleaning of rooms was a bit more awkward. A lot of patients had several pieces of medical equipment and these took up a lot of space. Deep cleaning would have only have been possible if this equipment was removed.

- 19. We did discuss these concerns but were told by the nurses that it was important for **to** be isolated because of infection control.
- 20. From when we arrived in ward 3A in **and a**, we were told not to use the taps, other than those in the ward kitchens. Each patient bedroom had a small sink that was next to the patient's bed and we were told not to drink from those at all. There was a main kitchen on the ward and we were told if we wanted a drink of water we were to go into the main kitchen to get it. I think the advice also applied to the four bed bay as well because there was a kind of communal sink and you were requested only to wash your hands at it. I don't recall being offered bottled water in 3A, though we did have this previously sometimes in the maternity unit.
- 21. We didn't really stay over in the hospital at that time because we needed to look after **because**.
- 22. Though the rooms had TVs in them, it was common knowledge that the TVs would never work. Some of the nurses would say that when the hospital first opened, the TVs worked for about six months and then they all stopped working. We never saw anyone trying to fix them during our time there.
- 23. Not having TVs that worked did have an impact on us because we had the toddler, **we**, at the time. So if the TVs had been working, it would have meant we could have probably put a wee cartoon or something on to entertain **while** we administered to **we**. There was nothing to keep her entertained.
- 24. There was nothing else apart from a little playroom that the ward had at the very end of the ward but it meant that one of us had to leave room to actually take down there. That meant that the attention that was having was halved and the parent that was left in room would have to administer all those medical cares themselves while the other parent took

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away down to the wee playroom. There were many things that needed to be done for , including changing her nappies, cleaning and bathing her, cleaning her tracheostomy and gastrostomy stomas and lots of other tasks that needed to be done on a constant basis. So it was difficult to keep both girls happy all the time and at the end of the day it meant less time that we were able to spend with .

- 25. The urn in the staff kitchen was out of order so that presented a problem because you had to then leave ward 3A to go away down another corridor to get a cup of tea to bring it back and then stand outside the door waiting for somebody to let you in the door. So it all compounded itself. If something was out of order, it just exacerbated the whole thing and made it more frustrating.
- 26. Ward 3A always seemed to have major works being carried out. Some patients' bedrooms were completely closed off for deep cleaning and maintenance works. In fairness to the contractors, they tried to keep the noise and mess to a minimum. There were about two bedrooms going on at the one time. Ward 3A always appeared to be in demand for bed spaces and these works would only have added to the pressure.
- 27. There were big orange, zipped plastic bags over the doors and I presume this was to stop any dust and noise from escaping into the main ward. You could see through the glass panel into these rooms and there were machines going on inside. I don't know what the machines did, they were some sort of generator and I can only presume that they were maybe decontaminating or something. Sometimes workmen weren't present at all inside the rooms but these machines would be on all the time as if they were doing something to the rooms in the background. So I'm not too sure what was going on inside those rooms. We never asked and we never got told what was going on.

28. On 21 September 2019 we managed get a bit of a break to the RobinHouse facility in Balloch. By this time, the hospital seemed to think that

condition was indeed terminal, though they still didn't put a timescale on it. We had been scheduled to go to Robin House maybe about a week to ten days before we actually went, but that's when **was** diagnosed as having the Rhinovirus and we didn't want to take an infected child out the hospital and take her to Robin House. So that was postponed.

- 29. We were told Robin House was fun for the family, with lots and lots of staff to care for which meant that we could, as a family, enjoy the garden and the wee play areas without having to worry too much about medical procedures. So it was kind of sold as a wee light-hearted, fun-filled family time together. It was also trying to give the parents a break. If staff there felt the parents were getting kind of exhausted, they were there to help.
- 30. Robin House was absolutely fantastic. The noticeable thing for me was I felt little knew that she was out the hospital and she was enjoying all this attention that she was getting. They were coming over with musical instruments and giving her art therapy. I could really see her happy for the very, very first time. She was coming out her shell.
- 31. It was kind of a Friday to Sunday thing because on the Monday, was then scheduled back at ward 3A to go through with her orthopaedic surgeries, so they wanted her back. So they cut her wee holiday short because of this big, major operation that was getting carried out on the Monday.
- 32. On **Mathematical**, **Mathematical** got her orthopaedic surgery on her knees and ankles. This was pre-planned and they were waiting until she was slightly older, which was around nine months, before they carried out this procedure. She had a wee leg that didn't bend and she had ankles that didn't move, so they

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thought for a better quality of life for her they would try and help give her a wee bend, bending her bones type thing.

33. Everything went to plan. had slight swelling afterwards but that was to be expected. So there was no major adverse complications or anything like that and the surgeon was over the moon. was a wee fighter.

Plans for discharge from QEUH

- 34. On **Matrix**, **Matrix** became eligible for the discharge home and phased discharge plans were drawn up. The doctor said that for her bone progress and development **Matrix** would be much better off in a home environment. They believed that they couldn't do any more medically to improve her situation; it was just a case of taking her home and us administering medical cares to her to give her some quality of life.
- 35. I have a copy of the discharge plan and can provide it if required. So it would be something like Monday put in her pram, take her outwith the hospital grounds for an hour and then bring her back. And then Tuesday would look like take her out for two hours and then bring her back. So when you got to the end of the week there was a gradual exposure to more and more responsibility for . There was no definite timeline. They said they would be guided by us and how well we could adhere to the phased discharge plans and how well we felt.
- 36. When they were talking about the discharge plans, it was relayed to us that we would have to just take home and everything would be ok. You would have to sleep beside her and if she choked you would automatically wake up. There was to be no medical machinery provided and we wouldn't get a bleeper or anything like that. Realising that a baby relies on somebody not risking going into a deep sleep, we started to voice our concerns with the staff. We felt we were being pushed out before we felt

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capable of looking after properly, with all her complications. We felt a strain in the relationship between us and the nursing staff from then and it kind of just went downhill after that.

- 37. The Ear, Nose and Throat (ENT) team and Dr Louisa Pollock, the Paediatric Consultant, would argue with us that as parents we would just wake up whenever we heard in distress, and I would explain that I was also on sleeping tablets, and I still am, therefore, there is a tendency to go into a deep sleep. Could they guarantee me actually waking up? So and I thought that bringing home would be more risky from her point of view because we felt that we didn't have that backing to be able to look after her and keep her safe. The medical staff would argue with us all the time and would say, "Och, it's nonsense, you're lacking in confidence – plenty other families have done it, why can't you do it?" They'd be really, really rude and putting us down like that and that was hurtful. We had a meeting with the social services and the woman was guite upbeat and optimistic about the amount of help that would be forthcoming. I don't know whether she was quite new in her post, but then one of the girls or nurses in the hospital said "You're not going to get half of what she's telling you, you'll be lucky if you get one night a week. The problem with that is they're relying on carers but if the carer doesn't turn up, you have a problem because it's your responsibility."
- 38. As it happened, was never able to leave the hospital. On we were there and the nurse told me that had been unwell for most of the day with vomiting and diarrhoea. The nurse mentioned tachycardia, which is rapid heartbeat. had presented most of the day with a rapid heartbeat, so her heartbeat had been accelerated by something that they weren't sure of. They suggested maybe teething. The nurse administered paracetamol and ibuprofen to relieve symptoms. and I said goodnight to man and left the hospital at 10:30 pm to go home.

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39. Around 12:30 am on **Exercise**, not long after we'd got home, we got a call from the hospital saying **Exercise** had a seizure type convulsion. She was sleeping so we saw no need to go back to the hospital at that time and they were monitoring her. Then at 3:30 am, there was a second call to say that

had a secondary seizure and a subsequent cardiac arrest due to high potassium levels and a body temperature of 44 degrees. We rushed straight to the hospital and were with **see** from around 4 am.

- 40. The Doctor, Alastair Turner, took us in to a side room and expressed that there was major concern that **was** deteriorating and not doing well. He said he couldn't quite explain the reasons why but he mentioned her kidneys.
- 41. All of a sudden, soon after we got there, monitor just went to dead. The doctor started administering CPR. It was stressful watching getting compressed but I appreciate he was doing his best. But eventually one of the nurses came and said, maybe it might be better not to see what was happening and to allow the staff to get on with their jobs. Then it was all hands on deck. I mean, there were lots of staff in the room at the time. There must have been about eight or ten people all around doing their different procedures. So we were then taken away to a side room.
- 42. We were then alerted that was vomiting as well. I think it was just all the stress as she'd been woken quickly and taken over to the hospital. So we were trying to cope with that too. However, they stabilised . But they then came and told us that they thought there was possible brain damage because of the seizures and that it would most probably be best to terminate her life support. So it was agreed with me that I would sit with her in a chair and hold her and they would then switch off the life support machine. And that's how passed away.

43. My daughter was also hospitalised in Ward 3A for a few days in

after being diagnosed with Respiratory Syncytial Virus (RSV).

Building issues in ward 3A

- 44. In addition to the water problems, on **Management**, the door entry system to ward 3A became out of order. Other than a few hiccups before then it had been fine but then they just didn't seem able to fix it. It remained broken until we no longer needed to go to the hospital after **Management** died in the
- 45. To gain access, a telephone number was provided, but, it usually rang out. I have provided a picture of the notice on the door to ring the number [Picture SF/01 at Appendix 1]. We could wait in excess 30 mins to gain entry to ward 3A, unless we were lucky enough that a member of staff was going in or out of the ward.
- 46. You could have made your presence an awful lot more vocal to gain access, but you're not wanting to be thought of as standing and banging on the door or kicking on the door or things like that. You did realise that if you called the phone number you could be taking a nurse away from maybe doing a medical procedure. If somebody was, say, maybe doing a medical procedure on you would have hated to think that they would have to stop doing that just to simply go and open a door, and you just felt that was impacting on the staff. The nurses were quite rushed off their feet as it was and you just felt you were imposing on their valuable time banging on the door. So you tried to ring the bell a few times but you would ring it and then wait for maybe, three or four minutes and you'd maybe ring it again, you know, three or four minutes later. Or you might land lucky and find somebody who had permission and a pass. By that time we knew most of the staff and a lot of the time they knew we were entitled to go in. On

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occasion, we did try phoning the number but it just rang out and rang out, and I can only presume that maybe the phone was left in the duty station and there were no nurses in there at the time. Or maybe a nurse had put it in her pocket but had put it on mute. We couldn't understand why there was no one there actually lifting and answering the telephone. I'd say that the average delay in getting into the ward was 10-15 minutes.

- 47. We spoke to the staff several times about this and they just kept saying there was nothing they could do, that there were complaints that had been put forward to the contractor and it was outwith their control type thing. They said they'd reported it. I think they must have been embarrassed at the amount of people that were complaining at the time, you know, standing outside. There were other parents waiting with you to try and get into the ward. We would all stand out there like a bunch of pigeons waiting to get in and we would all be saying how ridiculous this was that they had to put us through this type of thing.
- 48. There were always barriers up outside the hospital due to scaffolding above because of loose cladding in the main external structure. Some entrances were periodically blocked off which meant you had to take alternative corridors or routes to get to 3A.
- 49. The main adult hospital is connected to the children's hospital via link corridors; they've all got these link corridors, so there's all different entrances all around the actual site. So it means if one's blocked off that day with the men up the scaffolding and the cherry-pickers, whatever you want to call them, you would have to take a detour and go through a different entrance. You would then need to find the link corridor to take you down to the children's hospital and then find your way from there up.
- 50. We kind of accepted that with a building of that size you're always going to have constant maintenance and stuff but I'd have said this was maybe more

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than just maintenance, it was more like reconstruction. It was more timeconsuming, as I say, because you had to then reschedule your journey to go and find another entrance and then find the link corridor attached to that to take you to the children's hospital. You had to have a kind of mental map of all the different link corridors that took you to ward 3.

- 51. Sometimes a lot of the problems were compounded because of a lack of parking. Sometimes you could park fairly near to the children's hospital but other times you had to park away at the far end, which was quite a distance away. Then you would have to go in to maybe one of the side entrances to the main hospital and then you would work your way through to the right area, which wasn't always easy.
- 52. When was in Ward 3A in was in Ward 3A in some time as was, because she had an infection, my partner opened the blinds of the hepa-filter bedroom she was in. I think this room had a different air filtration system but I'm not sure. Through the window there is a ledge overlooking the children's atrium. This ledge was covered in grey clumps of tumbleweed, like balls of fluff you'd get if emptying a hoover, visible from the hepa-filter room. We didn't speak to the staff about this but it seemed that the nurse kept closing these blinds as if to conceal the dirt.
- 53. On a separate occasion after died, we had to go to A&E at the QEUH on difference of A&E when difference of the overhead bed bay area of A&E when grey fluff was blown out of the overhead ventilation and the aircon. It was like clumps of dust particles and more dust clumps were witnessed by another family there. This was similar to the kind of stuff that difference saw on the ledge outside the hepa-filter room in 3A.
- 54. I thought it was a feather at first when it came down and then said, no that's not a feather, that's a big clump of dust. It looked as if it landed on my shoulder but it was actually just caught in my peripheral vision. We were

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sitting waiting on the doctor and right up above the bed was a big vent in the ceiling. So with a clump coming down, it either landed on the bed or it landed on the floor, depending on how the wind was blowing. This was in the general receiving area where people are triaged; the waiting bays with curtains around them where you wait for the doctor to come and see you.

55. It did seem bad given all the publicity that's been going on about the building but we didn't raise it as we were too focused on getting treated. The other family in A&E did take a picture and I thought about it but didn't do so. There was a slight high wind that night but you still don't envisage dust to be getting into these bed bay areas where the vent was. I don't know whether it's an extractor or whether it blows clean air in.

INFECTIONS AFFECTING FAMILY IN RHC

- 56. On **I**, **I** first presented with Rhinovirus, which showed as flu-like symptoms. She had a runny nose and she was dribbling more from her mouth. Her oxygen would de-saturate quite often, therefore, the medical team knew that she was struggling with something, there was something underlying going on. I think they conducted blood tests at the time and I think it came back as Rhinovirus and we were told at that time that Rhinovirus was very common around the winter months and it was almost expected in a wee tracheostomy baby. So they kind of played it down, "Och, she'll get over it, she'll be fine, a couple of weeks and she'll be fine", that kind of thing.
- 57. It was the children's coordinator, Jacqueline Riley, who told us this. She would often come in and visit us a couple of times a week to let us know how was getting on and she would tell us a wee bit about the Rhinovirus and the background to it and that kind of thing. I'm not exactly

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sure what her role was but she was always in a nurse's uniform. She seemed to be involved in helping people to go home, given the pressure on beds. She certainly seemed to have very deep medical knowledge and it was Jackie who was saying it was quite common for kids who had tracheostomies to contract this particular virus. I recall her saying that they expect all these things in the ward the winter months, like vomiting bugs and things. I think that the maternity unit had also talked about the kind of winter bugs that could happen in hospitals.

- 58. I can't recall what treatment was given for this virus, or whether it involved any antibiotics being given.
- 59. Around contracted her second virus, this time the Enterovirus, in ward 3A. This wasn't long after the Rhinovirus; it was put to us that it was just a routine little virus that is normal and quite accepted for babies at this time of the year to contract it. I can't remember if they gave her any antibiotics at that time or whether it was just a case of keeping her comfortable, keeping her safe and letting her own body repair itself. But she did require a wee bit of oxygen support that was quite apparent, and it kind of coincided with this Enterovirus. But they could never wean her back off this oxygen; she kind of needed it and demanded it, so we got the impression that she never, ever regained her full strength from this Enterovirus, that kind of knocked her immune system a bit.
- 60. We weren't sure whether the Rhinovirus had cleared by this point or whether whether had two infections. There was very little discussed with us.
- 61. So was on oxygen support, yet they were still saying she remained eligible for discharge home. They were talking about releasing her home despite her having at least one, and possibly two viruses at this stage. We argued with them and we asked if the fact that was now on oxygen would make her more eligible for additional social support at home. The

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ideal situation for us was to have her home with us as a family but we needed that social care, that social support to sustain her 24 hour needs. But we were told by the Ear, Nose and Throat (ENT) team, that **w** having the oxygen didn't make her more of a privileged patient to try and get more support; it didn't change her patient status and make her more eligible for social support. They still wanted to send that child home with oxygen dependence and expected us as parents to administer her medical cares 24 hours a day.

62. From around **Constant off**, **Constant off** a wee cough. Then it wasn't long after that until

the . It was maybe staggered over days after that.

- 63. I went to my GP and was diagnosed with Haemophilus influenza. The GP couldn't say how I acquired that. However, I do remember having three courses of antibiotics, so it was quite resistant to treatment. It was quite bad whatever it was I had.
- 64. was actually diagnosed with respiratory syncytial virus, RSV. Because she was weaker, it had a far, far greater effect on her. In early **1**, she was actually hospitalised as a result of this as well and ended up in ward 3A for a few days herself. So you had both your girls in 3A at that point. They were in different rooms, both single rooms. Was nearer the entrance and was much further in, deeper down the corridor. Nurses said "It is strange to have two sisters in at the same time. We'll try and accommodate you as a family, so we'll try and make sure that **1** gets admitted to 3A to reduce the inconvenience to the family." That was good of them to do that, to put the two girls in the one ward. And it meant we could leave and one perhaps go and visit the other one, type thing. Was in there for five days before being released.

- 65. I can't recall **constant** room number but like the others, the TV didn't work. She made do with a tablet and we'd bought a DVD player and a CD player to keep her amused.
- 66. We weren't told a thing about the infections. We normally keep very well as a family. Both and I keep very well and so does . So it was very unusual at that precise time for all three of us to come down with something so debilitating.
- 67. Ironically, in her final pathology report, the pathologist mentioned that was more susceptible to these infections because of her long hospital stay. So we actually had it in writing by the pathologist that the reason picked up these infections was the fact that she was in hospital for such a long, long time. So there's a correlation there. There's a relationship there. I think that's partly why they seemed so keen to get doubted out of the hospital, even when we didn't feel able to take on her care.
- 68. Given that was hardly ever out of hospital, other than the few days in Robin House, it can only have been in hospital where she picked up these infections.

Overall views about the hospital building

- 69. I think patient safety should be the top priority. I believe that there were some things in the design of that building that maybe compromised patient safety, especially in our situation with a wee child that couldn't press buzzers or cry for help or move. Couldn't move properly like any other baby. So the overall design impeded her welfare and issues like the nurses not having direct line of sight to her when she couldn't cry for help made me worried and anxious about her safety.
- 70. The issue for me was the shape of the 3A corridors. It was all in crescent shapes, circular shapes. That didn't lend itself to good staff observations. I

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also believe that the single rooms were not suitable for a small child that was so incapacitated as **1**. However, I do appreciate that **1** presented with viruses and unwellness when she was there and that the only place to put her would be in isolation.

71. I think the location of the building possibly leaves a bit to be desired as well because it's right beside the water treatment plant. The smell of poop sometimes could knock you over. I know the air a lot of the time goes in to the air conditioning unit, but you just wonder if it's like putting dirty fuel in your vehicle. But also, we talk about passive smoking being bad for people but to me if you can smell poop, there has to be something in the air, whether it be an infection or whatever. So it might not affect you or me because our immune systems are better, but sometimes we would take

down to the wee swing park there. I think we were there twice and we would take her down just to have a wee walk around the hospital grounds and then back again. The smell was very apparent every day there. In fact, sometimes you could actually smell what was like raw sewage before you even got to the hospital.

OVERALL EMOTIONAL IMPACT ON FAMILY

- 72. As you can imagine, losing our daughter before her first birthday had a huge impact on me and on . We still don't know why she died or from what, despite there even being two post mortems.
- 73. On the morning died on died of the support of the support machine. I death to the demise was so rapid and sudden, even though it was that Doctor who advocated the termination of died life support machine. I understood that it was his duty was to report death to the Procurator Fiscal for investigation.

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Dr Dawn Penman, Paediatric Pathologist, on **Constant**. On **Constant**, a death certificate was issued saying "Sudden unexplained death (pending results of further investigations)". On **Constant**, we were issued an amended death certificate for **Constant** stating cause of death to be: 1a) Prolonged seizure and 1b) Bronchopneumonia and Norovirus infection in an infant with multiple complex congenital abnormalities.

- 74. We are wanting answers from the medical staff to try and explain their side of the story.
- 75. In terms of impact caused by issues of relevance to the Inquiry, some of the issues I have mentioned, such as broken TVs and door entry systems might seem minor, but on top of everything else we were dealing with, they just added to the stress of our experience with the hospital. We knew about the Milly Main situation and links to infections and water issues in the hospital and that just added to our worries. It was a really stressful situation, especially when the staff seemed unable to explain what the problems were.

COMMUNICATION: GENERAL

76. We had some concerns about communication relating to medical treatment. The issues around the hospital, although they were all, kind of, relatively minor in themselves, they were on top of all the other challenges that you were facing. You just didn't really get the time to get in to the communication on that. With the structure of the hospital, we knew that we couldn't do anything to change that because that was bricks and mortar. But it was easier for us to then try and change the way that they treated

and treated us.

77. We felt that the ENT team and Dr Pollock were pretty dictator-ish to us. They were quite rude to us at certain points as well where if we didn't do

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what they said, they made us feel as if we were the ones to blame, us as parents, because we couldn't take the home. And when we were trying to stand up for ourselves and say, we can't do this without any form of social support, it was very dismissed, very put down, as if irrelevant. It was always passed off that we lacked confidence. But we used to say that we do have the confidence, we just don't have the sustainability to look after 24 hours, seven days a week. As humans, we need a wee bit of a respite, a wee bit of a break. But they always dismissed that and made us feel guilty.

COMPLAINTS

78. We have raised a complaint with Lisa Ramsay in the hospital. I think she's the Liaison Officer for Acute Services and Bob Doris MSP gave us her details. That's around **form** care or lack of care and demise. And the mystery around that and how she suddenly died and no one knew what was happening to her. We're not getting the answers we need. We seem to be getting blank at every cut and turn. Which just makes more suspicious to be quite honest. Bob Doris has been quite good in getting us, kind of, highlighted if I can call that.

OVERSIGHT BOARD / CASE NOTE REVIEW / REPRESENTATIVE GROUPS

79. We had heard of the Oversight Board and the Case Note Review but we were not involved with either of them. We heard mixed stories about the parents' Facebook page but we haven't been involved with that either. We were told that there was a Tracheostomy Group on Facebook but the ENT at the hospital were loathed to promote it because they said it had a lot of fake stuff and lies.

CONCLUDING COMMENTS

STATEMENT OF SAMANTHA FERRIER

- 80. If anything comes out of this, I just want to be recognised as a wee baby that deserved the life that she didn't get. I can accept that she was born with a serious congenital condition that affected her chances of life. But her short life would have been easier for her and for us if we didn't have to contend with all the other stuff, like the infections picked up in the hospital, the worries over the water and the wasted time caused by broken access door systems and the like. We just hope the Inquiry helps stop these things happening in the future.
- 81. 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.

STATEMENT OF SAMANTHA FERRIER

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