

## Scottish Hospitals Inquiry

Witness Statement of

**Annemarie Kirkpatrick**

### WITNESS DETAILS

1. My names is Annemarie Kirkpatrick. My date of birth is [REDACTED]. I am [REDACTED] years old. [REDACTED].
2. I am the mother of Stevie-Jo Kirkpatrick. Stevie-Jo's date of birth is [REDACTED]. She has just turned 17 years old.
3. I live with my husband, Steven, and our daughter, Stevie-Jo, in [REDACTED].

### OVERVIEW

4. My daughter is Stevie-Jo Kirkpatrick. Stevie-Jo was diagnosed with Acute Lymphoblastic Leukaemia ("ALL") for the first time on 28 February 2014 when she was 9 years old. She received treatment in Yorkhill Children's Hospital in 2014 and 2015. When Yorkhill closed and the services were transferred to the Royal Hospital for Children ("RHC") in Glasgow, she received outpatient treatment there for a few months before being discharged on 1 July 2016.
5. She relapsed on 3 July 2017 when she was 13 years old. Stevie-Jo was treated in the Royal Hospital for Children ("RHC") and Queen Elizabeth University Hospital ("QEUH") between July 2017 and May 2019 but her treatment had to finish 6 months early due to an infection. She attended both hospitals as an in-patient and an out-patient for almost two years. In the main, her care has now transferred back to Dumfries hospital and she has regular check-ups there but she continues to have some contact with the doctors at the QEUH in relation to an infection that she caught at the hospital.

WITNESS STATEMENT OF ANNEMARIE KIRKPATRICK

A34035285

6. Stevie-Jo spent time in wards 2A and 2B in the RHC. This is the Schiehallion unit and it treats children with cancer. When ward 2A was closed, she spent time in Ward 6A in the QEUH. She also spent time in a number of other wards throughout the hospital, namely 1C in the RHC and also 3C which is the cardiac ward in the RHC. She was admitted to other wards if there was no bed for her in the Schiehallion unit. She also received surgery in the theatres in the RHC and she was admitted to the Paediatric Intensive Care Unit ("PICU") in the RHC.
  
7. I was with Stevie-Jo when she attended the hospital. I stayed with her most of the time as Steven was working back in [REDACTED]. We also had access to and used the facilities at CLIC Sargent house. I can speak to the experience that Stevie-Jo and I had in the hospital.
  
8. There are some specific details that I would like to mention. Stevie-Jo contracted listeria meningitis in 2018 when in ward 2A and 6A. She contracted a line infection in February 2019, not long after being discharged as an in-patient from ward 6A. She contracted a mycobacterium chelonae infection in March 2019 after surgery to remove her line in February 2019, at the QEUH. She was prescribed anti-fungal preventative medication which I believe was connected to issues with the hospital environment. There were all sorts of issues with the hospital throughout our time there which, in my view, impacted on Stevie-Jo's treatment and on our family's experience. I will talk about these in more detail.

### **FAMILY BACKGROUND**

9. I live with my husband, Steven, and our daughter, Stevie-Jo, in [REDACTED]. We have lived here for eleven years, prior to that we lived in Australia where we stayed for two years before relocating to [REDACTED].
  
10. Stevie-Jo is at high school, [REDACTED]. She is going in to S5. She has just passed all of her Nat 5 exams, she achieved As and Bs. Due to her treatment

she had not been in school for a number of years and taking that into account, she did really well. Stevie-Jo wants to be a children's nurse and she wants to work with children with cancer; she is really focussed on that.

11. Stevie-Jo is a bubbly individual. She's just full of fun and carry on all the time. She's got a good group of friends, there are five of them and they're really close. Her favourite pastime is football. She is a Celtic supporter. She plays too and has started getting back to training for [REDACTED] girls football team. She plays centre left or striker. She has started her driving lessons and she got a car for her birthday.

12. She also plays the bass guitar. She goes to her room to play but she's not allowed to do it on amp in the house.

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

#### **Transfer from Yorkhill to the RHC: March 2015 to July 2016**

13. Stevie-Jo was diagnosed with ALL for the first time on 28 February 2014. She received treatment in Yorkhill Children's Hospital in 2014 and 2015. Some of the services were transferred to the RHC in around March or April 2015. At that point she received outpatient treatment at the RHC before being discharged on 1 July 2016. During that period she had some in-patient admissions if she had a temperature spike, for example.

14. After that she began maintenance treatment and she attended clinic monthly. She was about to switch to three monthly appointments when she relapsed in July 2017.

15. Maintenance treatment is where all of the chemotherapy is complete and at that point the cancer is away. The kids start taking a daily tablet at home, and it's to keep the cancer at bay. Because cancer is acute it can come back really quickly. Maintenance gave her a period off the intense chemotherapy

but kept her treatment at a level to reduce the chances of the cancer coming back quickly.

16. Clinic is in ward 1A in the RHC, it is to the right when you are in the atrium, so it's before you get to any of the wards. Clinics were all on the bottom floor and there were many different clinics. There was loads of chairs up the centre of the waiting area, everyone waited outside on the chairs and then the doctors would come and shout each of the children one by one. The doctors have separate rooms, just like in a doctor surgery. The kids get checked over and then they would sit back outside on the chairs and wait for their prescription to be provided to them.

17. Stevie-Jo saw Professor Gibson at clinic. She is a haematology consultant. She'd also see Anna-Marie Ewins who was the bone marrow transplant specialist, she was next in line from Professor Gibson. If neither of them were available she saw Doctor Story the registrar, or Doctor Heney, who was the oncology teenage consultant, but that was only really early on.

18. There was a bit of concern from parents that the kids were all sitting with just the general public. Those who are going through cancer treatment tend to have low immune systems. At clinic in the RHC before any of the kids have seen the doctors they were all mixing in together in the waiting area, which is quite a concern as the kids were there for lots of different types of clinic. The general public were able to just walk past the waiting, coughing and maybe with bugs.

19. At that point when Stevie-Jo was going up to clinic at the RHC, two days later we'd be in Dumfries Hospital with a temperature. We didn't really think much of it at the time. We just thought it's because she was coming to the end of her treatment. But every month that we were up there, two days later she'd be admitted to Dumfries and Galloway Royal Infirmary for about a week on antibiotics. She was always fighting temperatures.

20. Her liver was damaged too, so she always had jaundice, and her bilirubin was always really high. All her liver functions were always off. She went yellow in colour it had gone yellow including in her eyes, she used to say she was like a Minion. Nobody could ever fathom it out, because at that point Stevie-Jo wasn't actually getting intense chemotherapy. That treatment had stopped and she was just on her maintenance of check-ups at that point. No one could ever understand. The doctors did quite a lot of tests to see if her liver was actually failing or if there was anything wrong, but it always repaired within a couple of days, maybe about a week after being in Dumfries and Galloway Royal Infirmary (" DGRI") on antibiotics and she began to recover.

21. The clinicians didn't know why this happened during that time. They just kept putting it down to the amount of treatment that she had had over the two and a half years, they thought that maybe it was having an effect on her liver. They weren't sure.

22. Doctor McKnight was the consultant in the DGRI and she did remark that it was really strange that every time Stevie-Jo was up in the RHC within two days she was admitted with a temperature and her liver to the DGRI. Doctor McKnight was in contact with Professor Gibson a lot regarding Stevie-Jo's health and all of her treatment. At one point they weren't sure if she was going to need a liver transplant: her liver levels were already really high and she was on antibiotics frequently which they considered posed an additional risk. The doctors were always trying to balance things up.

23. Professor Gibson said that it could have been scarring from all of the chemo that Stevie-Jo had over time, but none of them were really sure what had happened.

**Relapse: July 2017 - admission to the Schiehallion Unit, Ward 2A of the RHC**

24. Stevie-Jo finished her treatment in 2016. Stevie-Jo's blood levels usually increased after chemotherapy, the blood levels would return back to normal.

At this time Stevie-Jo's never went back to normal. Her platelets and her white blood cells always stayed really low. We had check-ups at DGRI monthly for Stevie-Jo where she saw Doctor McKnight who checked her bloods. She started getting tonsillitis again and that was one of her symptoms when she was first diagnosed in 2014; it was how it began in the first place. She also had a high temperature. At that point nothing was showing up in Stevie-Jo's bloods that were concerning, but Doctor McKnight wasn't very happy with the way she was presenting. She got the labs to dig deeper into the blood samples. She asked them to look at it underneath the microscope to see if there was any abnormal cells. When those results came back it confirmed that there were abnormal cells in the blood.

25. On the 3 July 2017 we got the results and Stevie-Jo was immediately transferred by ambulance from the DGRI to the RHC in Glasgow to begin treatment. She was okay but she was a bit scared and unsure how things were going to go. At this point her colour was really good. She didn't actually look like she did previously when she had the leukaemia. This time she appeared to be absolutely fine and apart from the tonsillitis and a high temperature; you would never have thought she was ill.
26. Doctor McKnight told us that there were abnormalities in the blood and she suspected that it was a relapse. This was confirmed by Professor Gibson up in Glasgow who carried out a lumbar puncture and blood tests to confirm that it was leukaemia. A few hours after performing the tests it was confirmed.
27. Stevie-Jo was admitted to ward 2A in the RHC. Professor Gibson was her consultant. She was not given a treatment plan at that point due to the liver problems and infections that Stevie-Jo had been acquiring throughout maintenance treatment, so it was a bit of a concern. She started a course of intense chemotherapy for four weeks in the hope that she would go into remission. If she didn't go into remission then the proposal was that she would need a stem cell transplant.

28. Luckily Stevie-Jo went into remission in the first four weeks following intense chemotherapy. At that point, the treatment plan was to just carry on with chemotherapy and go through the chemotherapy stage by stage. The doctors monitored Stevie-Jo's liver and modified the treatment to accommodate Stevie-Jo's body. Professor Gibson juggled things about and played it by ear pretty much month to month. Normally, when a child is diagnosed with ALL they are given a treatment plan which sets out the protocols and treatments that will be followed. Girls are on the treatment plan for two and a half years and boys are on the treatment plan for three years.
29. From the 3 July 2017, Stevie- Jo was admitted as an in-patient and she stayed in ward 2A in the RHC for about 8 months. She had a line fitted straight away on the 4 July. It was a surgical procedure under a general anaesthetic. It took place in the theatre in the RHC which is 1B.
30. Stevie-Jo's line went in through a vein in her neck and sat on her chest. It was on the right side of her chest, and it was attached on to the skin. It had two tubes that hang out of it with clips on it, one for blood and one for treatment. The clips on the tubes are to stop the blood coming out or anything going in. The medical staff have to open the clips when they're taking blood or putting anything in. There was one tube going into her neck, and then it had a little box like a little square clip, and then it had two tubes coming out of that: a red one and a white one. The red one was for taking blood, and the white one was to administer treatment. The separate tubes were so they didn't contaminate the blood or the treatment lines. The clips were actually in the middle of actual tubes like little pegs, they gripped the tube to stop anything coming out for the blood line and sealed it off. When medical staff were taking blood or putting anything in they had to open that first then connect to the tube onto the line. On the end of both the tubes there was a connector which the blood bottles could be connected to.
31. It was maybe a few months following Stevie-Jo's relapse, at some point in 2017, the hospital introduced a little green cap for the end of the lines. I can't

be certain of the date. The caps had little disinfectant cloths inside them, which then screwed on to the end of the line and it was to keep it clean. Every time the line was used a new cap was placed on the end of the line.

32. It was one of the nurses who first fitted the caps onto Stevie-Jo's line. All of a sudden she came in Stevie-Jo's room with them. We asked what they were as we'd never seen them before and they were not used in Yorkhill. She explained that it was a new thing that was being introduced because a lot of the kids were getting line infections and infection control thought that the nurses weren't cleaning the ends of the lines properly.

33. The nurse said that a lot of the kids' lines had been getting infected, but they didn't know if it was because the lines were lying open. Infection control had thought that the kids were getting dirt or dust into the lines. One of the other nurses told us that infection control were blaming them saying they weren't cleaning them properly when they were using them. The cap was supposed to take away the risk of infection because the suggestion from infection control was that the nurses hadn't cleaned them properly with the disinfectant wipes. But the nurses were cleaning the ends of the lines and this would have kept the ends clean.

34. The nurse also said that the nursing staff didn't understand what they were supposed to do, because they were cleaning them. Unless the clip was open nothing would be able to get up the line because of the clamp, and the nurses always flushed the line with saline before they put anything in or took anything out of it. They didn't really understand what the purpose of the caps was; but they were told to use them. Everyone was just really confused about the caps and no one understood why all of a sudden these were introduced.

35. When Stevie-Jo was discharged from the RHC, she went for check-ups and monitoring at the DGRI. The staff in the DGRI had never seen the green caps before either. They didn't have a clue what these caps were. We ended up



having to get some from Glasgow to keep at Dumfries so that they had some for when we were running out at Dumfries. They were kept in a drawer in the DGRI and we collected them from the RHC whenever we were up at the hospital in Glasgow.

### **Description of Ward 2A in the RCH: the Schiehallion Ward**

36. Ward 2A is part of the Schiehallion Unit. It is the in-patient ward and it treats kids with cancers, bone marrow problems, tumours or haemophilia or other conditions where the blood doesn't clot. The name "the Schiehallion ward" was what it was called in the old Yorkhill, so it carried over.
37. Professor Gibson was Stevie-Jo's main consultant. Shazia Chaudhury was one of the other consultants and was coming in to take over from Professor Gibson because she's near retiring age. It was pretty much at the end of Stevie-Jo's treatment that we saw Shazia, and it wasn't very often. She saw Dr Heney and Jacob quite a lot, he was a trainee doctor. Jacob liked football and I think he liked to come and talk to use when the football was on. I do not know his surname.
38. When you go into the ward you go through a set of double doors. The ward is in a big, massive curve and the corridor goes round. The patient rooms are all single rooms. The ward itself is quite dull, a dark purple on the walls. Not like old Yorkhill where they had loads of kids' drawings and things on the walls. There are no windows looking out to the outside. Everything was inside and internal to the building. In total, I think there were about 32 patient rooms in the ward. They went down both sides of the ward.
39. Walking down the corridor into the ward, there is the parents room with a kitchen at the beginning of the ward. Half way down the corridor is the nurses' station which is in the middle of the ward. As you go further into the ward you come to the Teenage Cancer Trust ("TCT") unit which was a long corridor off the ward. The TCT unit had a room for the teenagers, it is chill area. The room

has a jukebox, a pool table, Sky, comfy chairs and a kitchen. Only the teenage patients can use that room, and their families could use it too but only if there weren't too many teenagers using the room; it is a facility for the teenagers. Off of that as you come out the TCT common room through a side door the unit has five TCT patient bedrooms. The TCT unit had another glass interior wall, so it separated it off the main ward, and it was its own little unit. It had the specialised TCT nurses in there.

40. The parents room in the main part of 2A had a kitchen with a microwave, coffee facilities, fridges and a freezer. It was a place where parents could store some food. There was a nice big table and couches, it was a place where parents could sit and just have five minutes. It was a comfortable and relaxing area. There was a little Costa coffee machine. I think there was a small TV in that room as well. There was a nice big window so you could just look out onto the parking area but it was still nice just to look out, you could see everyone coming in and out of the hospital.
41. The nurses station in ward 2A was half way down the corridor and it was a big half circle desk. All the children's monitors were there and that meant that the nurses could visualise them when they were at the desk. There were two patient bedrooms right behind the nurses' desk. We were unfortunate enough to stay in there before Stevie-Jo relapsed on two occasions during 2016. At night you can hear all the monitors going off; you can hear the nurses talking. You can hear all the private conversations about other patients as well, to be honest. That's obviously no fault of the nurses but due to the layout of the ward, they had their station and there were two rooms right behind it.
42. In July 2017 Stevie-Jo was admitted to a room the TCT unit, it was either room three or four. She stayed in that room for most of that admission. The room was awful. It looked out into the atrium of the main hospital building; it had no daylight whatsoever. It had some plugs, but nowhere near enough plugs for the kids considering the amount that they need in order to power all the medical equipment that they use. For example, various drips and

monitoring equipment. The blinds were inside the window, inside the glass. There was a knob on the outside of the glass but when that knob breaks you couldn't close or open the blind. The lights stay on in the atrium constantly, the room was lit up all the time. The room also had what looks like a wardrobe but it's actually a pull out bed for parents and carers; it is a single bed and a mattress. Then there is the patient's bed. There was a TV above it but the TV never worked. None of the TVs worked in any of the children's rooms. All rooms had an en-suite bathroom as well. There was also a separate sink in the bedroom next to the patient's bed.

43. The TCT unit was really good and organised a number of activities for the teenage patients on the ward. Ronan was the TCT coordinator, he always had a lot of people in the unit to lead on activities and he was in the unit Monday to Thursday. For example, he had people in doing pyjama making. That is also how Stevie-Jo got into the guitar. He always tried to have things throughout the day. He sat and played games with the kids or pool; anything to keep them entertained. We were quite lucky that we had TCT in that sense.

44. As regards her school education, there was absolutely nothing for Stevie-Jo. During her first treatment in the old Yorkhill, they had a primary teacher who come along every now and again. It wasn't daily and they didn't really push them at that age; they were only in primary school and they could catch up. Stevie-Jo used to always kid on that she was sleeping when she came in to see her in Yorkhill.

45. In the new hospital, during the whole time we were there we did not see a teacher until the day that we were getting home. The other kids on the wards had teachers coming in quite often and they were doing the work with them. We weren't sure if this was because of the different local authority areas, and that [REDACTED] local authority hadn't been in touch with the hospital. I don't know what happened. On the last day when Stevie-Jo was discharged the teacher came round to the room and said he was here to see Stevie-Jo. I told him that we were actually going home today. He said that as Stevie-Jo

had been in hospital for longer than seven days, it was against the law for her not to have education. I said that we've been here for eight months, and I asked who I should contact because we had not seen anyone. We didn't see him again after that.

46. Stevie-Jo had a close relationship with many of the staff, in particular a number of the nurses. She has pretty much grown up with the nurses that treated her, so she's got a very close relationship with them. When the services transferred from Yorkhill to the RHC, a lot of the nurse moved into different departments but they still worked in between Schiehallion and the new departments, so a lot of the nurses were still working in the ward.
47. The heating in the bedrooms was not great. Sometimes it would be absolutely roasting in the room and you were far too hot, especially on a hot day. At night the temperature would really drop and it was pretty much freezing cold. You couldn't regulate it. There were thermometers inside each of the rooms but they never worked; it was like one of the central heating controls that you get in a house. You should have been able to move it up and down to regulate the temperature but they didn't work. The staff couldn't regulate the heat either. The nurses came in and tried to help, they also got maintenance staff up a few times to see if they could fix it but they couldn't fix it. I don't think the thermometers in the room were connected properly.
48. One of the things that we noticed straight away when we got there was that infection control staff were constantly on the ward. There wasn't a day went past when infection control wasn't on the ward. The infection prevention team wear burgundy uniforms, it is different from the Schiehallion staff so they were easy to spot. I didn't really speak with them. In the old Yorkhill the kids were allowed to draw pictures and put them up in their rooms. We weren't allowed to do that in the RHC. The kids were allowed to put posters up to make it more homely and bring in their duvet covers at Yorkhill.

**March 2018: Day pass to CLIC Sargent House**

49. Following six to eight months as an in-patient, Stevie-Jo was given a day pass from ward 2A around the start of 2018. That meant that whilst she was able to leave the ward, we were not able to go home. She started a treatment plan of 3 days inpatient chemotherapy treatment at the hospital and then would go over to CLIC in between times. Even though she was at CLIC she was still in 2A officially and had to stay very near to the hospital.

50. We moved into CLIC Sargent house which is just off the hospital grounds. It is a house with separate rooms for families and patients, and it has a shared kitchen and sitting area. It is only for use by patients and families of the Schiehallion ward. Professor Gibson wasn't very keen on sending Stevie-Jo home to [REDACTED]. She was concerned because she had relapsed and it's not very often that the kids go through two lots of chemotherapy. When she was first diagnosed she had two and a half years of chemo, and then following relapse she was going through another two and a half years of treatment again. It's quite a lot on her immune system over a five year period. Professor Gibson was concerned about her immune system so we stayed there for a bit before we were able to go back home to [REDACTED].

51. A day pass meant that Stevie-Jo still kept her bedroom in the hospital. We could leave her belongings there and her room was always there for her. We would get to go over to CLIC Sargent throughout the day, and the odd time they would let her stay over there at night just to try and get to sleep. She couldn't sleep on the ward due to the light from the atrium and the noise.

52. CLIC Sargent House can accommodate up to six families at a time. It is a massive house with an upstairs and a downstairs villa. It has two big kitchen areas, one downstairs and one upstairs. In the kitchens there are two cookers, two fridge freezers, so as much as it was shared there was still plenty for everyone to use. In each area, there were two sitting rooms. There was a laundry area to wash and dry clothes and that was a god send. CLIC

Sargent house is about a three to five minute walk once out of the hospital grounds. It is literally just across the road.

53. At that time, Stevie-Jo was getting chemotherapy at night through her drip and her central line. She was also getting eye drops every hour and the eye drops were given for about a month. I think that she had finished the high intense dose of chemo and we were moving onto the consolidation phase. Her treatment was reducing down and was not quite as high intensity.

54. We stayed at CLIC Sargent until around May 2018. When the treatment finished she was discharged from ward 2A and we were able to go home to [REDACTED]. After that we attended clinic in ward 1C of the RHC for check-ups.

#### **Maintenance Treatment: June 2018**

55. In June 2018, Stevie-Jo moved onto maintenance treatment. This was administered as an out-patient at clinic in ward 1C. Her bloods were checked weekly and she got her prescription of oral maintenance chemotherapy. She took the oral chemo tablets daily. Once a month she was given Vincristine which is chemotherapy that goes through a cannula and not a central line, it's more intense rather than just a tablet that they take daily.

56. Stevie-Jo began to get headaches in June 2018 and they carried on for months. Between June 2018 and November 2018 Stevie-Jo was up and down to the hospital with temperature spikes. She was admitted as an in-patient on a few occasions.

57. There was one occasion in August or September 2018 when Stevie-Jo had been up at clinic. We came home and she wasn't feeling very well. So I phoned Glasgow and was told to bring her back up to the hospital. All of a sudden her breathing was really bad. She was given oxygen as her oxygen levels had dropped significantly. She was wheezing, she had a high temperature and was not feeling very well. She was admitted to ward 2A

RHC. The hospital worked through the procedure when the kids present with a high temperature. They took the usual blood tests and started her on IV antibiotics.

58. When she was lying down she couldn't breathe properly, but when she was standing up she wasn't too bad. Over time she began to get better but she still needed oxygen; this went on for a couple of weeks. The hospital carried out a lot of scans. They could see clouding in Stevie-Jo's lung, but they couldn't fathom what it was. Nothing was coming up on the tests or the swabs that they'd taken.

59. Stevie-Jo went to surgery in 1C of the RHC and the surgeons suctioned out some of the cloudiness in her lungs. They tested that but nothing ever came back to confirm what it was. From that point and throughout the whole of Stevie-Jo's treatment, up until a couple of months ago her oxygen levels always sat really low. They were just on borderline. If she got an infection she needed to go onto oxygen, prior to that this had never been the case.

60. Around about that time the five kids that were in TCT unit were really not well. Two ended up in PICU and another two of the patients had been preparing to go home when all of a sudden they had line infections. This all happened in that three week period when Stevie-Jo was admitted. All these kids had to get their central lines taken out at this point. That is when the infection prevention control team had visited the ward and they had turned off the water. We couldn't use the TCT kitchen, the water was off and we weren't allowed to use the dishwasher.

61. At first, staff said that the dishwasher wasn't working, but we asked why we were not allowed to use water from the taps either. We couldn't wash our dishes in the sink either. It pointed to an issue with the water. Staff told us that they were investigating the drains. Someone else said that the water needed cleaning agents put through it. They said because the kids were getting the line infections, they thought that there was something in the water.

62. After that the maintenance staff began putting cleaning agents through all the taps and all the sinks in the bedrooms as well. They poured a liquid down the drains, it was like a bleach. After they did that we weren't allowed to use the sinks for about three hours. They did try and do it at night. We couldn't use any of the sinks once they'd poured it down, or flush a toilet. The nurses gave us that information. The nurses told us that they were cleaning out the drains and they'd had quite a lot of issues with the water on the ward. The nurses were quite open, to be honest. I think because we'd known quite a lot of them for a lot of years they were quite good in just giving us information. The nursing staff told us that that the water's not right. They said that a lot of the kids had been getting really ill from the water and the hospital was trying to figure out what it is. We weren't allowed to wash in the showers at that point.

63. Infection control were in ward 2A a lot during that time. It was around this period that the Dyson fans were removed. The Dyson fans were removed because of the dust in the ward. Staff said that there was too much dust floating about. I pointed out that we used old fans at the old Yorkhill and it was never an issue, the old fans had the blades. I would have thought they would pose more of a concern than the Dyson ones which did not have any blades. Staff said it was too much of a risk and by removing the fans from ward 2A they were trying to eliminate that risk.

64. I noticed that every time the nurses came into the room they wanted to clean the kids' lines. Up on the area where the line enters the body, there is a dressing over that. Stevie-Jo didn't clean hers. Every day staff wanted to clean it. During her first set of treatments in 2014/2015 in the old Yorkhill, she had the central line in for the two and a half years and we had never once heard of a child who contracted a line infection at the old Yorkhill. This was all new to us.



65. During that admission we were able to go to on a day pass to CLIC Sargent throughout the day as long as Stevie-Jo's oxygen levels were at safe levels. Staff checked her before we left and if they were okay then she could go for an hour, but she'd have to come back just to check her levels again to make sure that she was safe enough.

66. During that admission she was still having headaches and she began to say that her eyes were flickering. Stevie-Jo was discharged after about three weeks as an in-patient. We went back to weekly check-ups as an outpatient.

### **November 2018: PICU and Ward 3A RHC**

67. In November 2018, Stevie-Jo's headaches grew more intense. One particular evening around about the 19 November 2018 we were at home and Stevie-Jo was complaining of really bad headaches, she couldn't look into light. I gave her some paracetamol and I phoned DGRI for advice. They told me to give her some paracetamol and see if it settled. She took paracetamol, during the night she woke up and came through to see me. She said her head was absolutely thumping and she felt sick. She'd been sick. When I looked at her face looked like she'd had a stroke. One side of her face was all level, the other was drooped and she couldn't see properly out of her eyes. We phoned DGRI and took her up.

68. She stayed in there overnight, but she started deteriorating. She really wasn't well at all, and the nurses were really concerned about her. The doctor was convinced she had an ulcer and I don't know why. An ENT saw her and said it was a mouth ulcer. She was sent for a scan. I thought it would be an MRI or a CT scan, but they sent her for an ultrasound on her mouth thinking that she had this ulcer. I tried to explain with Stevie-Jo's treatment that in the past she had her whole mouth covered in ulcers but never had these symptoms.

69. Throughout the night the nurses suggested we ask for a second opinion because she wasn't right. We thought she maybe had a blood clot or something. You could tell it was something in her brain. In the morning her own consultant, Doctor McKnight, sent her straight down for an MRI scan. It confirmed that there was a mass on the back of her brain. She did say it wasn't cancerous. She didn't think it was cancer; she thought that it looked more like an infection. Doctor McKnight called Professor Gibson and they decided between them to send her straight back up to Glasgow.
70. Stevie-Jo was taken by ambulance straight back up to the QEUH. That night she ended up in PICU, because the part of the brain that had the infection controlled her swallow and the movement in her face. That's why the muscles were so relaxed on one side of her face.
71. She was in PICU for two or three days. The problem was that because she hadn't been so well they begin the sepsis protocol of giving them lots of antibiotics. She went for a lumbar puncture to determine what the infection was, but the antibiotics masked the infection at that time.
72. No one was sure what it was at all. They thought it was maybe an auto immune thing. She was given really high doses of steroids which seemed to improve her.
73. After a few days she was moved up to 3A, which is the neuro ward in the children's hospital. We stayed in there for three weeks. She did improve but I could still see in her face that there was something not 100 per cent right. She was a lot better than what she was.
74. The layout of ward 3A was similar to 2A. All the wards are pretty much the same with patient rooms going down both sides of the corridor and the nurses' station in the middle. I can't remember what room she was in or what the room was like. it's just a bit of a blur given everything that was going on at the time, She was in for about three weeks.

75. There wasn't a kitchen and things like there was in 2A. It wasn't equipped for the long term patients, and the Schiehallion was. The nurses could make you a cup of tea or coffee but you still had to go down to Marks and Spencer or something to get food. It didn't have the facilities that had been available in ward 2A. There was no parent's lounge. They had a play room, for the younger kids but Stevie-Jo was too old for that.

76. Stevie- Jo was pretty ill during that admission and she didn't use any of the facilities. There was nothing for parents. If I wanted some time to myself, I had to walk down to the atrium and maybe to the front door. Stevie-Jo was so ill I rarely left the room, apart from going for food and even then it was straight back up to the room. I stayed with Stevie-Jo the entire time. Steven came up to stay two nights through the week and also at the weekend. We were not able to use CLIC Sargent at all at that point as technically we weren't Schiehallion patients.

#### **December 2018: PICU RHC and ward 6A QEUH**

77. Stevie-Jo was discharged about two weeks before Christmas, around the middle of December 2018. She began to get really bad headaches again as doctors had begun to reduce her steroids. It happened a day or so after she was discharged from the RHC.

78. I took her to the DGRI who sent us straight up to ward 6A in the QEUH. Upon arrival the neurosurgeon examined Stevie-Jo, but he wasn't concerned; he thought it was just the effect of the steroids reducing. She was examined by a consultant from neuro and another from the PICU. They had a look at her eyes and checked her with the light and reactions. The neuro consultant said that really severe headaches was a common side effect from reducing down

steroids, and he believed that this was the cause. He wasn't concerned. They sent us back home that day.

79. Over the next few days, she still had really bad headaches and she was taking a lot of pain relief. We tried to manage her pain with co-codamol, morphine and paracetamol.
80. On early morning Christmas Eve 2018, Stevie-Jo was really not well again, she had bad headaches and was being sick. She had a bit of a temperature and she was screaming in pain. Steven and I took her back up to DGRI. The doctor who we saw there originally in the November, was just going to send her for an eye test. However one of the other consultants who'd seen Stevie-Jo before said that she had to go for an MRI straight away. She was seen by Doctor Ecclestone. Luckily she went for the MRI. The scan showed that the mass on the back of her brain had got bigger.
81. On Christmas Eve Stevie-Jo was transferred up to daycare on ward 6A in the QEUH where more tests were performed. Then throughout the night into Christmas morning she deteriorated again. Her breathing was reduced and she could not eat. On Christmas Day Professor Gibson asked for the PICU team to come up and have a look at Stevie-Jo. By this point Stevie-Jo's swallow was gone, so the theory was if her swallow was gone her airways would collapse as well. They phoned for the rest of the PICU team to come up to transport Stevie-Jo from the adults hospital to the children's hospital. It was a mission in such a rush.
82. The PICU team arrived in ward 6A. They had to make a plan of how they were going to get her from the adult hospital to the children's hospital. They had to make up plans for what would happen if Stevie-Jo crashed; they had to work out how and where they might be able to resuscitate her. I speak about this event later on.

83. As soon as Stevie-Jo got on to PICU another lumbar puncture was preformed, this time before she had any antibiotics. It was too much of a risk to put her under anaesthetic with her airways closing and her swallow gone. PICU staff told us that they weren't sure if they would have to put her on life support during the procedure, they were not sure what was going to happen because they weren't sure how quickly she was deteriorating. Professor Gibson actually took the lumbar puncture and took it to the labs herself and tested it.
84. After they performed the lumbar puncture they started Stevie-Jo on a lot of antibiotics just to try and fight whatever it was. From Christmas Day to the 27 December we didn't know what it was. No one did. None of the results were coming back with anything that they thought it was.
85. On the 27 December 2018 it was confirmed that Stevie-Jo had contracted listeria meningitis. She was put on IV antibiotics for 4 weeks. The antibiotics that she had been given up to that point were not the ones that fight the meningitis. So they stopped all the other antibiotics and put her on the one that actually fights the listeria. The nurse in PICU actually told us first then Professor Gibson came in and officially told us. She said that it's something that's ingested. We went over if she had been near anything, went through all her food; but she hadn't really eaten anything that might be a risk. We didn't really know where it had come from.
86. Once she was taking the proper antibiotics she started improving within about 48 hours. She was in PICU until New Year's Eve. On the 1 January 2019, Stevie-Jo was moved to ward 6A. She was there for approximately 4 weeks in room 5.
87. In January 2019 Stevie-Jo had a new central line fitted so that she could receive her IV antibiotics. It was a replacement, because her line had actually split so they had to take that one out and put a new one in. This was in surgery in the RHC. When she got out of theatre, she really wasn't well. She needed oxygen, which had never happened before when she had surgery. After surgery she

kept coughing up massive blood clots. We were quite concerned about it. The nurse looking after her said she'd never seen that from someone getting a line in before. Each day the doctors checked her over and she seemed fine.

88. Stevie-Jo's cancer treatment was stopped completely all the way through this period, from November 2018 right through till New Year's Eve. In January 2019 when she came out of PICU, Professor Gibson decided to give her weekly Vincristine just to try and hold the leukaemia until she could sort out a new treatment plan.

### **Description of Ward 6A QEUH**

89. Ward 6A in the QEUH is a big straight ward. The nurses' station was a bit better, because it wasn't in front of any patients rooms; it was on the corner. You walk straight down a massive corridor and the ward has rooms on either side. There is a big room at the bottom of that corridor and that was day care, which was formerly ward 2B in the RHC. To get to day care people walk right through the entire in-patient ward. There was a wall in the middle of the ward, it was in a horseshoe shape, and there were rooms round the other end and up the side of the ward.
90. There were about 40 odd rooms on the ward. Stevie-Jo was in room 5. It was very basic. It was worse than ward 2A in the RHC. It is an adults hospital; it's not equipped for parents staying. The hospital had to bring in fold out beds for the parents rather than having the beds that pull out from the wardrobe. There were no TVs. There was an en-suite with a toilet and shower, and a sink next to the kid's bed.
91. There was no kitchen facility. I couldn't even make a cup of tea. For tea, coffee and food I had to use the canteen or Marks and Spencer.
92. There was nothing for the kids. There wasn't even a play room for the small kids. They just had a tiny little table sitting in the corridor with some colouring

sheets on it. It was right outside Stevie-Jo's room, at the entrance to the ward. The table was so small that it could only accommodate one small child at a time, one 2-4 year old. There were no play leaders or educational specialists. There was a play specialist, but she was never on the ward.

93. The temperature in the rooms was just as bad as in ward 2. It was really hot through the day and cold at night. I couldn't control the temperature, there were thermostats but they were not working.
94. Overall, the layout of the rooms in ward 6A was probably a lot better than in 2A, because you could see round the corners. The nurses weren't having to be really cautious with trolleys, they didn't have to worry about kids who were playing and running into them. The ward is brighter and some of the rooms actually look outside. Day care has a nice big, bright window so you could actually get some daylight in that ward.
95. Before entering ward 6A there is a room off it. It is a massive room and it had a nice big table. I asked Emma, the ward sister if parents could have that as a parents' room or a play room for the kids. Emma asked management but she was told "no" and that it was not possible because some of the bosses use it for meetings.
96. The hospital food is bad and the kids wouldn't eat the food. It was really hard without a kitchen, we didn't have a microwave or a fridge. I didn't really have anything hot to eat when we were staying there.

#### **January 2019: Events on Ward 6A QEUH**

97. Once Stevie-Jo was moved back to Ward 6A, I noticed that there were air filter machines in the corridors. I asked the staff on the ward what the filters were for. They told me that they were HEPA filters for the air. I was told that the hospital tested the air quite often and they just wanted to fit these in to purify the air. At first I thought that was fine.

98. Gradually each day the staff started turning up the filters; up and up and up. They were really noisy so you could tell when they'd been turned up. The kids were really dry from it in their noses and their throats. Everyone was getting a really sore throat. The nurses were the same, they were not feeling very good around the air filters either.
99. Then they moved the HEPA filters into the bedrooms. This was around the end of January 2019. One was moved into Stevie-Jo's room. I asked staff why the HEPA filters was being moved into her room. I asked if there something wrong with the air in her room? They said, "no, no, we're just putting them in some of the rooms". Later on that day, around nine o'clock at night Professor Gibson and the microbiologist came round the patient bedrooms and they were looking in the showers. I thought it was very strange and so I asked if I could have a meeting with them both to find out what was going on. At this point Stevie-Jo was really vulnerable and was recovering from the meningitis.
100. The next day Steven and I had a meeting with Professor Gibson and the microbiologist. I cannot remember the name of the microbiologist, but she's had quite a lot to do with the investigations of what happened. She has actually left the hospital and she spoke out publicly about all the issues in the hospital.
101. During the meeting I asked them both "what is going on in the ward?". I pointed out that I noticed that HEPA filters had been brought into the ward, and that I saw them both looking at the showers in the bedrooms at 9 o'clock at night. Things weren't right. They told me that mould had been found in the wet rooms as the flooring had come away the water was getting down the back of it, sitting in it and was causing the mould. They said they were a bit concerned about that having an effect on the transplant patients. They told me that they were going to move some of the transplant patients from ward 6A down to ward 4 in the adult hospital, just until they got the mould sorted. I then asked "is Stevie-Jo safe in this hospital?". She was recovering from meningitis and



the last thing we wanted was for her to end up back in PICU. The microbiologist replied by saying, "well she's as safe in here as she is outside". I responded by saying that we're not in the middle of a war, she's not being treated in a desert; rather we're in a hospital, it should be clinical. I was quite angry about that. They reassured me that she was safe enough, that there were no issues and that Stevie-Jo's was not at risk. They said that the HEPA filters were there because of the mould, to disperse the spores coming from the mould to reduce any contamination.

102. The next morning, Professor Gibson came to speak to us in Stevie-Jo's room. She told us that she was driving home last night and that she had been thinking about the best way to keep Stevie-Jo safe. She told us that she I could send Stevie-Jo back down to the DGRI in Dumfries, as long as Doctor McKnight in Dumfries was happy. She trusted Doctor McKnight with Stevie-Jo's care. She said she could send us back to Dumfries, and then that would mean that Stevie-Jo is out the hospital and she would be safe down there and she could finish her course of antibiotics there. We were happy with that; we'd prefer to be closer to home anyway.
103. The next day Stevie-Jo was transferred to DGRI and we were glad about it. Even with the transfer, there was no communication between Glasgow and Dumfries hospitals. We just drove down to Dumfries, Stevie-Jo was well enough for me to take her in the car. We arrived at the DGRI, and no one knew that we were coming. They didn't have a bed for us, they didn't have any notes. The staff were angry. Communication between the hospitals was bad anyway, but that was quite a bad example.
104. Stevie-Jo remained in DGRI until she was discharged at some point between the 12- 16 February 2019. She noticed that the area around her central line was going red, it had begun to get red before she was transferred back to the DGRI from the QEUH.

105. Shortly after that Stevie-Jo was re-admitted to the RHC to get her central line taken out, and the area around the line was still red. The line had been fitted so that she could receive the IV antibiotics for meningitis. After her line was removed the area of her skin where she had her line started going really puffy. Around about the 27 February 2019, we went back up to the RHC and Stevie-Jo went back into surgery and they cleared out the area. The surgeons had to cut into the area and it was filled with green pus. They cleaned it out and packed it. Samples were taken and tested but nothing came back at this time. Stevie-Jo was discharged.
106. I asked to speak to the sister of the ward, Emma. It was obvious that there was an infection in her line. She had not long had that line put in, and it seemed that it had come from surgery. She only agreed to speak to me because I wanted to put in a formal complaint. She had agreed it definitely looked like it had come from surgery, but asked that I wait until we get the results and then put in the complaint, but that just never actually happened and as there was so much going on with Stevie-Jo; I found myself caught up with that.
107. Around about that time Stevie-Jo started getting sores on her arm. It came up in a big lump on her arm. We just thought it was a big bite on her arm. Stevie-Jo was in the DGRI to have blood taken and we asked the doctor to have a look. They gave her some medication in case a bite had become infected. She had this lump for about two or three weeks, and then it had started to burst open, it was bleeding and really sore. Around about this time we were in the QEUH for a check-up with Professor Gibson. She said that it was really not right and had phoned the dermatologist, Doctor Beattie.
108. Stevie-Jo was sent for a biopsy that day. We went to the old Yorkhill as that's where dermatology is based. The biopsy was taken and the doctor who took it looked really intrigued by it. She had an assistant with her and she was saying "look!", and she was pulling out all this orange stringy stuff from it. It was weird.

**March 2019: Healthcare Associated Infection: Mycobacterium Chelonae**

109. It took ages for the biopsy results to come back. First of all we were told that Stevie-Jo had tuberculosis. That was what they thought had come back on the test results. Professor Gibson had phoned us one Saturday morning, this was about three weeks after Stevie-Jo first originally got the biopsy taken from her arms. We knew that the biopsy results would take a bit of time to come back. Professor Gibson phoned the house to say that the results had come back and that Stevie-Jo had tuberculosis. She wanted us to go back up to Glasgow because we had to re-look at a plan for Stevie-Jo. We went back up to Glasgow and Stevie-Jo was admitted to the neuro ward which I think it Ward 3C. We stayed there for about a week because Professor Gibson was off and we had to wait for her to come back.
110. From our perspective, that was really stressful. We didn't know if Stevie-Jo would be going back on chemotherapy. We didn't know what the other options were. We didn't know what was going to happen. We stayed up in Glasgow for a week, not knowing. None of the doctors would speak to us because they were waiting for Professor Gibson to come back. They couldn't authorise anything without her. Stevie-Jo did not continue on with her chemotherapy treatment.
111. When Professor Gibson returned to the ward the following week, she came to speak to us with Conor Doherty. Conor is the infectious disease doctor. They had literally just got the test results back which confirmed that Stevie-Jo actually had mycobacterium chelonae. They told us that the infection was very rare. As it was so rare they had to send the biopsy to a specialised lab up in Dundee or Aberdeen, I can't remember where. By this point Stevie-Jo had lesions and scars all over her body.
112. At that point, we still didn't know what the plan was for Stevie-Jo. All we knew was that there was only one antibiotic which could fight the infection. The side effects were really severe, and given the cancer treatment that Stevie-Jo had

already undergone Conor was reluctant to give her that antibiotic. Instead the doctors hoped that they could bring Stevie-Jo off her chemotherapy completely. This would allow her immune system to kick back in, and the hope was that would start fighting the mycobacterium chelonae infection itself.

113. Conor was very open with us. He said that it can take up to three years before we even start seeing any improvement. This was due to the nature of the infection; it's so slow-growing, that it can take a while to show as clear. It is now two and a half years since that infection was confirmed and Stevie-Jo's still got the infection in her body. She still has big marks from the lesions on her body: she will be scarred for life.

114. Professor Gibson held a multidisciplinary meeting with other clinicians to discuss Stevie-Jo's case. This is when there's a complex case; all the professionals attend and discuss the best course of action. During that meeting they decided that that because the infections that Stevie Jo was contracting were becoming more rare, the concern was that they wouldn't have an antibiotic that would fight the infection. If Stevie-Jo relapsed she still had treatment options available. She still had a stem cell transplant, and CAR-T therapy, which could be used. The concern was that if she developed another infection there wouldn't be an antibiotic to treat it, but there were still options for her cancer treatment if she relapsed.

115. A few days later, Professor Gibson then called us back to Glasgow as a family. She wanted to discuss the infection with us. On the 29 March 2019 we met with Professor Gibson and the microbiologist. They had confirmed that the infection that Stevie-Jo had come from the operating theatres in the RHC. Microbiology had traced it back to the time when Stevie-Jo wasn't really out the hospital. They knew that it had come from the hospital.

116. Mycobacterium chelonae has a long incubation period. Once the infection was confirmed, the microbiologist knew how long the incubation period was. She was able to trace that back to when Stevie-Jo had her line removed in surgery.

They had found the infection it in the water, in surgery in the RHC. They had tested the water.

117. Stevie-Jo did receive antibiotics to begin with. Originally, when they thought it was tuberculosis she was given some IV antibiotics for about a week. I wasn't sure if she had anything else. When the people who did the Case Notes Review looked back she had antibiotics right at the beginning, before they knew what the infection was. It was confirmed, and these antibiotics just continued on after that.

118. I was really angry when the infection was confirmed and when I was told that it had come from the water in surgery in the hospital. Like a lot of the parents, I'd had concerns for quite a long time. Everyone knew that there was something not right with the water. I remember being in the old Yorkhill when the new hospital was being built, and at that time a lot of parents were really anxious about it being next to the sewerage works. We couldn't actually believe that a hospital that was treating kids with cancer, could actually have issues with the water, and that this was actually making the kids more sick than they were already. Your kid is going through cancer treatment, your biggest worry should be the cancer, not what infection the hospital is going to give your child. For a lot of the families, I think the infections from the hospital were worse than the cancer, especially for us. We knew that if Stevie-Jo relapsed, that there's treatment available to fight the cancer. But when you're told that they might not have medication to keep fighting the infections that are coming from a hospital, it is a bad situation. The hospital should be keeping her safe. It was and continues to be really stressful for me, and for us as a family. The risks of her relapsing are still there. She gets regular blood tests.

119. Stevie-Jo saw the doctors in Glasgow: dermatology; the skin nurses; and Professor Gibson, just in the hope that the lesions would start improving. It took a long time and although it has improved now it's still there.

120. Once we found out that Stevie-Jo had the mycobacterium chelonae infection on her skin, communication from the hospital staff was okay. The breakdown in communication from our perspective, was before that when no one knew what it was that was making Stevie-Jo unwell. When the clinical staff were trying to work out what was wrong with her, we had quite a lot of back and forth from [REDACTED] to Glasgow. She underwent a lot of tests.
121. The pros and cons were weighed, along with the risks for Stevie-Jo. On the 12 May 2019 the decision was taken to completely stop her chemotherapy. It was concerning. Stevie-Jo had already relapsed. At this point she had already missed six months of maintenance chemotherapy due to the meningitis and being ill with this infection, and she was going to miss the final six months of chemotherapy. When she relapsed, instead of two and a half years' treatment she had about a year's treatment of chemotherapy.

### **OBSERVATIONS ABOUT THE HOSPITAL BUILDING**

122. On one occasion there was water in the atrium, I think it was sewage. There's a linking corridor between the atrium, heading through to the adults' hospital, which takes you to the food court. There's an x-ray room on that corridor as well. I was down in the atrium and the link corridor had been closed off. There were little barricades around it and the sewage was coming up through the floor tiles. The tiles had burst, and all the sewage was oozing up through the tiles. It was disgusting, the smell was awful. This was in the November or December of 2018 when Stevie-Jo was in PICU.
123. There was an occasion when part of the roof blew off in the adult's hospital. I think this happened around October and December in 2018. We were down in the food court, and we heard a big almighty crash. On the way back to ward 6A we looked up, there was a corner at the left-hand corner of the food court where part of the roof had actually blown off. I had tried to take a photograph

of it, but a security guard approached me and he was shouting at me to stop. I didn't actually get a photograph of it. I was a bit too scared to try.

124. There was an issue with the windows. The whole front of the adults' hospital, and the children's hospital is coloured glass windows. At least twice the windows have fallen out, near the front entrance. Now there is scaffolding with netting round it, so if any windows fall it protects the public underneath.

125. In the children's hospital there was the issue with the cladding. I understand that I had to be removed and changed due to the issues highlighted by the fire at Grenfell.

126. The front door into the main entrance of the adults' hospital is glass. The door goes round and round, it revolves. The door shattered because the wind blew it in. I think this happened because of the shape of the hospital; the wind just seems to catch in that shape and the whole door shattered. The hospital has put up a false wall up behind the moving door, just to protect it from the wind and to save it coming in. The ladies who were sitting at the reception area, always had big massive blow-heaters on just to keep warm.

127. There were not enough plugs in the bedrooms for the kids' equipment. This was a really a big issue, especially through the night, when I had to get up every half hour and change the plugs round to power the equipment. The batteries in the equipment didn't hold a charge either. Stevie-Jo was often on morphine or ketamine, and her chemotherapy. During the night if she needed the toilet I had to unplug all her medication and drips from above her bed, carry her to the toilet, with her drips and monitors on wheels. In the bathroom there was nowhere to plug in equipment, which is not great when your child is receiving medication. You couldn't just unplug it from the bedroom and plug it into the bathroom, like I could at Yorkhill. The cables didn't stretch enough into the bathroom. When she was on fluids and she needed to pee, this could happen a lot during the night.

128. As regards the design of the rooms, the rooms on the external part of the corridor had a view outside. The rooms on the internal part of the corridor, looked inside to the atrium. The atrium lights are on all the time, so the bedrooms never get dark. It's like trying to sleep through the daylight but all the time. Within the atrium is where they had the adults' NHS out of hours, service is located, so at nights it was really noisy, people who were drunk were coming through the children's hospital, shouting, screaming. On a Friday and Saturday night, it was worse. It was really awful.
129. The ventilation in Schiehallion ward 2A was different from that in the old Yorkhill. It was one of the things that we noticed as soon as we went into the children's ward. In the old Yorkhill, you entered the ward through a set of doors and then those doors would close, then you would go through another set of doors and into the ward. This was for the ventilation and to keep the air clean. They didn't have this in the new hospital, in either the kids or the adults hospital. I have already mentioned the heating in the bedrooms and that the temperature regulator didn't work. I'm not sure if that was connected in any way to the ventilation system. I think it was Ronan, who's the TCT Coordinator, who told me that when they had carried out tests on the ventilation in ward 2A before they actually moved the kids into the hospital, that for a normal person it was sitting at 50 per cent lower than what it should operate at, and for a cancer patient with a low immune system it was sitting at 70 per cent lower than the average of what it should operate.
130. In both wards 2A and 6A the rooms were hot. We used to have old fashioned fans in the old Yorkhill. In the new hospital, a charity had actually donated loads of the big Dyson fans and these were in the patient rooms which was lovely. Once the infections all started, hospital staff took the fans away. When the kids have a high temperature, the fans could be placed around about them to help them cool down; but that stopped. If the kids had a temperature, and the room was boiling, sometimes we questioned if they did actually spike a temperature, or if it was the heat in the room that was causing it. It was awful.



131. The design of the building meant that dust gathered all throughout the building. It was a big issue. The design of the building is that there are lot of different layers and ledges, but you can't actually get into the layers to clean them. I could see piles of dust sitting on all around the building, on different parts. There were little gardens on the roof of the buildings, but no one could get to them so the grass was overgrown and there were weeds were everywhere.

### **CLEANLINESS**

132. The cleanliness of the hospital was not great. The cleaners would use the same bucket of water for every room. When we were in the old Yorkhill the rooms were cleaned three/four times a day. It was only ever in once in the new hospital and it was just a quick mop round the floors, and a quick wipe down. Whereas in Yorkhill they would have the beds off and have the mattresses scrubbed down; the whole room would get a deep-clean. Provided the kids were ok, we had to leave the rooms whenever it was cleaned.

133. I don't think they have enough cleaning staff in the RHC and QEUH. In Schiehallion ward 2A and ward 6A, there were two cleaners and quite often only one cleaner at a time who was doing all the rooms. Whereas in Yorkhill they had four or five cleaners.

### **IMPACT OF THE MOVE FROM WARD 2A RHC TO WARD 6A QEUH**

#### **Distance from other services in the RCH**

134. One of the biggest concerns that we had when the children moved to ward 6A was when Stevie-Jo needed to be admitted to the PICU. On Christmas Day in 2018, Stevie-Jo had to go to PICU which is in the children's hospital. Ward 6A is six floors up in a different part of the building in the QEUH which is the adults hospital.

135. The staff wanted to take her in the patient lifts as it is a bit more private but their keys wouldn't work for the lifts. They then tried to use to the cleaner's lift, but there were other people coming up and down in beds in there. We ended up having to go all the way around the hospital. We had to come through where the public were, using the public areas to try and get Stevie-Jo from the adults' hospital to the children's PICU. It must've taken a good 10/15 minutes to get from the adults' hospital to the children's. In that time there was a lot of concern from the staff about Stevie-Jo's airways closing or her crashing. The team had to make a lot of plans for this journey, and they had to change their plans really quickly when we had to change route.

136. If she crashed, they didn't want to be attempting to resuscitate a child in the middle of an atrium with members of the public present; but there wasn't really anywhere else that they could go to make that journey. If she did crash the plan was to run to a room, any room, which most likely wouldn't be equipped, or to an office just for a bit of privacy if anything went wrong. Thankfully, it didn't. On the way down we were discussing this with the medical team. They had a lot of concerns about a child crashing up in ward 6A, it was their view that there was no way that the PICU team could run from the children's hospital to the adult's hospital, up six flights of stairs carrying the crash equipment, and then be able to resuscitate a child when they got to ward 6A. They thought that it wouldn't be possible; they'd be absolutely exhausted, and they wouldn't have the energy to be able to resuscitate a child once they got to the ward.

137. The teams need to carry a lot of crash equipment. They've got massive bags which contain oxygen bottles; a defibrillator; adrenaline shock plates; a heart rate monitor; a blood pressure monitor. It is big kit bag that staff carry on their backs, and they run with it to get to wherever is needed. In the adults hospital the lifts don't work, but even when they are working, the lifts are at the back of the hospital and are quite far away from ward 6A. Even if all the lifts were working the staff had to run from PICU in the children's hospital to the adults hospital in the QEUH; wait for and then get the lift up six floors; then run from

the back of the hospital to ward 6A. Either way, it wasn't going to work with the distance and the lifts. Staff were really worried about that.

138. There tended to be six to eight staff members in a crash team. It was a big team comprising the ICU doctors; cardiology depending on the issue; and an anaesthetist. They had to try and fit six to eight staff, the kit, parents and the patient plus their bed into the lifts. Lifts that were often full and sometimes not working.
139. That experience and having these conversations with the doctors was terrifying. In that situation your quite heightened anyway, as your child needs intensive care. But then the added stress of not knowing how they're actually getting your child from the ward to ICU; it was terrifying.
140. PICU is on floor one in the RHC. Schiehallion in on floor two in the RHC. It is literally down the lift and you're there in PICU. When the kids were in ward 2A, the doctors, the crash team, everybody could run up a flight of stairs to the ward.
141. When the kids were moved to ward 6A, they were not situated near any of the services and departments in the children's hospital. These are services that need to be accessed very frequently. For example, the pain nurses were still over in the children's hospital. If the kids are really unwell and they need to go on morphine, or ketamine, a specialised nurse attends and prescribes that medication. They set the kids up with the machines and the medication. When we moved to 6A there was always quite a bit of wait for that nursing care, particularly when you add in that they had to travel across from the children's hospital.
142. The kids needed to go for regular surgeries for bone marrow and lumbar punctures, and that was all situated in the children's hospital. The porters had to come over from the children's hospital, try find a lift that was working, collect the kids from the adults hospital and get them back to the RHC. A lot of the

time the porters would just actually walk them back via a link round the back of the hospital. There was a corridor that you could go through. It was a very long way round; it is about a 15/20 minute walk.

### **Lack of amenity**

143. When the kids were in the children's ward the young kids had a playroom, and the teenagers had the TCT unit. When the kids moved to the adult's hospital, they had nothing. Especially the little ones, they had a tiny little round table with two little plastic chairs, the proper kiddie ones. This was set up in the hallway in the corridor; they didn't have any playroom at all.

144. The lack of a TCT room had a huge impact on Stevie-Jo. The TCT common room is a place for the teenagers; it's away from all the little kids. It's a chill out room and they can come out their bedroom and they can talk to each other. When kids are going through treatment, it's okay for them talking to their parents, but you don't understand what they're going through. Really, they need other teenagers who are going through the same thing, because they have an understanding. The common room gets them out their bedroom as well.

145. We found that Stevie-Jo was fine going through her treatment in ward 2A; her and a couple of teenagers were always in the common room within the TCT. In the adult's ward they were never out their bedrooms. A lot of them started getting really bad depression, and I would say that was probably when Stevie-Jo had to start going to see a psychologist. The kids are sitting in their room thinking about everything; all day, every day. Whereas, at least with the TCT room, they're out with other teenagers. They've got their juke-box, they've got their pool table, and they've got their Sky, Xboxes. Whereas in ward 6A they had nothing; they were just in their room. I know a lot of the kids ended up on anxiety medication because of that.

146. In terms of the impact on me and Steven, we don't stay in Glasgow so we don't have family local who could bring us food. The lack of a parents kitchen or TCT common room meant that when we were in ward 6A we had to go to Marks and Spencer's to buy food daily, because we couldn't even keep anything in a fridge. It is not as if we could nip into Asda and get a couple of bits, and keep it in the fridge. There was no fridge.
147. There was no microwave on the ward either. If we wanted anything hot, we had go to Marks and Spencer's and buy microwave meals then wait until after 3pm which was when we were allowed to use the staff microwaves. The staff microwaves are in the atrium. Stevie-Jo was the same because she wouldn't eat the food in there, so we'd have to heat her food up in the microwave that was down in the area for the staff. There were three microwaves there, but they were never cleaned. The staff would just run in, put their food in, and go away. For Stevie-Jo, that was quite a big risk, with her immune system.
148. If Steven was in [REDACTED] and I was up in Glasgow myself, I couldn't just nip out if Stevie-Jo wasn't well. That would mean going all the way down to the canteen, or to Marks and Spencer's in the atrium to get food. The lack of facilities meant that I couldn't just nip into the kitchen and just grab something from the fridge. Instead I had to wait until she was either sleeping, or feeling a bit better so I could leave the ward and actually get some food. Even to get a cup of coffee, I had to go all the way down to the canteen and leave the ward.
149. It wasn't too bad on the days that Steven was up, but he was at home working quite a lot of the time. Through the week, I was there on my own.

### **PHYSICAL IMPACTS**

150. There have been physical impacts on Stevie-Jo. She is self-conscious about the scars on her body from the mycobacterium chelonae. A prime example is that the other day it was 24 degrees, and Stevie-Jo was out with jeans, a tee-shirt, and a jacket on; she won't wear anything that shows any of the scars

whatsoever. She won't go swimming, which she used to love. She doesn't want to go abroad on holidays, because she won't wear shorts or tee-shirts due to the scars on her arms.

151. She hardly takes part in PE now, because she doesn't like getting changed in front of people. She had loads of steroids because of the infections, so she put on six stone because of that. That has had a big impact on her self-image, and she's really struggling to get the weight off because of it being steroid weight. She's got issues with her knees related to the steroids and as well. Stevie-Jo has a lot to deal with.

## **EMOTIONAL IMPACT**

### **On witness**

152. The experience at the hospital has definitely had a big impact on our lives. I suffer from really bad anxiety and panic attacks, now. I have been seeing a psychologist. My triggers for my panics were on the motorway. Every time I got on the motorway driving to Glasgow, I'd have to stop about four or five times with panic attacks. My psychologist has said that's related to the trauma of what's happened at the hospital, and the thought of going back there.

153. Luckily, I've not been back for two years, so that's not an issue now. But at the time, when we were going up for clinics, Steven would have to take the day off work just to come up with us because I couldn't drive up the motorway. That wasn't very good.

154. As a family, when Stevie-Jo had her first diagnosis and her first round of treatment at Yorkhill we were fine: but this time, we've really suffered given all the issues at the hospital. Stevie-Jo sees a psychologist regularly now. I have really bad anxiety. I suffered with panic attacks and PTSD this time round. I think it is because of the additional stress of everything that happened at the hospital. The impact on our family has been huge this second time round,

especially when compared to the first time that Stevie-Jo was diagnosed. The difference is because of the things that were going on at the hospital, it added to the stress and worry. Things like moving from the children's hospital to the adult hospital. Things like losing the parents rooms in ward 6A.

155. When your child's really ill, some days you're not out their bedroom for days. When they're on morphine, or ketamine, or they are really ill; you don't leave the room. When I was in that situation, sometimes it was nice just to go into the parents' room and just have five minutes. Have a cup of coffee; just take a step out and take a breather. But you couldn't do that up in ward 6A, because there was nowhere to go. Even if I was upset and I didn't want to sit in the room and be upset in front of Stevie-Jo, I could go to the parents room. But in Ward 6A all I could do was go out in a corridor, with everyone else walking past as well. It was really quite hard, there was no time or place just to gather myself.

156. The number of additional hospital visits added to my worry and anxiety too. I can't even count how many more hospital visits we've had. Stevie-Jo definitely had more hospital visits this time round, especially with all the infections that she had. I don't think there was a week that we weren't up there either two and three times a week, or alternatively we were having to stay long periods.

### **On Stevie-Jo**

157. Stevie-Jo used to be a very bubbly child; she's got [REDACTED] as well, so she used to be constantly on the go. Now, she's very reserved. She takes quite a bit time to build up trust with people. She's quite shy. When she goes into new situation, she used to just go; for example she would just go to a football club and that would be her, she'd be away. But now she hangs back and stays with her dad until she can sort of get used to people. The experience has definitely impacted her confidence, and her trust of other people.

158. She's like that at school as well, when she finally got into school. Stevie-Jo hadn't been to school from primary six to S3 simply because of all the time that she was in hospital. She didn't have a teacher in all that time.
159. She should have had a teacher the whole time that she was in the hospital. The week that we were getting out of the hospital, the teacher came to visit Stevie-Jo, and he said, oh I'm here to give Stevie-Jo some education, and I said, oh we're actually going home today. And he said, oh well, I need to inform you that Stevie Jo has been in for seven days, so it's the law that Stevie Jo should have some education. And I said, well that's funny, because we've been here for eight months, and we've never seen a teacher, so who do I phone to find out about this. And then we never seen him again from there. Stevie-Jo was due to start in S1 [REDACTED] when she relapsed but the school just left it. I think their thoughts were her getting better would have been the better option. The other kids in the ward had teachers coming in daily, but Stevie-Jo never had any teachers whatsoever.
160. There was bit of an issue when Stevie-Jo went into S3. We paid for private tuition for her for maths and English. We were getting a bit concerned about her education, so I had contacted the Education Department, who had no idea that Stevie-Jo had leukaemia. They were going to put supports in place but COVID hit and nothing actually happened with that. But she has just passed all her Nat 5 exams and got As and Bs, somehow.
161. Stevie-Jo [REDACTED]. She has seen a psychologist quite a lot, and it has really helped her. It has also helped that she's not been at the hospital for such a long time.
162. Stevie-Jo was petrified. Every time we had to go to the hospital, she was crying and she didn't want to go. Before the experience in the RCH and QEUH, Stevie-Jo pretty much grew up in a hospital environment as she was in treatment from a young age; she used to love going up to the hospital, it was



like going up and visiting family when she went up. But after all this, every time we had to go, she was crying and petrified of what she was going to catch in that building.

### **OTHER IMPACTS**

163. I estimate that it costs us around £18,000 in fuel and other costs to travel.

Through it all, the hospital didn't understand that we don't just live five minutes round the corner. The staff wanted us up at the hospital three and four days a week for check-ups, or appointments. Me and Steven took time off work. I don't think that there was any understanding from the hospital. We were trying to live up in Glasgow and run our house in [REDACTED].

### **PREVENTATIVE MEDICATION**

164. Stevie-Jo was on preventative medication called posaconozol. It was an anti-fungal antibiotic. We were told that was part of the treatment, but obviously we knew it wasn't part of the treatment as she was not on it at Yorkhill. It was something that was introduced at the RHC. Steven and I spoke with Professor Gibson about it. We knew that it wasn't part of the treatment. Professor Gibson said Stevie-Jo was on it because of all the work that was going on around about the hospital. She said that she would rather prevent the kids from getting anything, rather than trying to fight something if they got it. She said they were giving it as a prevention rather than trying to then cure anything if they caught it from the works that was going on.

165. We have a really good relationship with Professor Gibson, we trust her with anything with Stevie-Jo. She's been Stevie-Jo's consultant for quite a few years. We've always taken the approach that what she needs, she needs, and you make that decision on that basis. But if she doesn't need it, obviously we would rather that she wasn't on some of the medication.

## **THE INDEPENDENT CASE NOTE REVIEW**

166. Stevie-Jo was one of the patients that was included in the Case Note Review. The Case Note Review took a closer look at what happened with the circumstances of her mycobacterium chelonae infection. We have received a copy of Stevie-Jo's individual report. We weren't surprised with the outcome of the review into her case. The panel found that it was very highly probable that the mycobacterium infection that Stevie-Jo contracted came from the water supply in the operating theatre in the RHC. It concluded that the infection has had a severe impact on Stevie-Jo's life, and it is continuing to have a severe impact on her life.

167. We've had quite a lot of engagement with the Case Note Review through one of the parents, John Cuddihy. He's been really good and he has communicated between us and the review group. I think he goes to a lot of meetings. He simplifies and shares a lot of the information with the parents; it has been really helpful. It has been good having him do that, sometimes things can be a bit hard for us to understand in terms of the legal terms used. Personally I have not had a lot of contact with the Case Note Review directly.

168. In terms of the impact on my family, the process of going through the Case Note Review has been quite emotional. I have had to revisit what happened. As a family, we have gone through the treatment for seven years now; we tend just kind of get on with it. We don't usually get involved in things; we usually just get in, get the treatment done, and go home. But with this, I have had to a connect more with my feelings; I can't really just shut it out.

## **COMMUNICATION**

### **Communication: water**

169. We were told that the kids weren't allowed to use the water. It was never really explained why. All of a sudden, the kids had to have bottled water and these were introduced to ward 2A. The kids weren't allowed to brush their

teeth with the water, but they could have a shower – that was in the beginning – they were allowed a shower, but they couldn't brush their teeth, and they couldn't drink the water.

170. Staff said that they were having some issues with the water. They said cleaning stuff had been put down through the pipes, and they didn't want the kids drinking it in case it wasn't safe. I think the kids still drink bottled water on the wards. It was never explained why. We saw people coming into the rooms putting stuff down the sinks; it was constant. There was one point it was almost every day they were putting stuff down the sinks. For us the most serious thing was the water situation when Stevie-Jo was on another ward. Sometimes there were not enough beds within the Schiehallion Ward for the kids, or sometimes if your child had an infection they would go to another ward to protect the rest of the Schiehallion kids on the ward.

171. A couple of times Stevie-Jo ended up in Ward 3A or 3C in RHC. The staff weren't told that the Schiehallion kids weren't allowed the water. Each time we went into another ward, we had to tell the nurses that the kids in Schiehallion aren't allowed to drink the tap water. Nine times out of ten we'd have to go and buy Stevie-Jo bottled water, because the nurses never went and got water for her, or if they did they couldn't find any within the hospital. It was really concerning. Some of the families whose kids began treatment after the move to the adults' hospital might not have known that there were water issues in the children's hospital too. They might not have known what had happened in ward 2A RHC. They might have thought that it was just an issue confined to ward 6A. They might have thought that their kids could drink the water in the children's hospital; that they could face a risk. There was no communication between the wards in the hospital.

**Communication: move from Ward 2A RHC to Ward 6A QEUH**

172. We were at home in [REDACTED] when the move happened. But the following day Stevie-Jo had to go up to clinic, which was in ward 2B or 2C in the RHC. When we arrived in ward 2 in the RHC, nobody was there apart from workmen. I asked the workmen where the ward was. The workmen told me that the ward had been moved up to the adults' hospital. We went back down to reception and asked where the Schiehallion unit had gone. Staff on reception told us the ward was moved to the adults' hospital, up in 6A. That is how we found out that they had moved. That day there were quite a lot of families who were going up to day-care, and didn't actually know the ward had moved.
173. I was really angry finding out in this way. The most concerning thing was that, if we needed to get to Schiehallion in a rush, we wouldn't have known where to go. When it is something like a temperature spike, or your child's not well, you need medical treatment quickly.

#### **Communication: Cryptococcus event**

174. Throughout my experience at the hospital communication has been awful, right through from the top to the bottom. It was particularly bad when the kids got moved out the children's hospital up to the adults' hospital in September 2018. I felt that everyone in the hospital just closed down; no one was being told anything. The nurses were in the dark a lot too. I remember when they started bringing in the HEPA filters, up to ward 6A. This was when there was the Cryptococcus outbreak on the ward but just before everything started kicking off in the media about that. I think it was around the end of December 2018 and the start of 2019. We didn't know what was going on in the ward.
175. The nurses were really concerned about the HEPA filters being put in the wards. When this was happening a couple of the nurses came into our room and asked us to go to the media. They told us that they had been told nothing by management, and they felt they could not go to the media because it would risk their jobs. They felt that there was something seriously not right in the

ward. During that whole week, the nurses were in and out of meetings with hospital management. A lot of the nurses were really upset during that time. That's when me and Steven started asking for meetings with the hospital.

176. Our family have been on the Schiehallion ward for around seven years; first in in Yorkhill and now in the new hospital. We've got quite good relationships with many of the nurses. A number of them came to our room to talk, and they were in tears. They said things like they knew that there's something serious going on, but they didn't know what. They felt terrible because they couldn't tell us. They felt like they were fighting against something but they didn't know what they were fighting against; it was a big concern to them and to us. A few of the staff were pregnant at the time, so they were concerned for themselves and their babies. All they knew was that there was an issue, and a couple of people had died on the ward in December 2018. It was really quite scary at that time.

177. The hospital said that if any parents wanted to arrange a meeting to address their worries, we could arrange a meeting with Professor Gibson and the microbiologist. I asked for a meeting. Stevie-Jo had just come out of PICU; Steven and I were really concerned. At that meeting I asked if Stevie-Jo was safe is she stayed in this hospital. I said that over the past couple of months she'd fought meningitis; she was just out of PICU; her immune system was not great. I asked if she was safe here?

178. I found out about the Cryptococcus event in ward 6A on the news. It was only when it hit the news that we knew that that's what the actual issue was within the hospital. No one from the hospital had said anything to us. When it had hit the news, I think that we were all sent a letter or we were told at clinic but I'm not a hundred per cent sure. We were told that Professor Gibson and the microbiologist would be holding meetings with any of the parents who wanted to speak with them, but only meetings of up to three families at a time. A meeting was held with our family and another two families. We met to discuss the Cryptococcus and what that meant for the kids. We never really got much from the meeting. We were told that the patients who had got the

Cryptococcus and died were already very ill, and their immune system was really low before they got the infection. During that meeting I said that Stevie-Jo's immune system was almost at zero and said that would suggest she might be at risk. I was told that she was not at risk, and although Stevie-Jo's immune system was at zero, the ones who had passed away from this were even lower than zero.

179. We felt like we got nothing at that meeting. During the meeting I asked about the infections. I pointed out that when I looked up the infections that all the kids were getting, they were from soil, water, and environment. I asked if there was any link between these issues and the infections? The microbiologist said, that she had questioned it herself but that she had got a separate answer for each infection and therefore she was not linking them together. I didn't really understand what that means, but it turns out that they are all from the water.

#### **Communication - Meeting with Jeane Freeman: September 2019**

180. I was involved in setting up the meeting between Jeane Freeman, the Cabinet Secretary for Health, and the patients and families of the Schiehallion ward. I started realising that things weren't right in the hospital. I'd emailed Jeane Freeman in 2019, and explained the whole situation about Stevie-Jo. I told her about the infection and set out the concerns that I had with the hospital. I asked her to clarify why the hospital was opened earlier than planned, and whether they opened the hospital too soon. I asked why someone was willing to take a risk with these children's lives and I asked her who had signed everything off. I was quite angry, so it wasn't a very nice letter that I wrote. Someone must have signed off the building without doing the proper checks; you don't just put sick kids into a hospital without there being loads of checks done. In my view, someone must be held liable, there must be someone who said that this hospital was okay for these kids to go into. Clearly they hadn't done the proper checks of the building.

181. I then spoke with another couple of the parents in the ward, and told them that I'd emailed Jeane Freeman. Following that a few of the other parents had emailed her as well. She must have received quite a few emails from parents. All I got was a letter back from her, the letter pretty much said the same thing for everyone: that she was really sorry, and she was going to do what she could to find out what happened, and try and find out the answers. Pretty much the usual response from politicians. However I think because the parents kept pushing her by correspondence she decided that she was going to have a meeting with us, rather than everyone messaging her at different times. I think she thought it would be easier having a meeting with whatever parents wanted to go.
182. The meeting took place at a hotel in Glasgow Central in around September 2019. The head nurse for Scotland was there too. Around 8 or 9 families attended that meeting. When she started hearing the stories of different families she seemed shocked. I don't know whether she was or not, but she said she was shocked. She genuinely seemed like she didn't know half of the concerns that were raised during this meeting. She said that what had happened at the hospital wasn't acceptable, and that she was truly sorry for the pain, and the heartache, and the trauma that it had caused to the families. During that meeting we explained that "sorry" is not really going to cut it. Something needs to happen; someone needs to look into this properly and find out what's happened; what's gone wrong. This was so things could be fixed for further families who attended that hospital; because there are still families who will need to access treatment at that hospital. If they are starting treatment, their kids were going to be really vulnerable at certain stages in their treatment.
183. As a result of that meeting, we did not get any answers to our questions. I felt that she was there because she had to be there. I didn't feel like she was really listening. It was not very helpful. She couldn't answer anything that we asked her and I don't think she'd done much research prior to the meeting. I think it was a quick option she tried to use to make the peace. My general

observations from that meeting were that it wasn't her fault and she didn't have any answers to give us.

184. At the end of the meeting she said that she was going to look into it further.

Once the media started getting involved it put pressure on. Our family had quite a lot of media coverage. I think it was from a journalist at the Sunday Mail. The journalist had messaged me to see if she could come down and speak with myself and Stevie-Jo about our experience. She had been given documents which had been leaked, someone had left them on her desk. She said, *"look, I know that sometimes in the media things can get spiralled out of control, and your story is not told the way that it should be, but I'll bring down the papers that I've been given, left on my desk, and I'll show you them, and then we can take it from there. If you don't want anything published, then that's absolutely fine"*.

185. The journalist came down to [REDACTED] and we met with her at our home. She showed us the papers she had which showed that things had been missed, way before the hospital was opened. They had tested the ventilation, and they knew it wasn't fit for purpose within the hospital. There were issues with the water before they opened it, and there had been lab test results that had went missing as well. It seemed that they couldn't get the test results either. The hospital's microbiologist was really concerned about the levels on the water, and she had asked a few times for to get reports on it, but they kept saying that they didn't have the reports.

186. From there the journalist did a piece on us in the Sunday Mail. Not long after that Jeane Freeman announced a public inquiry. I think that she knew a public inquiry was the only way to get the answers. Jeane Freeman said it was for the parents to get the answers that they needed, but to be honest, she didn't have any other option.

187. I think that the media coverage has really helped raise the profile of what was happening at the hospital. At the point that we went to the media things



started spiralling. That was when more parents started questioning what was happening at the hospital. In the new hospital, the parents weren't socialising with each other like they used to in the old Yorkhill. Nobody was really talking to each other due to the way the ward was set up, and following the move to ward 6A this got worse. Whilst my child had this infection, none of the other parents really knew about it. Once the media started to publicise the issues with the buildings, and the fact that kids were getting infections parents began to ask questions. At that point we were using the Facebook group that was set up and run by parents of Schiehallion patients. I was a member and still am a member of that group. Things started spiralling from there, people were talking and were realising their child had the same infection as another child on the ward. Others began to question why their child had X amount of line infections. For the first time, I think the media actually really helped us as parents. People began talking, sharing and realising that our kids were getting the same infections.

### **COMMUNICATION: GENERAL**

188. Communication was awful. Even now, especially from up the hierarchy in the hospital. We always said that we felt really sorry for the doctors and the nurses, because you could tell that they weren't allowed to tell us what was going on. I think they were really held over by concern for their jobs.

189. I was a member of the closed Facebook group which was run by NHS GGC, but only when it was first set up. I am no longer a member of the Facebook group. I didn't really see the significance of it. The board said that it was to keep families up to date with what was going on before it hit the media, but things were still going in the media before the families found out. I left the group as I didn't really see the point of it. NHS GGC didn't like the Facebook group that had been set up by parents for the parents, this was because they had no control over what was being said there and they didn't know what was being said or discussed. I think they were trying to move it onto a group that could be monitored by staff and by NHS; but that wasn't going to work.

190. I did have some engagement with Professor White at the Scottish Government. I think Professor White was just an intermediary between the NHS and the parents. A couple of times I emailed him to ask if the listeria meningitis that we were told Stevie-Jo had on December 2018 was ever proven to have come from the water. The reason I asked that question was because Stevie-Jo was drinking loads of water out of the water cooler in the ward and then she began to get the bad headaches. I've asked a few times if I could get the water sample test from that period of time. We emailed back and forth, four or five times, and I was sent some water samples but they were just regular ones that had just been done, some standard water samples that had been taken at the time, nothing that showed if the water had been tested for listeria meningitis. It was not what I was looking for. I wanted samples from a specific period of time when Stevie-Jo was in Ward 2A, but they were never received.

191. For me, one of the things that really annoyed was when the head of the board at the NHS was on the news recently. It was when the Oversight Board Report and the Case Note Review report were published and they had found that there were faults. The microbiologist, whose name I cannot recall had said, "sorry", and that was it, just that she was sorry. But she has blatantly lied and covered up, all the way through. She is happily sitting in her job putting these kids at risk, without actually doing anything, about it. Then she just said, "sorry".

192. I am aware of the Oversight Board and the Report that was produced, but I did not have any contact with the Oversight Board.

### **CONCLUDING REMARKS**

193. I do not want Stevie-Jo being treated in that hospital, whatsoever. Prior to the experience in the RHC and the QEUH, we had never had concerns before.

Our medical team is still amazing, but we certainly wouldn't want Stevie-Jo being in that hospital again. We've asked that if it is possible for Stevie-Jo just to go to DGRI for anything that she needs, rather than going to the hospital in Glasgow. I don't feel safe in the hospital, and I know for a fact that Stevie-Jo certainly doesn't feel safe. It is not just the infections, I don't even feel the actual building is safe. I don't feel that the structure of the building is safe. Taking that together with the infections, the water, and the actions of the Health Board; I actually don't feel safe. I don't feel that the Health Board has got the kids' best interests, or their care is at the centre of it.

194. In terms of the Health Board, I am angry and disgusted that they've actually just covered up so much. They knew what the situation was at the hospital, and they did not tell parents how much risk the kids were exposed to. I feel like they're still just trying to cover up and save themselves.

195. The only way that my concerns about safety can be addressed is if they knock the building down and start again, somewhere else. We've been down the line of trying to get the Health Board to be honest, of trying to get them to build up the trust with the patients and the families, but it's not happened. I can't see that happening any time in the future, either.

196. Communication from the Health Board and the hospital has not improved. They said that they were going to be more transparent, and be honest with families. They said families would find out anything before it went through the press. But it's been going through the press before families are finding out. We feel they're only telling us what they think we're going to find out from the press. I know a few other parents feel that way too. It's not that they're being transparent and being open with us. Rather, they only tell us what they think we're going to find out anyway.

197. Personally, I don't think there is anything that the Health Board can do to gain my trust. Maybe for people using the hospital in the future, they might be able to build up a bit of trust by being more transparent. They actually need to be

open, and not just tell them the basics that they feel they can get away with telling them.

198. Even now when we were finding out things about the hospital in the media, it made me so angry with the Health Board. Sometimes I think, "right, that's fine, we're here, we're at the public inquiry, things will start improving" and then there is something else about the hospital in the media and it's just straight back to square one with them. I feel like I'm constantly fighting a losing battle with them.

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