SCOTTISH HOSPITALS INQUIRY

SCOTTISH HOSPITALS INQUIRY

Hearing Commencing
20 September 2021

Bundle 6 – Witness Statements for Week commencing 25 October

This document may contain Protected Material within the terms of Restriction Order 1 made by the Chair of the Scottish Hospitals Inquiry and dated 26 August 2021. Anyone in receipt of this document should familiarise themselves with the terms of that Restriction Order as regards the use that may be made of this material.

The terms of that Restriction Order are published on the Inquiry website.

SCOTTISH
HOSPITALS
INQUIRY

Table of Contents

Week 4

Scottish Hospitals Inquiry

Witness Statement of

Molly Cuddihy

WITNESS DETAILS

1. My name is Molly Heron Cuddihy. I was born on [redacted]. I am 19 years old. I am a student at [redacted].

2. I live with my parents and my brother in [redacted].

OVERVIEW

3. I was diagnosed with metastatic Ewing's sarcoma with a primary site in my 11th rib. At the time of my diagnosis, I was 15 years old and was in 4th year at high school. I was studying for my National 5 exams.

4. I was a patient and received treatment at the Royal Hospital for Children in Glasgow ("RHC") and the Queen Elizabeth University Hospital in Glasgow ("QEUH") between January 2018 to 2020.

5. I now receive most of my treatment at the Beatson Hospital in Glasgow, although I am occasionally required to attend the QEUH.

6. I was treated in wards 2A and 2B of the RHC which is known as the Schiehallion Unit. The Schiehallion Unit treats children with all types of cancer. I also spent time in other wards on the RHC, namely 1E, 3A, 3C and the Paediatric intensive Care Unit ("PICU"). Following the closure of the Schiehallion Unit in 2018, I was treated in ward 6A of the QEUH. I can speak to the experience that I had on these wards.

7. There are some specific events that I would like to mention. I contracted mycobacterium chelonae in May 2018 when in ward 2A and I contracted an acne infection in February 2019. I was prescribed preventative medication which I believe was connected to issues with the hospital environment. There were all sorts of issues with the hospital throughout my time there which, in my view, impacted on my treatment and on my experience. I will talk about these in more detail.

FAMILY BACKGROUND

8. I live with my father, John, my mother, [redacted] and my brother, [redacted]. [redacted] is my older brother, he is [redacted] years old. He has moved back home with us after finishing university where he studied [redacted]. I am really close to my brother. We get on well, so it is nice having him home as much as I complain. We're very different, he's very sporty and I don't go near anything that involves any physical activity. He was a bit disappointed in me for that side of things! I have a good relationship with all my family.

WITNESS BACKGROUND

9. I am a studying physiology at the [redacted]. I am in my [redacted] year and have just finished my exams, I spent the last year studying biology and chemistry and an elective in maths. I did well actually, considering I was doing my lectures from home for a year. Hopefully, I won't be doing that for too much longer.

10. I enjoy my studies and it has been really important to me that I do well. That's always been my biggest thing. I have a big ambition, I've always wanted to be a doctor. It has been something that I've wanted to pursue. I've never felt forced to do it, and it is certainly what helped me throughout being in the hospital. It was something else for me to focus on. Once I finish my degree in physiology I hope that I can go straight into a degree in medicine.

11. Outside of studying, I am really into music. I have played the piano since I was about three or four years old. I started off young because my brother used to get piano lessons and I had to get piano lessons too. Out of the two of us, I was the one that stuck it out. I enjoy singing as well. The two always came hand in hand throughout school, and that was my biggest hobby outside of my studies. I love going to concerts, me and my pals go together. One of the biggest things I've missed is going to concerts, I've just not been able to do so physically. In addition, being that close to people with bugs, and in that kind of environment, was not the safest thing for me when going through treatment.

12. I was fortunate and actually sang with Paolo Nutini who's been my favourite since I was a kid. It was through the Make A Wish charity and this was my wish. I grew up listening to him, so that was incredible. I went down to London and sang with him in a recording studio.

13. I like a range of music, and don't tend to stick to one genre. I like a lot of older music, my dad will tell me about songs he used to listen to and then we listen together. The Killers are one of my favourite bands, I went to see them at TRNSMT. I love Sam Fender and even musicals.

14. I am on the committee of the Anthony Nolan branch at the [redacted] . The charity have student-run branches within some major universities. Students tend to be a group that they target to seek donors for stem cells. During my treatment, I saw a lot of people who needed transplants on the ward. I was fortunate that I had my own stem cells for transplant, but a lot of my friends weren't that lucky. I began as one of the donor recruitment coordinators, encouraging people to join the stem cell register. I'm moving on to help with the social media campaigns. For example, making sure that we have frequently answered questions available on social media platforms; you'd be hard pushed to find a student that doesn't use social media. It's one of the best spaces to put information out there, it is easily accessible and it might catch someone's attention.

15. I enjoy spending time with my friends and I'm a big reader. Now that university is finished for the summer, I enjoy having time to read.

EVERY THANK YOU COUNTS

16. I founded a charity called Every Thank You Counts along with my friend,[redacted]. I met [redacted]on the ward; we both were in the Teenage Cancer Trust ("TCT") part of the Schiehallion unit in the RHC. [redacted] and I were fortunate in that we had access to the social room for the teenagers on the ward, it was provided by the TCT. That was where we met and it was where we spent time together; it was what brought us through the experience of treatment.

17. We did notice was that whilst the youngest kids in the Schiehallion Unit had the playroom and teenagers had the TCT common room, there was a gap in the provision for the eight to twelve year old group. There was one particular story that kind of stood out for us. A boy came in to the TCT common room; he was a patient and he didn't look very well. He had asked me and [redacted] how to use the PlayStation. We set it up for him and he began to play with it. You could see his mood lift and he looked like a very different boy; he didn't look as sick anymore. One of the nurses came into the room as a he was not a teenager. We hadn't realised that he was under 13 years old, and so unfortunately he couldn't stay. It was a horrible job for the nurse; no one likes to do that. As a result of that event [redacted] and I wanted to do something; we wanted to change that and provide something for the kids aged eight to twelve years old.

18. We started off with the idea of a ball to fundraise and the idea grew from there. Originally we thought if we could raise £50,000, that would be incredible. Today we're sitting at well over £300,000. The ball was held in October 2019 and we raised £250,000 on the night. We're really proud of ourselves for that.

19. We have used the money raised to provide a room in ward 2A of the Schiehallion unit in the RHC. Work on the room is almost finished and it was

carried out whilst the ward has been getting rebuilt. It has been one of the only good things about ward 2A getting rebuilt; we've been able to get work done to create this new room. We hope that the room will be finished in July 2021, and I understand that the Ward 2A might open in September 2021.

20. It will generally be for eight to twelve year olds, but we're leaving it to the discretion of the staff within the ward. It is for anyone that is in that middle age that's too young for the teenagers' room and too old for the playroom. We want kids to use this space, we do not want to cut it off and then there be another gap in provision. If we were to do that we would never stop trying to build rooms for kids, so we're not keeping it strictly within an age limit in that sense. We are keeping the "ETYC" name, so that it's the "Eight to Twelve Years Club" kind-of-thing, whilst it is "Every Thank You Counts" at the same time. Generally it will be for that age group, but there may be some exceptions.

21. As regards the facilities in the room, one of the main things that the families have asked for is somewhere that they can go and watch movies together. It is important. Whilst we have the cinema within the hospital, patients are not allowed to go if they're on a drip, and that is the majority of Schiehallion patients. You'd be very hard pushed to try and find someone that is not on a drip, therefore getting to the cinema is actually quite difficult. Being able to have a movie night that is not on a tiny iPad would make all the difference for families. It would give them something to do and something that they're used to doing together. They can all sit in big comfy seats. The kids can meet each other there and watch TV and movies together. We'd also like to have gaming consoles: the PlayStation, Switches or whatever everyone plays now.

22. We'd also like to provide board games or Lego; things that would be a comfort to people. We've planned a reading nook. People might like to use their iPads there. I really like my books, but I know that a lot of people probably won't always want to read.

23. Personally, the main thing for me is to provide a table. During my treatment, that was something that made a big difference to me. Because of the medication and treatment, I didn't want to eat but I was adamant I was not going to have a feeding tube. Having somewhere to sit down and eat was important to me. It broke up my day and I did not want to eat in my bed. Being able to sit and have a cup of tea or one thing to eat, even if it's a packet of crisps; it was something. It is the one thing that you don't realise that you're going to miss; sitting down together as a family, being able to sit down with other people or with siblings.

24. The space we have for the room it not the biggest space, it is not as big as TCT common room. We think that we've got it planned out well enough that there's room for everything within it. The space that we are using was formerly a patient room behind the nurses station in ward 2A. It was horrible for whoever was staying in it. It was not nurses' fault but they had to be able to communicate during the night and the lights had to be on for them to do their notes; it was never a great room for patients to stay in. Staff didn't like to put people in there unless they had to. It wasn't great for nurses either, access in cases of an emergency was restricted because their desk is directly in front of it. So the hospital has rejigged that space. I think the pharmacists have an office within some of that space too. The new ETYC room used to be a patient bedroom with the en-suite bathroom. It is quite central and the staff can keep an eye on the users of that room.

25. Surprisingly we've got a lot of money to spare after funding the ETYC room. We've helped buy a blood analyser for the Schiehallion ward. Within A&E and the Paediatric Intensive Care Unit ("PICU") at the RHC, the wards have their own blood analyser which means blood samples do not have to go through the central system within the hospital. If you are in a ward that has a blood analyser machine, within ten minutes maximum a patient can have a blood counts and any other important information from their blood sample. The difference that makes in this kind of environment is incredible; sometimes I could be waiting hours in Schiehallion and then I'd have to get my bloods redone because by the time it got through the system, it wasn't viable to be

tested anymore. It is a lengthy and unnecessary process, especially for the wee ones to get their bloods taken repeatedly. The blood analyser will make such a difference and will be used across wards 2A and 2B.

26. The last thing we hope to do with the funds raised is to create a resource within PICU; a relief for the staff. The difference between the Schiehallion ward 2A and with PICU is that whilst 2A is a high-dependency ward, the consultants can go home when they're on call. However all the staff within PICU, including the nurses, are in the patient's room from the start of their shift to the end of their shift, apart from their breaks. We would like to provide a space that staff can go to get a break, even get a nap if they could. We would like to ensure that the PICU staff are rested and at the top of their game. The PICU staff are incredible, and I think a well-deserved break would really make a difference. That's our grand plan at the moment and it is what we would to pursue. We intend to speak to the same management that we've worked with for the ETYC room, to see if it is viable. If it isn't, then there are other things we can think about getting for the PICU to make people's lives easier.

SEQUENCE OF EVENTS: PATIENT EXPERIENCE AT THE RHC AND THE QEUH

Diagnosis: January 2018

27. I was not well for about six months before my diagnosis. Prior to that I never went to the doctor. Even if I had a cold, I was always still at school. During this time, I had cold sores or colds or flus that wouldn't go away. I had quite a large swelling on my side which was very painful. I struggled along and no pain relief was really touching it.

28. I had a big loss in appetite and lost a lot of weight. I was tired all the time. I attended school all week and I was working really hard as it was the lead up to National 5 exams. I was preparing to sit my prelims in January 2018 and was studying a lot. I'd come home from school and put my jammies on. Once

I’d done my homework, I’d have to go to my bed. At the weekend, I’d sleep. It wasn’t really like me at all; I just wasn’t right.

29. I went back and forward to different doctors for a while. I think it was to do with my age and the fact I was a girl, there were a number of things that they thought it might have been. Eventually I saw a GP that was a family friend of ours, and he knows me. Apart from the symptoms of the mass and the pain he noticed I had a cold sore that would not go away, and he suspected something was wrong. I saw him on Friday and I had a scan scheduled for the following week, on Tuesday 16 January 2018.

30. I had attended A&E at Inverclyde Royal Hospital (“IRH”) a couple of times prior to that. A couple of weeks leading up to my diagnosis, the pain was getting really bad. There was one night that I couldn’t sleep due to the pain and my mum woke my dad up and asked him if he’d take me up to A&E. He took me and blood was taken, but my bloods were fine then so I came back home.

31. On the 16 January 2018 I attended at my local hospital which is Inverclyde General Hospital for an ultrasound scan. I had quite a large mass on my side. Initially, they thought it was maybe my kidneys. I knew something was wrong right away, the staff performing the scan rang the consultant. I had gone for the scan on my own and my mum was in the waiting room. We weren’t expecting anything like this to happen. The consultants came to speak to me and I was checked into A&E at IRH, and referred for a CT scan straightaway. The CT scan was performed and we waited for the consultant’s report on it. One of the doctors who was working in A&E had actually worked in Schiehallion Unit in the RHC, and she came in and she told us that I had a sarcoma. She said that I had to go up to Schiehallion ward at the RHC right away and that the staff in Schiehallion knew I was coming.

32. We phoned my dad who was at work. He met us right away and drove us up to Glasgow. My brother was in his year abroad in [redacted], so he wasn’t there at the time.

33. When we arrived at the RHC I attended Ward 2B which is the day-care ward in the Schiehallion Unit. I met Dr Sastry. He did a few checks, he asked me about the type of pain I was having. Staff took a lot of blood samples from me and that night I was admitted to ward 2A RHC as an in-patient.

34. I was in ward 2B for a few hours while the staff made sure that I had a room to go to in ward 2A. They made sure I had a room that was at the very end of the ward. They ensured that I wasn't around many other people, had some privacy and I could be by myself. The staff were really good about that. Even when I was in initially in ward 2B, they made sure that I didn't have to sit in the middle of the ward and see everyone around me.

35. I was diagnosed with metastatic Ewing's sarcoma, with my primary site on my 11th rib. It was spread across the ribs above and below and in my diaphragm. I also had tumours in my lungs and in my tenth vertebrae.

36. That was my first day in Schiehallion. From the get-go, the staff were very soft in their language. It was never "you have cancer". Rather the language used was "there's this small mass, it's also here", "this is what we're going to do about it, we're going to treat it". I was never alarmed. I understood that something was wrong and I knew it was not good but it was never alarming in that sense. There was never this big horrible speech. I don't know if it is different for adults, but certainly within the children's unit the staff were really kind about how they communicated with me.

Ward 2B – the Schiehallion Unit: RHC

37. Ward 2B is the Schiehallion day-care unit in the RHC. It's where child cancer patients go for day case appointments: blood samples, tests and check-ups. Some patients can receive their chemo there if they don't have to stay overnight and don't have to be admitted as an in-patient. It is a ward where

staff can provide treatment without actually having to bring you in as an in-patient.

38. Day-care is also your first point of call when you’re not well. Usually in non-COVID times, that’s the first place you phone and that you attend when you have a temperature or if you just don’t feel right. Patients might go to day-care if their bloods are low and they need a blood transfusion. A transfusion does not have to be an overnight procedure, a patient can attend in the morning, receive a transfusion that day and then go home that night.

39. The Schiehallion Unit is made up of Wards 2A for in-patients and ward 2B for out-patients. The ward staff work closely together. The doctors work across both wards, so as a patient you see the same doctors. There are some doctors that work in the day-care ward, and they work in 2A at the weekends for example. The position it slightly different with nursing staff. There are specific day-care nurses but that is because their shifts are different; they do not work 12-hour shifts, and therefore they can do more days. During the week, you always have the same nurses, and they take turns for who gets the day off that week depending on when their shift patterns. It tends to stay the same and you very easily build up a relationship with the staff there.

40. In ward 2B there was the waiting room and they had toys set out for the younger kids. Noreen, was the staff member who worked on the reception desk; everyone got on well with Noreen. She organised a lot of the things for patients, blood samples and appointments. The ward also had individual rooms where patients could see the doctors or where they might be placed if acutely unwell. When I first arrived in ward 2B, I went to one of the individual rooms and it was where I received my diagnosis.

41. There are treatment bays in day-care. There is a Teenage Cancer Trust four-bed bay and it is set up with chairs, but there is space for beds if needed. There is another bay for patients that are not teenagers, I think it has more than four seats, maybe six or eight, although I have never actually used the other bay. The bays might be used to receive chemo or blood products.

Admission to Ward 2A – the Schiehallion Unit, RHC

42. On the 16 January 2018 I was admitted as in-patient to room 7 in ward 2A in the Schiehallion Unit. I stayed for four nights and three days and was discharged on Saturday 20 January 2018.

43. Room 7 was not in the TCT but it was up at the end of the unit beside the TCT. There are four rooms in the TCT and at that time they were all occupied. I was still next to all the teenagers though.

44. Whilst I was not in a TCT room during the first admission, the staff still made sure there was an adult bed. The TV was a bit temperamental. It was just for couple of days so I wasn't too bothered. At the time I was shocked about my diagnosis. I was about to start my prelims a couple of days later. The only thing I could really think about was the fact that I'd studied for so long, and I wasn't going to be able to sit them. I was worried that I didn't get the chance and I spent a lot of time trying to organise school and my studies.

45. I didn't get back into school that academic year. Instead I sat my prelims at the same time as my exams. I took one day at a time, and sat my prelim the day before I sat the actual Nat 5 exams. I sat my prelims and my final exams in the first couple of weeks of May 2018.

46. The RHC had been sent my CT and ultrasound scans from IRH. The following day all the main scans went ahead in the RHC. I had two full MRIs, a biopsy and bilateral bone marrow aspirations. They did every test they could in order to find out how much the cancer had spread. Tests confirmed that the cancer wasn't in my bone marrow. I was informed that the tumour was malignant, and present in my initial site on my ribs, my lungs, and then my spine.

Hickman line

47. During that week I had a Hickman line fitted. It is a surgical procedure under general anaesthetic and was fitted the same day I had my bilateral bone marrow aspiration. I went down to theatre on the Friday and stayed overnight following the procedure just to make sure my line was okay, and then was discharged on Saturday 20 January 2018.

48. I had the Hickman line fitted and it is a bit different from a central line. A central line goes in your neck and down into the main vein into your heart, whereas a Hickman line goes in just at your armpit and it goes under the skin and in through the same place in your neck and down into the main vein into your heart. As the line goes into that main vein you have to be under general to get it fitted and to have it removed. A Hickman line is what all the kids tend to get, and it is more permanent.

49. A Hickman line is used for taking blood samples and receiving blood transfusions, and for administering medication. Due to the nature of the treatment, our veins are rubbish and collapse as soon as we start it. The line makes it easier than just using cannulas, it means we don’t have to be jabbed so often.

50. The Hickman line has a dressing to cover it using something called a “seatbelt”, it sticks on your body and your line fits in that. I got quite good at disguising my line in my clothes so that people were never really able to see it.

51. When you have a line, it has to be flushed every few days. When I was an out-patient I relied on the outreach nurses for that kind of thing, particularly if I was not attending day-care for a few days. When it was first fitted, I was newer to my line and was attending day-care more frequently.

52. Later on in my treatment, when I was not at day care as frequently, line flushes were sometimes carried out by an outreach nurse. That could even happen when I was at school. There are specific outreach nurses that work for Schiehallion. They cover different geographical areas so each patient had

their own outreach nurse. I think there were three outreach nurses and they travelled all over Scotland. They flush lines, take bloods and sometimes if I was not well, they might check me too. They also attended my school and made sure that the staff were fully informed about what to do about my line in case there was an accident, for example if it was pulled and also to ensure they were informed about infection. They make sure you've got everything under control in that sense, that you're safe in whatever environment you are in.

53. A line flush is where a fluid is passed through your line to clear it, to ensure that the line didn't get blocked when it is not in use. The line is a tube into your heart so blood can flow back into it, but is locked off so nothing can come out the end. Blood is very sticky and it does stay in the line, so if it is not flushed it gets blocked and then you'd have to get a new line and that would be another operation. It is an important process.

Medical team and treatment plan

54. Dr Sastry was my consultant. He is a paediatric oncologist. I had a very good relationship with Dr Sastry and have a lot of trust in him. If someone told me he walked on water, I'd believe it. He's incredible. It was Dr Sastry that spoke to me about my diagnosis and it was him that I dealt with primarily. I got on well with the majority of the staff and had good relationships with them. Patients call the younger doctors by their first names. There was Courtney, Ann-Marie, Suzanne and Albert. There were also FY1s and FY2s called Rebecca and James. All the doctors in the ward were incredible. You would be very hard pushed to find someone who chose to work in there that didn't have a big heart. It would be a hard job to do if you didn't.

55. Dr Sastry devised a treatment plan at that point and I was allowed out on the Saturday. The plan was that I would attend day-care the following week before starting chemotherapy the following Friday.

56. I was a bit older and got on well with the doctors. I'm sure they were great with the younger kids too. They knew what that I wanted to study medicine and all of them, Dr Sastry included, would explain everything to me in more detail than they had to; they knew that I wanted to know. The surgeons did the same thing, Mr Andrews, my main thoracic surgeon, talked me through the whole surgery.

57. As regards communication with me about matters related to my treatment, everything from the clinical staff was upfront. The language was very soft at the start. Dr Albert in particular was very good at knowing how my mind worked; he understood me and accepted that I wanted to know everything and communicated with me in a way that was good for me. A lot of people do not want to know everything and prefer to know only what they need to, and let the medical staff do what they have to do. It was a comfort to me to know and understand what was going on, and that made it a bit less scary.

58. All the clinical staff were always incredible at keeping me informed about my treatment. When they didn't know things, they'd say that and it was a comfort to me. The junior doctors were particularly good at that. I didn't like it when people used flowery answers in order to cover up what they didn't know. I liked it if someone was direct enough to say, "Look, I don't know but I'll find out". I knew where I was and I could never complain about that. For the most part, everyone was brilliant in that way. Even when things went wrong and when I caught infections, Dr Sastry, always told me, even when hospital management maybe didn't want him to be so upfront with me. He was very good at exercising his duty of candour and he was always told me what was wrong, why it was wrong, and what he was going to do to fix it. I speak about that in more detail later on.

59. I had a great trust in Dr Sastry. I like plans. I like things that are quite strict, but for cancer treatment plans there is wiggle room involved. He explained to me that my chemotherapy treatment was dependent on my blood counts, which meant that it wouldn't necessarily be an exact 21 day cycle for each block. My plan was organised and the staff knew exactly what they were

going to do; what each thing was going to target; how it was going to get rid of it. It gave me comfort. I liked knowing where it was going and why I was doing it. Ultimately the plan was like a checklist that I went through myself, each step closer to the end. For a lot of my friends on the ward, their parents dealt with this but I wanted to be involved.

60. The timescales in my plan were not exact. Nothing was exact with dates for surgeries and it was dependent on my blood counts coming back up in time for the 21 days to start. I could roughly work out when my treatment would finish give or take a month. I hoped to have surgery in the summer of 2018.

Description of Ward 2A – the Schiehallion Unit, RHC

61. I spent the majority of my time in Ward 2A. There were four specific rooms that the Teenage Cancer Trust had completely funded. They are generally for ages 13 years and upwards, sometimes from 12 and a half years. The TCT rooms had adult-sized beds, they were bigger and the mattresses were better - but that was our secret! The rooms were created for bigger people. There was a parent’s bed as well, it fitted into the wardrobe and it could be pulled down. My mum stayed overnight with me and my dad visited every day.

62. The rooms had wardrobes and cabinets. The TCT rooms had bigger wardrobes than the other rooms on the ward. You could hoard more things and it is possible to accumulate a lots of stuff while you’re in there. There were drawers, one of the drawers was for all our own medicines; that’s where I used to hide all my sweets too. We had space on the wall and there was a whiteboard so you could put stuff up. I tried to make my room my own. I had my duvet and other things brought in. The TCT bedrooms had bigger TVs too. They were all bigger than they are in other parts of the children’s hospital and also the adult hospital.

63. The decoration and colours used in the TCT bedrooms were different. In the other rooms in ward 2A the rooms had rainbows on the wall, which is absolutely lovely for younger children but when you’re a teenager and you’re

there for months at a time you don’t really want to be staring at this rainbow the whole time. The TCT had worked hard to talk to teenagers about what they wanted and used colours that were calming. They put a lot of thought into it and it was a more grown-up environment.

64. We all had our own bathrooms in ward 2A. They were wet-rooms with showers and a toilet. It was a big bathroom so no matter your mobility, it was easy to manoeuvre. It was possible get a wheelchair in the bathroom. Sometimes if you were put on bed rest even if you were going from your bed to the bathroom, you still had to go in a wheelchair. There were railings fitted to the walls and emergency buzzers just in case. We all had our own space and we didn’t have to share a bathroom.

65. Teenagers also had a TCT common room. It had TVs, a PlayStation, an X-box or whatever you wanted to play. We could sit on big sofas and there was a pool table. The common room also had a kitchen where we had our own fridge. My favourite thing was the table. It makes me sound quite sad that my favourite thing was the table, but I loved it. That’s where I spent time with all my friends and that’s where I did my schoolwork. It was really important that we were able to have that space.

66. Further down ward 2A, they tended to group patients together by age. The nurses station was halfway down the ward, and across from that was the playroom for the youngest kids. There was a parents’ kitchen. We didn’t really need to use that because we had TCT but that was where the majority of the patients would store any food they had. There were microwaves with a grill so you could reheat things, store anything you might need, and make a cup of tea.

67. Further down the ward there were transplant rooms. They had double-doors, and an area where people could gown up or take off their shoes, their jacket, everything, before entering the room, so it was all very safe. If a patient needed to isolate or if they were getting their transplant, there were rooms to accommodate that on ward 2A - unlike how it is now, where transplants are

split up on two different wards cross two different floors in wards 6A and 4B in the QEUH. Everything was done on ward 2A. It was our specific space; a wee safe haven.

68. Ward 2A was different to the other wards in the hospital. We had to live there and so those kinds of facilities, there was a lot of extra care put into them that might not be done in other wards. A lot of families funded and fundraised for the facilities and services when their children were better. For example there were snacks provided by fundraisers. People tried their hardest to make it a home from home, as much as it could be. It was never clinical.

69. Ronan was our TCT support coordinator. He was brilliant, everyone's pal. He worked for TCT and ensured that we had everything we needed, even if he was just coming and spending time with us. Thanks to Ronan I've got some of my closest friends. He was very good at knowing who you would get on with if you weren't sick; that was something that was really important. As much as you did have an understanding with people because you were all sick, it's life, not everyone's going to like each other. He was very good at knowing and understanding us, identifying who you would get on well with and introducing you to them. Ronan organised days out and group chats. It made it a lot easier having friends on the ward; someone to spend your time with. It made the days pass a lot quicker and that was the really hard thing about us moving from 2A into the QEUH. We went from being able to spend all day every day together and being able to make our own meals and sit and watch the TV, to being stuck in our rooms. Maybe if we went on a wee walk around the ward, you might pop in and see someone in their room but you didn't really spend time with anyone. It was isolating and being in hospital is isolating anyway.

70. Within the TCT common room, when people's counts were up high enough Ronan would order Domino's pizza for us. It very rare that everyone had counts high enough to allow us to do that so when it did happen it was a celebration. Otherwise Ronan went to the Marks and Spencer's, he knew what we liked and our eating habits and he would bring food up for us to eat. We had days where we could just eat rubbish. During treatment we were

encouraged to eat and anything was good. If it that was ice-cream, it was ice-cream.

71. We had a bit of a laugh on ward 2A. It was a very happy place, which a lot of people think is quite a weird thing to say, considering it is a cancer ward. The smaller kids didn't know what was going on, so they just played all day, running about in the trolleys and having races, standing on their trolleys. I worried that they would pull their lines out from all the running about! It was really happy and to go from somewhere which was a "home from home" to being confined to your hospital room was a bit of a shock. I know that not everyone is lucky enough to go to hospital and when they are there they have got somewhere comfortable to stay, where they watch TV and to sit and make friends. That was not the reason why were in hospital; we were there for treatment. Child patients and families were spending months and months at a time on the ward, so it was important that we had facilities that made it easier.

72. There were a number of charities that provided support on ward 2A. Different families had set up charities, a lot of these were in kids' names. For example, there was Team Jak who provided a snack trolley for the ward. There were crisps, sweets and juices. The charity staff figured out what you liked and for me it was the salt and vinegar crisps. People were so generous. The idea of kids with cancer broke a lot of people's hearts. For example, at Easter there was chocolate and so many Easter eggs. It was really nice. Everyone made a big effort to make life on the ward as easy as it could be, whether they were sending in toys or games or food.

Treatment: January 2018 to January 2019

Initial Chemotherapy treatment: January 2018 to May 2018

73. In January 2018 I began treatment. My first six cycles involved a treatment called VIDE. It was four chemotherapy drugs that would alternate at the same time as having fluids. Initially I attended ward 2B where I was started on fluids and then I was transferred into 2A. I was admitted as an in-patient to ward 2A

and was hooked up for four whole days straight to IV medication. It was usually across five days, and I received all my chemo and my fluids and the other drugs to help with all the side-effects. The day I started, I only took some of my anti-sickness. I don’t know why, for some reason I assumed that I could manage it. That was something I quickly changed for my next round of chemo. I made sure I took all the anti-sickness I could take. I underestimated chemo. I don’t know what I was expecting but it was difficult. A lot of people I spoke to, they weren’t necessarily hooked up for days the way I was, 24 hours a day. I was hooked up for quite an intense period.

74. It was a difficult time. Due to the nature of my diagnosis, there were a number of big decisions I had to make before I started my therapy. Right away I had to decide what would happen if I wanted to have kids. The chemotherapy that I needed and that I received meant that the likelihood of having kids after treatment is practically nothing. Therefore if I wanted kids of my own, there was the option get an operation in the hospital in Edinburgh to take a section of one of my ovaries. The whole procedure would have taken a period of three weeks and it had to happen before I started chemotherapy. I spoke to Dr Sastry. He didn’t think that I had the time, and “waste” is the wrong word. It appeared that I might not be able to spend three weeks having that procedure, and I needed my treatment more. At the age of 15 years old I had to make that decision and I did make that decision. As much as I would have liked to, I didn’t have the procedure and began treatment straight away. It is better I’m here. I can always adopt, but that was a hard pill to swallow.

75. I began chemotherapy and due to the intensity of my regime, I lost my hair really quickly all on one day. It happened after my first chemo which was unusual, it usually takes a couple of cycles. I went straight to the hairdresser. Girls are lucky in the sense that we can put on a wig, boys have a bit more difficulty. Whilst chemo was very physically demanding, emotionally there was a lot more to contend with to start with, which meant that the facilities on the ward were all the more important; to have people that understood, who you could talk to and spend time with people to take your mind off what was going

on. Just being able to access the TCT facilities for that support was incredible. It was amazing the positive difference it made to me.

76. I had my first round then I was discharged and I went home. I practically crawled to the car that first weekend and I really wasn't well after that. I didn't take all the anti-sickness I should have, which was a bit silly, I was being stoic. I then had to deal with the flushing of the line in between and things after I got out. Anne was my outreach nurse so she went with my dad to the school after that first chemo to talk about the procedure, for example, what would happen with my line. It goes into my heart, so if that was ever knocked out it would be very dangerous. I'd bleed out. Someone in school had to know what to do while they were waiting on an ambulance coming. Anne spoke to the school and her and my dad organised what would happen about prelims and schoolwork. It was really important to me that that all continued. That was my focus and I was adamant that I was going to be a doctor. It didn't scare me off it, quite the opposite as I was all the more determined.

77. For me day ten was the low point for my blood counts in the 21-day cycle, that was when I hit zero and had no immunity. A couple of days after my tenth day, I had my first temperature spike. That was normal and it was anticipated. I knew that my body might take a temperature spike as a reaction to the treatment.

78. For paediatrics a temperature spike is 38 degrees or above. If we are hovering at, say, 37.8, 37.7, 37.9 degrees, the staff tend to ask us to come in to the hospital. Sometimes we know before our temperature does. The nurses especially told us if we didn't feel right to come in because we know our own bodies.

79. When you spike a temperature the protocol is that you call the ward. The nurses tell you to take paracetamol and then you head up to the hospital. If you are more than an hour away you get an ambulance. The staff tell you to take paracetamol as they had to know and record the time it was taken. No matter what was wrong, even if your temperature was because of a cold, we

had to follow this procedure because it could change so quickly with us. That is why it was such a strict protocol and why our temperatures had to be checked every four hours whilst we were in hospital.

80. When I got to hospital I attended ward 2B where staff carried out a check-up: listened to my chest, took my blood pressure, took my temperature. From there I was admitted to 2A and IV antibiotics are given and blood cultures were taken. At that point the timer starts from the last spike, if you spike again then your 48 hours restarts. More often than not the cultures come back clear, but it's important that they know what's going on there. In order to be discharged, your temperature has to be below 38 degrees for 48 hours and provided the blood cultures don't show anything then you are allowed to go home.

81. When I had a temperature spike and this protocol commenced, the impact on my chemo treatment was dependent on where I was in my cycle. I always spiked on the tenth day of my cycle after I had my IV medication. I was allowed to restart the next cycle after the 21 days of the current cycle had finished, as long as my white blood counts had risen enough to start. If the counts were not high enough then treatment would be postponed until they rose.

82. My second chemotherapy was the first time I experienced mucositis. All the way from the mouth right through to the stomach is all one type of lining in your body. Chemo is incredible at killing off cancer cells, but it doesn't know the difference between the good and the bad cells, which is why you lose your hair. It also attacks these types of cells in the lining of the body, because they're really fast-replacing like hair, and the body just breaks down. It begins with ulcers and the lining peels away right through. The first time I had mucositis the nurses described it like it was third degree burns inside the body. It is painful. A lot of the kids experience it as a reaction to the treatment and in that sense it is quite a normal thing.

Admission to wards 3A and 1E in the RHC: second cycle of chemotherapy

83. Just after day ten of this cycle, I had a temperature spike with pain and was admitted to ward 3A in the RHC. I started antibiotics and had both morphine and ketamine PCA for the pain. That was the first time that I experienced shifting between wards and it was awful. When I was admitted, because I was not requiring to receive chemotherapy treatment I didn’t necessarily have to be on Schiehallion. Ward 2A didn’t have enough beds, so I was admitted to 3A which is a more general ward.

84. It is Schiehallion protocol that we have our blood oxygen, our heart rate and our blood pressure and our temperature check every four hours without fail, and so that has to be done wherever we are. Unfortunately we often find that when we move to another ward, it’s very difficult to keep up with that. There are different priorities on different wards. But that was the first time I experienced having to advocate for myself, of ensuring that the monitoring had to continue. I ended up getting these things called Tempadots that were very accurate for measuring temperatures. We used them at home and it’s what staff used to take our temperature on Schiehallion. We got some Tempadots from Schiehallion so I could take my own temperature because the temperature thermometer that they were using on ward 3A was out and so my temperature was actually two degrees higher than was being read. Things like that that were difficult when not in Schiehallion. We are needy patients, there is no beating around the bush, and whenever we have to go elsewhere in the hospital issues can arise.

85. The only other wards that were consistent with the application of the Schiehallion protocol for monitoring were PICU and 1E in RHC which is cardiology; both wards have the same monitoring system as Schiehallion.

86. The Schiehallion doctors came to see us on their rounds after they’d finished the round on Schiehallion; they called us the boarders. Wherever we were staying they carried out a check-up and made sure we were all right during their morning rounds. Nursing-wise, you had the nurses from whatever ward you were on.

87. It’s no secret that the Schiehallion ward is referred to as the Hilton by other wards and that’s often a barrier we come up against in wards that aren’t as intense as Schiehallion, and 3A is one of them. During that admission I got to the point when I had to be given ketamine patient-controlled analgesia (“PCA”). I was moved to the Schiehallion because they can do ketamine PCA and teenagers don’t really get morphine. We can but we’re not supposed to get a high dose, it just makes teenagers sick, so I was thankful I was able to be moved.

88. After a few days, I was moved to ward 1E in the RHC because they needed the bed in 3A. I was better and I asked to go home after that, because I’d had enough of shifting about. That brought me to the end of that cycle and that was the first time I went past the 21 days. I had to wait for my blood counts to recover before I could begin the third cycle. At the time I was worried because I was concerned that this wasn’t following my plan. Dr Sastry was very clear, he said he expected this to happen a couple of times and it was all okay.

89. Eventually I started my third cycle and it was a similar experience again. I started having mucositis very early in this cycle on the last day of my chemo. I went home but was back and forward to day-care for treatment. During the third cycle I started harvesting my stem cells and was put on injections that would stimulate my bone marrow to work harder. I harvested my stem cells in day-care during the break in my 21 day cycle. During that cycle I didn’t spike and it was probably because of the bone marrow injections as my immune system had a bit more help. I got a bit of a break and that was the first time I went back to school for a whole day, this was in March 2018.

90. I started my fourth cycle and that was when things started to go a bit wrong again. On the 13 April 2018 it was the tenth day after my the fourth cycle, I was really unwell and I attended day-care. I had really low bloods. My CRP (C-Reactive Protein) was incredibly high, it is a marker they look for in your blood to check for infection. I needed blood transfusions and platelets too. I had an allergic reaction and whenever I get a blood product I have to get anti-

histamine cover in case of a reaction. I was admitted to ward 2A as an in-patient. I was acutely unwell and had sepsis for the first time. [redacted] was home from [redacted] and he visited me when I took ill.

91. In addition I was reacting to the chemotherapy drugs and the soles of my feet had started to lose the skin. My feet were very raw and my neuropathy had got really bad. Neuropathy is nerve loss, the vincristine drug that was part of my treatment attacks your bone. It is very good for treating bone cancers but it's also very good at cutting off your nerves in your extremities in particular. I began to experience trouble walking. I started using crutches at this point and the hospital performed x-rays and tests on my nerves. I got a wheelchair as I couldn't really walk: it was the best thing but that was a low point for me. I felt like I started to look sick. I could throw on a wig and I could do my makeup when I saw my friends and I would look perfectly healthy, but I hated being in a wheelchair. Things started to take a mental toll in April 2018.

92. Unfortunately I was due to start my prelims on the last day in April and it wasn't the best timing. I was an in-patient for a while and was discharged on 20 April 2018. I had issues with my blood count not coming up so my next round of chemotherapy had to be pushed back a week. I managed to sit my first exam at home on 30 April 2018. The next day on 1 May I started my fifth chemotherapy cycle and was admitted to 2A for four days of IV chemo. This time I sat my French prelim, my maths prelim and my maths final exam, all in the hospital while in receipt of the fifth cycle of chemotherapy.

93. I had a lot of anti-sickness drugs to get me through it but I did it. The exams helped to pass the time in that cycle. In hindsight, I have no idea how I did it though. This was not the plan: had I not experienced the push backs on my previous chemo cycles I would have been out of hospital to sit my exams. Due to the push backs and because I hadn't been well I had to sit my exams in the ward. This was the start of things getting bad and of the infection starting but I didn't know it at the time. Everyone on the ward made provision for me, the staff were so excited, they put up posters, like "exams in

progress", "everyone quiet". I was the first to sit exams on the ward, it was quite a big deal.

94. I was admitted to ward 2A with another temperature spike on 9 May 2018. Blood cultures were taken but nothing came back at that time. I was an in-patient for a week and was discharged on 16 May 2018. My temperature came down and like before it was hovering under 38 degrees, but I was allowed to go home and then start my next cycle. We knew something was coming, during that admission I kept spiking. A temperature spike is 38 degrees. I had really high temperatures and they never quite came down, they always came to 37.8 degrees and sat there. My temperature was hovering and it was not a good sign but I was allowed to go home.

95. I began my sixth cycle of chemo on the 22 May 2018 and was discharged on 26 May 2018. I really wasn't well on the tenth day after the sixth cycle. I was admitted to ward 2A on 31 May 2018. This was the second time that I was rigoring with the high temperature. My haemoglobin was on the floor. I needed a few blood transfusions. My rigors were going crazy and I was given boluses which is fluid resuscitation. That was the second time that had happened. This seemed to be worse this time.

96. It was really, quite frightening. There were eight or nine members of staff in the room all trying to get access via a vein. My line could not be used as it was believed to be the problem because my haemoglobin was so low and because my temperature was so high. My body was in septic shock, my extremities started to shut down to keep the blood where it needs to be in the main central system. It was hard for staff to get a line in my veins and that was why there were so many of them in the room.

Healthcare associated infection: Mycobacterium chelonae – May/June 2018

97. I found out about the mycobacterium on 1 June 2018. However the result was from blood cultures that they had taken from me on 9 May 2018 when I was admitted after my fifth cycle. It took until 31 May 2018 for the mycobacterium

chelonae to grow. It is called the silent bacteria because it can take 20 days to grow. That is a lot longer than the usual 48 hour for blood cultures, unless you have the special bottles for mycobacterium, which the hospital didn't have because they didn't anticipate it was this bacteria. Therefore it took a long time to grow.

98. On 1 June 2018 Dr Sastry told me that I had a bug called mycobacterium chelonae. He told me that it was an environmental bug, most likely waterborne, and that I would have to have IV antibiotics for at that time they believed to be two months before I would continue on oral antibiotics and we would have to liaise with a specialist in Edinburgh because no one really knew and understood what this bug was. It wasn't normal.

99. He was very upfront that he didn't know anyone that had had it and he'd never dealt with it. He said he understood that it was the first case in 20-something years in paediatrics, that it was an environmental bacteria and it was usually water related. He was also upfront that they were just going to have to wait and see how to treat it and that he was going to have to trust the specialist, Professor Lawrence, who he was in discussion with in Edinburgh.

100. That was when I saw Dr Sastry waver a bit. That was when he was starting to be held accountable for that which he was not responsible. Dr Sastry was responsible for my whole treatment and my overall health, meaning antibiotics and other medications and procedures. However, I was made sicker by the environment, therefore he was being held responsible for something which should not have happened, he had to come up with treatment plans for things other than my cancer. He had to start balancing what was more important: was it treating me for this bug and not giving me my chemotherapy which in turn could cause cancer to take hold, or would it be giving me my chemotherapy, bringing my immune system down and making the bug take hold? It was scary enough without having to see the staff not knowing what to do. It is an impossible decision. It's something that no one should ever have to decide. It was a balancing act. It wasn't fair for Dr Sastry.

101. On 1 June 2018 I had an emergency surgery under general anaesthetic to remove my Hickman line. I was put on PCA for pain relief.

102. I started on IV antibiotics, all day every day. I was on them for a month. No one in the hospital had really used these antibiotics and I don't know what type they were. Half the time, the nurses couldn't even pronounce them. The side-effects that came with the antibiotics were horrible. It was like bleach running through my system so I was really very ill and I unfortunately started to have problems.

103. I kept collapsing. The staff found out that the electrical activity of my heart was off so when my heart pumped blood it wouldn't fill up quickly enough which would cause me to collapse. I was confined to my bed, I wasn't allowed out of my bed unless it was to use a commode. At the age of 16 years old this was embarrassing. It's just yet another bit of dignity that was taken away from me at that point. It was not fair.

104. Eventually I was allowed to get a line again, but before that I had to have cannulas all the time and the staff were really having a hard time with them. My cannulas kept tissuing which is when my veins would collapse and so the cannula would come out of my vein but it would still be in my hand so while the medicines were going in, it pumped into the surrounding tissue and that would solidify and swell up. It was painful. My veins just weren't having it. If I hadn't caught the bug then I wouldn't have had to go through this; on that view this was unnecessary but I needed my antibiotics.

105. Due to what had happened and the impact of the bug on my treatment plan, I couldn't have my surgery at that point. My treatment plan had to change. Instead of surgery I went straight onto the next chemotherapy block. This was yet another cause of anxiety because I don't like plans changing, I like organisation.

106. I was an in-patient for the whole of June 2018. Professor Lawrence in Edinburgh had said that he thought that the month would be enough at this

point, and so from doing the two months of IVs I just did one month then I went straight onto oral antibiotics, so I was allowed home. I still had to attend day-care in between then for a couple of days. I think I got about a week home and then I was back in again for chemo.

107. I didn't have a new line fitted straight away, the doctors wanted to get the bug under control first before they put more plastic in my body, because the line is plastic and the bug likes to cling to things like that. A new line meant another surgery and another general anaesthetic.

108. So my new line was fitted under general anaesthetic. Dr Sastry had to re-arrange my plan. I started a different regime of chemotherapy and the new plan was that I have my surgery after my tenth chemo. After surgery I'd have two chemotherapies to round up any last remaining cells after surgery.

109. The regime required three days IV treatment instead of four whole days, and it was a new drug and two were dropped. I underwent radiotherapy at the same time.

110. My dad and I went back and forward to the hospital every day. I had my weekends at home. I continued to experience issues still with my mobility and I still was in a wheelchair. Mentally I wasn't good because I didn't have my focus anymore. A lot of my friends had now left. They'd all finished treatment so it was just me and I had this bug and I had no idea if it was actually treated: no one could tell me that, no one could tell me if it was gone, if it was going to come back, what it was going to do. No one really had many answers.

111. That was when I became more aware of issues my dad was dealing with in the background, he was trying to find out what this bug was. The thing that always got me was that management never spoke to me and as much as I get that I was under 16 and they were dealing with my Dad, all of the doctors on the ward never saw my age as an issue. With the clinical staff, Mum and Dad would always be present, but the staff always spoke to me. This change in communication was new and that was uncomfortable. It was something that I

had to start dealing with, which was that they were not always going to come straight to me when that bug came on board.

Surgery: 19 October 2018

112. I continued to receive treatment. I was admitted in between treatment for mucositis after all the chemo. Eventually I finished my radiotherapy and I was generally okay. The bug seemed to be gone. I was still on antibiotics and my surgery was scheduled for 19 October 2018. Prior to surgery I was given two weeks of a break at home.

113. The night before surgery I was admitted to the surgical ward 3A in RHC. I knew that it was a big operation, the surgeon was operating on my chest and I was aware of all the complications that entailed. I knew they were working with my diaphragm, and that I might have difficulties breathing. I knew recovery was going to be painful. I knew I needed reconstruction surgery. The surgeons talked me through it all and I was generally okay with it. I had a lot of faith in my surgeons and the night before surgery I refused a sedative which is normal procedure for the kids that get the big surgeries; we usually get a sedative. I genuinely felt I didn't need it, but later at night I couldn't stop shaking and everyone thought it was maybe nerves. Eventually I thought, "Maybe I am nervous."

114. I was adamant that I was okay, but one thing the staff didn't do was the Schiehallion protocol of testing my temperature overnight every four hours. I was first on the list the following morning for surgery. On the morning of 19 October 2018, everything was signed and ready to go. I was in my gown, the bed was outside the room, and ready to take me down to theatre. I even had my surgical stockings on. The surgical team were performing the last checks, and they checked my temperature. It was over 40 degrees, which is incredibly high. The anaesthetist said she wasn't happy, it wasn't like it was just a couple of points of a degree over, it was a few degrees. She said it was way too high and she was not taking the risk. She was very apologetic. Of course I was grateful that no one was taking the risk.

115. I was admitted to ward 6A. At this point Schiehallion had moved from the RHC to ward 6A in the QEUH. I started on IV antibiotics again. Staff took all the blood cultures. This time they had the proper blood culture bottles for mycobacterium and it was confirmed fairly quickly that it was mycobacterium. In the anaesthetist's words, "Thank God we didn't do the surgery because had it gone ahead with that bug on board, it would have been catastrophic". I understood that to mean that I probably wouldn't have woken up. I think someone was looking out for me that day, that's the only way to put it.

116. I had my line removed again, this being the second time my central line was removed. After a few weeks in order to resume chemotherapy, I was given a PICC line in my arm, I had a line going into and just up my arm so I could continue getting my antibiotics and my chemotherapy.

117. I started again on antibiotics for the bug, only this time the doctors had to think of new ones because the bug was likely resistant to the antibiotics that I had been on before. We sat down with Dr Christine Peters, the microbiologist who had been liaising with Professor Lawrence in Edinburgh, and Dr Sastry. They came up with a different group of antibiotics for me to start on; each as horrible as the last. And at that point I asked the doctors if they knew that it wasn't going to come back again. They were quite frank and said that they didn't know, that they could only try. This time I was prescribed two months' IV antibiotics and I started on that.

118. As horrible as it was the last time being hooked up all day and overnight to antibiotics, this time the issue was that I was in ward 6A. I didn't have the TCT. I didn't have any of my friends around me. I didn't have the opportunity to leave the room. I didn't have a kitchen. Depending on who was working, they'd make a hot water bottle for me, but the facilities were lacking. I felt very sick and was back to that mind-set of "Yes, you are sick". In 6A the TVs were always broken; if they were working, they were a lot smaller in the adult hospital. My mum didn't have a proper bed. My mum has rheumatoid arthritis and she had a bed she had to pull down every night and try and shift the

mattress on top. I was concerned at mum having to do this when it was already hard enough her dealing with me.

119. At this point we were all acutely aware of all the issues going on in the hospital. We weren’t in our ward and most days we would find out what was going on from the news before we would find out from any management staff. The clinical staff didn’t know what was going on either, they were finding out what was happening on their way to work in the morning from the radio. There was no one telling us what was happening. Very rarely did anyone come round and say ”This is what’s happening, this is what we’re doing to fix it”. You could see how exasperated the clinical staff were, they knew something was wrong and they had all these other problems they had to balance with providing care: prophylaxis, the antibiotics. You could see the trust was breaking down between clinical staff and patients and you need trust during all that.

120. I still had complete trust in Dr Sastry. Staff told me that I was going to be okay with this bug, no one could say that it wasn’t going to come back in another couple of months’ time. Most of the time I thought “Why was I feeling so bad if it was going to come back?”. It made it very difficult to focus on school. I had been doing six Highers but I had to drop three, so I only did English, Spanish and French. That impacted on what I wanted to do. To study medicine I needed five ‘A’s first time and I needed sciences. I couldn’t do sciences because I was stuck in the hospital. I couldn’t get in to school to do the assignment which was an experiment. I couldn’t sit any sciences. I still applied for medicine at university, but I knew at that point that I wasn’t getting in to the course. It was yet another thing to contend with; another thing that was taken away. It is difficult enough having cancer as a teenager never mind everything else that’s thrown at you: the bugs and extra time in hospital, extra sickness, extra complications. I had an issue with my heart, the long QT and staff had to balance medications. They had to consider the benefit of stopping symptoms versus what it was going to do to my heart; it was yet another balancing act that they shouldn’t have been required to undertake.

121. Prior to starting these antibiotics, I'd had my kidney tested. Every two chemo treatments I received a kidney function test. My kidney function had remained steady at 98 per cent the whole way through treatment and it was still at that point in October 2018. They tested it again in December 2018 and it had reduced to 54 per cent. No one could categorically say what caused the reduction in kidney function, but the only thing that was different in terms of my treatment was that I was on all of those new antibiotics; ones that were known to cause issues with your kidneys. At that point I knew that would cause issues for me, also taking into account the fact that I hadn't had my surgery and I had to go away with my other chemos to make sure that they finished. The change in my treatment plan meant that I wasn't going to be able to have two final chemos after my surgery to mop up any cells, to ensure cells weren't left over. I ended up having these chemos before surgery rather than after. I had to just trust in the surgeons to ensure there was nothing left behind and that's not something that they could definitely control.

122. If no one else in the ward had this bug, how do they know the treatment was going to work, and how do they know the bug was gone? Another worry that I thought about all the time was what this was doing for the cancer, which of course was the reason I was there in the first place. I knew that my particular diagnosis was difficult and I knew that the chances of it coming back were high, but it was unsettling to know that what would be the preferred treatment plan was no longer viable.

123. It was hard to feel completely safe at that point and it was nothing to do with the clinical staff because I trusted them implicitly. I knew that I had the best care and I could only put my trust in them, but I would have had to be blind not to see the issues in the building itself. It was very uneasy. I got out just before Christmas, everyone made it their mission to help me get out. I was discharged on 21 December 2018. I was still on oral antibiotics. My surgery was scheduled for 16 January 2019 which was a year to the day of my diagnosis.

Surgery: 16 January 2019

124. I had my surgery on 16 January 2019. Following surgery I was admitted to ward 3A in the RHC. The drugs I was given differed depending on the ward I was in. For example, after my surgery, I wasn’t supposed to be sick, because I’d just had surgery on my abdomen and chest wall. I wasn’t supposed to be on morphine because teenagers got really sick on morphine. Originally it was intended that I would go into PICU but I went back to the surgical ward 3A instead. There wasn’t a bed in PICU. As I was on surgical, they wouldn’t give me ketamine, which is the PCA I would have been given if I was in Schiehallion. The epidural that I had been given didn’t work because of the tumour in my spine, so I was without pain relief for three days until eventually the doctors from Schiehallion kicked up that much of a stink. On the first night a PICU nurse gave me a special PCA, so I could get ketamine, and then after that Schiehallion nurses came and gave me pain relief.

February 2019 to August 2019

125. Following surgery I finished treatment. My scans were clear and I rang the bell in February of 2019 to mark the end of my treatment. I still attended day-care because of the antibiotics I was on. Due to the side effects and other problems they were creating, I had a lot of problems in my gastro system. I had trouble absorbing anything from my food so I was on supplements to try and keep my vitamins and my electrolytes up. I had to constantly go for ECGs because of all the medications I was on, to make sure that that electrical activity in my heart was okay and it wasn’t going to cause an arrhythmia. The antibiotics made me quite sick and due to the side-effects I was constantly being monitored and having my bloods checked up at the hospital.

126. My PICC line was removed just before I got home in February 2019, so I had to be jabbed constantly when I was up at the hospital. I think the nurses used to dread when someone had to take my bloods when I was going up to day-care.

127. I stopped taking the antibiotics for the mycobacterium chelonae in July 2019. This was agreed between Professor Lawrence and Dr Sastry because the antibiotics were doing me more harm than good. Initially they had expected me to be on them longer but because of all my gastro issues, they didn't think it was good that I continued taking them any longer.

Communication about another case of Mycobacterium Chelonea: July 2019

128. I was back and forward between February 2019 and summer of 2019. On one occasion in July 2019 my dad was away on work, my mum and I were in day-care for a check-up as usual, so we didn't anticipate anything happening. Dr Sastry sat us down and told us that someone else had contracted mycobacterium chelonae.

129. I built up a relationship with a lot of kids on that ward. When I was in 6A everyone did their own walks around the unit and said hello. Eventually I got really close with a lot of the wee kids, but I also had other friends from TCT too. All I could think about was who it was and were they okay. The only reason I was ever okay when I had sepsis was because I lived under an hour away and got to the hospital in time. You only have an hour to get to hospital when you have sepsis. Maybe they weren't checking their temperature, maybe they didn't know?

130. It was in IMT minutes that my dad was to be told so Dr Sastry was under the impression we had been told at this point, but of course we hadn't been told. When Dr Sastry realised we didn't know, he told my mum and I himself as he felt it was right that we knew. After he told us, he was on the phone to a member of the management team about the fact that he had told us. He had to step out the room because we could hear the conversation on the phone. It all went very quiet when they found out that we knew. We later found out that an order was given that someone was to tell my dad but that message had never been passed on. This comes back to what I said about how I completely trust Dr Sastry, his communication was always amazing. He felt

that it was part of his duty of care that he had to tell me. In terms of trying to investigate what happened, the only reason a lot of things weren't getting done was because it was thought that I was an isolated case. But this was no longer the case and it would benefit to know if anything was connected.

131. It was really hard for me knowing that someone else had mycobacterium chelonae. I was very close with a lot of the wee kids and the idea of them being that sick and them potentially having to go through that was really difficult to deal with. Of course I was never told who it was, that would be wrong, but amongst patients you end up finding out. We speak to each other and we end up telling each other; of course, the staff never told me who it was. I now know that the other patient is okay, and I'm so glad but at the time I didn't know that.

132. This event set me off again and this was when I started to get really angry. There seemed to be no answers. No one was really learning or listening. Certainly not anyone outwith the clinical staff, and we could see the frustration within our team on the ward. They wanted something to be done.

Relapse: August 2019

133. It wasn't long after that that I relapsed. That was in August 2019. As my kidney function was reduced, my options were limited. There were a lot of things clinicians couldn't do because my kidneys would shut down. I presented with: maintenance chemotherapy to give me time; a lighter chemotherapy that might work but unlikely; or we could take the risk on my kidneys and try a programme called ME-ME which was really, intense chemotherapy followed by a stem cell transplant. For the intense option the chemotherapy would be so harsh that my counts wouldn't recover, therefore I'd need a stem cell transplant for my blood. Thankfully Dr Sastry had the foresight to harvest my stem cells in 2018, so I could be my own donor and there would be no rejection.

134. The risk was whether my kidneys would be able to take it or not, but for me that wasn't really a choice. Of course I was going to try, I'd never forgive myself if I didn't. I chose to go ahead with the intense chemo and the stem cell transplant. The plan was that I would undergo this treatment twice: chemo and transplant.

135. Before that I asked if I could go onto the maintenance chemo to get them all over with. To me, it was important to do something as important as that in case things didn't go okay. They let me do that and so I did. As it was on a form of chemotherapy, I had temperature spikes. I was back and forward to the hospital but I was never put back on antifungal prophylaxis because of my long QT in my heart. We didn't anticipate me having to be in the hospital building that much. It was expected that I wouldn't need antifungal prophylaxis because it would cause more harm than good at that point. Of course things are never that simple with me. I took temperatures which meant I had to go in as an in-patient a couple of times. I was in the hospital with no prophylaxis on board. In November 2019 I was admitted to the hospital with PCP pneumonia and I ended up in PICU because I needed help to breathe.

Admission: November 2019 - pneumonia

136. I was an in-patient for about a month. PCP pneumonia is fungal pneumonia. Dr Sastry believed that the most likely cause was because I wasn't on the antifungal prophylaxis. That is something I don't know for sure but it was yet another thing.

137. I got out of hospital just in time for my Make A Wish in the December 2019, just before Christmas. I had a respiratory physio and it was a big deal for her to get my lungs working again so that I was able to sing with Paolo Nutini. Everyone was helpful and made sure that I got out in time to do something good for me.

138. We were waiting on kidney results, and if they deteriorated any more, I wouldn't be able to get the stem cell transplant. Dr Sastry let me go on holiday

with my family. I went away at the start of January 2020 to Dubai. The day I came back, I got a phone call to say that my kidney results hadn’t dropped. The next day I went in to the hospital to get another line fitted so I could receive my stem cell transplant.

Stem cell transplant: January 2020

139. When I had my transplant that I asked to receive the transplant in ward 4B, because I wasn’t getting a donor for my stem cells there was an argument that I stay on 6A. However a couple of nurses on the ward had advised us to really argue for receipt of the transplant in ward 4B.

140. They said just to make sure I was in Ward 4B because the nursing is practically one to one and that is needed after transplant and the ventilation in the ward was different. I believe that ward 4B had its own ventilation system because it was a transplant ward. I think it was similar to what it was supposed to be on Schiehallion that we had our own system in ward 2A. I don’t know exactly how the different systems worked. The nurses that were close to us advised me to ask to go to 4B for those reasons. We did argue the case and eventually I was transferred to ward 4B for transplant after I’d had finished my conditioning chemo. But I wasn’t on 4B particularly long because I went to PICU where I stayed for 18 or 19 days and then I just went back up to 6A rather than returning to 4B.

141. I knew the transplant was going to be harsh. The melphalan in the drugs in particular, you’re only supposed to get one dose but because of the sarcoma I got four days of it. The doctors were a bit worried and they kept coming in to check on me. However it wasn’t the melphalan that was the problem. On the Sunday of my conditioning chemotherapy, I was given an overdose of etoposide phosphate, which was one of my chemotherapy drugs. I was given 14 per cent extra, and that all came with its problems. I got mucositis and according to the doctors, it was the worst they’d ever seen. The dentist couldn’t believe it. I lost a whole part of my tongue. Everything had burned away and it that was the chemo that did that.

142. I was admitted to PICU because of the pain relief that I required. Given the amounts of pain relief that I was on, it was very easy to forget how to breathe and I did that couple of times, giving everyone around me a fright.

143. On Tuesday night I was admitted to PICU and on the Wednesday morning I had an episode of delirium. It was due to the combination of drugs in my system and I was thinking about the overdose and the bug and all of the other things that seemed to go wrong. I had a manic episode where I thought that everyone was out to get me and I didn’t really recognise anyone, including my mum. I tried to take my line out and I managed a bit but staff stopped me in time. I was given propofol and was knocked out for a bit. The emergency buzzers went off. All the staff were in the room and lots of staff came down from Schiehallion. Dr Sastry didn’t come in the room just because of how I was, he wanted to maintain the same kind of relationship with him.

144. This happened due to of the amount of medication I was on because of the pain I was in. My pain didn’t seem to go away and it seemed to be getting worse. There were different pain reviews and there was a change of pain medication to see if it would make a difference.

145. Eventually clinicians found out there was a problem with my liver. At the time they thought it was VOD, which is veno-occlusive disease, which is something that they anticipate can happen with my treatment, so I was treated for veno-occlusive disease. There is no treatment as such, they ensure that you have platelets because you go through platelets very fast when your liver’s got problems. The staff were having to get the freshest platelets they could and pump them into me. Because of that and due to my blood type not being the most common, something happened with one of the bags. I don’t know if it wasn’t completely screened, but I was given a bag of platelets that had a bug in it, a bug responsible for acne. Acne is not a big deal to people, but I had just had my transplant so I had no immune system. A newborn baby had more of an immune system than me because they have their part of their mum’s

defence antibodies. When you have a stem cell transplant you have absolutely nothing.

146. This new bug was on board, but at that time I didn’t know it was there. I started having the temperatures again and similar symptoms to the mycobacterium chelonae bug. I thought it was back and that was something I feared because having the transplant could knock my immune system back, allowing the bug to rear its ugly head.

147. Dr Sastry wasn’t there, he was away on a conference, so it wasn’t him responsible for me that week and it was another doctor. He decided that they felt it would do more harm than good to tell me about the acne bug at that point. This is where my dad and my opinion differs. He thinks that that was the right thing, I don’t. I would have preferred to have known rather than think the bug was on board. I understand why they did what they did and why they didn’t tell me. They wanted to wait until I was a bit more stable before they told me something like that, especially after what happened with the delirium.

148. I understand it. Maybe it is just me being stubborn, wanting to know. But it was yet another thing; every time I’d tell this story I just seemed to have problem after problem but that’s just the way it’s gone for me. I seemed to get every side-effect, every problem. In terms of future options, I can’t go ahead with the second stem cell transplant because of the issues with my liver. Surprisingly my kidneys stood up and they’ve not changed, but my liver is really damaged. Now clinicians don’t think it was veno-occlusive disease. It looks like I have chronic liver disease and that will never go away, whereas veno-occlusive disease does.

June 2021

149. I managed to get a year post-transplant then unfortunately a tumour they had believed to have been dead has grown in the last couple of months; so it’s back. I will start radiotherapy in a couple of weeks, a new type of radiotherapy that’s sublative. Where I’m sitting now, there are limited options for treatment.

I've got my problems with neuropathy, so I still can't feel my feet or my fingertips properly. I can walk better, but it is not great. I've got chronic liver disease. I have half of the kidney function I should have. I've lost the highest pitches of my hearing because of the antibiotics. I've got prolonged QT in my heart. As regards my gastro system, I have problems with absorption. I have oesophageal motility and I can't swallow food properly. I can't get the right nutrients from food, there are certain things I cannot eat and my diet had to completely change.

PHYSICAL EFFECTS

150. I'm still here, but there's a lot of things wrong with me that shouldn't be. I shouldn't have lost parts of my hearing, nor should I have reduced kidney function or have my liver not working. Neuropathy, is expected from the cancer treatment. I probably shouldn't have the prolonged QT but I was on too many drugs that that was inevitable. These are all avoidable things that I now have to live with. In the event that cancer comes back, these physical effects make my options for future treatment very reduced. Thankfully, at the moment I have just one isolated tumour which is treatable, but if it wasn't then I would be in a very different position right now.

151. In terms of my treatment options, there's not very much we can do because of all of the physical issues I have. My body probably wouldn't be able to take it. It is a worrying situation.

152. I also have to contend with the fact that the mycobacterium chelonae bug could come back at any time. It's a cousin of tuberculosis and it lies dormant in the body. I will never be rid of it. I can only hope that it is suppressed enough. As long as I don't need any more treatment, I hope that it stays that way. If I ever I need any more chemotherapy treatment, it should stay suppressed but I can't guarantee that.

EMOTIONAL EFFECTS

153. As regards the emotional effects related to the building and what happened, when I was first diagnosed, I didn’t get upset as such. Obviously I was upset but I didn’t need help. I didn’t need to speak to anyone as I’m quite good at dealing with things. But there’s only so much someone can take and with everything that went wrong, everything that could have been prevented, I ended up at the stage that I couldn’t deal with it myself and was in quite a low, dark place. I needed my psychologist for help, and it is something I don’t like to think that I need. It’s not something I ever wanted. I would have dealt with it myself if I could have, but it’s now at the stage I can’t and so every two weeks, if not every week, I have a space available every week to speak to my psychologist. We go back and forward and I don’t know really where I’d be if I didn’t have that.

IMPACT OF THE MOVE OF SCHIEHALLION TO WARD 6A IN THE QEUH

154. After the move to Ward 6A, Ronan’s job got very difficult. All he was able to do was go around the rooms, see people individually and spend time with us individually. He tried once or twice to get us organised into this wee corner room, but invariably the doctors needed it because they didn’t even have enough facilities on ward 6A either. Any kind of socialising was dropped. I tended to get pizzas more often because that was the only good thing, because if you weren’t with other people, if your counts were good, you would get pizza.

155. We all became very isolated. Ronan had to split his time and run about the ward to see people so that they weren’t on their own. He would get things just to keep people occupied and try and organise games. There was only one mobile PlayStation so unless you had your own, you probably didn’t get to use it as much. It was easier to be sick then; for a lot of us “sick” was a mindset too. It was easier to believe you were sick when you were in ward 6A. The food in hospital is horrible and there’s no sugar-coating it. No one ate it, and we really heavily relied on the TCT kitchen and the parents’ kitchen in ward 2A. Once they were gone, that was it. We were either forced to eat what was

on the trolley or you didn't eat and you had a feeding tube. The first time I got a feeding tube was on 6A.

156. After ward 2A closed, it was difficult for the charities to access ward 6A. Ward 6A was quite full as both wards 2A and 2B were moved to ward 6A. Day-care patients were coming and going. It was hard for charities to come in, but they handed sweets in and they were brought round our rooms. Eventually a parents' kitchen was created, but it wasn't the same. It didn't have the same space or fridge or facilities; but it was something. That was done latterly when I was in at Christmas. The only Christmas I had in hospital was in 6A. I am told by other patients and staff that it was different. For example we used to have different football teams come in to see the kids, and that Christmas they still came round but they would see people individually, whereas before I know a lot of my friends all met footballers and rugby teams together.

157. One of my closest friends on the ward was a big Rangers fan and I would have absolutely loved to see his face when the Celtic team came in. It became more difficult to facilitate things. It wasn't the same atmosphere on ward 6A. People were striving to make things easier for patients, but it was harder for them to do that. The move made a lot of people's lives very, very difficult.

158. There should have been a lot of activities organised that couldn't take place because we were all in separate rooms. There was nowhere to meet. We were still very lucky though. People sent gifts and food. We still got all of that but individually. The isolation was difficult. Group activities couldn't happen.

PREVENTATIVE MEDICATION

159. I was on prophylactic medication. From the very start of chemo, depending on age, patients are put on cotrimoxazole which is a broad spectrum antibiotic. As I was a teenager I got it more often. I was always on antifungals as well, one was fluconazole I think.

160. At the start of treatment we just believed that was normal and it might have been. As 2018 progressed and when everything started to go wrong for me and in the hospital, we were aware that all the other patients were on these medications, particularly the antifungals, and that it was due to the issues with the hospital.

161. We were told that it was because of the issue with the cladding at the entrance to the front of the RHC, that everyone was on antifungals. Dr Sastry was always quite frank with me. I’m not entirely sure how I found out, because a lot of the time we knew things because of my dad pursuing things and other times we knew because of Dr Sastry, so there was a bit of overlap there. Certainly with the antifungals, Dr Sastry was very upfront with me, because he was quite frank when I got the PCP pneumonia that I had to be on antifungals.

WATER

162. When I was first admitted to ward 2A in January 2018, I was able to use the water. There were signs up in the rooms saying that we had to run the water for three minutes before going in the shower. We weren’t on bottled water at that point. We were allowed to fill up the kettle from the tap, but then in February 2018 we weren’t allowed to do that anymore. At that point we started to use bottled water and then that was when things started to change, occasionally the water was switched off in the wards and we were not allowed to use the toilet, we had to use bedpans. For patients bedpans are fine if you have to be monitored, but if you weren’t on fluids and you didn’t need to be monitored, it was horrible. The staff brought these stands into the wards for washing hands, like what you would get to wash your hands at a festival. It was horrible.

163. There were filters on all the taps and on the showerheads. People would come into the patient rooms and test the water with these filters on quite regularly. I got used to guys coming into my room fairly regularly on both wards 2A and on 6A.

164. The filters were put on after the issues with the water started coming about in around 2018. We were just told via written letters from management and general discussion on the ward that the filters were to filter out whatever was in the water. We didn't know what it was in the water, we just knew there was something that wasn't good so they had to put filters on to make sure that it didn't affect us.

165. We just kind of knew there was an issue with water, we didn't know what was wrong. It was all very disjointed. No one exactly knew what was going on. The staff didn't exactly know what was going on. We were just told not to use it. We used to get letters and they would send it round the lead nurse on the ward to come round and she told us that for the next however many hours we couldn't use the water.

166. Bottled water was introduced in February 2018 and we have been drinking that on the wards ever since, in both wards 2A and 6A. The water was okay to shower in apart from one time when the water was turned off. When the patients were moved from ward 2A to ward 6A we were told it was a different water supply. Once we were in 6A, the management came round with the lead nurse and they were very quick to reassure us that it was all okay and that it was different water supply. They told my dad when he was working with them that it was a different water supply, that it was fine, that it was perfectly safe. The clinical staff were under the impression it was a completely different water supply. It was us that told Dr Sastry that it wasn't.

167. When I was first diagnosed, I was told by staff to run the shower for three minutes before I could use it. There was a sign up in all the bathrooms saying this. On the days that the water was switched off, we weren't allowed to use the shower if they were doing something to the water. We were told a couple of hours in advance that the water was going to be switched off, and if we wanted to shower to do it before then. The staff gave us the hospital grade wipes for patients to use when this was happening. You don't really feel clean if you just wipe yourself though, it was not nice. The water was often switched

off in 2A. There were times we weren’t allowed to use the showers and I couldn’t flush the toilet.

OTHER OBSERVATIONS ABOUT THE HOSPITAL BUILDING

Hydrogen Peroxide Vapour (“HPV”) cleaning

168. The hospital did hydrogen peroxide vapour (“HPV”) cleaning on the wards. During the summer of 2018 when I was an in-patient on ward 2A with the bug, I was moved from room to room as they blocked off the rooms to do HPV cleans. The staff made sure that people were not on the ward unless they absolutely needed to be. I was so unwell and I had to stay on the ward so I witnessed what was going on. I was moved from room to room as the cleaning was done throughout the ward.

169. When the HPV cleans took place, a machine was put in a room and then the rooms were sealed off with orange tape to stop any fumes getting out just because of the type of patients we are. After a period of time the room was unsealed and they’d move onto the next room.

170. I knew that I was being moved so the cleans could take place. I wasn’t aware why they were doing it, I just knew they had to do it. We got a letter explaining that they were going to do this clean and then the lead nurse again came round to speak to us. The first time it happened, I was moved right away. When the cleans were going on, we just didn’t unpack. Eventually they moved me back to my room, it was the room that I was always in, which was room 6 in Ward 2A.

Cladding

171. We also got a letter at one point about the cladding on the outside of the building, we were no longer allowed to use the entrance to the RHC due to fungus in the cladding. We weren’t allowed to use the main entrance in the adult hospital because the windows were falling out. We had to go and use

the door at the discharge lounge, that was where everyone smoked, but that was the best option. It was either walk in through the cladding that had all the fungus, walk and have a window fall on you or go in through smoke: so we chose the smoke.

172. I received the letter about the cladding. I think it was when I was an out-patient and visiting the day-care in ward 6A. I got given the letter then.

Windows

173. I was getting the taxi back from radiotherapy at the Beatson when I was an in-patient in the RHC, while I was still receiving chemotherapy. I came out the taxi in my wheelchair and a window had fallen out of the building in the QEUH. The glass was everywhere on the ground. When I was going into the hospital building in my wheelchair, the taxi driver stopped and he lifted the wheelchair up and over so that I could go round rather than my wheels going through the glass.

COMMUNICATION

174. Clinically, the staff’s communication was always incredible. I could never complain. It was with the management that I have witnessed issues in not being upfront. I feel like they don’t learn, even to this day. Some communications are insensitive and very generic. They just don’t quite seem to understand that it’s real people they are dealing with.

175. When the Oversight Board report and the main Case Note Review Report was published, patients and families received a letter from the Health Board. Everyone that had been a patient since 2015 received the exact same letter: so whether you were still in treatment, you were out of treatment, the patient was now over 18 and you’re receiving the letter yourself, or if the child had passed away - everyone received the same letter. The letters were written to parents about children in the present tense, it was completely insensitive. A lot of these children didn’t make it and were no longer here. I was annoyed as

they wrote to me as if I was a parent, but when you compare that to writing to parents as if their child's still there - it's horrible. In my opinion it's unforgivable to put someone through that when they're already suffering enough.

176. There's a closed Facebook page between the hospital and families and I am now old enough and am allowed to be on it. I used the page to make it very clear to the hospital about how I felt about the letter that was issued to families. I received a letter from the Chief Executive apologising which was wholly inappropriate as she addressed the issue as if the biggest thing in my life was COVID. The response had the line "hope I am keeping well in these strange times". COVID is not the biggest concern, cancer is. I feel as if they don't seem to get that it's people at the centre.

177. In terms of the closed Facebook group, I don't know about the impact that it has had. Sometimes the administrators could do a bit more with it, for example how they communicate and answer questions. I understand that that's not their job necessarily but parents are obviously stressed and they've been told that that the Facebook group is their way to communicate with the hospital. The page administrators need to communicate to the clinical staff what people are saying in the Facebook group. Sometimes the clinical staff aren't aware of it and that is causing a breakdown in trust. It's a bit disjointed. I am aware of a few times where people have been stressed unnecessarily because a message posted on the group is not passed on right away to clinical staff. Maybe it's because it's not the right place to put it, but that might be a good thing to communicate to people. There seems to be an imbalance, whether or not that's the right place for people to put these kinds of medical worries. The hospital needs to tell users rather than have this in-between stage which is where we are at now.

178. I am not exactly sure who runs the close Facebook Group because different people answer at different times. Sometimes Professor White would maybe put an update on behalf of the Oversight Board but other than that it seemed to be the communications and engagement people from the Health Board that answered. I think there were a couple of times when Craig White had posted

an update but I think someone put it up on behalf of him rather than him running it.

Communication: the move from ward 2A to ward 6A and issues on ward 6A

179. I was admitted to 6A in the October 2018 after ward two 2A closed. I was discharged from ward 2A at the end of September 2018. The decant happened over a weekend and then I was admitted to 6A for chemo during the first week following the move. I found out that the Schiehallion ward 2A and 2B were going to be closed when the staff came round and told me, we got a letter. I believe at this point management spoke to us as well, they came round with the lead nurse and the nurse in charge. What they said was that ward 6A would be a lot better, that the issues with the Children's Hospital were not issues in the QEUH, and we would be fine in the Queen Elizabeth. But when we got to Ward 6A there were filters on the taps, we weren't allowed to drink the water from the taps and we had to use bottled water. The hospital staff did HPV cleans all the time.

180. Sometimes maintenance staff would come and test water, change the filters, the sink traps and they would do deep cleans so the rooms would be shut off. I remember there was mould in the staff kitchen in 6A and we weren't actually told it was mould by the higher-up staff, we were just told that they were rejigging the staff kitchen. The auxiliaries told us, we were quite close with the auxiliaries and the cleaning staff as well. Latterly found out that that was the case.

181. When ward 2A and 2B were closed, the hospital said that they had to fix the problems so they were going to take stuff out and refit the ventilation and everything and make sure that it was safer for us to be on. We were told it would be a couple of months. We're still in 6A now. At the time they thought that we would be back in 2A in the new year of 2019. I understand that the ventilation was fitted backwards, or that it was blowing out the wrong air rather than taking it away. I'm not an engineer. My dad seems to understand it all a lot more than I do, this is more his remit.

Communication about issues with the building

182. As regards the water we got some letters on the wards and it was also in the news, so if you watched the news you used to find out. We knew there were issues with ventilation because of letters we received from the hospital and because of things in the news.

183. In terms of communication about the issues with the hospital think it’s slightly improved since I was treated there as in-patient. I still feel that we still don’t have answers. It is different now to when we used to find out what was happening from the news, but we still don’t really know much at all, so you can understand why we were stressed.

Communication: Healthcare Associated Infections

184. Dr Sastry was never as blunt as saying “This is where you caught the bug”, but he would vent his frustrations with issues with the hospital. I remember one particular time in May 2018, he came into my room on ward 2A and he was really angry. He is not a man that gets angry, he’s got a gentle manner. He had gone to use the toilet in day-care and no one had told him that they’d switched the water off, and it took him five rooms to try and wash his hands; he was appalled. He was really strict about handwashing, it had to be done a certain way. He watched people like a hawk to ensure they washed their hands, when they came into the room, especially if they were doing a check-up on me. If he was not happy with how they washed their hands then they do not going near the patient. He never said anything that in front of the patient but he’d always speak to people outside. The fact that he had to go to five different rooms to try and wash his hands, he was absolutely appalled and he told us there was no communication between the hospital and the staff and the staff didn’t have any idea. He was very angry. I think he wanted us to know because we were doing something about it, or certainly my dad was trying to do something about it. But he has never been as blunt to say “This is where I think you got the infection.” I have however had a letter from the Chair

of the Board apologising for a hospital-acquired infection, it was sent to my dad on 4 September 2018. My dad can provide the letter.

185. When I had the bug for the second time in October 2018, I spoke to Dr Christine Peters. She took over from Dr Teresa Inkster as my lead microbiologist. In October 2018 I requested a meeting with Doctor Peters. As I was over 16, I requested that I be there and she came to my room with Dr Sastry and I spoke to her along with my mum and dad, whereas the first time I had the bug, Dr Inkster only spoke to my mum and dad in June 2018.

186. Dr Peters was very frank, she said that she didn't know whether it was going to work or not. She explained that the bug was resistant to the antibiotics that I had the first time so they needed a new lot, explained that when she'd spoken to Professor Lawrence again and if those antibiotics don't work, they'll find more. If they could find more, they would. She was upfront, which I appreciated, because I'd rather know that they don't know than have them cover it up.

THE INDEPENDENT CASE NOTE REVIEW

187. My dad can tell you more about this. When I first received my letter sending me my individual report, at the section where it addressed whether they were answering any points raised by myself or someone from my family, it said that they hadn't received anything. But that was not the case. Right at the start of the review, my dad had sent the panel a long report on my mycobacterium chelonae. It was to be passed on by other people and it turned out it was never passed on to the panel. I emailed them back and then they had to reconsider their final report based on the information that they should have had from my dad in the first place.

188. As regards my individual report, it’s a bit disappointing that they cannot categorically make conclusions but I was pleased with my report in the sense that I felt that it was really clever. The report explained that if samples had been taken at the correct times that we would be in a very different place. It also explained about how samples that had been found of mycobacterium chelonae had been previously found in rooms that I was staying in a lot of the time leading up to the period when I got the bug. Further that perhaps if the hospital had looked at the time I had got the bug they might have found it. The biggest thing for me was that the report also said that I wasn’t the first case, but we were always told right from the start that I was. But there was a case earlier than me, and so that damaged my trust in the hospital for a while.

189. I’m still very angry about it. I feel that if the hospital had any knowledge that it could have used it should have, and had they told us about another case I think we would have pushed even harder for the samples to have been taken of the ward. But the argument at the time had been that I was an isolated case and there was no need to do that. It created a lot of uncertainty for me, I don’t really know what I can trust anymore when it comes to the circumstances of my infection.

190. I am planning to meet with Professor Stevens and his team. I couldn’t have my meeting right away because of exams, but he said that he would keep the time for us and we’ve just to organise that and I will do that. I’d like to meet them along with my dad to discuss more about the report and certainly to find out where that information came from, because as far as Dr Sastry was aware I was the first patient. I do trust Dr Sastry, and I trust that he would have told me because he told me when someone else contracted it after me.

191. As regards the overall main report, it was a hard read. I was really upset at the findings that two kids died and at least in part it was as a result of hospital-acquired infections. I just think that’s horrific, two kids had passed away. Even if it was just in part, it’s completely unforgivable. To think it could have been prevented, I can’t even imagine how the families are feeling.

192. I was appalled at how many of the cases were suspected to be linked to the hospital in some way. At first, at the very start when I first got sick there were around 21 or 22 cases reported and now it's 84 cases with over 118 incidents: the majority of them with possible or probable links to the hospital. I think it's only 7 or 8 where it has been ruled out that they aren't to do with the hospital. It is hard enough to manage what we have to deal with without having to have all that on board, because the place that's supposed to make you better was actually making you worse.

CONCLUDING REMARKS

193. As regards the hospital, I was very glad to move to adults because I'm now based at the Beatson in Glasgow. If I can, I'll avoid going back to the to RHC and QEUH as a patient. I find it okay to go for scans, but I don't really want to go for anything more than that, if I'm honest. I hate that it's come to that because we're doing so much for the ward with Every Thank You Counts. It's such a happy place and it's going to be a happy place, I know it will be when it's all fixed, but it's tarnished for me now. After putting in so much work for the facility, it's horrible to think that but it is.

194. It's something that comes up a lot when I speak with my psychologist. For quite a while I didn't even want to be a doctor because I didn't want to work with a health board because of my experience. This is an ambition I had since I was a kid, and it was ruined. I worked so hard whilst being sick and it felt it had been for nothing. I'm eventually coming round to the idea and I understand that I don't have to work for the NHS, maybe I'm being a bit precious but the best way to describe it is that I don't feel comfortable.

195. The Health Board need to remember that there are patients involved. We are live patients, and we are at the centre of it. People make mistakes and that's fine, and if people held their hands up and said, "Look, this happened, we're sorry, we're going to fix it", that would be fine. I'd be a bit angry but I'd get over it. But things are constantly coming out about what has happened, for example that this sample wasn't taken or it turns out someone had the bug

before you and you weren’t actually the first person to contract it. I understand that there’s no singular person responsible but I don’t trust them because of this; it’s the only way to say it. It’s horrible to think that I don’t trust something that I am going to need for the rest of my life, because I’ll never be out of hospital. I’ll never be done with it because of all the side-effects I’ve been left with; all the issues in my different organs. I will always be in and out the hospital and to think that I don’t trust the Health Board is quite frightening.

196. In terms of addressing how I feel, the best thing best thing for me is to know more about it. Getting answers: this is what’s happening now with the Public Inquiry. Uncertainty is probably the worst part, not knowing what’s happened. Anything that can be found out is a comfort. For the families of those two kids, anything that can be found out could give them a bit of justice.

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

Scottish Hospitals Inquiry

Witness Statement of

Professor John Cuddihy

WITNESS DETAILS

1. My name is John Cuddihy. I was born on [redacted]. I am [redacted] years old. I am a member of the FRSA and run a consultancy business.

2. I am the father of patient, Molly Cuddihy. Molly's date of birth is [redacted]. She is 19 years old.

3. I live with my wife, [redacted], and children, [redacted] and Molly.

OVERVIEW

4. My daughter is Molly Cuddihy. She was diagnosed with metastatic Ewings Sarcoma in January 2018 when she was 15 years old. Molly was treated at the treated in the Royal Hospital for Children (RHC) and the Queen Elizabeth University Hospital (QEUH) between January 2018 and 2020. Molly was an in-patient and an outpatient during this time.

5. Molly presently receives most of her treatment at the Beatson Hospital in Glasgow, although she is occasionally required to attend the QEUH.

6. Molly was treated in wards 2A and 2B of the RHC which is known as the Schiehallion Unit. The Schiehallion Unit treats children with blood cancer. She also received treatment in other wards on the RHC, namely 1E, 3A, 3B and the Paediatric intensive Care Unit (PICU). Following the closure of the Schiehallion

Unit in 2018, Molly was treated in wards 4B and 6A of the QEUH. I can speak to the experience that Molly and I had on these wards.

7. There are some specific events I would like to mention. Molly contracted a mycobacterium chelonae infection, which was a Healthcare Associated Infection. Throughout her treatment there were issues with the water supply, ventilation, cladding, windows and drainage all which impacted on her experience with the hospital. I will come on to talk about these events on more detail.

8. This statement will provide information about my background and my family background. I will provide a narrative of the treatment that my daughter, Molly Cuddihy, received in the hospital including her initial diagnosis, her treatment plan, the clinical care and infection control.

9. I also provide an overview of my experience with the Independent Review; the Communication & Engagement Sub Group; the Oversight Board; and the Independent Expert Case Note Review. I offer some perceptions related to Duty of Candour in so far as it relates to the factual narrative related to my experience at the hospital. As regards these matters, I will provide further more detailed evidence to the Inquiry at a later date.

FAMILY BACKGROUND

10. I am [redacted] years of age and live at the address stated with my wife [redacted] ([redacted]), son ([redacted]), and my daughter Molly (19). I have been married to [redacted] for 32 years and have lived at this address for 29 years. During his university studies, [redacted] spent a year working in France for the British Council, developing his linguistic abilities, which resulted in him being overseas when Molly was first diagnosed in 2018.

11. At the time of Molly's diagnosis, she was a 4th year student at [redacted], [redacted] with a clear academic pathway to university with ambitions to study medicine. Indeed prior to her illness she worked within her local medical practice

as part of her school placement and had also been accepted for a short-term placement at Glasgow Victoria Infirmary, although had to withdraw following diagnosis. Away from schooling Molly was very active socially and was fully engaged in areas of music and drama.

PERSONAL BACKGROUND

12. I am Visiting Professor at the Centre for Trust, Peace and Social Relations, Coventry University, where I support research in areas such as Terrorism and Counter Terrorism, Organised Crime and Countering Organised Crime, Protective Security, Corruption and Anti-Corruption, Insider Threat; identification and Mitigation, Violent Extremism and Countering Violent Extremism. I am a member of the Royal United Services Institute, Strategic Hub for Organised Crime and a Royal Society of Arts Fellow.

13. I am a board member of Action for Children (Scotland), SIDE STEP, Strategic Advisory Group and a member of Scottish Government Minimum Age of Criminal Responsibility, Community Confidence Group.

14. I am a member of the Scottish Government initiated, NHSGGC Oversight Board, member of the Communication & Engagement Sub Group and Independent Case Note Review, Communication and Engagement Sub Group. I engage on each group as a Patient and Families representative.

15. Over the last five years I have acted as a consultant to United Nations, US Department of State, UK Home Office, Scottish Government and a variety of other international organisations, governments and agencies, particularly in high-risk areas of conflict and fragility.

16. In 2015, I retired following 28 years' service with Strathclyde Police and then Police Scotland where I acted as Detective Chief Superintendent, Head of Organised Crime and Counter Terrorism. During my time I managed numerous

high-risk, multi-agency investigations across Scotland, United Kingdom and internationally.

17. Prior to joining the police service in 1988, I worked for 6 years with NHS Greater Glasgow Health Board having trained with them as a mechanical and production engineer.

INTRODUCTION

18. For the last 35 years I have operated in high-risk threat environments recognising the need for effective processes that enable the identification, mitigation and management of threats. From my first days as a police officer; to guard watch and patrol, preserve life and protect property, to operating strategically in high-risk areas of conflict and fragility, developing high level strategies that contribute to more stable environments.

19. Such actions were predicated on sound prevention strategies, designed to better protect communities from the various threats, risks and harm that they would face. It has always been my experience that planning and preparation enabled more effective protection of the most vulnerable from current and emerging risks. Indeed, effective information gathering would serve as the basis of knowledge leading to informed decision making in the management and subsequent communication of action plans. I have always been aware that such decision making would be subject to scrutiny, both internally and externally but when underpinned by effective governance structures and oversight with completion of decision logs and risk registers, those decisions can be justified.

20. I knew that I would not always be effective in protecting everyone all of the time but ensured that I had a prevention strategy that reflected the environment that I had responsibility for, enabling me to more effectively identify, manage, mitigate and communicate current and emerging threats in a way that developed relationships, built trust and better protected communities, keeping them safe.

PARENTAL RESPONSIBILITY

21. My first duty as a parent is the care, safety and wellbeing of my children; to protect them from the various threats, risk and harm that may expose and exploit their known or as yet unknown vulnerabilities as they progress through their young impressionable lives.

22. Such protection is influenced by information, both from my own experience and the experience of other, trusted sources and as such, informed decision making is critical in identifying, managing and mitigating the various risks that are prevalent during their lifetime, including those impacting their health.

23. However, when my daughter Molly was diagnosed with cancer, I realised that I had neither the knowledge, experience or expertise required to adequately identify, respond, manage or communicate on behalf of, and to Molly, the complexities and impact of her medical condition.

24. Decisions made during her prolonged treatment may have a profound impact now and in the future. As such I required to place my faith, trust and honesty in those who would care for Molly. I required to have implicit trust in ‘strangers’, relinquishing that first duty to protect and care for the most precious of commodities, my child. To hand over such control is the hardest of things, a decision that will influence the physical, emotional and psychological effect now and in the future of both my daughter Molly and others within my family.

25. This resulted in my having a tremendous sense of helplessness, fear, anguish and guilt; guilt that despite all my experience of preventing terrible things from occurring across communities and within environments, protecting people, many of whom where strangers, I failed to protect my child; guilt that I have devolved responsibility for Molly’s care to people I know nothing about; fear that I have

placed my trust in individuals and an organisation that I hope will make decisions in the best interest of Molly.

26. It is for the above reasons that I had to have confidence in the health service, believing that there will be processes and procedures in place, governed by experienced and knowledgeable professionals. I had to have a belief that during the hardest times, they will respect, protect and fulfil their statutory requirement to ensure that the best interests of my child would be a primary consideration in all actions concerning them. The treatment of cancer, especially in children, is distressing for all concerned, not least of all the child.

27. There is an absolute requirement for open and honest discussion between the clinicians and the patient and their families. The risks associated with the treatment of the cancer are laid bare, however nothing prepares you for the heartache of watching the 'treatment' take effect; the physical, emotional and psychological trauma that develops with the many identified side effects articulated by those with whom you have developed relationships and built trust. Understanding the likelihood of infection, including hospital acquired infections as a result of being immunocompromised is part of the learning curve and an acceptable risk that is managed and mitigated with increased awareness and implementation of necessary and proportionate control measures. However, this risk becomes unacceptable when those identified control measures are not adequately implemented.

MY DAUGHTER MOLLY CUDDIHY: SEQUENCE OF EVENTS: EXPERIENCE AT THE RHC AND THE QEUH

16 Jan 2018: Molly's Initial Diagnosis

28. Following a prolonged period during 2017 where my daughter Molly experienced recurring pain, weight loss, loss in appetite and a noticeable mass on her left side, requiring numerous visits to her doctor and several hospital visits, she was

eventually referred to the RHC, Glasgow, where in January 2018 she was diagnosed with metastatic Ewings Sarcoma.

29. Molly was placed under the care of Dr Jairam Sastry, Paediatric Oncologist within the Schiehallion Unit, located across wards 2A and 2B of the RHC; 2B was the Day care facility whilst 2A was designed to accommodate ‘in-patient’ care. Molly had developed a large tumour on her 11th rib, positioned second from bottom to the left of her ribcage. She had also developed tumours in both her lungs and 10th vertebrae.

Molly’s Treatment Plan

30. Due to the aggressive nature of the cancer, a detailed treatment plan was designed for Molly that would involve a combination of chemotherapy, radiotherapy and surgery. The treatment plan would commence almost immediately with 6 consecutive sessions of VIDE chemotherapy (VIDE-Vincristine, Ifosfamide, Doxoruvicin and Etoposide); each session administered over a 21-day cycle, delivered as an in-patient on ward 2A where the chemotherapy would be administered intravenously.

31. The chemotherapy lasted for four whole days during which the chemo was administered continuously over each 24-hour period. I should highlight that prior to each session of chemo, Molly would first attend ward 2B, where she was prepared for chemo prior to moving across to ward 2A and as such would at times cover a five-day period, depending on the start time for the chemotherapy; this was the agreed protocol within the Schiehallion unit.

32. At the end of the fourth/fifth day and providing she was medically fit; Molly would be allowed home to rest and recuperate ahead of the next session. Following the 6th chemotherapy session, Molly was to undergo surgery, under the care of Mr James Andrews who would remove the primary tumour and her rib. Thereafter, Molly would undergo reconstructive surgery under the care of Mr

Stewart Watson. The procedures would occur simultaneously lasting over 12 hours.

33. Following surgery the plan was that Molly would then undergo a further 8 sessions of VIA chemotherapy (Vincristine, Ifosmamide and Actinomycin-D), following the same regime as previously identified but over three days, to be delivered as an in-patient within the Schiehallion Unit. Again, depending on the start time, this process could last 4 days in total. Similarly, if Molly was medically fit, she would be discharged to rest and recuperate prior to the next session.

34. During this period of chemotherapy, Molly was also required to travel from RHC or from home, depending on where she was within the chemotherapy cycle, to the Beatson Oncology Centre, Glasgow where she would undergo, 30 consecutive sessions of radiotherapy, delivered over 6 weeks: 1 session per day.

35. This combination of treatment would serve to address different aspects of her cancer; the chemotherapy would target the primary tumour on her rib with the aim of reducing its size and also target those tumours in both her lungs. The surgery would be required to remove the remainder of the primary tumour, her rib, tissue, muscle and other identified areas considered exposed to the cancer. The radiotherapy would specifically target the tumour on her spine as it was not possible to carry out surgery due to the risks involved.

Initial Communication and Engagement - Clinical Care

36. From my first interaction with Dr Sastry, I found him to be a compassionate, informed and humble man, considerate of our feelings and understanding of the impact this diagnosis would have on Molly, myself and my family. His language throughout was wholly appropriate, softening it to minimise the immediate impact whilst ensuring understanding throughout. He was an empathetic man who instilled a confidence and belief in his abilities and those of his team without ever compromising the integrity of what he had to say. I found myself having to trust

this stranger, trust him with my young girl’s life; what other option did I have? I had to place Molly’s life into his hands and those of his team, which was emotionally distressing.

37. I could see Molly was terrified and so could he. He immediately recognised Molly required knowledge if she was to understand and ultimately cope with the treatment and as such, he answered every question she posed, taking time, care and every effort to assist her. Indeed, Dr Sastry would always communicate and engage directly with Molly, developing a relationship of mutual respect and unrivalled trust.

38. It was during this time that I was to experience the ‘Schiehallion family’. A family I would never wish anyone had to join but one that when you needed them, were the most caring, loving people you could ever meet. I remember being told by a friend who had experienced cancer, that friends would become strangers and strangers would become friends. The kindness, support and indeed love shown to Molly was incredible; if love and kindness were a medicine, Molly had a ready-made cure, but if only it was that easy! The ‘strangers’ within the Schiehallion Unit were to become our critical ‘friends’.

Ward 2A – the Schiehallion Unit: Initial Ward Experience

39. My first experience of the RHC and indeed the Schiehallion unit was when Molly was first diagnosed. But to be honest, my initial recollection of the ward (2B) itself is pretty vague as we seemed to be chaperoned from our first arrival and almost cocooned to protect us all. However, as I recall, I left the hospital to travel home and collect an overnight bag for Molly and my wife who was allowed to stay with her as further tests were required ahead of Molly’s treatment.

40. Over the following days and weeks, we experienced the Schiehallion family which operated across both wards 2A and 2B. From the doctors and nursing staff to the

auxiliaries, cleaners and support staff, we experienced a ‘family’ who were there to individually and collectively care for Molly.

41. Over time, I would recognise that Ward 2B was for ‘day-care’, the first point of entry to Schiehallion, during working hours, which were from 0700 to 1900 Monday to Friday. Should there be a requirement to access care out with these times, ward 2A, designed for in-patient care, would be the point of contact however when there were no doctors on the ward, invariably after 2200 hours, there was a requirement, following discussion with the senior nurse on duty within Schiehallion, to access the hospital via Accident & Emergency. This was principally to ensure that a doctor could assess my daughter before moving onto ward 2A.

42. I found the processes and protocols to be clear and understandable if not daunting but after a while, I became ‘socialised’ to the procedures with access to staff being a comfort rather than a concern. The Schiehallion team always portrayed an air of confidence, which enabled our relationship to develop into trust. They would take control of any situation and I knew when I was with them, Molly was in the best hands possible.

Environmental Awareness/Infection Control

43. From the outset staff would highlight the importance of infection control. This was a constantly recurring theme which was embedded in everything that we would do as a family, either on the ward or at home. Infection control would become our lives and whilst my wife [redacted] was a ‘clean freak’ with bleach her domestic companion, we were to go much further with regards to our home and any environment in which Molly would be. From deep cleaning to our dog being ‘hibi-scrubbed’ weekly; to the use of paper towels and hand gels at every sink at home; no outdoor shoes and access for those entering our home on condition of taking appropriate steps with regards to hygiene.

44. We were fortunate enough to have a dedicated bathroom for Molly, again to cut down any potential risk of infection. We had been warned repeatedly by staff and families on the ward of the dangers of infection especially when Molly would become immunocompromised due to treatment. The costs were too great, and we were not prepared to take any chances. Even when we would go out, cleanliness was the key to any decision to access. Even down to taking our own cutlery for fear of bacterial infection. During the cycle of chemotherapy there would be points, invariably around day 10 where Molly would be at her most vulnerable; this is known as neutropenia or being neutropenic. As a family we would ‘shut down’ and not socialise with others for fear of contracting even a cold, which could be a danger to Molly.

45. Even on the ward, my wife and I would clean down all surfaces of the room, even after cleaners had been in. We were encouraged to report any areas that we considered were not clean and my wife would have no hesitation in doing so, ensuring that Molly’s room was cleaned twice daily.

46. There was no doubt that the staff in Schiehallion were more acutely aware of infection and the impact and implications for patients. There was a clear environmental and cultural difference when we found ourselves in other wards or areas of the hospital. Indeed, I would often hear staff in other wards refer to Schiehallion as the ‘Schiehilton’ which in itself gives some sense of the perception across the hospital estate. However, this was no hotel, it was a professional environment where clinical teams and staff on the ward delivered the highest level of care with very high standards required across 2A and 2B. Indeed, before the world experienced COVID 19; the various catch phrases like Hands, Face, Space or F.A.C.T.S were well known to us. We were well versed in social distancing, isolation and hygiene practices. It was common to place a ‘risk radius’ around Molly to protect her and prevent her from contracting any bacterial or fungal infections. However, we relied on the medical team to advise us of any emerging challenges that would require Molly to take prophylactic antibiotics to help prevent infection.

Description of Ward 2B (outpatient)– the Schiehallion Unit

47. This day care facility was controlled by the Day Care Manager, a band 7 nurse called Angela Howat who was outstanding. She set the professional standards of clinical care and her team knew exactly what was required of them. Angela was very clear in her instruction to myself and my family with regard to Molly’s care and understood every aspect of her treatment, enabling her and her team to manage any questions or concerns. Even when there were questions outwith their clinical knowledge, they would ensure that the most appropriate doctor was on hand to assist.

48. When you arrived at day care you were met by the receptionist Doreen who knew exactly who Molly was to see and what room she was allocated. Doreen always had time to ensure we were managing and would assist Molly with support needs like linking with hairdressers who would make bespoke wigs etc. Nothing was too much trouble and her knowledge of the hospital and associated departments meant she would escort you to wherever you needed to go if you were unfamiliar; she always ensured there was someone to walk with you and support you during particularly difficult times.

49. The nursing team were all experienced nurses who had previously worked on the ward and as such were familiar with the treatment regime as well as patients. They worked very closely with the nursing staff and doctors on ward 2A. I developed close relationships with all the staff who cared for Molly and we would become familiar with their family lives; birth of a child, wedding, breakups, child going to school and social events. They would laugh with us and acknowledging the closeness of our developing relationships, as with other families, we would also share a tear or two during the most challenging of times. This underscores the close family atmosphere that prevailed across Schiehallion.

50. Within 2B, as well as the treatment/consulting rooms, there was a large open plan area where fluid and chemotherapy treatment would commence. In Molly's case, after having her bloods and other vitals recorded, she would move into the large room, consisting of four open plan bays, where she would commence her intravenous chemotherapy treatment via her central line. This was the start of the 3 or 4-day treatment. After a couple of hours, she would transfer over to ward 2A which was on the same floor and separated by a link corridor.

Description of Ward 2A (in-patient) – the Schiehallion Unit

51. Once Molly transferred over to ward 2A she would be allocated a room. As a teenager she would be given a room within the Teenage Cancer Trust (TCT) wing located to the far end of the ward. The TCT consisted of 4 separate self-contained rooms, no different to all other rooms on the ward. However, within the wing was a large common room, with dedicated kitchen area, dining table, pool table, juke box, seating area and large interactive TV with associated gaming technology. There was also access to dedicated fridge, board games and musical instruments. The TCT area had a dedicated resource person, Ronan Kelly, who cared for the needs of the TCT patients. He was an inspirational young man who had the trust and confidence of the patients.

52. This room was to deliver more than my first impression; the dining table provided for a meal with family, such a precious thing, enabling normality within hospital surroundings. The table would also become the focal point for nutrition and would often be the last defence of a feeding tube as Molly and those other young people were inspired and encouraged to eat by their peers. The room, located outside of the bedroom areas, provided a focus and a reason to get out of bed, become mobile even if requiring of a wheelchair. It exercised their limbs so important with developing neuropathy. The room would also assist with emotional therapy; young people would see each other as equals, not different from other kids, despite the loss of hair, reduced weight, loss of limbs and requiring of intravenous aids to administer their treatment. The room enabled those young

people to come together and talk about mortality and the impact their disease had on them. My daughter was able to talk about difficult and sensitive conversations that she did not want to discuss with us for fear of upsetting us. She could also share with those in the room the loss of close friends who had died as a result of their cancer; sadly, my daughter and those other children experience the trauma of such loss at such an early age, which in itself brings to stark focus their own battles and mortality. This room, a home from home, personal space, allowed Molly to engage in everyday teenage activities. It provided a focus, even for a short time, to forget her illness and the impact it was having, as there was always another young person having a more challenging time. It was a lifeline and vital in her emotional, physical, physiological and social wellbeing.

53. Molly has often said to me that the room gave her two additional gifts. It provided her with an environment where she could continue with her studies, so important in her ambition, as her illness would not define her but would instead inspire her to become like those 'wonderful doctors.' Secondly, she stated that whilst it's never a place she wanted to be or would ever wish for any young person to have to experience, the room brought her and [redacted] (fellow patient) together, forming a friendship that otherwise may not have happened.

54. Indeed, it was this same room that provided a broader friendship with [redacted] 's family with whom we would develop a relationship that continues to this day. This friendship offered additional support for one another as each knew of one another's challenges with a level of intimacy of surrounding emotions that could not be accessed elsewhere. You would never wish to expose wider family or friends to some of the challenges that we faced or where likely to face. This developing and trusting relationship was made fostered within this central focal point.

January 2018 – May 2018: Commencement and delivery of treatment timeline

55. On 17 January 2018, following initial diagnosis, Molly embarked on her treatment program which commenced with a full body MRI and Biopsy. This was a daunting experience for her, and I found myself having to develop an understanding of medical processes, language, jargon and protocols in order to assist Molly in her understanding. In reality, she was ahead of me in so many areas, as she adopted a mentality that would see her learn from the experience which would assist her ambition of becoming a doctor. I could see that she was frightened, and this was her way of coping. Molly has a very analytical and logical mindset, which requires information. She would crave information and if I could understand that bit better, we could discuss the impact and implications of her treatment and the progress of it throughout the journey. However, whilst mature in many ways, she was still a vulnerable child not yet equipped to deal with the trauma that was to unfold. I knew that she would require full disclosure of information which would lead to her involvement in discussion and therefore assist her cope.

56. Over the coming days I watched as Molly underwent a series of further tests and preparatory procedures, including surgical with the insertion of a central line that would be used to administer her chemotherapy and other fluids intravenously. I, along with my family, embarked on a roller coaster of emotions, fear, anxiety, sadness and heartache which turned me inwards, trying to shelter my emotions to protect Molly. To reassure her that everything would be alright whilst in truth I had no idea. Molly knew this and actually protected me more that I her.

57. Over the first few cycles of chemotherapy, save for the hospitalisation within ward 2A, Molly seemed to cope as well as expected. I had been told by Doctor Sastry that the ‘treatment’ would result in significant impact on Molly.

58. On 2 February 2018, following discharge after the first chemo cycle, I, along with an outreach nurse, attended at Molly’s school, [redacted] and there updated staff as to Molly’s condition, advised of the protocols should Molly take unwell on days

she would be at school, and provided education that could be cascaded to teaching staff and pupils concerning children with cancer. This was a hugely significant event as it provided a confidence to the school staff as to how to manage Molly's clinical needs and more importantly provide support as to how to deal with an emergency and how to mitigate against infection. The school were extremely supportive and continued to engage with myself and hospital staff, supporting Molly at hospital during periods when she was an in-patient. I knew that by engaging with the school Molly would see a future, which was important for her psychologically and socially.

59. On 6 February 2018, I experienced Molly have her first temperature 'spike' I had been advised as to how to identify and manage a temperature 'spike', an increase in body temperature. This was often an early indication of infection and as such an identified protocol, in line with hospital admission, had been shared with myself and my wife. Molly's temperature should normally be 36 degrees however should there be any rise this would be monitored closely through the use of 'tempa-dots'; a small, sterile strip that is placed under Molly's arm. Should her temperature rise towards 38 degrees I would contact a dedicated telephone number for wards 2A/B and after discussion would convey Molly to hospital. Time and distance were extremely important and if less than an hour away, I would drive Molly. If more, I would call 999. Also, following discussion, Molly would be given, under instruction by ward staff, two paracetamol tablets in an effort to lower temperature.

60. On arrival at hospital, protocol dictates that Molly would be placed on IV fluids for 48 hours from the last identified "spike'. During this time, bloods would be drawn and screened for any routine bacteria. If her temperature returned to normal, she would be discharged home with instruction from doctors as to any treatment. If she continued to 'spike' she would receive further fluids and her bloods would undergo further screening in line with protocol. I was reassured that the information supplied by the clinical team enabled us to respond to the clinical needs of Molly. During these early days, everything appeared 'major' however

staff and indeed other families, enabled understanding of “major’ in the context of child cancer and as such I was better equipped to manage each developing episode.

61. On 25 February 2018, following her second cycle of chemo, Molly began to experience mouth ulcers and throat pain. I had been advised that the chemotherapy would cause a number of side-effects, including mucositis; when her mouth or gut becomes sore and inflamed. It was the first visible sign that the ‘treatment’ was having an impact on Molly. I began to be introduced to the many treatments for such side effects and the growing number of medicines required to deal with each.

62. As a result of the mucositis, Molly experienced further temperature ‘spikes’ and was admitted to ward 3A due to capacity issues on ward 2A. Ward 3A is normally dedicated for patients requiring Neurosurgery, Neurology, Complex respiratory and Long-Term Ventilation. I was advised that this was the only bed available. Molly was still under the care of Dr Sastry and his team although the nursing staff were drawn from ward 3A and not Schiehallion. There was a noticeable difference in resources on ward 3A which was far below that of Schiehallion. In addition, the normal facilities available to you, are not available on ward 3A, such as TCT wing, common room and dedicated kitchen. In addition, when it came to patient monitoring, protocols differed; in relation to temperature monitoring, ward 3A staff utilised an electronic thermometer rather than tempa-dots. I had concerns due to calibration of the thermometer and the absolute need to know Molly’s accurate temperature whilst in the ward. As such, I accessed tempa-dots and requested staff use them when taking Molly’s temperature. I actually compared the electronic temperature reading to the tempa-dot and there was a 1.8 degree difference! The tempa-dot had shown an increase in temperature whilst the electronic device did not recognise this critical difference.

63. As a result Molly was administered morphine, antibiotics and sent for various tests during this hospital admission. The antibiotics were the first use of such that I had experienced and were prescribed by doctors to treat the mucositis.

64. On 03 March 2018 Molly was transferred to ward 2A, TCT room 3. Molly required a combination of pain medication including the use of ketamine. However, due to different protocols, staff on ward 3A were not permitted to dispense and use ketamine and as such she was transferred to ward 2A once a bed became available. Arriving back in ward 2A, there was an immediate relief around Molly's care, not that I thought the nursing team on 3A were below standard, simply they were not trained to the level of those on Schiehallion and the protocols did not cater for immunocompromised patients and their associated needs. I and Molly had greater confidence now that she was on the Schiehallion ward. However, on 6 March 2018 she was transferred to ward 1E. Ward 1E is designed to cater for cardiology patients. As such the level of nursing care is comparable to Schiehallion and there are monitoring equipment available that are not routinely available elsewhere. Molly was transferred to ward 1E as there was a requirement for bed space in ward 2A, especially to enable chemotherapy to be administered.

65. As Molly was not requiring of chemo at this stage, she was displaced to ward 1E. Whilst this was not ideal, we had to consider the needs of other seriously ill children and as such we were accepting of the move, although concerned as to the extent of her care and the impact continual movement from room to room and ward to ward would have on her. I was also cognisant of the fact that, whilst protocols did not differ as much, their focus and training was not aligned to cancer patients. In addition, there was limited access to the support needs, accessible on ward 2A. This highlighted to me the issue of capacity and the need for protocols to follow the patient, ensuring there was never any drop in care or indeed, perception of care. This also had me considering 'business continuity' not necessarily a term associated with cancer treatment, but my mind and previous experiences would have me think of such processes as they had a fundamental

impact on the ‘business’ of cancer treatment. What if Schiehallion were unable to treat Molly - as the previous examples had shown - where would she be treated?

66. On 13 March 2018, Molly embarked on the third chemo cycle and was admitted to ward 2A room 22. Room 22 is not within the TCT, however whilst on the ward a TCT patient can access TCT facilities. As soon as a room would become available, Molly would be transferred and on the following day she was moved to room 3 within the TCT wing.

67. Molly’s hair was falling out and I could see the distress this was causing. On the way home from hospital, she asked me to go via her usual hairdresser and asked them to shave off the remainder of her. This was huge for Molly and she was aware others would identify that she was ‘sick”.

68. I was seeing the impact that Dr Sastry spoke about, she was now requiring of blood products and more pain relief and antibiotics. I also noted that she started on other tests that would measure the impact the treatment was having on her organs; kidneys and heart.

69. The first example of the foresight of Dr Sastry, was on 26 March 2018 when Molly was prepared for a stem cell harvest. He had arranged for Molly to have her own stem cells harvested in case they would be needed at a later date during treatment. The team who carried out this procedure came onto the day-care ward to explain the procedures and alleviate growing concerns. They communicated and engaged with Molly, taking time to explain each step within the process and answer any questions that she had. The following day the team carrying out the procedure demonstrated the functionality of the machine and requested student nurses attend to watch the procedure. Molly welcomed this approach and was entirely comfortable with staff who were using her procedure for learning. It total, the team harvested 9.4 million cells from Molly, sufficient for four stem cell transplants. I had no idea at this stage that Molly would need them.

70. Following her fourth cycle, Molly began to feel unwell and on 13 April 2018 attended ward 2B and there had a platelet transfusion. However, she took an adverse reaction to the platelets and was administered medication before being admitted to ward 2A. She would require ‘cover’ for such transfusions in the future to proactively mitigated against such reactions. During this time as an in-patient, Molly had also taken a reaction to one of the chemo drugs, Etoposide which resulted in the blistering of the soles of the feet. This looked like burns across the soles of her feet. At this time Molly was in Room 6 of TCT and would shower daily in the walk-in shower unit of the room. I had to complain regarding issues with the drainage system in the shower as water would not drain away. This was during the time where issues with regards to the water were being reported and a time leading up to further media reporting of drainage problems on the ward resulting in the replacement of sink trap sets. I recall asking if the drain traps in the shower rooms would be re-placed but advised that this was not planned at this time.

71. On 17 April 2018, following issues with the shower room, Molly was moved to rooms and was eventually discharged on 20 April 2018.

72. The further deterioration in Molly physically was on 24 April 2018 when she was provided with crutches due to the increased impact of neuropathy. I was told by Dr Sastry that peripheral neuropathy develops when nerves in the body's extremities, such as the hands, feet and arms, are damaged. The damage is caused by the chemotherapy. This also started to impact on Molly socially. Molly plays the piano and guitar however such was the impact in her hands and feet that she could no longer play either which was a significant blow to Molly as she derived enormous enjoyment from this. Indeed, within the TCT room there were guitars available that allowed her to remain socially and musically active until that point. Mucositis was also preventing her from singing, something that she also loved to do.

73. However, Molly was determined not to allow any of the challenges affect her schooling and her ambition to go to university and study medicine. She was driven by the fact she needed good grades and used this to keep focus and to motivate her. I watched her push herself and regardless of what I said, she was not going to stop. I agreed to support her throughout and would go between home and school to collect assignments and arrange for tuition at home. Her school were superb and supported Molly throughout. On 30 April 2018 she sat her first exam (National 5 Spanish) at home with one of her teachers acting as invigilator. The following day she was admitted to ward 2A and allocated Room 17**.**

74. Whilst in hospital Molly sat her French prelim and maths exams before being discharged, this time with a wheelchair as she was no longer able to walk due to the impact of the neuropathy.

75. On 9 May 2018 Molly was admitted to ward 2A with temperature of 39. This temperature spike was indicative of infection and, in hindsight, perhaps an indication of the presence of Mycobacterium chelonae. As part of the protocol blood samples were taken from Molly and screened for bacteria.

76. Between 9 and 16 May 2018 she was treated for infection however the medical team were unable to identify at that time why Molly's temperature was so high for such a prolonged period which resulted in further blood screening.

77. On 22 May 2018, Molly Commenced VIDE chemotherapy cycle 6 and admitted to ward 2A. The cycle was completed without incident and she was discharged on 26 May 2018.

78. On 31 May 2018, I took Molly to Day care due to high temperature. Following initial examination, she was diagnosed with low haemoglobin (24) and high temp. In line with protocols her central line was accessed to administer medication, however almost immediately her body started to rigor Molly was given fluid

resuscitation, which was a deeply distressing thing to see. The staff had no idea as to why her body was reacting the way it was, and they were rapidly ripping open fluids with both myself and son assisting to rip open packaging. They could not utilise her central line as this was identified as a potential source of infection and as such had to use a number of cannulas inserted into her hands and arms to administer the fluids. There was a number of staff attending to Molly in day care and whilst I recognised their professionalism, I could see they were concerned. I thought we were going to lose Molly that day - it was a frightening experience. I cannot begin to imagine how terrified Molly was. After some time, Molly stabilised and she was admitted to TCT, room 4.

June 2018 - Hospital Acquired Infection (HAI): Mycobacterium Chelonae

79. On 01 June 2018 I was advised that Molly had contracted mycobacterium chelonae which required an emergency operation to remove her central line. Molly was also placed on PCA for pain relief. At this time, we were extremely concerned as to what was ongoing with Molly; how would this bacterial infection impact her directly and how would it impact her cancer treatment. Dr Sastry advised that they required to suspend her cancer treatment until they could assess the nature of the bacterial infection. Dr Sastry was very open and transparent with regards to the bacterial infection in that he knew little about it as it was so rare, but they would embark on a plan with the assistance of colleagues in Edinburgh.

80. The whole issues with regard to the environment were in the background until that point and it was only now that I truly appreciated the impact on my daughter. Whilst not confirming the source of the infection, I was advised by the medical team that the bacteria was associated with the environment, water, drainage, air conditioning. Molly was placed on a combination of three antibiotics which were to be administered for one month followed by further oral antibiotics.

81. I was extremely concerned as to what this meant for Molly's primary treatment relative to the cancer and also, this 'secondary' issue and what this would mean for her health. In real terms it meant an initial delay of two weeks on her cancer treatment. Physically, I had no idea how this would impact on Molly but knew enough that prolonged use of antibiotics was never a good thing. Mentally, this was a further setback for Molly, and she required further information as to how this would impact her treatment but no-one knew. We were advised that this very rare pathogen had only been evidenced in GGC on four occasions in the last ten years. As such, little was known about the bacteria or indeed how to treat it.

82. This proved to be the catalyst for me to look for answers. If the hospital could source the cause of the infection, perhaps this could inform the medical team as to how to treat it. If we could treat it effectively, we could impact on Molly's cancer treatment and her overall health.

83. I embarked on my own due diligence of internal protocols relative to Hospital Acquired Infection, Infection Management Teams, Investigation of bacterial outbreaks and internal governance for such. I began to look for answers to many questions and could then see an absolute divide between clinical and corporate information management and disclosure and more specifically, communication and engagement. Indeed, in June 2018, I sent my first letter of concern to Dr Catherine Calderwood, Chief Medical Director for Scotland. The letter, 'A Parents Concern" proved the catalyst for prolonged and detailed communications with numerous individuals within NHSGGC, Scottish Government, Statutory Authorities; including Children's Commissioner, Crown Office and Procurator Fiscal Service and various other corporate entities associated with the developing crisis. I am willing to share all such communications and reports with the Public Inquiry from June 2018 until the present time, should this be of assistance. I have ingathered hundreds of documents, emails, pictures and associated reports that reflect my investigations.

June – July 2018: Immediate impact of the Hospital Acquired Infection

84. During this time, Molly remained an in-patient on ward 2A and the focus of her treatment was the bacterial infection.

85. On 15 June 2018, Dr Sastry took the decision that he would alter Molly's treatment plan and instead of embarking on the surgical procedure following the VIDE Chemo cycles, he would commence the 6 cycles of VIA chemotherapy, at the same time as Molly was receiving the antibiotics. I welcomed this decision in respect to the cancer, but I remained extremely concerned as to the impact of the bacteria and what was happening to Molly in this regard. The cancellation of the operation had a significant impact on Molly and we all had concerns as to the delay in operating.

86. On 16 June 2018, during the administering of chemo, Molly had to get out of her bed to go to the toilet. Whilst walking to the toilet Molly collapsed. Following assessment, she was given a heart scan and whilst awaiting results Molly again collapsed. It was discovered that one of the antibiotics, given to deal with the bacterial infection, was having a detrimental impact on her heart function. Physically she was no longer able to walk to the toilet and had to make use of a commode. This had a terrible effect on Molly, her dignity and mental health. She had to undergo almost daily tests such as ECG, ultrasounds and various other scans. She remained in hospital until the 29 June when she was discharged home. Molly was in a wheelchair, required assistance showering and going to the toilet . As you would expect, this was not something she would wish her dad to see. It was a terrible time for Molly.

87. On 6 July 2018, Molly commenced VIA chemo cycle 2, administered whilst an in-patient in ward 2A and was then discharged on 8 July 2018. The following day I drove Molly to the Beatson Centre to commence her radiotherapy treatment which would run parallel to her current chemo cycle.

88. This was very much an ‘adult’ environment, although the TCT had a wing within the Beatson, Molly did not access this area. On the days she attended, the waiting area was invariably occupied with adult patients, although kept to a minimum so early in the morning. However, the staff were outstanding. They comforted and protected Molly from the first moment she arrived to the last. The reason for taking her in the morning first thing was to prevent Molly having to wait in an adult orientated environment. Each day Molly attended, the staff made every effort to cater for her needs, whatever they were. They communicated and engaged Molly, involving her in every aspect of her treatment. They took an interest in her studies and got to know Molly, which made her feel special. They were so kind to her.

89. On 11 July 2018, it was Molly’s 16th birthday, and the staff had a birthday cake, card and gift for Molly. It was so wonderful and made her feel fantastic. This from a team who only a few days earlier had met Molly! Radiotherapy continued for 30 consecutive days, save for weekends, when she had some rest.

90. The radiotherapy was taking its toll on her and she was becoming increasingly tired, although never once complained. She was also taking an array of oral medication, including antibiotics for the bacterial infection.

91. On 27 July 2018, this was day 15 of radiotherapy and Molly had to commence VIA chemo cycle 3. I took her to ward 2A where she was treated as an in-patient however, each morning she would be transferred to the Beatson for radiotherapy, before returning to ward 2A to continue with the chemo. It was during the one of the transfers that Molly experienced one of the main glass panels falling from the floors above the main entrance exit. I speak about this in more detail later on in my statement.

92. During this time, I requested various meetings with Corporate Services within NHSGGC together with microbiologists and clinicians to better understand what was being done in respect of the bacteria contracted by Molly. I challenged the

group with regard to communication about the hospital environment; that it was reactive rather that proactive, with a failure to ensure timely and informed reporting to families who were concerned with media reporting and commentary from members of staff. I raised with them subjects such as business continuity, risk management, resilience, leadership, investigation of outbreaks and reporting to the Board. I challenged the group with regards to the quantity of bacterial infections reported to the board and eventually I had it confirmed that Molly's case had not been reported to the Board. I asked repeatedly as to the extent of the investigation to determine causation of the bacterial infection and was told that it was in accordance with guidelines. I repeatedly asked for the water to be tested and was repeatedly told it was safe.

93. I received agreement that communication and engagement with me would improve with proactive engagement rather than reactive and that Mr Jamie Redfern would be my single point of contact.

<u>September 2018: Closure of Wards 2A and 2B (RHC)</u>

94. I requested a further meeting with Jamie Redfern, Dr Teresa Inkster and others as I understood that wards 2A and 2B were to be closed, confirming my suspicion that the environment was unsafe. If it was safe, why close the wards? I was concerned as to where I would take my daughter should she require treatment. I was advised that various options had been considered and, following assessment, ward 6A in the adult hospital was identified as the most appropriate location. I was advised that the ward would be prepared to accommodate immunocompromised patients. I was advised that the ward had a different water supply from ward 2A however measures would none the less be taken to ensure the safety of patients.

95. I asked what impact assessment had been carried out with regards to any decant and was told that an SBAR had been completed. However, at no point was there ever an impact assessment relative to the children and young people themselves

something that I raised again during the Oversight Board meetings. In particularly I asked why the Scottish Government, Children Rights and Wellbeing Impact Assessments were never completed by NHSGGC as this was a structured guidance framework designed around children and young people. To date, I have not received any response as to why this was never considered or indeed if any form of impact assessment relative to patient care was ever completed.

96. In relation to the decant I was advised that they considered a number of options including decant to another oncology site in Aberdeen but that had been discounted as the infrastructure required for such vulnerable patients was limited there; a dedicated self-contained modular unit was considered but discounted due to a number of different factors. An existing ward within QEUH, which due to the time needed for the decant, was the preferred option. I asked what was the existing Business Continuity Pplan for decant from the Schiehallion ward? I never received an answer but from the information I received regarding options, I formed the opinion that there was no Business Continuity Plan. I asked if the preferred site, namely ward 6A was safe. I was told it was. I asked for assurances and was told that all the appropriate infection control and monitoring checks would be conducted pre-occupancy. I was told that the taps would all be fitted with filters which I questioned. I asked, if this was a safe ward in the QEUH why a need for filters and was advised that it had a different water supply but as an added precaution to protect the children, would be fitted. I asked them to reassure me that this was a safe environment for my daughter, who not only required to have the best cancer treatment but required care in relation to a bacterium contracted whilst in the hospital. What if another child contracted this bacterium, what was being done to prevent this? I was assured that everything that could be done was being done.

97. I then read in the news that patients were being decanted from ward 2A to ward 6A on 26 September 2018. As Molly was an outpatient at the time, the move did not directly affect her but would impact on her when she returned both as a day

care patient and thereafter as an in-patient. Even the very basic of details such as will the telephone numbers remain the same, had not been confirmed.

98. Following initial examination of the ward 2A, media reporting carried comments from NHSGGC stating that they would take the opportunity to upgrade the ventilation system on the wards but maintained a position that the environment was safe. This public statement was at odds with reports I had accessed from an independent expert company, INNOVATED Design Solutions who, in October 2018 following detailed examination of the existing air conditioning system in ward 2A, stated that the original design philosophy was not intended for immune supressed patients. Further, the existing strategy would appear only likely to promote risks associated with uncontrolled ingress of infectious aerosols to patient areas. The report went on to state that air change rates were not in accordance with recommendations; no identified agreement to any deviation from recommended guidance; numerous deficiencies and inadequacies; with significant modification/replacement being necessary. In conclusion the report states that failure of this system gave rise to the risk of infection. They recommended that not only should the air-conditioning system in ward 2A be replaced, they stated that it was probable that these issues applied to other air handling units across the hospital.

99. This was at a time when NHSGGC were aware of the emergence and significance of the ‘lost’ 2015 DMA canyon report, first submitted to NHSGGC electronically and by hard copy in May 2015. The 2015 report highlighted a raft of very concerning issues with water management and bacterial control resulting in a number of high risks being identified, including no formal management structure, written scheme or communication protocols; and filters having been bypassed introducing debris into the system.

100. In addition, DMA Canyon provided a further report in 2017, during which they expressed significant concern that ALL recommendations including those HIGH RISK recommendations from 2015 had never been implemented. They further

detailed concerns with regard to the filtration system, bypassed due to issues with pumps and filter sets, which would introduce contamination, debris and (potentially bacteria) into the system. As tanks had not been cleaned, even since recommendations in 2015 to do so, any material or contamination then present, could potentially have been flushed into the system and have colonised parts of the system. The report also made reference to positive tests for bacteria in 2017 indicating potential bacterial control issues. However, this report, a statutory requirement, was also ‘lost’.

101. Remarkably a third DMA Canyon report, compiled in January 2018 as a gap analysis reflective of legionella requirements, seems also to have been ‘lost’ as no-one makes any reference to the fact that the report highlighted significant concerns across estates with individuals responsible as ‘authorised persons’ being untrained and unqualified to carry out their role. DMA Canyon recommended ‘corrective action as a matter of immediate urgency”. However, rather than implement the immediate urgent recommendations, the report was once again lost, exposing my daughter and every other child to significant risk!

102. I find it incredulous therefore that the GGC management maintained that the environment was safe and were simply taking the ‘opportunity’ to upgrade the ward!

103. I would wish to understand how such information as detailed within each of the expert reports influenced the decision with regards to continued occupancy of ward 6A; was the air conditioning system for ward 6A subject to the same level of scrutiny and examination as ward 2A?

104. I noted during our time on ward 6A the introduction of HEPA filtration units; was this a result of any findings and was this indicative of an environment where they consider the air was not as clean as it should be for immunocompromised patients as highlighted in the INNOVATED Design Solutions Report?

105. My enquiries have also disclosed internal communication where significant concerns were raised with regards to the environment in ward 2A and also ward 6A with a specific internal report submitted in August 2019 which detailed a catalogue of risks to immunocompromised patients in ward 6A with recommendations stating that a re-assessment of options appraisal was urgently required; ward 6A had significant unacceptable levels of infection risk for immunocompromised patients due to the built environment; a peer review should be carried out with the likes of Great Ormond Street Hospital.

106. I am in no doubt that from the numerous external expert reports I have accessed, the many internal communications I have read, and the various internal reports made available, my daughter was in an environment in wards 2A and 2B that was unsafe, exploiting her vulnerability and exposing her to increased risk. I am also in no doubt that she was then decanted to another ward in the hospital where the risks were known and not acted upon.

October 2018: Molly's surgery

107. Around the 18 October 2018, Molly was admitted to Ward 3A under the care of Mr Andrews and Mr Watson. Mr Andrews would perform the main part of the surgery - removal of rib, muscle and associated tissue and Mr Watson would reconstruct the area with muscle from other areas of her body. The operation was explained in considerable detail with each of the surgeons, Dr Sastry and anaesthetists explaining the complexities and risks associated with the surgery. All provided a level of confidence whilst acknowledging an understanding of the complexities and associated risks involved. The nursing staff were drawn from the surgical ward and not Schiehallion.

108. I noticed that Molly was shaking but not like rigors previously, it appeared more nerve related as this was a significant surgical procedure. I remained with Molly until late that evening and thereafter left leaving my wife overnight with Molly. I returned early the next morning on 19 October 2018, ahead of surgery, and was

present when Molly was being prepared prior to going into theatre. Molly was shaking more and was not feeling well. Nursing staff took her temperature, which at that time was nearing 40 degrees.

109. Doctors were called and after discussion the anaesthetist immediately cancelled the operation saying it would be catastrophic for Molly had she undergone surgery. It was suspected that mycobacterium chelonae had resurfaced, and her central line was removed with blood cultures being taken. This was devastating for Molly and I recall wondering what next. How could this bacterium be back following all the antibiotics intravenously and then orally?

October 2018: Admission to Ward 6A

110. Molly was transferred back to ward 6A where she was placed on a new regime of antibiotics, designed for patients with leprosy. This in itself had a major impact. I could see that Molly was having difficulty coming to terms with this latest major clinical intervention, firstly the cancelling of the major operation, the second time the surgery was postponed, then further surgical procedure to remove her central line as a result of the bacteria. How was this going to impact on her cancer treatment? If they were unable to perform the surgery, the cancer was still there and all the chemo and radiotherapy will have been for nothing. I could see Molly was distressed and having difficulty in coming to terms with this latest setback. It was bad enough with the cancer, but the bacteria were having a greater impact on Molly and was determining the course of her treatment, further reducing her chances and quality of life.

111. I was then advised that it was indeed the mycobacterium chelonae that was present in her body. I was informed by Dr Sastry that new antibiotics had been identified by Dr Lawrence in the hope that they would deal with the mycobacterium chelonae. I asked how confident were they and he said they had to try different combinations to see what works. It would have to be by process of elimination. Molly was advised that she would undergo IV antibiotics for three

months and likely to be on oral antibiotics for 12 months thereafter, although this may be subject to change depending on how she responded.

112. As Molly was on ward 6A there was no access to TCT facilities nor were there kitchen facilities or other support facilities as it was intended that the decant from ward 2A would be short term. This next hospital stay was extremely challenging and with further concern and media reporting regarding the hospital environment, I was extremely concerned as to the environment in which Molly was being treated. The initial plan to decant for a few weeks was now being reported as a few months. However, work commenced on ward 6A to provide a parents' kitchen area. This and other work ongoing seemed to me to indicate an even longer stay. I could also sense from staff that there was concern as to ward 6A environment due to an increase in infections.

113. In terms of the lack of facilities in ward 6A there was an impact on Molly. Something that she would reflect on often was to compare and contrast the physical nature of what was happening to her and consider that and always try to derive the benefits from it. This was hugely important when it comes to body image. When it comes to being in hospital, when it comes to having access to facilities like the TCT where you see similar kids. When you're young and you're in that environment and you're bald, if you're amongst other girls and boys who look similar to you, it's acceptable, but when you go out of that environment it is noticeable and impacts socially as well as emotionally.

114. Even when you can put a wig on when you go out or put make-up on it doesn't truly mask how they feel. The TCT room afforded some comfort and protection from the outside world. But not to have that facility afforded to them in ward 6A is a significant impact that has been felt not only by the patients and the families, the staff have felt it because they can see the trauma these kids go through and without that support it is detrimental to their overall wellbeing.

115. On ward 6A you were confined to barracks, quite literally, because of the environment. That's a huge, huge pressure because all the patients are doing is looking at themselves, looking at their body image and recognising their illness and their limitations.

116. Reflecting on that experience and following discussion with Molly, we found ourselves being held captive within the hospital. Not because of the cancer, but because of the bacteria. Molly's quality of life that was already diminished was further eroded because of everything that was ongoing in relation to the issues with the hospital building. This operation had been postponed by a number of months: Molly couldn't get on with her life because of it, because of the bacteria. I keep coming back to that.

117. In January 2019, ward 6A was closed to new patients. Widespread media reporting provided information regarding an alleged outbreak of cryptococcus and associated hospital deaths including that of a child. It was a very difficult and challenging period. The crisis seemed to continue to envelope other areas of the hospital. No-one had a grip of this crisis and further increased the concern, anxiety and fear as to the overall safety and health of my daughter. I repeatedly asked if it was safe, but there was an absence of reassuring messages from NHSGGC senior management. There was an obvious vacuum relative to timely and reassuring information and a clear divide between staff on the ward and corporate services.

January 2019 – February 2019: Surgery wards 3B RHC

118. In January 2019, Molly was admitted to ward 3B ahead of her rescheduled surgery. The same medical team would perform the surgery and as such there was a confidence around the procedure, if not considerable anxiety about the re-emergence of the bacteria and overall safety to Molly relative to the hospital environment. However, we had to balance the risk of the environment against the risks to Molly from the cancer. It was a dreadful position for her to be in.

119. Molly was scheduled to have her operation on the 15 of January 2019. This was a date that had been identified by Dr Sastry and Dr Andrews, as such we were well aware of the risks involved with the operation because they had been so detailed during October 2018. However, the additional concern that we had and which was ringing in my ears was the wording from the anaesthetist at the time who said when they identified that something was wrong with Molly as she prepared to enter the theatre, that had that operation gone ahead it would have been catastrophic. That was my concern, over and above everything else.

120. We went to the hospital, we went through everything and Molly, she was terrified. As we were in 3B and not in the Schiehallion, we had taken additional tempa-dots with us because we wanted to ensure that we would take her temperature. Probably you would say it’s because you don’t trust people but it wasn’t that; it was because the protocol’s different, as I’ve outlined previously. A temperature increase was our indication if something was wrong with Molly.

121. We went in that day; the ward staff were there. Everybody was ready for Molly coming in because we knew and understood the challenges previously. My head was in the space of the bacteria; I was terrified of it. Absolutely terrified of it. Even the best doctors in there were unable to tell us if Molly still had the bacteria. That’s the scary thing about this whole thing. Even now, we still don’t know if her body’s clear of the infection.

122. That evening [redacted] was allowed to stay with Molly. I had to go home that night. In the morning, Molly was first in to go into surgery. [redacted] and I went for a walk and we waited; it was hard. Following surgery [redacted] and I were in the ward as she came to. Molly was in a lot of pain. She was really suffering with it. Mr Andrews described the surgery as an injury. He said that the surgery she had undergone and the trauma resulting from it was likened to her being hit by a double decker bus to her side. That was the description of the trauma that she went through. He said she would experience a lot of pain. She was given an epidural and as a

consequence the plan was that we would manage her pain as we went along. Molly has a high pain threshold, but at that time we could see that she was in excruciating pain.

123. [redacted] and I asked the team if there was anything that they could do, but nobody wanted to give her anything further, and we had to wait for another anaesthetist to come in. We went through that night and it was extremely challenging. Molly was in a huge amount of pain.

124. The next day when the staff were trying to change Molly's bed, the bed sheets were wet around the base of her spine. That was the first indication that the epidural didn't work, this was because of the existing tumour in her spine; it blocked the pain medication and it was just seeping out at the back. That was hard to take because everybody assumed that she had sufficient pain cover, but she didn't have any. [redacted] and I had been told that the surgery she had was like she'd just been hit by a double decker bus. She had been hit by a bus and had no pain medication. We were watching her go through that and it upsets me when I think about it.

125. The protocols in the Schiehallion Unit are such that pain medication can be administered in different forms. After surgery, Molly was in ward 3B in the RHC and as a consequence everyone knew that with Molly's history, that she would have a combined pain med of ketamine and oxycodone. Ward 3B's protocol does not allow for the administering of ketamine, and because of Molly's other complications there was a challenge in actually getting the right pain medication. It lasted 48 hours when Molly was going through this.

126. There was an intervention on the part of Dr Murphy. Dr Murphy and I had a number of hard discussions, but on this occasion Dr Murphy's approach came to the fore. He demanded that regardless of the protocol we had to ensure that the appropriate pain medication was administered to Molly because of the complexity if the situation. Given her pain score at this point, she would ordinarily be a

patient within PICU. But on this occasion there was no bed in PICU, therefore Molly was then given one-to-one nursing where there was a nurse drawn from PICU who would be on the ward to help her throughout the whole period, and that happened over a number of days.

127. This event coincided with a period of concern about ward 6A, particularly around the safety of the ward. Whilst Molly was recovering and my main priority was surgery. had they got the tumour away? Had the reconstruction work been successful? Were there any other issues in terms of infection? I was also concerned with regard to the bacteria. Is the mycobacterium chelonae infection going to take hold again?

128. Molly was recovering in Ward 3B RHC for approximately three days. Molly wished to move to ward 6A because she would then be in and around an environment that was familiar to her, with people who were familiar. However, we understood that we had to be in the surgical ward because she was under the care and charge of Mr Andrews, so that is where she stayed.

129. Following the surgery, Molly wished to be transferred to ward 6A. Some of the medical staff suggested that we should not go to 6A. The staff had concerns over the environment as there was a number of other bacterial infections within 6A. There was a lack of confidence that the displacement into 6A from 2A was solving a problem. It was only displacing a patient group. My understanding is that the medical staff were referencing that because they may have understood there were bacterial infections on the ward.

130. Following the operation Molly was in hospital for roughly seven days, give or take a day. It doesn’t seem a long time when you consider what she had been through and the trauma that she had gone through. It was certainly a long seven days, and then she came home.

February 2019: Discharged home and outpatient care in CDU (RHC)

131. She was released from ward 3B and she came home with us. The medical staff considered that coming home was the safest place for her. We could better protect her there. Her release home was on the condition that we would go back every second day to the hospital for Molly to go through the various checks both in terms of the operation and also for the wider treatment.

132. Molly coming home made such a difference. She had her own things about her, she'd the comfort of it and it aided her recovery, there's no question of that. She was treated as an outpatient at the hospital up to and including the second or third week in February 2019.

133. The most important thing when Molly came home, was that she came home. Those words say it all. She came home. That's something that I reflect on every single day, is that she came home and she's still here. We need to be thankful for that and we are, but it was an emotional challenge.

134. When we came home, there was always the trauma of going back to the hospital. At this time, day care had been displaced from 6A itself and it was actually down on the ground floor. The reason for this was because the hospital took the decision that no-one was to go onto ward 6A. It further reinforces that if that was the case, it was indeed safer for Molly to come home rather than move onto the ward.

135. At the time, there were mixed communications, particularly when you compare what was being said from the corporate level, which was the message that everything was safe; there's nothing wrong. But to me there was everything wrong. No-one could give me any reasonable explanation, no-one could give me anything that would counter the view that the critical ward, the bespoke ward, had been closed. The move from ward 6A to CDU, the displaced ward had further displaced patients and the day care had to have another contingency in place

where they could treat patients elsewhere in the building. But the patients were still going into the same building to receive treatment.

136. It didn’t seem logical to me. I’m not a microbiologist but the very environment I was stepping into was the same environment that had given Molly her infection. I couldn’t see beyond that.

137. The day surgery people are fantastic. They are caught in a difficult position because they were often the conduit of information to parents and patients. They were used. They were used because they had an excellent relationship with us and so if they said anything about the issues with the building, it was more palatable to us and we would be more trusting. I am in no doubt about that, and I can understand that because if senior management consider that such a message can land more effectively then they adopt that approach. Perhaps they wanted to alert but not alarm. However, in this situation, we were already more than alarmed and nobody was actually alerting us to anything then. The information was not forthcoming.

138. The messages being provided to us about the building, there was no good news in any of this. But actually, by delivering what we already knew about the building, they would think that this was the worst news that we’d ever heard. Of course it’s not. As a family we’ve been living with the challenges of a child with cancer; we’re dealing with the challenges and the traumas that are depicted. Telling us that an environment is unsafe, that this is what we’re going to do, would actually give me comfort, would actually make me feel better. By contrast when I went home, I had comfort because I could control my environment.

139. It took me back to a conversation when I questioned that water. I actually asked if I should bring Scottish Water into my own house to test the water and I was told no, there was no need to do that. All of the answers that I would get from those that I engaged kept focusing me back to that environment. Whilst there was no, publicly available, causal link at that time to be established, notwithstanding that,

there was significant impact and significant perception that there was something wrong.

140. Perception is truth. Until someone could start to articulate to me in some reasoned form that that environment was safe, I found it very, very difficult to believe them. But I still had to go to the hospital because the very good people that were saving my daughter's life were there. I put up with that risk and I tried to manage that risk but it's not something that you should ever be faced with.

141. Those individuals who were not responsible were being held accountable, by this I mean that the clinical people were being held accountable for an environment they were not responsible for. They should not have been put in that position, nor should we. That continued in day care and the recovery for Molly, the operation and the healing process.

142. Her care throughout was something that needed a lot of attention. It was painful to go through it. But I cursed every one of them in relation to bacteria. And I'm ashamed to say it because they've saved Molly's life. At the same time they presided over an environment that put her life at risk. That's a hard thing to take, and at this point I am talking about the emotion of it. That's when I have that guilt because I feel as though I'm drawing negative attention to the people that have done the most precious thing for me. Of course, it's not about the clinicians it's about others. But people don't see that and the perception is there.

143. That is something that Molly currently rankles in her own head: she doesn't want any criticism whatsoever to be levelled – perceived or otherwise – towards the men and women of the Schiehallion Unit because they've been remarkable. You've got that balance in your head that you're cursing the hospital but then again, you're praising the clinicians in the hospital.

144. When it comes to communication, the communication would come through a single portal and there was no distinction made from the health service about the clinical communication and the corporate communication. That is key in all of this.

145. Clinically the communication was always there, they gave us as much or as little information as we thought that we needed. Indeed the clinical staff adhered to the duty of candour throughout, in my opinion. There's certain aspects that they didn't tell us about at the time, but I'll talk about that further. Throughout, communication was a significant recurring issue.

February 2019 to June 2019: treatment concluded

146. Molly rang the bell around the last week in February 2019. This coincided with ward 6A reopening up and people could move about again. What is important when a patient rings the bell is to have those others that shared the experience with you, to have them beside you. There is an opportunity to read some words and to recognise the event. It's a really big deal. I couldn't believe when I saw it, but I was filled with joy because from that point on I was seeing my daughter starting to flourish. I was seeing her putting weight on. I was seeing her walking, she was getting better. I was starting to see all of the things and her desires and her ambitions coming alive again. That's huge, absolutely huge for a father.

147. Molly has always had aspirations to go into medicine and she was accepted to study at the University of Cambridge for two weeks during the summer beginning on 30 June 2019. As a family we were building up towards that and we were able to leave behind the hospital, that horrible place. I'm ashamed to say it because there were people who helped me in that horrible place, but I didn't want to see it again.

148. I knew that I then had to take the baton and support the next family who's children required treatment at the hospital, or the next person with Ewing's Sarcoma. I knew that if the next family asked me about the journey and all of the

issues at the hospital, that I would be honest with them. In that situation, you are honest with people who are on the journey because what it allows them to do is to raise the risk threshold. From the first day you're told about cancer or the first day you're told about bacteria, you as a parent have a risk threshold. As that experience builds, your threshold goes up and you're willing to put up with certain things because you've still got your daughter, you've still got your son. And that's wrong.

149. This is where I consider there's a vicarious responsibility on the part of the hospital to recognise that. That's why I asked throughout, did anybody ever conduct an impact assessment? When they shut the ward down, what was the impact on these patients? What would it be? To date I've never seen one. I asked if they had considered the Scottish Government's Impact Assessment for Children and Young People that follows the path of the United Nations, this is something that's in the statutory framework for all local authorities and public authorities. Yet, nobody did this. This tool was actually available for use on the shelves from 2014.

150. As a parent of a patient in receipt of treatment in the hospital, I shouldn't have to think about these things but I was. Within my headspace I was starting to think, how can you make this better for the next group of kids or cohorts coming through? But wait a minute, I want to enjoy seeing my daughter grow up, I don't want to have an anchor pulling me back to that hospital. That is what was happening, and with those thoughts I experienced feelings of guilt.

151. Molly is understanding. I knew she wanted to see me, to see her dad but at that point I was away to meetings in the hospital or to meet the Children's Commissioner or some other statutory body and it was because of all of these things that were happening in the hospital and related to the building. Some people maybe say, "That was really nice of you, John, it's really admirable what you did". But at times I cursed it, I absolutely cursed it. It is terrible to say that.

This is what I felt, this is what I mean when I talk about the emotional journey and what it does to you.

152. I actually consider I'm quite a strong person. I know what it's like to go through and identify risk, to manage risk. I've seen trauma before. But when it is your own personal trauma and associated risks, it is different. When it is your own and there's stuff that happens that you consider is preventable, that's really hard to take. If I saw a bus coming I would hold Molly's hand and stop her from walking out in the road. But I was unable to hold Molly's hand when she was walking towards the bacteria. I was unable to hold Molly's hand when she was diagnosed with cancer. That is the hugely, hugely difficult bit.

153. All of these emotions; anger, shame because you think like that, because you don't want to consider the future of these other kids, it's what eats away at you. Molly was progressing and she was getting better. Over that period I was going to these different meetings. I considered that the communication from management was terrible because you could see what was ongoing with other families. I could see that there was the need for somebody to grab a hold of this, put their foot on the ball and say "Right, we've got a grip of this. How bad is this? Let's tell the truth. Let's say we had shut this ward because we're going to get to the bottom of what's happening".

154. That's not to have an admission that you did something wrong, that's being responsible and accountable for the role which you have as the Chief Executive or Director. In that position you are there to ensure that you manage and mitigate any risk, particularly within an immunocompromised patient group.

155. Over that period of time in Spring 2019, Molly was progressing towards her journey at Cambridge and it was a happy time for our family. In parallel I was banging the door of the Health Board to say please, please, communicate far more effectively. Please go and engage a communications specialist. You have different audiences here. You have to talk to the patient group but you have to

talk to the families. You have to talk to different groups within it. Some families don't want to know, they don't want to see the horrors of it, because you don't want reminded. For me, in order to make an informed decision about Molly's health, I needed to be in possession of the information. This was the discussion I was having throughout that time.

156. That is the reason why I said to Health Board Representatives and hospital management at various meetings that I consider that we were entering into a human rights violation. We were being deprived under Article 12 and Article 13 of engagement, of a right to have information. It is for us to choose not to have it. It's not their right to deprive us of it. This is where the Health Board would conflate confidentiality with a duty of candour.

157. I encouraged hospital management and the health board to speak to the Information Commissioner. It's a statutory being. If you're in doubt, please go and speak with them. Part of being a Chief Executive or being a Director is to have humility and understanding when you don't know something. These people are there for you, go and engage them. Indeed, that's why they should engage with the medical people, because they know better.

June/July 2019 – University of Cambridge

158. Eventually I started to reengage with my day job as well. On the 30 June 2019, and I drove Molly down to Cambridge to begin her university course during the first fortnight in July. I was chuffed to bits, because I didn't think we'd be doing it. It was the loveliest prize we've ever had. It was magic. It was lovely. Molly was selected from hundreds of students. It was great for Molly because it gave her a value; it gave her a sense of worth that I'm no longer the sick kid. It was a big thing; it was about identity. She attended with children from all over the world; from India, from Pakistan, from USA. At the end of the fortnight, Molly was awarded the dux of the course and what the course leaders wrote about her was

incredible, absolutely incredible. Molly was in a happy place; she was on a journey.

159. After taking Molly to Cambridge, [redacted] and I had driven back up the road. I was going over to Afghanistan for work. I felt safe in the knowledge that Molly was in a happy place. Whilst I was going to a place that was madness, I chose that. I chose to go into that risk environment by knowing and understanding the risk because I had the information that allowed me to make an informed decision.

160. Prior to attending Cambridge Molly was invited to the Royal Albert Hall by the TCT, and she was there with one Roger Daltrey. Molly said to me, who is this guy, dad? She didn't see the irony in it. She was onstage and she was speaking on behalf of the TCT in front of 6,500 people. Molly was in a happy place. She was in a good place. While she had a wig on and she walked funny, she was a million dollars. She was going places. This was important as we progressed.

161. Molly returned from the University of Cambridge as high as a kite. She said "That's it, dad, I'm going to be the next Dr Sastry". She couldn't have a better role model, to be honest. But then things changed. This is another thing within the cancer journey, you want to have the scans and you want to have the check-ups and you want to go through all of the prevention but you don't want to know the answer. It is like you're taken to a cliff edge and they hold you over and then you get taken back from the cliff edge; everything's okay. It's horrible, horrible.

August 2019: Molly Relapsed

162. Molly found the process of MRI scans, CT scans and check-ups quite reassuring. Where I was seeing it as almost a rollercoaster ride from the depths of a catastrophe to standing in Cambridge University grounds, standing with Roger Daltrey, and I'm saying could this happen again? Where is this bacteria? I've got a relationship with this bacteria. I wish it was a thing or a person because then I could do something about it.

163. In August 2019, I had to go back out to Afghanistan. We had to have an air of normality. If I didn't go to Afghanistan, Molly would think that I was in a dip. I went but my emotional baggage wasn't in a happy place. It was times like this that I wanted the hospital to recognise and to reassure me and to give that advice.

164. About five or six days after I left, [redacted] got a call from Angela Howett. Angela's the most wonderful person, she's brilliant. And I said to you earlier about the medical team being considered the best option for giving you bad news. Angela called us regularly and on this occasion when Angela came on the phone [redacted] knew. Angela said to her, is John there with you? She said no, he's away. [redacted] knew then. It was Angela's way of trying to soften what was coming. Angela told her that Dr Sastry needed to speak to us. At this moment in time Molly was still flying at 3,000 feet following her summer school.

165. I returned from travelling for work, [redacted] picked me up at the airport and that's when she told me. Molly had relapsed. [redacted] didn't want to tell me the full detail over the telephone. Molly did not know at that point, so I told her when I got home. We sat and went through it. Molly being Molly, she's actually the one who comforted us through it. She said, "We need to wait and see what Dr Sastry's got to say. I've been looking at this anyway, I thought this might happen".

166. Ewing's Sarcoma is a dreadful – I mean they're all dreadful cancers – but Ewing's Sarcoma, the percentages that you operate with are not great, but you accept them. If Ewing's Sarcoma comes back quickly then the chances of survival are not great. My head was in that space.

167. We went to see Dr Sastry. We spoke about options. He told us that the treatment options were reduced because of the trauma in Molly's body, particularly because of all of the antibiotics that she had over the prolonged period of time to treat the mycobacterium chelonae. Molly had only 54 per cent function in her kidneys. Treatment was going to be a strain on her. Dr Sastry told us that he really didn't

know what we were going to do but he said “Okay, I’ll come up with a plan” and he did, he came up with a plan. The plan was that Molly would have an operation. There were two nodules in her lung, one is bigger than the other. Dr Sastry spoke to the anaesthetists and Mr Andrews. Both Dr Sastry and Mr Andrews wanted to do the surgery, and that gave us a lot of comfort.

168. We saw Dr Sastray within a few days around about the 9 or 10 of August 2019. He made an immediate appointment, spoke briefly with Mr Andrews and then on the 12 August 2019 Molly was admitted for her operation. That indicates to you the concern that clinicians had and how quickly they were doing to deal with this.

169. The plan was that there would be surgery to deal with one aspect of the cancer, and it would give us a fighting chance. That fighting chance would then be a certain type of chemotherapy. At that point Molly was planning the Every Thank You Counts Ball and she wanted to see it through and participate in it. We hadn’t told the majority of people that Molly had relapsed; we didn’t want to. This was Molly’s business and she would choose. Molly wanted to speak to Dr Sastry further and she did. They decided she would take a tablet form of chemo called melphalan. At the end of the day, Dr Sastry said another month was not going to make much difference and that became part of the plan.

August 2019: Surgery – ward 3A RHC

170. Molly took unwell after the surgery and we were concerned about her. She had to be assisted with a number of her bodily functions, they just weren’t working. At this time Molly was given a drug, nabilone which is a type of a cannabinoid. She was given it because it would help relax especially when thinking about everything that was ongoing.

171. However due to the impact of all the antibiotics and various other things, the clinicians didn’t recognise or realise how Molly’s body would respond. The way it responded was her eyes, she couldn’t see because of medication. It then

transpired that this was a known side effect and Molly's luck being Molly's luck, that's what happened. The significant issue was because of the kidney function. The anaesthetist advised us that because Molly's kidneys are not functioning the way they should, as a consequence the drug is not dissipating in the way it should. When Molly was getting a dose of nabilone, it was hitting her almost like a double dose. Molly stopped taking the medication and eventually her eyesight rectified. They told us it wouldn't be anything lasting.

172. Molly was cleared after surgery and she came home on the 30 August 2019. She was still taking the chemotherapy drug in tablet form. In September 2019 she became very ill again and we just didn't know what was happening, she had high temperatures and rigors and different things. And everything about it was just about bacteria, bacteria, bacteria. It sounded as though we were becoming paranoid and we probably were because all you ever saw in the news, all you were hearing from everybody, was so and so's got a bacteria, so and so's got this, so and so's got that.

173. You actually try to address it, saying look get this into perspective, we know that these things are ongoing. But I was starting to recognise that the numbers of bacterial infections that were being reported to the Board were only gram negative and they were not reflective of gram positive or indeed wider. People were becoming fixated with the quantitative analysis of the bacteria but nobody was considering the qualitative analysis of the bacteria and the rareness of the bacteria. I was meeting with the microbiologists and others and trying to talk to them and to get a sense of it. All of this was going on whilst Molly was still ill.

174. On 15 September 2019, Molly then started to get various blood transfusions, lots of platelets. This was all in ward 6A. And it was horrible. It was just the most dreadful place to be. I described the Schiehallion previously, ward 2A and the environment, as never a place you want to be and it's never a place I would wish for anyone. But when you're in ward 2A, it's the most comforting environment because they just cuddle you with love, with support, with kindness and with the

most wonderful clinicians that are there. But here we were in an environment I just didn't want to be in, because I didn't want it wrapping round Molly, I didn't want it wrapping round me because of what could happen. That was in my head and it's very difficult to shift it.

175. During Molly's admission when we were on ward 6A there was a leak in the ward, which was reported and the kitchen was closed. We were being told, it is just a leak. But given previous issues with the building I didn't believe anything that's being said. I wondered what do you mean it's just a leak? The kitchen is closed.

176. When you're in an environment and you're confined, you watch everything, every minute has a purpose. You look at it and you know who's coming through the door. You see certain people on the ward, you know there's something. At this time I could start to see a collective on the ward, microbiologist, managers and some others were there. As soon as I noticed them, I thought something is not quite right here. That reinforced my concerns.

177. I later found out that t leak wasn't just a leak that happened overnight, there was actually a leak that had been there for some time. The significance of the decant from ward 2A to ward 6A. I was told there was a deep clean prior to the decant. I was told that all of these things had been done but when you see the pictures and if you hear the opinion from the microbiologist I spoke to, this was a leak that been ongoing for some time, creating mould that creates spores.

178. For me this was further evidence to question the organisation and the maintenance structure, within a high-risk ward, immune suppressed environment. I know a bit about this because I was an engineer for seven years in the hospital before joining the police. I knew the maintenance routine, you get job cards and you get stamped. There's certain things that you go in and you do, routine checks. Whether it's through engineering or through plumbing or through electrical, it's your prevention plan. Within a high-risk ward I would have expected

such a plan. It was at odds with the communication that was coming that it was just a leak.

179. Ward 6A was not a nice place that you wanted to be in. Eventually after numerous blood transfusions and platelets, Molly was released from the ward around mid-end September 2019. She was reasonably well. As well as could be, bearing in mind she was on her chemo, bearing in mind what she had just come through.

5 October 2019: Every Thank You Counts Ball

180. The Every Thank You Counts (ETYC) Ball was on 5 of October 2019. Molly looked a million dollars. She just looked fantastic. It was important for us in many ways because Every Thank You Counts was about thanking the staff. 70 members of staff were invited as guests. We had the cleaners sitting with the consultants and nurses sitting with the play leaders because that's how they are; they're a family. They offer each other the respect that each other deserves but there's a mutual respect that they are a family. It was important for Molly to see that happening because the aim of Every Thank You Counts was two-fold. It was to say thank you – before it became fashionable with COVID when everybody was clapping on a Thursday night – we were doing it there and it was the people we all wished to thank and it meant something. There were other teenage kids there as well with their families. It was also to fundraise.

181. There were 750 people at the Ball; the great and the good came out. We appealed for support for the Every Thank You Counts fundraising efforts. Molly and [redacted] spoke at the Ball. [redacted] spoke and she was fabulous, talking clearly about the wonderful staff and what they had done for her. She was a visible demonstration of everything that's good within it. We took the conscious decision that nobody would mention anything bad about that hospital. Nobody was mentioning bacteria or water or anything. That's not what the night was about. It was another example of the separation of the clinical from the corporate

governance. It is no surprise there was nobody there from the corporate world of the hospital.

182. Molly spoke and she too was fabulous. She told the guests that we were there for two reasons and she explained everything about the people there. Molly explained about the lack of facilities for children aged 8 to 12 years old, and she told the story about the young boy who had come into the TCT room but was too young to use the facilities. There wasn't a dry eye in the room. Molly explained that she did not want another child to be in the position that young boy found himself in; her and [redacted] wanted to provide a room for these children in Ward 2A. The people who attended the Ball committed and gave £250,000 cash on the night. That was a good feeling and it was good news. The ability to create and work on the ETYC room has been one of the good things about the ward being closed.

183. Professor Gibson was there and other clinicians, and they were over the moon. We'd also got commitments from others that would result in a revenue stream that would go further. What it allowed them to do is be positive and to put a positive spin on it. I recognised this as an opportunity here for the communications. When I was attending the Corporate Governance meetings in my capacity as Families Representatives, I would say to the meetings, turn this into a positive. Tell them that you're not just changing the air conditioning system because you're taking advantage of the fact the ward is closed. Because that was utter rubbish; reports told them that the air conditioning system was faulty. They were ripping up all of the plumbing because they knew there were challenges in there and mycobacterium had been identified in the ward, amongst other infections. However again, the Health Board's narrative downplayed the reality and that was shameful.

184. I am not suggesting that the Health Board should put fear and alarm out there. We, the patients and families, were already afraid because the ward was closed. They could have reassured us by saying "we're going to strip this out so that

nobody will go through anything like this again". There was an opportunity for a positive spin. They chose not to do it and I couldn't believe that they missed an opportunity like that. We were unable to change the past and the failure to protect our children from the environment but there was an opportunity to change that environment, ensuring other children do not suffer.

October 2019 – November 2019: Admission ward 6A QEUH

185. Molly took unwell that night at the hotel where we had the ETYC Ball and eventually she was admitted back onto ward 6A. Over the course of October she was not well. She had temperatures, back and forward, and then on 23 October 2019, I had to take Molly into Accident and Emergency. The reason for A&E is just simply for no other reason than it's out of office hours. The doctors would be on-call but they weren't on the floor so there would have to be an assessment.

186. We got in there about nine o'clock and we had to go through A&E and it took us over three hours to then get onto the ward, which wasn't great at all. It was something that I remember when I was speaking again with the Chief Executive and the Chair, about the patient pathway. A patient pathway in relation to the Schiehallion patients surely should have something far more effective. They gave an undertaking to look into it at that time because of the experience we had.

187. Again, this was just about us becoming more and more driven by the events in the hospital and every time something happened to Molly or something was ongoing I would draw a correlation with the physical infrastructure and say what are we doing about this, where are we going with that? It was taking me further into it and that's why I would continue to acquire relevant documents and make inquiries.

188. Eventually Molly was given various platelets. We had to stop her chemo tablets. They didn't know what was wrong with her because she was just so poorly. Then

on the 29 October 2019 she got further MRI and CT scans to try and see if there was anything further ongoing and we were waiting for the results in relation to it.

189. In the intervening period Molly did her entrance exam to Cambridge. Whilst feeling good regarding the potential around Cambridge, Dr Sastry reported that scans had come back and he said that Molly's lungs were consumed with dots. It was the collapsing timeframe from when Molly had the operation, she took the decision in relation to the chemo and it was the pace of it that I couldn't quite comprehend. He was flummoxed. He said I don't know if this is what I think it is, I just don't know. We were really concerned, we were wondering what was happening to the rest of Molly's organs. The staff were checking her heart, her lungs, everything was all being checked because of this and would entail test after test. For me all I could think about was the mycobacterium chelonae, was this it again?

190. It turned out it wasn't tumours. This is where the risk threshold changes. You think, "Fantastic, it's not cancer, it's not tumours". But what it was, was PCP which is a form of fungal pneumonia. The medical staff don't know how she got the fungal pneumonia, but my head goes back straight to the kitchen, it goes to the environments where there were leaks. At that point I was reading material that says where fungal spores come from within the hospital and I automatically start to join it in my head.

191. I tried to still maintain a sense of perspective and said to myself that just because it looks like it, it might not necessarily be it. It takes you back to the discussion, how is this happening and is this a safe place that my child is in? Because all the evidence is that it's not safe, you're not reassuring me and continually your communication and your narrative is undermining exactly what's going on especially when Molly is so affected by bacterial infections.

192. Molly then had to undergo a BAL test. It was an immersion in her lungs, a horrible thing that she had to go through. It swabbed the inside of her lung for bacteria.

Molly was being put through these processes, which are nothing to do with cancer but because they think there's bacteria within her body.

193. Molly also had a sub-cut pump inserted because with everything that was ongoing and because of the pain, there was a build-up of morphine and her kidneys are not working. They had to get rid of it. There was a lot of concern about her organs and what was happening and it made me start to reflect on Molly's decision, thinking everything's going against her and it's not looking good. Then you just see that happy place has gone again and you're going through that emotional wringer once more.

194. Molly stayed in hospital for some time, up to the end of November 2019. Dr Sastry at that point recognised that Molly needed some emotional therapy. She had to get out of there because we were confined in this barracks in Ward 6A. Every day was just sadness. Every day was just dwelling on what it was. Every day took you back to the same issues. Where are we? Two weeks went to two months, longer.

195. Molly was discharged from hospital on the 27 November 2019 but again on the condition that every two days we were back and forward. As Molly does, she put her lipstick on, put her wig on and she went for an interview at Edinburgh University the day before she had to go for chest x-rays. Molly wasn't fit to go for an interview at Edinburgh University but we weren't going to stand in her way. Having been in the door of Cambridge, she was now struggling to get up to the door at Edinburgh, but it wasn't going to stop her. This was a demonstration of the impact on Molly that went beyond the clinical aspects, it is a demonstration of the impact of the infection, of the building, on her life.

196. At that time there were further issues with ward 6A, it makes you question the extent of the issues on that ward. I later found out it was due to the bacteria. I also learned that they had swabbed ward 2A in 2019 and found mycobacterium chelonae in different sites. The hospital management never told me that. It was

the microbiologist that told me that. It actually becomes significant in that a year later when the Case Note Review is ongoing, they identify that those swabs that had mycobacterium were from particular rooms, which I didn't know. Those were rooms that Molly was in during 2018.

197. I'm used to recognising the importance of evidence and I was beginning to ingather evidence– however when it came to bacteria, it's about the balance of probability as the microbiologists informed me. There's more than a balance of probability here. Which made me question, why is nobody telling me this? Why will nobody actually be honest with us? What have they got to hide? Again, this is where I become extremely frustrated with the lack of open, honest and transparent communication.

December 2019: Make a Wish

198. In December 2019, Molly had to get various chest x-rays in furtherance to what was ongoing. Whilst it was positive news that she had this pneumonia and we could treat it, and it wasn't cancer. Her body had endured so much that it was still a massive challenge for her.

199. The best thing for her was to go and see Paolo Nutini as part of her Make a Wish. We travelled to London as he invited her into a recording studio. Molly was in a happy place. He'd written a song for her, Mad for Molly.

200. Due to Molly's issues with her neuropathy, she couldn't play the piano. She's great on the piano and the guitar; I love to listen to her playing. She was really nervous about seeing Paolo whose music she's grown up listening to.

201. Paolo said "Come and sing, Molly". I was looking at her, thinking about her lungs and wondering how's she going to manage it? Molly sang, she did it and she was brilliant. They sung together and he's kept in contact with her, which has been brilliant. When she's been in that sad place, she plays the video of them singing.

202. At this point in time, Molly was getting more in need of a crutch and further away from her strength because of all of these things that were happening. Whether it was a fungal infection; whether it was the mycobacterium chelonae; she couldn't get her operation: she was held in and she just wasn't seeing a way out.

203. Throughout the journey, the way things work is that dates just go by, birthdays and anniversaries. You try to respect them but you don't. On Christmas Eve 2019, Molly had to go and get a scan. Following the scan we made the best of Christmas, but it was one of those times where we were being taken to the edge of the cliff. Coupled with all these other things that were ongoing, I was left thinking what's going to go wrong now?

204. At that time Dr Sastry said to me, "Go and book a holiday". Where does your heart sit with that? You go through the journey and the clinicians tell you not to travel because of the risks. You say, "Oh we're going to go on a family holiday, it's great". But it's because you think there might not be another one. That's the finality of it. That's the emotion of it. The clinical people understand. I understand absolutely that in order to make informed decisions within a high-risk environment you cannot be clouded by emotion. But you can't be devoid of it also. So much so that you don't recognise what your words are saying. So much so that you don't recognise what the visual impressions say.

January 2020: Holiday and preparation for Stem Cell Transplant

205. We went on holiday and we had a lovely time. It is a really good memory that we've got. Molly had a ball, she had the freedom to take her wig off. Actually it was funny, she was in a lift, we were going back up to her room and there was a wee tot in there and pointing to Molly. She told her that she was just trying to get closer to the sun and she's trying to get a tan on her head.

206. As a family we knew we were coming back to something, we didn’t know what but we didn’t have a good feeling about it. We returned on Monday 20 January 2020. We’d had a great holiday and all we said was we’re just going to continue to live a life, we’ll chap their door, Molly, when we need to, but in the meantime, live your life.

207. I went back for some work in Afghanistan and I got a telephone call from [redacted] advising us to take Molly into the hospital. Dr Sastry said we need to go forward with the Stem cell transplant. He didn’t think they would be able to do anything with Molly’s kidney function but said it hasn’t got any worse and was marginally – just under a per cent – better. Dr Sastry came up with a very detailed treatment plan, he spent a long time on it.

208. He told me there was only one other occasion he’d gone ahead with this combination, but he still felt we should go for it. You’ll take anything but we recognised the risks. We believed in Dr Sastry, or more importantly Molly did and she had absolute confidence in him. He had the foresight to harvest Molly’s own cells away at the very start of her treatment. It was those cells that were her lifeline now.

209. Molly was admitted to ward 6A. We were walked through the risk management plan. Dr Sastry showed it to us. He showed me all the doctors that were involved, including the anaesthetists. It gave me confidence that there was a plan. The clinicians had worked this out and with the risks involved, there was no margin for error as far as they were concerned; everything was thought out. We signed those documents, acknowledging the risks and acknowledging that plan.

210. What was significant within that plan were the details of the drugs that would be administered, the dosage was there and written down, because they knew that the impact on Molly’s body was such that it would be very demanding. When they worked out all the figures, influenced by Molly’s height and weight; so it was

60 milligram per kilo so 60 times 60 kilo was 3,660 milligrams of etoposide phosphate – it was all written down.

211. This level of planning, this approach was all because Molly was limited in her options because of the antibiotics she had to take because of the mycobacterium chelonae. That is why there was a careful plan.

212. We went ahead. First of all, we were upstairs in the Schiehallion unit in Ward 6A in the QEUH where Molly went through the preparation for the transplant. She was then transferred down to Ward 4B where the transplant would take place.

213. At the time I had been reading documents about the transplant ward, particularly 4B. It was documented about the air conditioning within these units and concerns that had been raised in relation to the air conditioning. Indeed, when I considered Molly going through the operation, I was really worried because there were only four rooms in Ward 4B that would have a system in it that would give me an assurance that it would be suitable for a patient like Molly.

214. At that time, we actually started to see evidence of this. White HEPA filters were appearing all over the patient pathway, all around Ward 6A. They're not there because they're aesthetically pleasing. They're there to clean the air and the hospital doesn't spend money on these things if it doesn't need to. That, again was a visible demonstration, for me, that the air conditioning system within Ward 6A was certainly not fit for that type of patient.

215. Therefore to be displaced round to Ward 4B, with only four rooms, Molly's options are reduced further. We wanted an assurance that Molly would get one of those rooms because, of course, the Schiehallion unit at Ward 2A had dedicated rooms there but it was shut. This is when I start to then combine the water issues and the air conditioning and the drainage issues, because it all had an impact. Whilst I didn't really know evidentially at this stage what was the cause, I did know that

reports were available, detailing significant concerns with revelations with regards to exposure to risk of infection.

February 2020 - Stem Cell Transplant

216. Molly embarked on a stem cell transplant. Thanks to the foresight of Dr Sastry, cells had been harvested early in her treatment as a contingency.

217. Molly's treatment plan had been carefully and meticulously planned by Dr Sastry and his team with each drug identified with the appropriate quantity, in terms of dosage which was carefully calculated and recorded within an Autologous HSCT Schedule for relapsed Ewings Sarcoma. This plan was explained to Molly, my wife and I, ensuring we understood the risks involved.

218. Molly was admitted on the 27 or 28 January 2019. For the first three days, the plan was that she would take particular drugs which would deconstruct Molly's body, effectively taking her to ground zero. They described it like a new-born or even before a new-born baby, in terms of the cells that are still forming. The plan was to take her down to ground zero. Molly had to be in an environment that was clean and sterile because the risks were even greater now. The fear factor was there.

219. The Schiehallion nursing staff attended ward 4B to administer the medication, and they are absolutely meticulous in how they go about their recording. There were always two individuals. They walk into the room and bearing in mind they knew Molly intimately, but they would still say, "Molly, CHI number". Molly would read her CHI number out. They would record it and the process was followed religiously. The bag and the label, they would go through everything in that detail because it had to be right as they went through it.

220. Molly went through that whole process. From the 4th into the 5th of February, she wasn't well. She was really ill. She had mucositis. It was just dreadful and her

tongue was swollen. It was like somebody with leprosy, with bits of her tongue coming off. It was as though she was getting burned. Of course, mucositis is a side effect of these drugs. We know that but this was horrendous. That which was visible, we knew was being mimicked inside her. We didn't understand what was happening. Surely this can't be the bacteria that's doing this?

221. What I was to find out was that in February 2020 whilst within Ward 4B Molly was administered an overdose of Etoposide Phosphate. On 02 February 2020, Molly was given an infusion of Etoposide as per the detailed schedule. On 07 February 2020, whilst dealing with another patient, it was noted that Molly had been administered 4120mg of Etoposide Phosphate rather than 3660 mg, a 14% overdose. Later that evening Dr Sastry was advised and thereafter on the morning of 08 February 2020, he informed my daughter and my wife of the overdose, expressing considerable anger and sorrow about the harm caused to Molly. I was advised when I arrived at the ward later in the morning and requested a meeting with Dr Sastry to understand what had happened and what impact this would have on Molly.

222. I was still asking the question about the impact on her and being told that we don't really know. I could see the impact on her and Molly was going through a lot of pain. However, within a couple of days, the pain for her was still there and that seemed to be the issue. Dr Sastry told me that the transplant was working. Her figures were excellent. He said, we'll get through this. He said, the investigation will take care of itself. It shouldn't have happened but he was the first to say to Molly, I'm sorry that this has happened to you. I'm sorry as she's under my care. I'm responsible for my patient. But that's the measure of the man, that's the measure of the doctor. Of course, he's not done anything wrong. I've seen the report.

223. Following investigation a report was produced, and there was a whole catalogue of errors, but it was considered to be an 'honest mistake'. It said that it wasn't done deliberately and I don't imagine it was done deliberately, but that is not the

point. It should not have happened. There are strict protocols and rules. What this was, in Molly's head was "You've done it to me again. I'm in your care. I've got limited options and you have now given me an overdose". Her body was falling apart.

February 2019: Admission to PICU

224. Thereafter Molly was transferred to the PICU where she was treated for 17 days. It was a couple of days into her admission to the PICU where she had intensive support round about her. She started to rigor and there was a concern it was the bacteria. She had an overdose, her body was shutting down and the staff were thinking that this bacteria is going to exploit the vulnerability here. Molly was lying in the bed, she was covered in tubes. She was just shaking, her whole body just shaking. I had to hold her head to support her.

225. Whilst in intensive care, Molly suffered a number of challenging episodes that each threatened her life. During a period when Molly required multiple blood products, she developed signs of significant bacterial infection. I thought this was the Mycobacterium Chelonae and when I asked, doctors were unable to say, although they suspected the presence of Mycobacterium Chelonae.

226. The staff were testing her for everything, all her organs, all her body, but she continued to shake. As I was holding her head and she's just looking at me, somebody came in and said, "The only place we haven't looked is her head which is her brain". When they mentioned her brain it was so hard to take, it wasn't right.

227. A man called Matt came in. He was an interventionist. I'd never heard of that. He's an anaesthetist in the PICU. He came running into her room. It reminded me of managing the terrorism police operations rooms. When there was a high-risk incident, you would record every discussion and it was because you had to be held accountable. He described everything he was doing. He said I'm putting five

milligrams of such and such in. I am now putting the needle in. I've discharged the dosage. I'm taking it away. I'm now doing this, I'm now doing that and I'm doing this. A calmness came about and Molly settled. He was just remarkable. He saved her life.

228. All I could think about was her head, her brain. People don't understand the impact of this, the emotion of it. This is not about numbers. Cancer's bad enough but this is just torture. You wouldn't torture people with that.

229. Molly came through it and she started to get better over the next few days. A conversation took place one day and I heard it. Staff were questioning the date on platelets and it was about platelets that were given to Molly on the 17 February. I recall during one of the episodes, discussion between nursing staff relative to dates on a bag of platelets administered to Molly. I thought nothing more of it at the time, but it stuck in my mind. I speak about this in more detail later on in my statement.

230. During this admission Molly suffered from an episode of severe delirium, and it was a consequence of all of the drugs that she was on. She was screaming that you are all just trying to kill me. In her head, was all these things and she's going through it. Now, Molly would be mortified with this. She didn't know [redacted]. She tried to pull the central line out and [redacted] was on top of her trying to stop her doing it and Booboo was one of the doctors. Molly loved Booboo. It was as though somebody took over her body. She wanted to die, she said "I just want to fucking die because that's what's going to happen to me in here." It lasted over a number of hours but Molly didn't know anything about that.

PREVENTATIVE MEDICATION

231. There were times when Molly was given preventative medication. It was explained to us by Dr Sastry that it was for the benefit of Molly. At no time did I experience the medical people giving Molly a drug that she didn't need. Did they

give her a drug that they didn't fully know the impact of? Absolutely. They said to us, in relation to the mycobacterium we don't know the effect the antibiotics will have because this was a new type of bacteria to them, but we were always informed.

OTHER ISSUES RELATING TO THE CONSTRUCTION OF THE HOSPITALS

Cladding

232. On 10 September 2018 I drove Molly to RHC to attend an out-patient appointment. On arrival I parked within the carpark adjacent to the RHC and walked into the hospital accessing via the side entrance. At the time I noted scaffolding and work ongoing around this entrance, although access was permitted. On entering Day care, Molly and I waited for her treatment to commence and during this time, a member of staff provided a letter outlining issues with cladding.

233. The written communication advised all patients and parents that due to ongoing cladding works; alternative access arrangements had been put in place. The letter further stated that as building materials posed a risk to infection, measures would be taken to protect those patients at risk. Whilst the letter was welcomed as it informed of measures to be taken as a result of increased risk to infection, myself and Molly had already parked our car and accessed the hospital via the area that posed the risk, thus exposing Molly.

234. The letter was once again, a reactive measure and failed to proactively protect Molly. I asked the medical team why there was no communication prior to the commencement of the work, and they advised that they had only been provided with the communication and asked to share with families attending day care. I understood that those who were in-patients had also been advised. However, no provision had been made to proactively engage with families of patients being

treated as outpatients, who were more at risk as they were the ones requiring to access and egress the building.

235. Following the above, I met with Mr Jamie Redfern, Dr Teresa Inkster and members of the medical team and raised my concerns as to the lack of proactive communication that would have prevented exposure of Molly to the identified risk. I also stated that as a result of being unable to access the main entrance, due to the risks associated with windows falling out, we were now no longer to access the side entrance to RHC leaving us to access via the ‘discharge lounge’ an area known for smokers to congregate. Access to the hospital for our children was through a smoke filled environ which in itself exposed them to risk as there had been no overt measures to address this problem. I re-iterated my concern that even before Molly could embark on treatment for her cancer, she had to overcome numerous risks from cladding, windows and now smoking. This was unacceptable and I left them in no doubt about that. Through more proactive planning and engagement, they could have mitigated such exposure to risks, that they themselves identified, and in the case of the cladding and indeed other building materials, exposed Molly to infection, requiring of prophylaxis antibiotics.

Water systems

236. With regard to water systems, I have detailed my experience in the body of this statement but more specifically in the document presented to Oversight Board in 2020 relative to Mycobacterium Chelonae. There has been further correspondence and I reflect on a number of documents throughout this report. I was also involved in a number of meetings related to this matter and intend to provide more detailed evidence to the inquiry in due course.

237. In terms of my experience, the impact that the water issue had on Molly and our family was to deprive Molly of a basic right to drinking water and water for washing. When water was cut off, this also had an impact on Molly as she had to revert to using a commode, with further erosion of her dignity. The constant

mixed messages that the water was safe, yet drink bottled water; the water is safe, yet use portable, self-contained sinks; the water is safe, yet use only taps fitted with filters; the water is safe, yet sink traps were being replaced; the water is safe, yet there were independent reports stating it was not; the water is safe, but we are closing the wards.

238. This left me angry, concerned, anxious and distrusting of the hospital at a time when I needed to have absolute trust as my daughter's health depended upon it. There was a lack of openness, transparency and honesty.

Windows

239. As previously mentioned in my statement, my daughter had been transferred from RHC to Beatson Oncology Unit to undergo radiotherapy before returning to the RHC to continue chemotherapy treatment. Molly left the RHC via the main entrance to QEUH. On her return, there were internal security staff outside and as Molly exited the vehicle, she was escorted around shattered glass covering the ground of the main entrance. Once inside Molly returned to ward 2A. I was advised that this resulted moments earlier, from a glass panel falling from its secure fixings on the 10th floor.

240. Following this incident, I contacted GGC CEO Jane Grant to express my concern and detailed a number of issues including the incident with the window. I asked her "Are the windows safe - a number have fallen out - what is being done in this regard?".

241. I received the following written response : "We are extremely sorry that you experienced a panel falling from the building on entering with Molly. It may be helpful to clarify that no windows have fallen out of the Queen Elizabeth University Hospital (QEUH) building, nor the Royal Hospital for Children (RHC) building; all double glazed units have remained intact without issue, the windows are safe. The glazing failure we believe you are referring to, is decorative glazing

panelling, and this remains under investigation. If a failure occurs they are designed to shatter into tiny fragments to which are much less likely to cause harm. We will let <u>you the outcome</u> of this investigation."

242. Whilst understanding that clarity was required around exactly what had fallen, I was not reassured as to the response that a large decorative glazing panel falling from a great height was designed to shatter on impact and therefore, less likely to cause harm. If that decorative glass panel had struck my daughter or a passer-by, there would have been considerable harm caused, if not a fatality, as the point of impact would be their head! Again, I was completely taken aback by the attitude of GGC to this incident. In addition, their update to let me know the outcome, was never fulfilled, although I accept that in their statement, they never actually used the word 'know'.

<u>Drainage</u>

243. In furtherance of my experience of the drainage system, specifically within the shower room of room 6 of the TCT unit on ward 2A and of the replacement of sink trap sets in May/June 2018 following concerns of bacterial infection, I asked CEO Jane Grant: "Why were the drains within the shower rooms not replaced when each of the other drains/traps were replaced?"

244. I received the following written response: "The shower floors were designed so that water flows away appropriately, and this was not seen as a risk. There are no problems with Ward 6A showers that we are aware of. As part of the work underway in Ward 2A, we will refit all of the en-suite bathrooms, including floor coverings, to ensure that this is not a subject of concern going forward. The work to refit the en-suite facilities will include a revised design detail and new materials which should reduce the need for the same level of regular repair. Due to the constant usage of facilities in a hospital environment, it is inevitable that repair work does need to be carried out at times, but these measures have been taken

to ensure that the chance of disruption to day-to-day ward operations is as minimal as possible."

245. Whilst the update was welcome with assurance that changes to ward 2A were ongoing, the update remained silent as to any acceptance of an issue with the drains in ward 2A, rather than stating that due to constant usage, repair work is necessary. I would suggest that this was more than simply repair work and again was an attempt to underplay the significance of the issues that prevailed around drainage, especially as it was identified as a source of infection within ward 2A.

246. Indeed, during my investigations, I have been advised that the mould found within the bathrooms of wards 2A was the worst seen by microbiologists. Issues with the bathroom flooring and drainage that caused flooding, were made all the more concerning with regards to increased risk from infection as the wall coverings were not appropriate for such a facility. In addition, the absence of toilet seats exacerbated that risk with regards to toilet plumage which was drawn up into the air-conditioning and deposited into clean rooms.

Mould

247. Reference was made in various documents and reflected in the media in November 2019 that the kitchen area, more specifically the ward kitchen within 6A had developed a leak that had to be repaired. Specifically, it was reported that this was a minor leak that did not present any issue with regard to potential infection.

248. This at a time when ward 6A had been closed on two separate occasions and had been subject to external review by HPS with updates that the ward was safe. This further demonstrates an organisation who underplayed the significance of environmental issues and the relationship such issues have with infection. This leak which, from the view of microbiologists, resulted in the build up of mould and from its presence, suggested it had been there for some time. This ward was

allegedly subject of a deep clean following review and re-opening to patients susceptible to fungal infection.

249. In addition to the above, it has been suggested to me that there are images and reports which detail the extent of mould within ward 2A, identified during extensive renovations.

COMMUNICATION AND ENGAGEMENT

GENERAL

250. Communication is done in different ways, it’s in words, it’s in pictures. It can be non-verbal communication.. When the hospital remained silent even in circumstances where reporting demands commentary you get really concerned about it, why are you not answering that when you should? Later on in my statement I speak about the BBC Disclosures programme, and the Board not coming forward and giving proactive communication in terms of notifications to patients and families. The Board found the need to send proactive emails to all the staff the day before the programme aired, highlighting their recognition of how the program may be perceived. But they did not have the emotional intelligence for the patients that are actually suffering as a result of the environment and would be significantly distressed on watching and listening to the content disclosed through the program.

251. The program actually acted as a further catalyst for disclosures about the hospital, the management, culture and behaviour. I began to receive and ingather information from different sources because people were approaching me and asking, “Will you take this, because this is what’s happening. Have a look at that email from Jonathan Best. If they can send that to the staff, why are they not communicating with families?”

252. In terms of the clinicians and the microbiologists who have spoken out about their experiences at the hospital, They took a Hippocratic Oath and they not only have a duty of care, they have that oath that if there is anything that will be detrimental to their patients' health and wellbeing, they would say something, they would do something. In my opinion, this is what these individuals have done. They have spoken out because they consider there's something ongoing which is detrimental to the health of the patient group and it would be wrong for them not to say anything. Whereas these other people who knew exactly that same environment , those who are best informed, they decide not to tell anyone, that's just wrong. This is what's unfolding so why don't we report it, why don't we tell people? The failure to report in such circumstances exposes our children to increased risk and they knew it. This in my opinion is not only shameful, it is criminal.

253. The whole catalogue goes all the way back to when the twice-removed Shona Robison as the Health Secretary stood up at the Scottish Parliament in April/May of 2018 to say there is no problem with the water. She said there is absolutely nothing wrong with the water and that she had assurances. This was May 2018, when they were aware of the DMA Canyon report the one they claimed had been lost in May 2018.

254. When you go back in time you have to have a good memory of the communication that you engaged in because the narrative has been that that report that said the water was contaminated in 2015 sadly was lost. The report in 2017 sadly was lost. Then it was admitted it was found in March 2018. Well, why then would Shona Robison stand up and say that the water is safe? I find that incredible, within a communication narrative. Indeed that's something that we continually reflect on. And that's one of the things as well that I raised with Jeane Freeman when I said to her, are you confident about the information that you've been given, because I'm not?

255. Again, when you compare the clinical approach to the corporate approach, what's the contingency plan when they built that facility if there was a fire? Where would those kids go to? If there was a flooding, where would those kids go to? The Health Board were scrambling about in the dark. I asked what was your business continuity plan? They couldn't show me it. They said, oh it is getting revised. I said, I bet it is. They didn't have one.

256. That takes you into wider challenges within wider terms of reference about the design and the building, in that if you co-locate so much within one place, what's the plan if there is no fallback position. What is the contingency in relation to it? The contingency plan was to displace these kids into another ward in the same hospital. Then when we start to find out that that new ward is not performing, we displace them to another ward or rooms within the same building. In terms of risk management it is utter madness. They were operating in 'a ten minute bubble' with no strategic thought or plan.

257. The Health Board was dealing with a crisis and this was demanding of crisis management. Those that were dealing with the bacteria outbreaks, the IMT, the Infection Management Team, their role and responsibility is to manage and mitigate the risk from the bacteria. However, the responsibility for crisis management was being devolved to that group. That was wrong, totally wrong, and this is when the visible communication is required, yet there was no person willing to get up and take responsibility.

258. The issues go wider than my daughter, and the bacterial issues there. I think about it strategically. How can we manage this crisis more effectively? Do we have someone who can manage a crisis?

259. They didn't have anybody internally to deal with what they identify as a unique event. I accept that. It hadn't happened before. But they were comparing and contrasting within their communication strategy with the old Yorkhill Hospital or Aberdeen Hospital. It's not a like for like and, again, they were being drawn into

the quantitative analysis. This was a bespoke unit, heralded as such. There was nothing like it anywhere in Scotland, so how can you compare and contrast and give confidence. You should go down to England and go down to the Great Ormond Street and actually get a comparable hospital in terms of build, structure, immunosuppressed patients, and it would assist you far more effectively, but they weren't doing anything like that. When I would go to speak to them, they never gave me any confidence that they could articulate the management of the crisis.

260. I accept that during this whole time that some of those in charge of corporate communications may not be the best letter writers, may not be the best individually. But the Health Board has got access to behavioural psychologists, they've got individuals that know and understand the impact and implications that poor communications about the issues with the hospital can have, so surely you can write something that would recognise that.

261. Indeed, when I sat on the communication and engagement subgroup, I ended up, together with Craig White, and Phil Raines from the Scottish Government, scribing the templates of letters that would go to families in relation to the Case Note Review because the draft that was given to us was awful, not fit for purpose. We were going to open up the most terrible, terrible heartache for families that had lost 21 children and we were going to tell them, “There's a Case Note Review ongoing” without any recognition of the significant ramifications of doing so.

The Independent Review

262. I first became aware of the Independent Review (IR) on 26 February 2019 following announcement by the Cabinet Secretary Jeane Freeman MSP, in response to growing concerns from the public and politicians regarding patient safety at the RHC/QEUH. I was aware that the IR would be led by Doctors Fraser and Montgomery with a report expected in the spring of 2020.

263. The IR set up a website and I continued to monitor the progress of the IR and in particular through accessing their update bulletins, of which there were four. Over this period my daughter’s health was my focus and it was not until 25 November 2019 that I emailed the IR as part as their continued call for evidence. Following email exchanges over December 2019, I provided a witness statement to the IR. I actually provided two statements over a total period of six hours. Each interview was recorded under tape recorded conditions. Following interview. I heard nothing further from the IR until the publication of their findings on 15 June 2020.

264. Having read through the report and spoken with families of patients, staff and others, there were a number of significant concerns that individually and collectively we had. In addition, on 24 June 2020, BBC Scotland aired Disclosure Scotland - Secrets of Scotland’s Super Hospital.

265. I found this to be a difficult program to watch as it presented a number of issues surrounding the IR, not least of all the limited number of ‘informed’ clinicians, families and patients that they had engaged in order to assist their findings. In addition, they had made some significant statements relative to the safety of patients within the hospital which for me, lacked substance and clear evidence. I was also extremely concerned as to the lack of response from NHSGGC to the allegations made during the program, their failure to proactively engage with families prior to the program being shown in order to support them in line with previous recommendations from the Communication and Engagement sub-group, despite having awareness of many of the points being discussed.

266. As such, and following discussions with various families, patients and staff I was engaged in further correspondence on this issue and I was involved in further meetings on this topic. I will provide further detailed evidence to the Inquiry in a future witness statement.

Oversight Board: Communication & Engagement Sub Group

267. On 23 October 2019, I attended J B Russell House, Glasgow and there met with Professor Craig White, newly appointed Families Liaison lead. Professor White outlined his role to lead and direct work to ensure that the voices of families affected by the infection outbreaks at NHS Greater Glasgow and Clyde were heard and that the information asked for was provided. Thereafter I provided him with an update of concerns I had around communication and engagement with NHSGGC. I welcomed his appointment albeit some 18 months following the height of the first outbreak in May 2018 and nearly 8 months since the Cabinet Secretary announced in Parliament that she would look to address concerns about patient safety in the QEUH & RHC, noting that since 2015 it had experienced problems with microorganisms. I outlined my experience of communication and engagement with NHSGGC and Professor White undertook to follow up on questions posed by myself and my family to NHSGGC previously, especially where we had never received a response or had received unsatisfactory responses.

268. Later that day, I along with my daughter Molly and my wife [redacted] attended Atlantic Quay, Glasgow and there met with the Cabinet Secretary for Health, Jeane Freeman, and Chief Nursing Officer (CNO) Professor Fiona McQueen. I expressed my concern of the lack of open, honest and transparent communication and engagement between NHSGGC and myself. I updated that I was concerned as to the level of under reporting with regards to the bacterial and fungal outbreaks, providing examples of where such had not been reported to the Board. I invited the Cabinet Secretary to consider whether she had a confidence in the figures and types of bacterial outbreak being reported to government. I provided a number of examples of poor communication and engagement and of a culture concerned more with reputation within the media and criticism from political figures than one concerned for the safety and well-being of a vulnerable patient group. I outlined a number of instances of what we considered reactive communication rather than proactive and also of an organisation who utilised the

media, at times, as a conduit of information, rather than directly with patients/families which in itself destabilised families, fracturing trust and confidence. Throughout my discussion with the Cabinet Secretary, I was careful to distinguish the outstanding care and communication by clinicians at the point of care whilst focusing on the opposite from GGC corporate services. During this meeting, myself and my daughter also outlined our concerns with regard to a minimum standard of education for those children, through no fault of their own, found themselves for extended periods within a hospital setting, without adequate educational support that ultimately damaged their long term ambitions. The Cabinet Secretary listened whilst her Special Advisor (SPAD) noted our concerns.

269. Following the meeting, the Cabinet Secretary agreed to take forward our concerns and also gave an undertaking to explore those other issues, around the minimum standard of education with her colleague, Cabinet Secretary for Education, John Swinney.

270. Having taken a confidence from Professor White's involvement and active engagement, I agreed to become a member of the communication and engagement sub-group as a Families representative and on 05 December 2019, attended a meeting of the Sub Group at Atlantic Quay, Glasgow.

271. I considered this to be a positive step that would lead to openness and transparency, the development of relationships and the building of trust. I firmly believed that there was a collective responsibility to deliver solutions, and that by learning from experience, would serve to better protect my daughter and those vulnerable children and young people whilst within the paediatric haemato-oncology wards and associated environments.

272. During the meeting, I updated members that I had no issues what-so-ever with communication to/from the clinicians involved in my daughters continued health care. I updated that they were a remarkable group of men and women who had

and continue to do wonderful things within their sphere of expertise. I stated that they were a group who never asked for thanks, do not want our thanks but are deserving of it. I recognised the impact and implications for them during this last two years and observed a noticeable change in their emotional wellbeing; they were to be forgiven for believing they were under siege and responsible for the many issues, which they are not. However, through systematic failings on the part of as yet, unidentified actors, they have been held accountable for that which they are not responsible. They were required to further risk manage the clinical care in the face of environmental failings which led to an increase in fungal/bacterial outbreaks; I caveated that with the knowledge that various reviews and investigations were ongoing to establish the cause.

273. However, the fact that ward 2A/2B had been closed and thereafter, the ward where our children were displaced to, had also been ‘closed’, confirmed those issues and indeed the crisis that we were in. I stated that these facts could not be ignored and were the single biggest enablers in destabilising patients, their families and medical staff. I further stated that GGC appeared to fall behind a barrier of ‘confidentiality’ which impacted their ability to fulfil a statutory requirement with regards to Duty of Candour as harm was being caused. Indeed, communication to date had been reactive rather than proactive with messaging failing to address the growing media narratives, driven by commentary from ‘whistleblowers’. I also stated my perception that GGC were driven more by media headlines and parliamentary questions than communication and engagement with families, designed to reassure and alleviate growing concerns regarding patient safety.

274. On 15 December 2019 I met with Professor Fiona McQueen and Professor Craig White at Atlantic Quay, Glasgow during which time we discussed the role of the Oversight Board and my observations of GGC since my daughter’s diagnosis and commencement of treatment in January 2018. At this meeting I was asked if I would be prepared to join the group as the Patient and family’s representative. I considered that this would afford me an opportunity to work with the Board and

seek to deliver solutions and influence change across NHSGGC and as such, I accepted the role. I continued to participate in the work of the Oversight Board, I was involved in further meetings on this topic and will provide further evidence in a future witness statement.

275. The very nature of the communication and engagement subgroup, was whether we could enhance that communication and engagement? I welcomed being part of it. I thought that that was transparent. I thought it was a positive step, I described it at the time for those who came from GGC, that we were operating in a ten-minute bubble. It was like, there's a fire, there's a fire. What are we going to say? Can someone sit down and identify what are the key messages here and who are the audience that we're speaking to? Professor Craig White understood, he was very, very good. Gradually others and a number of people within GG&C started to expose a culture within the environment.

276. The organisational behaviour was such that there was no point in expressing empathy or emotional intelligence because you just get battered and I could see that in the people that I spoke to. I could see that from the quality of that which they put out because they didn't consider it.

277. If you surround yourself with a certain type of individual and you only open up the information to those individuals; if you always do what you always did, you'll always get what you always got. That's what was happening and you could see it. No-one could challenge them because if you're not in possession of the information, how can you challenge? Of course, that's what was happening to the board. The board was not being presented with the information so how could you hold to account? That's when I started to investigate further their management of risk and I asked for the risk register. Can I see it? Have you operated in accordance with the civil contingencies act? When you record the risk, who owns the risk? What are you doing to manage and mitigate the risk? If you're doing nothing, write that because if you do something it may exacerbate it. It was as though I was speaking an alien language.

278. They probably just thought I was a pain; they didn't want to respond to me and they didn't like what I had to say. I said to John Brown and to Jane Grant, if you can't withstand scrutiny internally, you'll never withstand it externally. The risks are too great and they had to take responsibility. I actually said to Jane Grant, she had neither the professional nor the operational competence to discharge her duty. Not everybody can in crisis management.

279. On 22 March 2021, the Oversight Board published the Final Overview Board Report which was shared with families, ahead of formal publication. This report made a number of recommendations across a number of areas, most notably recommending that NHSGGC remained within Level 4 until evidence of tangible change was evident. I was particularly vocal with regards to this as there was no point in delivering recommendations if there was not going to be acceptance, implementation and thereafter a period of assurance that such recommendations were making a difference to the environment and more importantly the health of immunocompromised patients.

280. For the most part I found the Oversight Board to be transparent in their sharing of information and accepting of recommendations put forward by the various sub groups with the required level of scrutiny being applied. However, what was apparent was that the Oversight Board, relied upon GGC to make available all documents and individuals associated with the areas of oversight. However, my experience was that GGC would determine relevance prior to disclosure rather than disclosure with relevance being determined by the Oversight Board.

281. In all the circumstances, my experience of the Communication & Engagement Sub group was a positive and progressive one. To actively engage me as the patient and family's representative demonstrated transparency and a willingness to communicate and engage, ensuring a collaborative response to the development of a report that detailed evidenced findings with recommendations for effective change. The progress of the Sub-Group was a result of the excellent

leadership of Professor Craig White who genuinely tried to influence positive change, whilst commending areas that were worthy of comment.

282. However, despite all the effort to develop meaningful relationships with members of the group, the building of trusted partnerships that led to the co-production of a report that would make a difference to everyone involved, NHSGGC consistently failed to develop any tangible evidence of change or even any evidence of attempts to implement identified recommendations. There are individuals who have strived to make this work and the examples during COVID demonstrated how effective communication and engagement can enhance the patient experience. However, there are those senior managers within GGC who operate a culture of denial, that there is nothing for them to learn as they have done nothing wrong; the example of their failure to communicate and engage, prior to and post the Disclosure Scotland programme exemplifies their arrogance and lack of appreciation for the needs of this vulnerable patient group. I have observed external stakeholders, express exacerbation, and disbelief at the behaviour of GGC who fail to recognise that their behaviour permeates the organisation, and it is their style, vision, values and leadership that sets the culture. They have failed in their statutory duty to engage and communicate; they have deprived families of information and from engaging in the process of healthcare as it pertains to their loved ones.

283. In my opinion, there is a requirement for strategic change in terms of GGC leadership, and approach to communication and engagement. I am convinced that until there is tangible evidence of change, there will continue to be failures to protect the most vulnerable and prevent their exposure to significant risk, leading to exploitation of that vulnerability resulting in serious illness and fatalities. When it comes to GGC and their approach to patient centre care and communication and engagement, I feel they are but mere concepts and from my experience, not a reality.

284. I was engaged in further correspondence on this issue and I was involved in further meetings on this topic. I will provide further detailed evidence to the Inquiry in a future witness statement.

BBC – Disclosure Scotland "Secrets of Scotland's Superhospital"

285. On 24 June 2020, Disclosure Scotland aired a programme on the BBC called "Secrets of Scotland's Superhospital". It examined the claims that design flaws at Glasgow's state of the art hospital helped cause infection to spread there. They asked if hard working NHS staff at QEUH were being let down and vulnerable patients being put at risk.

286. This was a deeply distressing programme which reflected on the Independent Review, hearing from 'whistle blowers' and 'experts' who all had comments that reflected an unsafe environment in which to treat vulnerable patients, including my daughter. I was extremely concerned as to the findings within the report and moreover, why GGC had not been proactive in their communication and engagement ahead of the program. All of the gains made in the last few months and more importantly, the recommendations and findings presented to the Oversight Board, quite clearly had not resonated with GGC. This was further evidence of a Public Body that considered itself above any form of scrutiny and public duty to reassure those patients who were being put at risk.

287. The Closed Facebook Site became a focal point for parents and families to air views and express anger at GGC. I waited to see what would be forthcoming from GGC hoping that they would operate within the faith of recommendations from Communications & Engagement Sub Group, although they had failed to update proactively on the showing of the programme or indeed what their statement would be. They failed to proactively prepare us, as agreed by them and endorsed at Oversight Board. Having received nothing during the 24-hour period,

288. I sent emails to the Scottish Government asking if anything had been sent to them from GGC. It is probably helpful to note that an aspect of being placed in special measures was a responsibility for all communications relative to the ongoing crisis, to be submitted to Scottish Government for approval prior to publication. Hence my reason for asking Scottish Government. Following communication with Scottish Government, I contacted GGC on 25 June 2020 using the Closed Facebook site and posed a number of questions. Their actions further fuelled concerns of a leadership in crisis, unable to manage the unfolding events which would further impact the emotional, psychological and physical health and wellbeing of everyone concerned.

289. Nothing was forthcoming resulting in me having a number of calls with Scottish Government. Scottish Government advised that GGC had sent them a proposed statement which Scottish Government rejected, but only after Scottish Government challenged them as to media releases and failure to comply with Oversight Board instructions. There was then a request for me to assist compile a suitable response which I found incredulous. I advised that this would be grossly inappropriate, not least of all as I had posed the question of them and to be asked to formulate an answer to my own question was absurd.

290. There followed lengthy calls with Scottish Government and I requested convening the Communication and Engagement Sub and/or Oversight Board in order to consider this episode and to hold the Board to account. I made it clear that this was more than a failing to provide proactive communication and engagement. This was a deliberate subversion of the stipulations within the Oversight Board- suspended due to COVID- and was now about leadership of both the Chair of the Oversight Board, Cabinet Secretary and the Scottish Government. This could not be allowed to continue unchallenged. It was agreed that Cabinet Secretary would be consulted. I then decided to send a further message to GGC.

291. I was engaged in further correspondence on this issue and I was involved in further meetings on this topic. I will provide further detailed evidence to the Inquiry in a future witness statement.

The Independent Case Note Review

292. On 28 January 2020 the then Cabinet Secretary for Health and Sport announced plans for an Independent Case Note Review. I very much welcomed this announcement particularly following my meeting on 12 December 2019 with senior management and directors of GGC during which time I expressed concerns as to their plans for an internal review of case notes relating to those children affected by bacterial and fungal infections. I had met with Mr Jonathan Best, Chief Operating Officer for Acute Services, Dr Scott Davidson, Deputy Medical Director and Dr Alistair Leonard, Clinical Director for Microbiology following discussions with Jane Grant, CEO who considered it useful for me to meet with members of her senior team within the Acute Division as they were "more closely involved in the detail of the situation" and would be happy to discuss issues I had raised. There was further correspondence on this issue and I intend to provide further evidence to the Inquiry in due course.

293. Having met with those individuals and having been advised by Jonathan Best that he was aware of my concerns and discussions with the CEO and other Board members, he proceeded to introduce his colleagues, inviting them to give a background relative to their areas of responsibility and how each related to my daughter and those other children. Following those introductions, Dr Scott Davidson advised that it was intended to conduct a review of patient notes and that this would be carried out by a recently retired colleague. I pointed out that I did not consider this to be an 'independent' review and was more akin to GGC checking its own homework. Further, having enquired as to how this review would be prioritised, Dr Davidson responded by stating it would be in line with *" that opposition MSP's concerns as detailed in the media"*. I responded by stating that I am sure that Anas Sarwar would be delighted to know that GGC was

responding to his concerns but from my perspective I found this tone, response and intention to be wholly inappropriate and would further fracture trust with families. All three were totally unprepared for the meeting, lacked any detail relative to my daughter's case and showed an absolute lack of any emotional intelligence. I told those present that I would not engage further with them and left the meeting.

294. I found this meeting to be reflective of an organisation that had no idea of the enormity of the unfolding crisis and were driven not by patient safety, rather comments from politicians and media reporting. This was a further example, at a strategic level, of a failure to appropriately communicate and engage and of a culture and organisational behaviour that refused to understand the extent of their failings. Moreover, if this was the senior management team ' more closely involved in the detail of the situation' I could not take any confidence that they had a 'grip' of this crisis.

295. NHS GGC set up a Paediatric Haemato-Oncology Closed Facebook Group to communicate and engage with parents and families of patients. My role was simply to act as a conduit of information between the CNR team and families. However, this platform was not the only means of communication with recourse to direct messaging, emails, telephone and verbal updates provided, all dependant on the needs of the families. At times, discussions would simply take place on the wards at opportune moments during in/out patient treatment.

296. It is the case that the CNR team set up a dedicated email account and telephone number for patients/families of patients involved in the CNR to make contact with them should they wish to address any specific questions they may have.

297. Throughout the period of communication and engagement Professor Stevens and his team considered the emotional impact of such reporting, the publication of such reports and the challenges between circulation of the overview report and individual reports. At all times, I found Professor Stevens and his team had

placed patients and families at the centre of their review ensuring, where they could, all communications were personal and appropriate to the intended audience.

298. I always recognised that whilst the CNR had published their terms of reference, method of approach and timescales involved, their outcomes may not necessarily be that which families would expect or indeed hoped for. However, from my perspective it was important to ensure transparency, openness and integrity, instilling a confidence in families that the team could be trusted to act in the best interests of all involved through careful consideration of all available information that enabled informed decision making. The challenge for the CNR team was access and disclosure of ALL material by GGC in order that they, the CNR team could determine relevance within the terms of their reference from Scottish Government. At various times throughout the review, I was aware of concerns as to data access, data analysis and data retention.

299. On 15 April 2021 a confidential report was compiled and sent to me in respect of my daughter Molly. However it did not take account of a considerable amount of information that I had provided on the 4 October 2020. I was advised that they were unaware of my request, however upon my disclosure of my email I was afforded an apology and assurance that this report would be sent. Following separate communication with Professor Stevens, he advised of receipt and his commitment to review and provide a supplementary report.

300. On 17 May 2021, I received a Supplementary Report. This report and the previous report made reference to disclosures around mycobacterium that totally contradicted that which I and my daughter had been told relative to her bacteria; specifically, that a paediatric patient had contracted mycobacterium in 2016 whilst an in-patient in ward 2A. I and my daughter had been told by those in GGC that she was the first patient from paediatric haemato-oncology at GGC to have contracted this rare pathogen. Indeed, I was informed only 4 cases had been recorded in the last 10 years, all within the adult population. The additional report

made further disclosures that identified the bacteria from samples taken in April 2019 from four separate locations in ward 2A of the RHC. This was also significant in that this was during the time the ward was closed and some 12 months after my daughter contracted the bacteria. I had consistently requested samples be taken during 2018 but this was never done. This additional report also identified that of the four locations in ward 2A that tested positive for mycobacterium chelonae, two were rooms occupied by my daughter in April 2018; the time she contracted the bacteria. Had it not been for my challenge as to why Professor Stevens had not received my report, and the subsequent submission to him for review, I am in no doubt that I would be unaware of these additional, significant findings as they were never before referenced or detailed within the first confidential report.

301. I found out that following the closure of the ward in September 2018, water samples were taken but not until 14 April 2019. At this time samples taken identified the presence of mycobacterium chelonae at four sites in Ward 2A. Three of these sites were identified as showers in rooms 6, 16 and 17 but the location of the fourth sample within the ward is not clearly identified.

302. Molly was in room 17 in ward 2A until 05 May 2018 and from information received from the Case Note Review, was one of the areas testing positive for Mycobacterium Chelonae. I was further advised that the CNR team were, however, unable to link the presence of the positive samples from Ward 2A in 2019 with Molly’s infection, first identified in May 2018 hence the caveat in their report that stated “….the subsequent finding (in 2019) of this organism in the water supply raises an obvious concern that, if it had been looked for, it might also have been found at the time of your infection, but this can only be our supposition.”.

303. I learned following enquiries with microbiologists, including Doctor Teresa Inkster that Mycobacterium Chelonae is not routinely screened for. It was also confirmed that these particular bacteria, were very difficult to identify and often referred to

as ‘silent bacteria’. Further at this particular time, Mycobacterium Chelonae was not listed on the national infection register, although was later included in 2019.

304. I was engaged in further correspondence in relation to the Case Note Review and attended further meetings on this topic. I will provide further detailed evidence to the Inquiry in a future witness statement including in relation to the following topics: Access to Staff; Data retention following completion of the review; access to water samples by microbiologists and disclosure of the Paediatric Trigger Tool.

A Paediatric Trigger Tool Review of Patients at the Royal Hospital for Children in NHS Greater Glasgow and Clyde (March 2021)

305. Whilst the Case Note Review reflected on some of the comments from the Paediatric Trigger Tool and that minor parts were referenced within the oversight board report which was also published on the 22 March 2021, there was no publication of the Paediatric Trigger Tool(PTT).

306. On 02 July 2021, the Case Note Review Team convened a meeting for the last time prior to formal closure of their work. The meeting was chaired by Professor Marion Bain, GGC and attended by a number of stakeholders involved in the Case Note Review. At this time, Dr Patricia O’Connor was to present on a report commissioned as part of the Case Note Review which focused on Paediatric Patient Safety using an internationally recognised and respected process that utilised a Paediatric Trigger Tool

307. Both Dr O’Connor and Professor Davey were included previously in the circulation to patient and families as part of the Biographies of the Case Note Review Team.

308. However, when Dr O’Connor asked if we had seen the report A Paediatric Trigger Tool Review of Patients at the Royal Hospital for Children in NHS Greater

Glasgow and Clyde (March 2021), it transpired that no-one at the meeting had been given access.

309. Whilst I recognise that I may not entirely understand the full detail within the report, I appreciated enough that this was an extremely important piece of work commissioned to review the circumstances around the infections contracted across QEUH/RHC specifically as it related to those identified children, including my daughter.

310. This provided further evidence of suppression of important information from those charged with impacting on infection control and patient safety. I am aware that Professor Stevens and Dr O'Connor have both written formally to Professor Marion Bain expressing concerns around the foregoing.

311. I expressed significant concern to all present that this was yet another example of ineffective governance, with a laisse faire attitude to risk management and patient care. This, like the incident with microbiologists, reflects the situation with the DMA Canyon Reports on Legionella dated 2015, 2017 & 2018 where ineffective governance had such devastating consequences. It appears to me that despite the best efforts of Independent Experts, GGC do not consider themselves answerable to anyone and are incapable or unwilling to learn from the experience. Indeed, they continue to demonstrate, at best, dysfunctional or at worst, corrupt, management practices that places vulnerable patients at risk.

312. As such, I have extreme concerns as to the conduct and effectiveness of the newly formed Assurance, Advice and Review Group (AARG), which has assumed the oversight role of the Oversight Board and one would expect, has the role of assuring all stakeholders that recommendations will be considered and where appropriate implemented. If not, they should be re-assured as to the reasons why not with clear auditing and recording within the identified risk registers with adherence to those other recommendations relative to effective governance and risk management.

313. That report was to have been published in March at the same time as the Oversight Board Overview Report and the Case Note Review Overview Report. It had been submitted by the authors on the 5 March. Dr Patricia O'Connell has said that, in her phrase, the world and her granny are trying to access this data for the learning because this is about interventions from a number of different variables that can determine when to intervene before a child has to go into PICU. How powerful is that as a communication document? We're learning from the trauma of these kids. These families have been willing to allow that data to be considered but yet it's not been made public.

314. A letter has been sent from Professor Mike Stevens to the Chief Executive of NHSGGC, to the chair of the Oversight Board (now called Advice, Assurance and Review Group) and to the new Cabinet Secretary and the new Chief Nursing Officer because, of course, the Cabinet Secretary and the Chief Nursing Officer have been replaced. They had two key positions in holding GGC to account. It seems rather opportune that when you lose two key players, the corporate memory seems to go with them and there is no corporate retention, which takes you back in to the very failing at the start in terms of corporate governance of the 2015 report. Here we are in late 2021 and the report from March 2021 has not seen the light of day. I have made contact with those at the Chief Nursing Officer Office and asked why this is the case. I've been foisted off on a number of occasions to say it would be considered, by the new advice assurance and review group to see what they will do with the report. I stated to them this report had already been commissioned and approved and should be made public. Why are we now going through all this again and depriving the knowledge that would serve to better protect vulnerable paediatric patients.

315. I will provide further detailed evidence to the Inquiry in a future witness statement.

DUTY OF CANDOUR

OVERVIEW

316. It would be fair to say that prior to my daughters' illness, the term Duty of Candour (DoC), from a health service perspective was not known to me, certainly not the statutory requirements associated with it. However, those key elements of openness, transparency and truthfulness were familiar to me as were the impact and implications of a failure to implement each, resulting in the loss of faith, trust and honesty between parties.

317. From my experience of dealing with NHSGGC, I found Dr Sastry, his team and those I engaged relative to the direct care and treatment of my daughter to be beyond reproach, open, honest, transparent and apologetic when the need arose. They placed my daughter, demonstrably at the centre of their decision making, communication and engagement.

318. The same cannot be said for my experience with NHSGGC corporate services; Chief Executive, Directors and Senior Managers who I found individually and collectively to be duplicitous, overly defensive, devoid of emotional intelligence and lacking in integrity with concern more for their reputation rather than patient safety. They infused a sense of distrust through a culture of secrecy, fuelled, at best, and as stated previously, by dysfunctional or at worst, corrupt practices.

319. I will go on to provide detail of five duty of candour events as they relate to the factual narrative of my experience at the hospital. I was involved in further meetings and engaged in correspondence as regards these matter and I will provide further evidence to the inquiry in due course.

Duty of Candour - March to May 2018: environmental awareness

320. In March 2018 I became aware from media reporting and open discussions across the ward that ‘bacteria’ was identified within ward 2A and allegedly sourced to the water supply resulting in considerable disruption, changes to ward hygiene procedures and instruction to refrain from drinking and washing in water, from domestic water supply servicing the ward.

321. In addition, medical intervention resulted in prophylaxis antibiotics being given to those children with compromised immune systems, including my daughter.

322. This proved to be a very difficult time with considerable impact on my daughter. I was extremely worried and concerned as to the safety and well-being of my daughter whilst being treated within the hospital ward. Media reporting at that time and discussion within the Scottish Parliament debating chamber, exacerbated my concern. The Minister for Health Shona Robison had to make an apology to the patients and families concerned.

323. In addition, a comment, attributed to NHS Greater Glasgow & Clyde was also widely reported in the press as follows: "As a result, it is hoped that the full water supply will return to normal within 48 hours after appropriate testing has been carried out…”

324. Despite this statement by GGC bottled water continued to be supplied with temporary filters fixed to the washbasin taps and shower head, all of which combined to cement my fears that something was acutely wrong with the ward environment.

325. Further, in May 2018 a further outbreak of bacteria, this time, according to media reports and following alleged comments from an ‘NHS employee’, the source was identified as the drains within Wards 2A and 2B.

326. My source of information during this time was not GGC, rather the mainstream media, with who GGC appeared to be communicating more regularly and effectively, then the patients/parents on ward 2A. Their approach with media was to be proactive, but reactive with families. The following represents an extract of reporting at the time: ″As the wards affected treat patients whose immune system is compromised, we have taken these immediate steps to apply a chemical disinfection to the drains and to inform the families of the situation.” "We have also taken the extra precaution of prescribing antibiotics to a few patients who are at risk of infection and we are sorry for the disruption this has caused to our young patients and their families in wards 2A and 2B at this time."

327. I was angry that GGC were using the media as a conduit of information which further fractured trust and confidence. It also demonstrated to me an absolute lack of emotional intelligence or adherence to their own policies around patient centred care. There was an absence of engagement and respect for our right to information, enabling us to make informed decisions with regards to my daughter’s health.

328. I began to observe a change in the demeanour of staff and experienced a palpable sense of frustration and anxiety that was transferring to patients and families. There was a real sense of fear and alarm about the environment and what impact it was having on patients.

329. I sensed a lack of transparency, openness and honesty coming from GGC. I also sensed that this was the feeling from staff, a number of whom shared with me their concerns, especially around a lack of communication and engagement between themselves and management.

330. There was something clearly wrong with the environment that was requiring of detailed investigation but regardless as to whether the cause was known, the impact was being felt and harm was being done, emotionally, psychologically, socially and physically. There was a clear lack of information from GGC corporate

services and it was having a detrimental impact on relationships between staff and patients. Staff were being held accountable for that which they were not responsible; the water and drainage and was fracturing trust.

Duty of Candour Event - June 2018 Bacterial Infection: Mycobacterium Chelonae

331. On 01 June, I was informed by Dr Sastry that Molly had contracted a bacterium called Mycobacterium Chelonae (MC). She would require undergoing an emergency procedure to remove her central line as the plastic tubes presented a significant risk due to the bacterial infection. The removal occurred under general anaesthetic, meaning that the chemotherapy treatment would be suspended. From the point of identification of MC, the clinical team, communicated, responded and tried to manage the effects on Molly. They were clear that they knew little of the bacteria due to this being a rare pathogen, never before experienced on the ward- although I was to later find out this was not the case, as alluded to earlier in my statement under the chapter, Case Note Review. Whilst concerning and frightening for my daughter and indeed myself and my family, the openness as to the challenges were appreciated. There was a clear plan as to how to progress and hopefully challenge the bacterial infection. The humility, particularly by the medical team, of saying ‘I don’t know’ when I asked as to the impact on Molly’s treatment was mitigated with the identification of someone who would know, Dr Ian Lawrence, a recognised MC expert in Scotland. I asked how Molly contracted this bacterial infection and was advised that it was unknown but that it was synonymous with water and the environment.

332. I was well aware of the perceived environmental issues in the hospital, particularly around the water supply and asked if this was the cause. Dr Sastry was honest in his response by saying he did not know. He also stated that whilst causation was unknown, harm was caused to Molly that would impact on her treatment. He told me that he had to manage the risk of continuing with chemotherapy, which would further reduce Molly’s immune system, enabling the bacteria to flourish. Conversely, if he stopped chemotherapy, it enabled the

cancer to continue to grow. I asked what treatment Molly would require and he stated that after discussion with Dr Lawrence and other microbiologists they decided to place her onto a combination of very strong antibiotics to be administered intravenously for one month and then orally, potentially for as long as one year. He advised that this was a very difficult bacteria to manage as little was known about it which would ultimately impact on treatment. He stated that the bacteria were not routinely screened as it was so rare and it was blood cultures, taken from Molly, several weeks previously that had grown the bacteria. The suspension of her cancer treatment would be closely monitored. I was extremely frightened as to what this would mean for Molly.

333. In all the circumstances I concluded that the hospital environment had a detrimental impact on my daughters’ health and was negatively impacting on her cancer treatment.

334. Thereafter I met with the microbiologist Dr Teresa Inkster with whom I discussed the bacteria itself, how it was contracted, what the source was or likely to be, what was happening to investigate the source, especially as this may inform the treatment going forward and what was being done to better protect my daughter and others. Dr Inkster advised that she was the chair of the Incident Management Team (IMT), which was responsible for managing bacterial outbreaks. She advised that Molly’s case had been discussed at the most recent IMT and that Scottish Government and Health Protection Scotland had been notified in line with guidance. I expressed my anxiety around what had occurred with Molly and was looking to understand ‘what now’; how would they seek to identify the actual source of infection as this could assist Dr Lawrence and Dr Sastry in their treatment of Molly.

335. Following this meeting I embarked on my own investigations and due diligence around processes and procedures surrounding bacterial outbreak in hospital settings; the associated investigative process, particularly around Mycobacterium Chelonae , Duty of Candour and governance within GGC. I had to ascertain the

truth about the environment, the extent of the risk to my daughter and what was being done to manage, communicate and respond to those identified risks.

336. During this time, I continued to observe a ward that was in chaos due to a cleaning regime requiring of the decant from rooms and clearing of cupboards, including medicines that were required in the treatment of those patients, causing significant distress for staff. I observed and listen to medical teams not advised as to when water was being closed off to effect maintenance and cleaning resulting in impact on basic hygiene with doctors unable to wash hands, and in one instance following their use of toilet facilities. I experienced us moving from room to room to affect the cleaning regime but due to lack of co-ordination with those removing and replacing component parts for sinks, there was requirement to move again to facilitate additional cleaning. I listened to families terrified of what was ongoing and how this would impact on the lives of the children. I also listened to the distress experienced by nursing staff, perceived by some not to be following rigid hygiene standards.

337. I observed a process entrenched in dealing with the bacterial outbreaks that prevented them from seeing the wider crisis that was unfolding. A process demanding of open and transparent communication that would reassure during a distressing and frightening period. The IMT was not the place for crisis management however, from my perspective GGC Senior management had devolved responsibility and accountability to the IMT, who whilst equipped to manage an out-break, were not so when it came to the management of a crisis.

338. Following the decant to ward 6A in September 2018 and assurances as to the safety of the ward, water supply and overall environment, ward 6A saw a spike in bacterial infections. This followed an extended period between January and May 2019 when ward 6A closed to new admissions due to concerns with an outbreak of cryptococcus and issues regarding sealant in shower rooms. In June another patient had contracted MC, something that I had expressed concern about, seeking assurances that the prevention strategy was robust enough to prevent

such occurrences. I had also been advised by Professor Brown, Chair of NHSGGC, as alluded to above, specifically, '*appropriate actions had been taken to reduce the risk of another patient contracting the same infection'*

339. I was not satisfied that this ward was safe and had received information from clinical staff that significant issues with regard to mould had also been found in the kitchen area of the ward. I had also been shown photographs of the effect that water egress over a period of time had in relation to the development of mould in that kitchen area. As such I was not satisfied that GGC were being transparent or open in their disclosures to me.

<u>Duty of Candour Event - June 2019: disclosure of further case of Mycobacterium Chelonae</u>

340. Indeed, on 27 June 2019, I was overseas on business when I received a telephone call from my wife [redacted] advising that whilst in ward 6A for a routine check-up of Molly, she and Molly were taken into a room where Dr Sastry advised that another patient had contracted MC. Dr Sastry further advised that he could not keep this information from us, due to harm already caused and likely to be further caused as a result of this. He advised Molly had to remain on antibiotics, recognising it had been 16 months since she was first prescribed antibiotics, but due to blood counts would otherwise see a recurrence of bacteria. I was also informed that staff lacked confidence in the hospital with risks too great for children.

341. I reassured my wife and daughter that GGC would be in contact as they had previously assured me that all communications in relation to such matters, especially MC, would be directed through a single point of contact, Mr Jamie Redfern, Director of Women and Children Services.

342. I was further advised that nursing staff had alerted my wife and Molly to the fact that at the IMT, for this recent outbreak, specific mention was made to update me

as a matter of urgency and that an ‘action’ had been taken in this regard. During the time that Dr Sastry spoke with my daughter and wife, I understand that he had a telephone call with Mr Jamie Redfern advising him that he had provided information to them with regard the MC.

343. Having returned to the UK I waited for an update from GGC in the knowledge that the disclosure could assist better understanding of MC in general as Molly was still being treated for the bacteria. However, having waited nearly three weeks and received nothing from GGC I contacted Jamie Redfern on 17 July 2019 by email.

344. On 08 August 2019 I met with Jamie Redfern and Dr Teresa Inkster. There was no doubt that Mr Redfern was anxious from the outset and he proceeded to outline the reasons as to why I had not been informed as per the instruction from IMT regarding the second outbreak of MC. He stated that due to annual leave, neither he nor Dr Inkster were available to speak with me, although he conceded he thought someone else would; he advised me that there was a thought that as the Chairman Professor Brown had been in contact previously, he would undertake this follow up. He also stated that there was no intent to cover up, simply a series of unfortunate events had occurred.

345. Having listened to everything he had to say and dealing with each point in turn, firstly his annual leave; surely there was sufficient capacity and resilience within GGC that contact could have been made to satisfy their Duty of Candour? In relation to the Chair Professor Brown, any dialogue I had with him, was between us and more over the action was allocated to Mr Redfern and Dr Inkster, not the Chairman of the GGC Board. As I went to address the third point, Dr Inkster interjected by stating ‘ tell Professor Cuddihy the truth Jamie”.

346. As you would imagine I was taken aback by this statement as it implies that I had been told an untruth. I stopped the meeting to ask for an explanation to which Dr Inkster advised that following the IMT, which she chaired, the action to speak

directly with me had been taken and that she and Jamie Redfern were identified for doing so. She stated that a number of members present highlighted the importance of advising me and my family of this further outbreak. It is worthy of note that Mr Redfern was the identified conduit of information between GGC and me, something agreed at previous meetings.

347. Having concluded the meeting Dr Inkster stated both made their way to Mr Redfern's office with the intention of calling me. However, Dr Inkster advised that they received a call from a senior member of staff telling them, under no circumstances was I to be told. Neither Mr Redfern nor Dr Inkster disclosed who had in fact called them, other than to say it was someone senior to them. I understand that the call was received on Mr Redfern's phone. From my perspective I was sitting with two very senior members of staff; Dr Inkster was the Chair of the IMT and Mr Redfern was the, then Deputy Director of Women and Children's Services. As such the senior person had to be a Director or member of the Executive. I challenged Mr Redfern to disclose the identity of the person who called him however he said nothing further and was decidedly uncomfortable at the disclosure made by Dr Inkster. Significantly he did not dispute anything that she had to say

348. I thereafter stated that I considered their actions wilful and a clear breach of the Duty of Candour. I advised them both that I would contact both the Chair of NHSGGC and the CEO to make a formal complaint. I left the room.

349. On leaving the room I was followed by Dr Inkster who apologised for what had happened and advised that she will stand by everything that she said. She advised that she had made contact with GMC as she had been encouraged to tell lies to a parent (me) of a patient, something she would not do. Further, Dr Inkster expressed significant concerns as to the environment and moreover the response by GGC.

350. Dr Inkster further advised that Mr Redfern was under significant pressure which I could see in his demeanour and actions. I was actually concerned for his wellbeing and prior to contacting the CEO and Chair, I emailed Mr Redfern to encourage him to look after himself as I thought he looked extremely stressed.

351. Further, on 12 November 2019, I attended a meeting with Professor John Brown, Chair of NHSGGC Board, Dr Jennifer Armstrong, Medical Director and Jane Grant, CEO NHSGGC. During this meeting I expressed concerns around a number of matters including this event. Jane Grant assured me that she would look into what I had to say and apologised to me. I advised her that she had already "looked into" this event and had sent me a letter regarding those findings! This had followed written communication from me posing a series of questions around the events alluded to earlier. In addition, Dr Armstrong articulated the response to the identification of mycobacterium chelonae, and proceeded to outline the events of June 2019 on ward 6A and how water samples and bacterial samples were sent for advanced Gnome testing. I had to interject and advise that the event she was describing was actually another patient and that such testing and comparison of water samples could not be made with regard to my daughter, as no samples were taken, certainly not to my knowledge. It was embarrassing for Jane Grant and Jennifer Armstrong and it was uncomfortable for John Brown who agreed to take away the issues and report back formally. This meeting was a further example of a lack of corporate knowledge and corporate memory and a leadership in crisis, unaware of what was happening across their areas of responsibility.

<u>Duty of Candour event: February 2020 – Stem Cell Transplant</u>

352. I have described the events 2-8 February 2020 when Molly was administered an overdose of Etoposide Phosphate.

353. On 11 February 2020, I met with Dr Sastry, Gail Calderwood, Director of Pharmacy and the Pharmacist from Schiehallion, who had identified that an

overdose had been administered. During this meeting, Doctor Sastry outlined his treatment and what should have been administered to Molly, stating that all labelling reflected the actual dosage to be proscribed. Gail Caldwell stated that it appeared that the error may have occurred due to a wrong calculation from the raw form of the drug Etoposide to the diluted form Etoposide Phosphate however a Significant Clinical Investigation had been initiated that would hopefully provide some answers.

354. Whilst emotionally distressed I was grateful to Dr Sastry for his openness and honesty as it enabled me to understand what was happening to my daughter who I could see was extremely unwell. I asked as to the long-term effect, the effect with her cancer treatment and did this threaten her life. Dr Sastry reassured me that Molly was in the best of hands, although I had serious doubts because once again, Dr Sastry was being held accountable for that which he, was not directly responsible.

<u>Duty of Candour event: February 2020 - PICU</u>

355. I have spoken about Molly's admission to the PICU in February 2020. Dr Sastry was not within the hospital during this period with Molly's oncology treatment being the responsibility of his colleague Dr Ronghe, whom had been involved with Molly previously.

356. Several days later, once Molly had stabilised, Dr Sastry had been discussing the various episodes with us at which point he mentioned Molly having contracted a bacterial infection, Propionibacterium acne as a result of a contaminated bag of platelets. I recalled the incident and discussions around this. I stated that this was the first we had known of this bacterial infection. Dr Sastry advised that Dr Ronghe had thought it better not to tell us at that time with everything that was ongoing. I was accepting of this and the rationale for withholding this information, although Molly was not and maintains this position. However, I believe that the Duty of Candour is designed to address harm in the broad sense and as such, I

considered that as long as the medical team knew and were treating Molly accordingly, more harm could have been caused at that point in time, should Dr Ronghe have disclosed this. The important point for me, was that we were told once ‘safe’ to do so.

357. I believe that Dr Sastry satisfied his Duty of Candour as well as Dr Ronghe although accept that my daughter Molly does not agree relative to Dr Ronghe.

358. The duty of candour is about harm and harm in all its forms. Causation doesn’t need to be a factor. For example or me, Dr Ronghe considered the broader harm of telling us at an extremely challenging time and I think that would have sent us over the edge, sent Molly over the edge. Whilst that should be up to the professional to consider that action, what should happen is that it’s recorded and you’re told as soon as reasonably practical thereafter.

359. That’s something I reflect on when the hospital failed to tell us about the other child with mycobacterium chelonae infection and then I was told in the meeting, “Tell him the truth”. I always left the option, if there’s a reason you’re not telling us, record it and allow others to determine then, why that’s happened. If there is a good reason why we’re not being told just now, fine, but I have never been offered any good reason in relation to the hospital’s failure to inform me earlier about the other child who contracted the same infection as Molly.

360. All of the foregoing strengthened my resolve to better understand the environmental risks, how they were being identified, managed, responded to and communicated, and to collectively seek solutions that would better protect my daughter and those other children. I would also seek to better understand the cause of her mycobacterium chelonae infection, that it may assist in some way, the complexities of her ongoing treatment. I hoped this would enable me to more adequately communicate and engage relative to those complexities on behalf of my daughter. In addition, It was apparent to me that the use and understanding of the Duty of Candour was something that was routinely absent across GGC. As

such, I co-authored a paper on Duty of Candour, reflecting on my personal experience, making recommendations. The paper was reviewed and subsequently published in the Journal of Medical Ethics. I can provide this paper to the Public Inquiry.

361. I intend to provide more detailed evidence to the inquiry in relation to this matter in due course.

IMPACTS ON MOLLY AND IMPACTS ON THE WITNESS

362. There has been an incremental impact on Molly. When I work my way back and I see everything that's in play; there's a golden thread that takes us back to Molly contracting mycobacterial chelonae. Her options for future cancer treatment are limited as a result of the infection. Her life is impacted as a result of the infection.

363. When I asked repeatedly, who's investigating this, and to be told, they're doing everything within the guidelines, but of course, there was limited reporting to the board, resulting in limited scrutiny as to whether they were operating within guidelines. Such lack of effective governance was at odds with the process adopted within IMT, with escalation of concerns to the likes of Scottish Government and HPS. The inconsistencies in effective governance give rise to considerable suspicion as to their rational and reasons for acting in the way they have. There is an escalation of distrust which impacts on your confidence that they are doing everything within their sphere of knowledge and understanding with significant detrimental impact to Molly and her treatment.

364. It appears as though microbiologists have presented all of the information to the Board or at least management, responsible for reporting to the Board but for whatever reason such information is supressed. For me there is an absolute corporate failing to discharge your duty of care and find out what's happening because this isn't just about causation in April of 2018, which emanated from a lack of prevention. This is a failure to protect the most vulnerable and implement

those control measures that have been clearly articulated by the many experts. Such failure has had a direct impact on the health of Molly, exposing her to increased risk; deprived her of critical support functions that will assist her cope with the many facets of cancer and deprive her of timeous treatment that ultimately impacts on her physical, emotional and psychological wellbeing.

365. My faith and trust in the hospital management has eroded my confidence that my daughter will be cared for in a way that continues to protect her, preventing her from exposure to increased risk; created as a result of corporate failings.

366. I cannot change the fact that Molly contracted cancer. This is something that many have been able to explain; why did this happen? However, I know that clinicians continue to seek such answers. I also know that I cannot change the fact that Molly contracted a hospital Inquired infection, but unlike the cancer, this could have been prevented. The management and certain individuals failed in their statutory duty to protect my daughter. They knowingly exposed her to increased risk from the environment in which she was being cared for.

367. Whilst we continue to feel the impact of their failings, while we cannot change the past we can collectively influence the future and those who have that duty of care to ensure that the environment is fit for purpose must be compelled to do so. We require to have assurance that change will be effected and that measures will be put in place to record evidence of tangible change.

368. Indeed, from what I have uncovered there are clear indications of increased risks from the environment that have exposed and exploited my daughters vulnerabilities. There were a number of identified points were intervention could and should have taken place that would have served to respond to the high risks, putting in place control measures that could have served to mitigate and reduce such risks. There failures have threatened my daughter placing her in life threatening situations and depriving her of an already recued quality of life. The

shame in all of this is that management had it within their gift to protect my daughter and prevent her being exposed to such increased risk.

369. As a parent I was hearing a narrative that everything is safe in the hospital and the ward is safe, but at the same time I was and am still reflecting on the fact that ward is closed. When Molly's surgery was delayed during her first round of treatment due to the mycobacterium chelonae, months later when she did go through that major operation, I was terrified. Not only of the cancer, not only of the operation; I'm terrified because of bacteria. You can't touch it, you can't feel it. Clinicians refer to it as the silent bacteria. Which, having taken hold, was going to be catastrophic for Molly. Now in anybody's dictionary - a big, pictorial dictionary – that word "catastrophic" is so graphic that you couldn't give us any other vision other than show us a coffin. That was the finality of what we experienced.

CONCLUDING REMARKS

370. In all the circumstances, I believe that there has been a corporate failing with regards to ensuring that the environment in which my daughter was treated, was safe. There appears to me to have been sufficient information available from 2015 that resulted in those responsible for infection, prevention and control, raising concerns that the environment presented increased risk to vulnerable cancer patients, such as my daughter Molly. I am also in no doubt that the leadership of NHSGGC, whether through dysfunctional and corrupt practices, failed to respond to, manage and communicate to those at risk. Despite numerous opportunities to engage proactively, they failed to do so and have actively suppressed information from those who could make informed decisions with regards to the outbreaks of infection.

371. What I find even more disturbing is the reluctance on the part of NHSGGC to accept that they have done anything wrong, that lessons are not being learned and increased risks remain that threaten the most vulnerable.

372. My daughter’s illness is not a result of a lifestyle choice. I cannot change the fact that she has contracted cancer. I trusted those within NHSGGC with caring for my daughter and, clinically, they have been incredible. They have saved my daughter’s life, on a number of occasions and their clinical skill has been outstanding. However, sadly the environment has not been fit for purpose, has not matched the world class doctors and has, on numerous occasions, made their task even more difficult.

373. My daughter contracted a bacterial infection whilst under the care of NHSGGC. I appreciated that she would be susceptible to such risks and did everything in my power to protect her. When I consider the actions or inaction on the part of NHSGGC, I am in no doubt that they could have done more, much more to protect my daughter from such environmental risks. They were aware of the risks, as identified in the 2015 DMA Canyon report, the 2017 DMA Canyon Report and the 2018 DMA Canyon report. They were aware of the increased risks from water, ventilation and drainage as they had been advised as such by their own microbiologists but failed to listen and take the appropriate action. They have systematically, tried to frustrate and supress each and every investigation and engaged in wilful acts so reckless as to show an utter disregard for the consequences. They have presided over a crisis which has become a scandal that has led to the exposure and exploitation of those whose lives have already been so dreadfully impacted through no fault of their own.

374. My daughter and those other children, our families and indeed staff, have witnessed a developing series of events that individually have impacted on our lives, physically, socially, psychologically and emotionally. Collectively, the failings of NHSGGC have reduced further the quality of life that my daughter has. They have further eroded her chances of survival when small margins mean so much and often the difference between life and death. The failings have led to further illness, which in itself, further complicates the delivery of cancer treatment. Even if my thoughts or conclusions are emotionally influenced resulting in my

judgement being impaired, one cannot ignore the fact that my daughter contracted a hospital acquired infection and in doing so, impacted her quality of life and chances of survival. One cannot ignore the comments from those doctors, microbiologists and other NHS staff who have disclosed their perception of the failings, raised and documented since 2015. One cannot ignore the fact that the bespoke ward 2A/2B, designed to cater for my daughter's treatment for cancer, has been closed for nearly three years, that the ward she was decanted to was closed twice, that review after review have been conducted, parliamentary questions have been posed and public inquiries have commenced. One cannot ignore an independent expert panel who conclude that 30% of the 84 cases they reviewed were probably linked to the environment whilst 70% were possibly linked. One cannot ignore that they concluded that two deaths occurred, at least in part, were the environment was a contributing factor.

375. However, even more shameful, is the fact that evidence exists that lessons have not been learned, increased risks remain, and vulnerable young people continue to be exposed to increased risks.

376. I remain concerned that whilst my daughter has defied the odds and continues to fight every day, she still requires the help of NHSGGC. I trust the doctors but even they cannot protect her from the environment. Molly will sadly require those services for the rest of her life, but I am afraid for her every time she enters the QEUH. I am afraid that whilst those who have presided over this scandal remain in position, Molly remains at risk, not only from the physical environment but the toxic cultural environment that exudes the very pores of those operating within the higher echelons of NHSGGC.

377. Cancer threatens Molly's life. Mycobacterium Chelonae threatens Molly's life. Sadly, I cannot change that. I can only take comfort and enjoy the time Molly is with us.

378. However, Molly is also threatened by the NHSGGC, organisational environment, or rather those who influence and direct that environment. They have had numerous opportunities to change and influence the environment. For whatever reason they continue to fail in their duty to protect and in my opinion, change will only be realised once those involved are removed as they have demonstrated that they have neither the operational or professional competence to discharge their statutory obligation relative to the provision of healthcare.

379. If you ask me, what do I think about Greater Glasgow and Clyde, clinically, I think I've made it very clear in that anything I say here does not in any way relate to those involved in clinical care. In terms of the corporate entity, they, as a group, have engaged in a series of wilful acts so reckless as to show an utter disregard for the consequences. That's what I think about them. I started in this believing that no-one would get up in the morning and do something that would hurt a child or, indeed, fail to do something that would increase the risks to that child. I am in no doubt that there are those who have devolved responsibility, who have abdicated their statutory responsibility and they have engaged in a dysfunctional organisation and knowingly suppressed documents that has ultimately increased the risks to my daughter, exposing her to a hospital acquired infection that has and continues to threaten her life.

380. When I eventually sat on the Oversight Board and I was going through their Governance Reports, this is the body that's been placed to hold to account the hospital management that have been placed in special measures. They are holding them to account and asking them to surrender information. I have read Governance Reports that have been put together by Price, Waterhouse, Cooper analysts and there's nothing on them about mycobacterium chelonae being identified in ward 2A. Indeed there's nothing on there about Molly Cuddihy ever contracting it. I then go back to the Governance Reports they presented to the Board and the questions that I'd posed to the Cabinet Secretary. How confident are you in the public figures, because Molly Cuddihy has not even been recognised in this? She has been in your hospital with a rare bacteria which your

reports tell me has only ever been identified on four occasions in the last ten years. The only reason why you've given us that is because you're not recording any other incident. That's why there's only four. For me, the Health Board communication – even at that level – was not supplying the information. I have real concerns about it.

381. You can reflect on the vastness of Greater Glasgow and Clyde Health Board and the very many datasets and the fact they don't have a system that actually considers all of the data sets. This may be considered as a corporate vulnerability and 'excuse' for a failure in effective corporate governance. This issue in data acquisition has been commented on by various reviews. However, when you have the likes of the Case Note Review asking for access to documents, from an informed position, and still being met with resistance, what chance to families have. This is why I quite often talk about the corporate structure of GGC has determined relevance which influenced disclosure, rather than them enabling others who are better informed to determine relevance when deciding on disclosure. They have consistently failed to disclose ALL documents to enable those charged with carrying out the various reviews to determine relevance. I am in no doubt that specific instruction should be given to GGC for FULL disclosure through specification of documents that extends to ALL email communication between relevant individuals, departments and governance groups, involved in this crisis.

382. Indeed, I am of the opinion that such named individuals, linked to relevant documents and emails, should be 'mapped' across corporate governance structures in an effort to identify corporate knowledge and therefore where disclosure to those requesting such information could and should have occurred, thus better protecting our vulnerable children.

383. Molly's going to need the NHSGGC and QEUH hospital. Molly's transitioned over to the Beatson Oncology Unit and I'm hearing myself saying I'm happy that she has. Of course, I'm not. I don't want Molly in the Beatson. I'm happy she's

not in the RHC/QEUH but Molly still needs to go to that hospital. It terrifies me because I know that there is a veneer of respectability portrayed as they hide behind outstanding clinical work and even better research. In hiding behind that, they mask their own deficiencies within corporate governance individually and collectively. They have exposed and exploited those children to increased risk, when they could have intervened to better protect and prevent their exposure to increased risk. If they failed to act due to information, not yet made public, they have a duty to update us in this regard.

384. I have worked in high risk environments for many years and I've always known that we can never truly save everybody, all of the time, even although this is what we aspire to do. I have always known that the best way to deal with anything is prevention. If we have information that allows us to better prevent through protection and we don't engage in it, there's something wrong. That is a failure in our statutory duty. Indeed, when there's a statutory framework in place that gives responsibility to identified individuals and they ignore it: it is shameful. When they continue to ignore the recommendations as though they've done nothing wrong, even when they had governance groups advising them: it is shameful. It is a teaching hospital, and where we teach we must also have the humility to learn. The failure to learn from those identified experts is shameful, absolutely shameful.

385. Much is made that this is an £840-odd million facility, of course it is, and there are some magical things are enabled as a consequence but that which was spent on the facility to house these children is meaningless if you do not effectively govern, manage and protect those you have responsibility for. Indeed, what price do you put on a child's life? I am not measuring that simply in terms of their mortality. I'm measuring that against their quality of life which has been eroded as a consequence of their failings. We will never get that back, never, ever get it back. I will continue to do my best to hold those responsible to account but recognise my limitations. I am fearful that those in position of 'power' within Scottish Government release Greater Glasgow and Clyde from level four special

measures. If they do so, in my opinion, there will be an undoubted repeat of what's ongoing just now and I would respectfully suggest that we may be dealing with corporate homicide. Those in such positions cannot say saying they didn't know- they do know and we must ensure tangible change is realised and no other young lives are lost or indeed their quality of life further eroded.

386. I have already experienced the emotions, the trauma of my child being diagnosed with cancer and then a rare pathogen. Nothing will ever change that, nothing, but when I heard that another child had contracted mycobacterium almost a year after Molly, I find that hard to take and I almost felt as though I was part of the problem. Should I have shouted louder? Should I have been more vociferous in my arguments? I thought I was doing the right thing to engage and to be part of the solution but I'm long enough in the tooth to know that when you look to negotiate and enter into dialogue, both sides need to be willing. NHSGGC are not willing and the problem is that there are those in management and those with responsibility for governance that don't have the skills to discharge their duty. That's the sad fact and they need to be replaced.

387. I'm not simply calling for someone's head. Move them, give them a job that suits their skills but take them out of harm's way, protect them from themselves, protect them from refusing to be humble and recognising when they don't know. They've got fabulous expertise on their door-step, they should tap into it. The microbiologists are there for a reason. We employ clever people for a reason: embrace them. If there is a contra-view, if there is evidence that substantiates a different view: educate them. The RHC and the QEUH is a teaching hospital, educate them, but they're not doing that.

388. We have a new cohort, sadly, of sick young people who have not experienced the trauma and the folklore of the crisis and quite rightly so, they shouldn't. But in order to challenge it, we need to expose it. We need to consider it. If I and others have got it wrong, the health board owe it to me emotionally to tell me that I am not worrying about taking my daughter to a facility that's going to further reduce

that quality of life and put the fear of God into her every time she goes near it. That happy, wee person is sadder every day. As much as Molly tries to pick herself up, it's harder every day. Molly sees that there is no change.

389. I've seen the document which says they've spent approximately £8.5 million on the works in ward 2A and 2B in the RHC. That's more than any air conditioning system. In addition, when NHSGGC seek to hold to account Multiplex and others to the tune of £74.5 million, this tells you that there's lots that went wrong in the hospital. But behind every pound that they claim, there is a patient, there is a life that has been impacted upon as a result of those corporate and environmental failings.

390. If you reflect beyond the Schiehallion unit, the risks exposed to date are across the entire hospital facility. What impact assessment has been carried out with regards to the wider, vulnerable patient population? Who else has contracted such bacterial infections as a result of this compromised environment?

391. As a young police officer, the first thing that I learned, about dealing with criminals, if you're going to tell lies, you need to have a good memory. NHSGGC have not got a good memory. They don't know what their left hand and their right hand is saying and they contradict one another. Somebody needs to control this and grip it and give us a confidence.

392. There's a balance that we have to strike, there is a patient population for Greater Glasgow that's served by that hospital. That's a political decision and they need to ensure that they have the trust of those people and that the public are not scared to go to hospital. I understand that but you don't do it to the detriment of an extremely vulnerable group who have, sadly, contracted a disease which is not a life choice. The failures need to be exposed and when we do, only good will come of it. We will not change anything in terms of what's happened to our children but you can prevent it happening to another child. That has got to be worth doing.

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

Scottish Hospitals Inquiry

Witness Statement of

Louise Cunningham

WITNESS DETAILS

1. My name is Louise Cunningham. I was born on [redacted]. I am [redacted] years old. I work [redacted] .

2. I am the mother of [redacted]. [redacted] date of birth is [redacted]. [redacted] passed away on [redacted] when she was 3 years 6 months old.

3. I live with my two sons, [redacted] and [redacted], in [redacted], [redacted].

OVERVIEW

4. My daughter is [redacted]. [redacted] was diagnosed with Stage 4 High-Risk Neuroblastoma in March 2017 when she was 2 years and 8 months old.

   [redacted] was treated in the Royal Hospital for Children (RHC) between March 2017 and [redacted], when she passed away. [redacted] was an in-patient during this time, and only attended as an out-patient for approximately 4-5 weeks out of the 10 months she was a patient at the RHC. With the help of my solicitor, I have prepared and provided the Inquiry with a timeline, showing the dates on which attended hospital and the wards where she was treated. The timeline is attached to this statement at appendix 1 (**LC/01**) and I confirm that it is accurate to the best of my recollection.

5. [redacted] spent time in wards 2A, 2B, 2C and 3A of the RHC. Ward 2A is part of the Schiehallion Unit. The Schiehallion Unit treats children with cancer. I stayed with [redacted] during her time as an in-patient and I can speak to the experience which I had with [redacted] on these wards.

FAMILY BACKGROUND

6. I live with my sons in [redacted], [redacted]. [redacted] is my youngest child, my oldest son, [redacted], is [redacted] years old and my other son, [redacted], is [redacted] years old.

7. [redacted] was crazy, absolutely crazy. She was always such a happy, go lucky wee girl. She had no fear whatsoever, not one bit of fear in her body until she started to become unwell.

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

Admission to hospital: March 2017

8. We had a couple of admissions to hospital during March 2017, where they told me [redacted] just had some sort of viral infection and then discharged her. The first time we went in they discharged us after a few hours and then the second time, on 12 March 2017, they kept her in for a couple of nights and then discharged us. I was told at that time that [redacted] haemoglobin level was slightly low but that it was fine and not to worry about it as that's what happens with a viral infection.

9. [redacted] was still not 100 per cent so on Thursday 16 March 2017, I took her back to the RHC. I went in first thing in the morning and later on they moved us to the Clinical Decisions Unit (CDU). A few hours after that we were moved up to

ward 2C. They didn't know what was wrong with her but then about half past one, quarter to two in the morning, a few doctors and a nurse came in and said that [redacted] had to go for an X-ray and a CT scan as they'd found something in her blood.

10. We went for the X-ray and the CT scan and were told then that her liver looked enlarged. They also asked if [redacted] had had an accident, like a bang to the head. I said she was constantly banging her head, she had two brothers and she acted like she was a wee boisterous boy because of them, but the nurse said no, this would be like a car crash trauma.

11. I was then left with no further explanation and later that morning [redacted] was taken for an ultrasound. A wee while after that a doctor said that they'd found two masses in [redacted] stomach and that she had basically no platelets in her body. Her blood wasn't clotting at all, it was just kind of floating about.

12. It was at this point they said they were moving her to ward 2A, the oncology ward. This is known as the Schiehallion unit.

[redacted] initial treatment Ward 2A: March 2017

13. Within 24 hours of [redacted] being admitted to ward 2A on 17 March 2017 she deteriorated quite a bit. It was as if [redacted] knew there was something wrong with her and that we'd all now found out too.

14. The doctors put her onto a platelet transfusion, a blood transfusion and they gave her a morphine pump. It got to the stage that I couldn't even change her nappy without her having two pushes of the morphine pump for the pain. I think her body was trying to fight it itself.

15. I spoke to Dr Ronghe, [redacted] consultant, that day and he said [redacted] needed to get a DMSA scan done, a bone marrow aspiration done and an MRI scan. The

DMSA scan is similar to an MRI, but you get a dye injected into you and it takes around five hours. The dye illuminates neuroblastoma in the body. He said that because this was the Friday and it was a skeleton staff on, so things would be getting done in dribs and drabs, he wanted to just keep her pain at bay and get some bloods into her over the weekend and start afresh on the Monday.

16. I agreed to that so on Monday 20 March 2017, [redacted] went down to the MRI Department on the first floor. She was there for five and a half hours getting the scans done. She was continuing to deteriorate and although Dr Ronghe had had an initial look at her scans, the official reports hadn't come back yet. As part of these investigations, [redacted] had a biopsy taken of her tumour that was sent down to Great Ormond Street Hospital for analysis. The results of this biopsy that came four to six weeks later showed that [redacted] had an N-MYC gene tumour which is a very rare tumour that only one in a thousand are born with.

17. [redacted] had surgery during that first week to get her central line in. This involved them doing an ultrasound of her neck to find the best vein and then they put the line in through the neck into the main artery in her body. At this point she was just getting more and more unwell.

18. On Thursday 23 March, Dr Ronghe said that he was really concerned that

[redacted] had stage four high-risk neuroblastoma cancer and that although he didn't have the results of her biopsies, it was his opinion that [redacted] needed to start chemotherapy right away or she might not see it through the weekend.

19. I accepted what he said and [redacted] started her chemotherapy straightaway. This was her first round of seven of the rapid COJEC chemotherapy. Each round lasted three or four days. Dr Ronghe said that she would pick up a wee bit after her first round but [redacted] was still really, really unwell.

20. Around about the 26 March 2017 [redacted] had her first line infection which was roughly ten days after her admission. [redacted] had a high temperature and she wasn’t eating or drinking. The hospital staff didn’t say what the infection was, just that it could be chemo related or that it could be coming from the actual tumours. They gave her antibiotics at first but these didn’t work so they ended up taking her back down to surgery to get her line taken out.

21. A couple of days later they put a new line back in. You have to wait at least 48 hours after getting a line taken out before a new one can be put back in but within a day or two [redacted] was like a new girl. The infection had basically been making her more unwell, but she started to laugh again and she wanted to eat and things. Every time that [redacted] had to get her line removed and replaced, it was two separate surgeries under a general anaesthetic.

22. [redacted] official diagnosis of high-risk stage 4 neuroblastoma was confirmed in the week beginning 27 March 2017, though I cannot remember exactly when.

Experience in Ward 2A: April 2017 – Rhinovirus

23. Sometime in April 2017 ward 2A was shut down for something called rhinovirus. We were shut down for nearly two weeks. This meant that we weren’t allowed out our rooms, we weren’t allowed visitors and we weren’t allowed to use the parents’ kitchen.

24. The nurses said that some kids in the ward had tested positive for rhinovirus and to prevent it spreading, the best thing they could do was shut down the ward. I had no clue what it was but obviously when they were putting us into lockdown, I knew there was something bad going on so you just listened to the staff and did what they asked.

25. I know we were definitely in lockdown on 16 April 2017 as my ex-partner's sister had come from Ireland to see [redacted]. They did let her in for about 20 minutes because she'd come a long way but at that time we weren't allowed out our rooms.

26. That was really hard going. [redacted] didn't understand why she wasn't allowed out her room and why she wasn't allowed to go to the playroom and I couldn't go to the kitchen and make her a tin of soup or pasta, as these were things that I knew she would eat. [redacted] was really close to me and she wouldn't go with anyone or let anyone else stay with her so I stayed with her every single day and night. I therefore had the strain of that situation and also a two-year-old child who couldn't understand why her gran and her brothers couldn't come up and see her.

27. I also remember at that time we were told to remove everything from

[redacted] room. At first when [redacted] was admitted to the ward, we were told that we could make [redacted] room her own and bring in anything she needed or wanted.

[redacted] had some teddies, her wee pram and doll and things like that, just a wee bit of home. But after that lockdown, infection control and health and safety staff came into the ward and made us send everything away, even down to pictures and cards. [redacted] was allowed to keep one or two things but the rest had to go. It was all removed and taken home.

28. It was at this point I thought, "What's going on here?". Shortly after that we started all being moved to different rooms. The nurses were using excuses like another patient needs a room closer to something or, other times we were told that we were getting moved because the room was getting deep-cleaned. The staff didn't say why the room needed deep-cleaned. We moved rooms a lot.

Experience in Ward 2A: April 2017 – September 2017 – [redacted] Chemotherapy Treatment

29. When [redacted] first started her chemotherapy treatment in ward 2A, we were allowed to go out and about in the ward. It took a wee while for [redacted] to get all her treatment at the start but after that we could leave the room and get her food from the parent's kitchen. At the start of her treatment she wasn't really fit enough to go out the bedroom but after that, when she was fit, she could go out and about the ward or go to the playroom.

30. Soon after the rhinovirus outbreak though, we were put into isolation every time [redacted] got her chemotherapy. We were in isolation every other week throughout her treatment. [redacted] had seven rounds of rapid COJEC therapy. Each round lasted three or four days and in those three or four days [redacted] was really, really sick and really bad with the runs. She was just so unwell and she was getting nosebleeds because her haemoglobin and her platelets were dropping because she was so unwell.

31. After the chemo stopped, the next thing was that she needed blood transfusions and platelet transfusions because she was neutropenic. They had to get a dentist up to put a special light in her mouth to try and help ease the pain of all the ulcers she had.

32. Once this passed though, she was able to go out of her room. But sometimes during this period, I would open the door and there was this big bit of tape over the doorway telling us that we can't get out the room. A big white sheet went up on the door that said, "You're in isolation". If you didn't know at night, you woke up in the morning and you opened your blinds, and the tape and sign was there. [redacted] was two, going on three years old and when she saw the tape and sign, she would start screaming "I don't want to stay in the room, I don't want to stay in the room". Most of the time it was just because [redacted] had a

wee bit of diarrhoea which was really, really agitating. It was caused by the chemo.

33. I ended up fighting with my oncologist and infection control to say, “Look, you are putting [redacted] onto this chemotherapy, you know the chemotherapy is going to cause a lot of diarrhoea, a lot of sickness, so you should not be locking the child down, just because they’ve got a wee bit of diarrhoea”.

34. The doctors knew sickness and diarrhoea were side-effects of chemotherapy, but they still locked us down anyway. When I opened that door and [redacted], or any kid, saw that there was a sheet on the door, they automatically got really upset, because they knew that this is a sign that they couldn’t step out their room.

35. [redacted] was only two going on three, she was three when she passed away, but she knew what was going on. She could tell you the names of the meds that she needed, like you'd say to her, “Do you need paracetamol?”, and she would say, “No I need morphine, I'm really sore, Mummy”. The hospital was her life. She didn’t know about running about with kids, she didn’t know her ABCs, she knew nothing other than the hospital. She would see other kids walking about, she would watch the dinner trolley coming and she wanted to go and pick her dinner too. She couldn’t because there was this marker on our door and a line of tape that you aren’t allowed over. That was really hard for her.

36. It was really hard for me too. We all have to do hard things but when you get put into lockdown every other week, it’s physically and mentally draining. It really got to me because I was seeing my daughter hurting.

37. I just didn’t agree with that. I mean the doctors all knew all the side-effects of the medication they were giving her. So by lockdown, you'd have thought

they'd all agree and thought there's no point in isolating them, these meds are going to give them sickness and diarrhoea. It would be different if you went into hospital and you had sickness and diarrhoea, or whatever then yes, but not lock them up every time there's a stool that’s a wee bit runny, because it wasn’t fair on them. For [redacted] it was a side effect of her treatment.

38. [redacted] got the full seven rounds of rapid COJEC and in-between we did start to sometimes get out for a wee day visit. We were allowed out for two hours here and there. But she then was straight back in because she was due meds at certain times, so we'd need to get back in hospital for the time that her meds were due. Basically, for the first seven rounds of her chemotherapy, apart from a few, couple of hour’s day releases, [redacted] was in ward 2A the whole time.

39. Once [redacted] had completed her rounds of rapid COJEC, I can’t remember exactly when that was, they scanned her but they saw that the tumours still had a bit to go before they could operate. The gave her two rounds of TDD, which is a high dose chemotherapy, and it made her extremely unwell. I think this was at the end of August or beginning of September 2017. After the second round of the TDD, [redacted] was ready for surgery.

40. The hospital staff had her on a morphine pump, but she was still in real pain and they ended up giving her ketamine, which is something I still don’t understand. I still don't understand why they would give a two-year-old ketamine. [redacted] was awake for 36 hours straight, she was hallucinating, and she was seeing things that weren’t there. This was at the weekend so it was weekend staff.

41. The medical team, who do the pain relief, came in on the Monday and they were asking why the hell was this not sorted sooner. They were really angry.

[redacted] had a high pain threshold and in her notes it had said, go in higher with the morphine, and you've got more chance of getting her peaceful. But the weekend staff didn't, they went in with wee doses and worked it up, so it wasn't getting to the stage where it was hitting her pain. Then they added in the ketamine, which was just horrific, it was so bad. When that finished, that's when we got to go home for a wee overnight here and there, but it wasn't often.

42. Before her surgery in September 2017, we managed to get [redacted] away for a few days holiday. We went to the caravan for three days and then we went back into hospital to prepare her for surgery.

[redacted] surgery: Ward 3A RHC – September 2017

43. [redacted] surgery was on 24 September 2017, I think. It took place in ward 3C of the RHC. She was due to go to intensive care after her surgery, but [redacted] being

[redacted] she bounced back no matter what happened. The nurses called her "the miracle one". After this surgery, she should have been in an induced coma for two days. But straightaway after theatre, [redacted] woke up demanding Irn Bru and nippy crisps, which were salt and vinegar square crisps.

44. They did take her to PICU though as she was still quite tired. [redacted] never left my side. Parents are not allowed to stay in PICU, because of hygiene and stuff like that. But even if I went to the toilet, [redacted] was getting herself worked up. It got to the stage that the nurses were that scared she was going to burst her stitches. They gave me a recliner seat and a wee blanket so I could sit with her, because they were more concerned that she was going to damage herself with me leaving her. I was told I wasn't allowed to fall asleep, but eventually they just gave me a blanket and told me just to doze off if I needed to. Parents are not allowed to sleep and stay with children overnight in PICU.

45. [redacted] had surgery and 95 percent of the tumour was removed.

Treatment after surgery – stem cell transplant: Ward 2A and 2B RHC

46. The next plan was a stem cell transplant. [redacted] was in Room 1 in ward 2A of the RHC. She was to receive her own stems back, so they had to do a stem cell collection. A nurse came in from the Beatson hospital and they hooked

[redacted] up to a big machine. She had to just lie there for a few hours, while they took all these bloods. It was done over the space of three days, because they had to take quite a bit to try and get her platelets for the stem cell transfusion. They basically took her stem cells, filtered them through a machine, cleaned them and put them back into her. When that was done, we were told that there was a 95 per cent chance that it would be successful. They couldn't guarantee 100 per cent because there could have been a stem cell which had still had the neuroblastoma attached to it.

47. We moved forward a wee bit and then we went to stem cell transplant, but I can't remember the date for this. At that point [redacted] needed a high dose chemotherapy, which was the biggest dose she could get, so sort of an adult dose. This broke her blood down so there was nothing left in it, it was so she could get her transplant. When they did do this, [redacted] was severely unwell.

48. Transplant was one of the harshest times, because we weren't allowed to have visitors. The room [redacted] was in was in Ward 2A and it had double doors.

[redacted] had such a high dose of chemotherapy and she ended up really, really unwell. She had ice packs in her nose, she had platelets running, and she had blood pouring out her mouth. It was the worst I had seen her through the whole part of the treatment. [redacted] was discharged at the end of October 2017 as her transplant had been successful.

49. [redacted] then attended ward 2B RHC frequently as a day case attender during November 2017 and we started to talk about the Beatson for radiotherapy. We went there and they put her to sleep to get a mould made for her face so that her brain wouldn’t be affected by the radiation treatment she was going to get.

50. [redacted] developed a fever in November 2017 so we took her to the RHC. It was a line infection that [redacted] had, she was admitted to ward 2A and she was treated with antibiotics. I speak about this later on.

Amenities on ward 2A: March 2017 to January 2018

51. Ward 2A was set up for children with cancer. The parent kitchen was really, really useful because [redacted] was a fussy, fussy eater. I would make sure that my mum, or whoever, brought home cooked dinners, or I'd go and get her tins of macaroni, or wee things from Asda, so that I could heat them up in the microwave. The kitchen didn’t have a cooker but the microwave was really handy and we had our own fridge. Everybody shared the one kitchen, so if the wee one was sleeping or at surgery, you could go to the parents’ room, watch telly, or get something to eat. That was really good.

52. The other facility was that there was a big boat sized bath on the ward. It was at the very start of the corridor before you went through the double doors into where the rooms were. My [redacted] was obsessed with baths and she liked to use that.

53. There was a playroom, which had play leaders. The kids did all different things in there, like painting, games and stuff like that.

54. They also had tellies and computers that some of the kids could have and there were DVDs that you could take into the room. There was also Freeview on the telly with wee games. Obviously, [redacted] was a bit young to play with that sort of thing, but there were a good few things on the ward that the kids could use.

55. I also had the opportunity to speak to other parents in the parent's kitchen. I remember once going into the parent kitchen. I had got myself quite upset the first time [redacted] went for her scans and I remember one man approaching me, he was [redacted], and his [redacted] was in with cancer. He had totally lost his faith by this point and was really upset. He'd had enough by this point. He actually did the Humanist funeral for my daughter, because I did become very close with him and the family.

56. There were two other mums on the ward that I was really, really close with. At night time, if the kids were sleeping, we'd go into the parents' room, and we would sit with hot chocolate and cups of tea. We'd sit there for hours, just talking.

57. When that was taken away from us and when we were put into lockdown or isolation, I was stuck in the four walls. It was physically and mentally draining. I would then have to make video calls, and then have to console [redacted] for an hour, two hours at a time, because she couldn't see her gran, her auntie, her uncles and her cousins. She was really, really quite distraught with it, because her routine was that when she woke in the morning, she saw the doctors, and then her gran would come up. When that was taken away it was really hard on her; her wee routine had gone.

58. [redacted] room had her hospital bed and I had a pull-out bed from within the wall. It folded up and you would pull it down at night. [redacted] and I liked our home comforts, so we had our own quilt and pillows, which I just folded up and put

away, during the day. Other than that, we had the wee small telly and a shower room with a toilet. There was a TV in the room with Freeview channels, a wee seat next to her bed and a few other seats extra if anyone was visiting.

INFECTIONS – MARCH 2017 – JANUARY 2018

59. [redacted] had eight different central lines in ten months. Staff told me she had infections and if antibiotics didn't cure them then the line had to be changed. One of her lines had a hole in it and that's why that one was changed, but the other lines she had changed were all due to infections. They didn't really tell us much, they just said it was an infection and the antibiotics weren't treating it. Sometimes when [redacted] was on antibiotics, there would be two or three different antibiotics but her temperature would still be spiking and she was still really unwell. At the start, staff would sometimes tell me it could be tumour related, but when the tumours were gone, they said it could be the aftermath. The answers that were given were always little answers and what it maybe could be that was causing the infections.

60. On 22 November 2017 we had to take [redacted] to the RHC after she developed a fever. I took her to ward 2B, I had a phoned the ward to say that her temperature had reached 38 degrees. When she was an outpatient and she got a temperature above 38 degrees this is what the staff told us to do. The staff told us to go straight up to ward 2B. The staff told me that [redacted] had a line infection, but they also said she had pneumonia. The high temperature triggered a seizure and we were moved across to ward 2A. [redacted] was admitted as an in-patient.

61. First of all the nurses on ward 2A were trying to deal with the temperature and the seizure. The next minute, the room doors burst open, and I heard the alarms sounding. The nursing staff said that [redacted] room was going to get really

busy with the crash team coming up. They worked on her for 45 minutes, just pushing water into her and things like that. There was a doctor on the ward called Booboo, I don't know his real name, but [redacted] just absolutely adored him and that is what she called him. She'd wake up in the morning, put her lipstick and things on for him, it was just so adorable. After 45 minutes of being in this seizure, they turned round and asked her if Booboo could look at her and

[redacted] said, "Oh I've not got my lipstick on". The whole room burst out laughing at her coming out with this. After this I was again told it was a line infection she had. She didn't have a cough or anything, but they had her on oxygen for a few days after that incident. I have pictures of [redacted] when she was in this position showing all the monitors and tubes attached to her. It was quite bad.

62. I now know from the Case Note Review (CNR) that it was enterobacter cloacae and raoutella plantilcola that [redacted] had, but at the time all I knew then was that she was given antibiotics and that they removed her central line on 29 November 2017. Her antibiotics were stopped on 4 December 2017 and she was discharged home on 6 December 2017. No one told me what infection she had at the time, or how she got it.

63. It was really traumatic for [redacted] to get all these surgeries, and she needed two surgeries for each line removal and replacement. It was really very painful as well. Just a horrific situation. There was one occasion when [redacted] was getting her line put back in and she sat up as nobody was sitting with her. I got called to go down to her. When I went into theatre, there were doctors pressing on [redacted] face. I asked what was going on and they told me that [redacted] had ripped her line out. This angered me as someone should have had been watching her; the line is attached to the main artery in her body which could have caused serious damage. One of the doctors had the cheek to say to me that I'll need to bring her in a Babygro next time. She's three years of age, she doesn't

wear Babygros. Two days later, she went down again and when I came to get her, that same doctor had wrapped her up like a mummy. I was angry and [redacted] was getting more upset and worried that there was more going on as she had all these bandages around her. As she had ripped the line out, the nurses were pressing bandages into her trying to prevent the bleeding. It was quite harsh.

[redacted] relapse and palliative care: November 2017 – January 2018

64. Whilst [redacted] was in hospital to have scans done, on maybe the 25 and 26 November 2017. I was told at that time that her cancer was back and it had reached the brain.

65. I asked them what this meant and Dr Ronghe said he could ask for a trial for her but that he didn't think it would work. I wanted to try anyway so [redacted] started on the Beacon trial, which was two rounds of chemotherapy. After one round she took so unwell. I was told the cancer was spreading. Her bladder had stopped working and she had to be catheterised in theatre on 3 January 2018. But it wasn't just her bladder, the cancer was spreading down her spine and taking over every part of her body.

66. We were back in ward 2A by this time. [redacted] was crying a lot, with pain in her head. Dr Murphy, who was also based on ward 2A, said the best place to go to was neurology. We moved up to ward 3B or 3C in the RHC, I can't remember which. We spoke to the neurology team there and one of the neurologists said that he could put a stent in if that's what I wanted him to do. He said he couldn't say if he could get [redacted] off the operating table and through the operation, and that even if he did she was at a high risk of taking a serious infection like meningitis.

67. I said no to that because I'd been told she had weeks into months to live. We left the hospital on the 5 January 2018 and I took [redacted] home. The hospital staff had sorted us out with palliative care nurses who come into the house and they put pumps into both of [redacted] legs for all her medications to go into her.

68. We were at home when, on 8 January 2018, I said to the outreach nurse that I thought [redacted] had a bit of an infection. She wasn't eating or drinking. The nurse said that it was probably to do with the cancer and there was nothing we could do.

69. A couple of weeks before that I had signed a DNR order, it was called a Management Plan. Dr Murphy did it with me. The Management Plan said that I didn't want [redacted] ventilated, but it did say that she could be administered antibiotics at home. [redacted] wasn't given any antibiotics at home, and the outreach nurses didn't mention this either when I said I thought she had an infection.

[redacted] passed away at home on the[redacted].

70. Looking back I do find it quite upsetting that [redacted] wasn't given antibiotics at that time. We were told when we left the ward that she had weeks or months to live but in the end we only got [redacted]with her. I don't understand why she wasn't given them.

WATER: EVENTS INVOLVING WATER SYSTEMS

71. I didn't really know much about the problems with the water when I was in with

[redacted], but since I've watched the BBC 1 Disclosure programme and spoken to other parents. I now wonder if [redacted] infections were caused by the water. was only ever in the hospital and wasn't anywhere else to catch the infections in her lines. We barely left the hospital for months. [redacted] had a bath in the big bath in ward 2A every single night until we were stopped from using it in December 2017. [redacted] wasn’t really fit enough to get a bath at this point though so I didn’t question it and wasn’t told any more about it.

72. The programme said that they knew about the water two years before the hospital opened and that they kept ignoring it and that if it hadn’t been for the whistle-blower we still wouldn’t know any of this. Hearing all this now, that makes me really angry and hurt.

73. You are still not able to use the water machines in the hospital. When I've had an appointment with my son, we were still not allowed to use the water machines. Three years on, surely they’ve sorted what’s going on? If they had then the water machines would be back working, which none of them are within any ward or any corridor. To me this must mean that there is some sort of infection or something wrong with the water.

PREVENTATIVE MEDICATION

74. Towards the end of [redacted] treatment, she was given preventative antibiotics. She was given posaconazole, septrin and gentamicin. I wasn’t given any information about these whatsoever. The doctors just said it was part of a new regime and that all the kids were getting them.

CLEANLINESS

75. After the rhinovirus outbreak in April 2017 we were always being moved rooms because they were doing deep-cleans. The nurses never told you why or anything, they just moved you.

76. At that time they brought in plastic drawers for the bathroom, and plastic drawers for the room; a wee set in both rooms. We had to put our stuff in there, we weren't allowed anything to be lying about the wards.

77. Towards the end of [redacted] treatment we were getting flung from room to room, while they did deep cleans in ward 2A. The nurses didn't tell us why but we were getting moved from one room to another room, and you were lucky if you stayed in a room for two nights before you were moved. When the rooms were being deep cleaned, there were big covers on all the doors in the rooms that were being cleaned so you couldn't see what was going on. I was walking past the rooms, sometimes with [redacted] in her pram and you do start to question, what is going on in there?

78. In the November and December 2017, it was industrial cleans they were doing. The ward was stinking of chemicals. They also started bringing in the cleaners twice a day at that time, whereas before it had only been once.

OVERALL IMPACT ON THE FAMILY

Overall impact on the witness

79. I watched the BBC Disclosures programme. I knew a few of the parents and it started with the kids from our ward and one of the children who had died. The hurt was there and the anger was coming. The more I was finding out, I was getting angrier and I was crying but it was sheer tears of anger. From the programme I was finding out about the water tanks; how long the water issues

had been going on for. Basically, if it wasn't for the whistle-blower who, basically put their neck on the line, we wouldn't have known any of this. The programme said that the hospital had been advised to change the taps on the ward in 2016, when all these babies were dying in Belfast, and they chose not to. I never knew anything about this, until it came on the telly.

80. The programme spoke to Jeane Freeman, and they asked if she thought they were cutting corners to save money, she said, "Oh no, I don't think that's what would have been done." I just wanted to jump through my telly and punch her in the face; she just looked as though she didn't have any care in the world, and look at what had happened. It looked like she didn't have any concern at all, for the parents that are sitting watching that, knowing their children went through it. It was really hurtful, and hard to watch.

81. Our children were put on antibiotics that weren't part of their treatment regime, so they could protect themselves. I found this out after [redacted] passed. The TV programme indicates that people knew about the water infections for two years before the hospital opened.

82. When [redacted] died I was told it was the cancer that killed her, but now after receiving the Case Note Review Report and watching the BBC Disclosures programme, I feel angry and hurt. I need answers. I have a lot of questions now.

83. After finding out all of this, there's just so many questions that hang over my head, and every day I wake up with a new one. I start to make myself physically ill with it all.

COMMUNICATION

84. [redacted] was included in the Independent Case Note Review and I was told this after she died. If you're in the ward, you're getting information. For the parents who are not at the hospital, if your child is involved with an incident at the hospital, even if it's ten years down the line, I feel that there should have been communication with me from the hospital. I had no communication with the hospital whatsoever. The hospital should have communicated with me about [redacted] infection.

85. It was the Scottish Government who contacted me and even after I got the letter from them, the hospital still didn't communicate with me. I had no communication from the hospital. When I received the letter from the Case Note Review, it told me that if I wanted to question anything, I could contact them and I could have a meeting with the consultant or with them. I didn't see the point in a meeting; they weren't going to give me the answers I wanted. They asked if I wanted my consultant to have a copy of the letter but I think he already had it.

86. The Health Board's lack of candour could have hindered my right to pursue a civil claim on behalf of [redacted]. Prior to receiving the letter from the Scottish Government, I was unaware that the Hospital environment may have contributed to my daughter's death. I am now being advised of my rights on behalf of my daughter by my solicitors. I wish the Inquiry to be aware, that it was only through my own investigations and contacting a solicitor did I obtain the information I should have been given in 2018.

OVERSIGHT BOARD / CASE NOTE REVIEW / REPRESENTATIVE GROUPS/HEALTH BOARD

87. I didn't know about the Case Note Review (CNR) until I received a letter from the Scottish Government on 20 February 2020 telling me that [redacted] was going to be part of it. I just fell onto my seat and thought. "My daughter has been dead for two and a half years, how can you now hit me with this bit of paper saying that my daughter was one of the ones involved?"

88. After I received the notification that [redacted] was included CNR in February 2020, it completely shattered me; it absolutely shattered my life. It felt as though my daughter's life was worth nothing, for them to write that to me, it really, really angered me and upset me. I was already in a bad place at that point in time, so I really couldn't do anything about it. I had to get myself mentally and physically better for my children and that's why I only went to the lawyer this year, when I felt I could.

89. It was totally shocking and horrifying to read that your daughter's case notes were being reviewed after all that time. For them to send a letter saying

[redacted] was a major case but that they're taking no blame once again. How can you take no blame when it's there in black and white? It was so hurtful. It came across as if they were saying, your child is dead, what do you want us to do? That's how it came across to a parent.

90. I haven't been through all the main CNR report. Unless you are a doctor or a specialist, you're not going to understand it. We don't know what we're looking for or what we're not looking for. There's a lot of pages with percentages and names on them so a lot of that, I didn't understand.

91. In April 2021 I received [redacted] individual report from the CNR. I found out that in November 2017 [redacted] had enterobacter cloacae and raoutella plantilcola.

92. When I read the report it said, [redacted] had this infection, she had that infection. The report said it could've been a contaminated line, but the review can't say for definite that was what happened. At the bottom of the report they say how severe the infection that [redacted] had was. That was quite hard to read because the report said it was a really serious infection; it was a major one. The hospital did take it seriously at the time, because they ended up having the crash team called to help her. The report conclude that they didn't really think that the hospital had anything to do with it. At the end of the day, I think there is a lot more information that shows otherwise. At first we didn't know anything about the issues with the hospital, and then this documentary came out and it gave everybody a new insight. The information in the documentary was provided by people that worked there; it's been specialists, the water level was never right from day dot.

93. It was just so hurtful, it's like the hospital didn't care about my child. That's how it came across to me and the more I watched the TV programme, the more I thought the infection was more dangerous than cancer itself. It made me think that if [redacted] did have that infection in her line, is that what killed her quicker? It made me wonder if the infection in her line was fighting off the chemo and preventing it from working and maybe that's why she relapsed. I remember getting so upset that day, I phoned the Legal Aspects team at the hospital and I demanded her medical notes. The woman I spoke to said I was not the first to be on the phone today.

94. Once I felt better I ordered [redacted] medical notes and I went to see Stephanie Young at Thompsons. I was angry that the DNR order I had signed said that I didn't want her to be resuscitated but that antibiotics could be given. I was

angry that the outreach nurse who was there when [redacted] was in palliative care at home, hadn’t offered them at all.

95. I wasn’t in the right place emotionally at the time when [redacted] was dying to remember that I had said she could get antibiotics but surely the medical team in charge of her care should have known this? I remember them saying they weren’t going to take any bloods but I knew that. My daughter was lying there, severely unwell so I’m not going to think “Wait a minute, you can give her antibiotics”. I didn’t know any of this until I went to look at the DNR order I feel let down in this aspect as well.

96. [redacted] DNR order is also not in her medical notes, amongst a lot of other information that’s missing too. I had lots of conversations with doctors and consultants so there should be plenty of notes in her medical notes but they’re not there. The copy I have given you is my copy, the hospital copy is not in her notes.

97. I am still a member of various groups on Facebook groups run by the parents and I hear a lot of information from there and through that I hear from parents that are still on the ward.

CONCLUDING COMMENTS

98. The staff and doctors were amazing, I can't fault them in any way. The only thing is that maybe they knew what was going on with the building and didn’t tell us. Whether that was to prevent upset on the ward, or to prevent something else, I don't know; there must’ve been a reason. But I can't fault the staff in any way, they were amazing with [redacted]: from the play team, right up

to her consultants, and her nurses, they were all absolutely fantastic with her. I can't fault any of them whatsoever.

99. I just feel there is blame there and someone needs to accept that the blame is on them. The CNR letter I got didn’t even have a thousand words on it and I just feel my daughter’s ten months in hospital is worth more than what this was saying to me. It’s disgusting, it’s just so bad.

100. Shortly after [redacted] passed away, wards 2A and 2B were shut down and moved to ward 6A QEUH and ward 4C QEUH for transplant. I’ve got two other kids so I’m in and out of the hospital and I’ve seen that the ward is still lying ripped apart. There’re still bits of the roof hanging down and bits of the wall are off. Why is it still shut after three years? I think there’s something more to it that they aren’t telling us and it’s answers we deserve.

101. I just feel as though I've been let down in every way. If I take the boys in to the hospital now I start getting anxiety and I start really being unsteady about going in. I just feel as though I can't trust the hospital. Why did we not know about any of this, why was I not told [redacted] had this infection, because clearly they knew. They knew [redacted] had this.

102. I will now question everything. If I take my son up to the hospital when he’s not well, I'm going to keep questioning the staff; I'm not going to let anything lie unturned and I’m not going to let them push me away. Right now, I just feel totally and utterly disgusted. I feel so let down by the NHS and also the trust with them has completely gone.

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

APPENDIX 1 – TIMELINE (LC/01)

- Early March 2017: [redacted] had a number of admissions to RHC where Louise was told [redacted] had some sort of viral infection and was then discharged.
- 12th March 2017: [redacted] was admitted to RHC for a couple of days for the same issue (viral infection) and was discharged. Louise was told [redacted] haemoglobin level was low, which is what happens with a viral infection.
- 16th March 2017: [redacted] is admitted to ward 2C of RHC after being examined in the CDU (clinical decisions unit).
- 17th March 2017: around one or two in the morning, [redacted] was taken for an X-ray and CT scan as they'd found something in her blood. The scans revealed that [redacted] liver looked enlarged, and that she had few pockets of blood on her brain. Later that morning [redacted] was taken for an ultrasound and two masses in [redacted] stomach were found. [redacted] platelets and haemoglobin levels were also seen to be extremely low. [redacted] is moved to ward 2A following the discovery of the two masses in her stomach.
- 18th March 2017: [redacted] condition deteriorates, and she is given a platelet transfusion, a blood transfusion and is placed on a morphine pump for the pain.
- 20th March 2017: [redacted] is given a DMSA scan, an MRI scan and has a bone marrow aspiration done at the request of her consultant Dr Ronghe. [redacted] also had a biopsy taken of her tumour that day so that it could be sent for analysis at Great Ormond Street Hospital. 4-6 weeks later the results of the biopsy showed that [redacted] had very rare N-MYC gene tumour.

- Sometime during the first week of her admission, [redacted] has surgery to put a central line in.

- 23rd March 2017: [redacted] is given an initial diagnosis of stage four high-risk neuroblastoma cancer by Dr Ronghe and begins the first of seven rounds of rapid COJEC chemotherapy at the advice of Dr Ronghe.

- 26th March 2017: around the 26th March [redacted] had her first central line infection. [redacted] had a high temperature and wasn't eating or drinking. Staff did not say what the infection was but said it could be chemo related or could be coming from the tumours. [redacted] was given antibiotics, but these did not work.

  [redacted] was then taken to surgery to have her central line removed.

- 27th March 2017: sometime in the week beginning 27th March, [redacted] official diagnosis of high-risk stage 4 neuroblastoma cancer is confirmed.

- 28th March 2017: [redacted] has her second central line fitted.

- April 2017: sometime in April 2017, ward 2A is shut down due to a rhinovirus outbreak. Louise and [redacted] are confined to her room, were not allowed visitors and not allowed to use the parents' kitchen. Immediately after the lockdown, infection control and health and safety staff asked that all personal possessions be removed from [redacted] room. Shortly after the lockdown, Louise and [redacted] began being moved to different rooms around ward 2A. Nurses often said that this was so people could be closer to something or because some rooms needed to be deep cleaned.

- August/September 2017: around August or September [redacted] completed her seven rounds of rapid COJEC chemotherapy. Scans showed that her tumours still had some way to go before she could be operated on. [redacted] then began two rounds of TDD high dose chemotherapy.

- 24th September 2017: [redacted] had surgery in ward 3C of RHC to remove her tumour, 95% of the tumour was removed. [redacted] was moved to PICU after the surgery.
- Shortly after the surgery, [redacted] went through a stem cell collection in preparation for a stem cell transplant.
- Sometime after the stem cell collection, [redacted] had a high dose of chemotherapy and then received her stem cell transplant shortly after that.
- October 2017: at the end of October, [redacted] was discharged after her stem cell transplant was found to be successful.
- November 2017: [redacted] attended ward 2B RHC frequently as a day case during November and discussions were had about [redacted] having radiotherapy at the Beatson Centre.
- November 2017: sometime later in November, [redacted] developed a fever and was admitted to ward 2A RHC. [redacted] was found to have a line infection and was treated with antibiotics.
- 22nd November 2017: [redacted] is admitted to ward 2B RHC with a line infection and pneumonia. Her high temperature triggered a seizure and [redacted] was moved to ward 2A where she was admitted as an in-patient. A crash team was sent to ward 2A to deal with [redacted] temperature and seizure. [redacted] was put on oxygen for a few days after the seizure and treated with antibiotics.
- 22nd November 2017 – [redacted] is diagnosed with Enterobacter Coloacae and raoutella plantilcola. Infection was identified in the case note review and Louise was not told at the time.

- 25th/26th November 2017: around the 25th or 26th November, [redacted] had a number of scans that showed her cancer had returned and it had reached her brain. Dr Ronghe suggested a trial treatment called the Beacon trial which involved two rounds of chemotherapy.

- After the first round of chemotherapy on the trial, Louise was told that the cancer was spreading down [redacted] spine to the rest of her body. [redacted] was then moved to neurology in either ward 3B or 3C RHC.

- One of the neurologist suggested an operation to put a stent in, but couldn't guarantee that [redacted] would survive the operation or go through it without another serious infection such as meningitis. Louise refused this operation.

- 29th November 2017: [redacted] central line is removed.

- 4th December 2017: Antibiotics are stopped.

- 6th December 2017: [redacted] is discharged.

- 1st January 2018: around the first of January, [redacted] had become unwell and was complaining of a sore stomach. She was admitted into to the RHC, though Louise could recall which ward. Initially the doctors thought it could be an issue with her gut and so she received antibiotics. When these failed to have effect, further investigations found that her bladder was no longer functioning.

- 3rd January 2018: [redacted] is taken to theatre to have a catheter fitted.

- 5th January 2018: [redacted] is discharged and taken home.

- 1st – [redacted] : [redacted] is in palliative care.

- 8th January 2018: During her time in palliative care [redacted] developed symptoms of having a line infection. As Louise was so familiar with line infections at this point, she immediately picked up on the signs that something was wrong. She asked the nurses to test [redacted] for a line infection and was told that they did not test children in palliative care for infections, they could only make her comfortable. Therefore, Louise is unable to establish the name of the infection. Later on, when reviewing [redacted] management plan she noticed that it said that [redacted] was to receive antibiotics if she spiked a temperature. Upon reviewing the medical records, we have been unable to establish a clear timeline of events that occurred in [redacted] final days due to only partial records being provided to Louise.
- [redacted] – [redacted] passes away at home.

Scottish Hospitals Inquiry

Witness Statement of

Samantha Ferrier

WITNESS DETAILS

1. My name is Samantha Ferrier. I was born on [redacted]. I am [redacted] years old. I am a student psychiatric nurse.

2. I am the mother of [redacted] [redacted] was born on [redacted] and she died on [redacted], when she was less than 12 months old.

3. I live with my partner, [redacted], and my other daughter, [redacted], in [redacted], [redacted].

OVERVIEW

4. My daughter is [redacted] [redacted] was born with congenital abnormalities, mainly arthrogryposis, which is joint contractures, and respiratory complications from an undiagnosed genetic mutation. She was born in the Queen Elizabeth University Hospital ("QEUH") maternity unit and was then in the Royal Hospital for Children (RHC) being treated for all of her short life.

5. During our time at the QEUH and the RHC, there were a number of issues about the hospital that concerned us while we were there, and I can speak to my experience of these issues.

FAMILY BACKGROUND

6. I live with my partner [redacted] and my daughter [redacted] in Glasgow. [redacted] is [redacted] years old and we really wanted to give her a wee sister.

7. [redacted] was a very much wanted second child. We planned to have a second child for [redacted] and would have loved to bring [redacted] home. As a family we wanted her very, very much. And we loved her, regardless of her disabilities. She was a very curious little thing. She loved to listen to different noises and different sounds. She loved her music. And she knew that we were there because she would reach out and try and grab me with her tiny hand. So she was a thinking, feeling wee child.

8. [redacted] had a wee sense of humour as well. She would bite on the catheter in her mouth and it was as if she was playing tug of war with the catheter. She knew that she was hanging on to it with her teeth. She would look at you as if to say, “And what are you going to do about it, mum?”

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

9. [redacted] was born on [redacted] in the hospital’s maternity unit. It is a separate building and is connected to the main building through a tunnel.

10. [redacted] had breathing problems, among her other medical challenges, which meant her staying in the maternity unit for several months. They tried all different types of procedures to help her breathe but it wasn’t happening for [redacted]. Therefore, the last resort was to give her a tracheostomy which happened around about three months of age.

11. The tracheostomy was carried out on the [redacted], in the maternity unit. After that, they were monitoring [redacted] condition and doing all sorts of tests and things.

12. [redacted] next surgery was a gastrostomy on [redacted]. A gastrostomy is where the food gets put directly into the tummy via a tube. [redacted] had quite a narrow - they called it a floppy - airway and she couldn't really swallow properly so you could never give her a bottle or anything. She also had a cataract removed at this time, to help her sight. Again, these were done in the maternity unit.

13. At some point when we were in the maternity unit, maybe around

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

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

Experience in ward 3A

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

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

16. If you had gone into Ward 3A through the main doors, [redacted] was about 15 metres in, which might encompass passing about four or five rooms on the left hand side and then the nurses’ station. Then she was a further four rooms after that on the left. Apart from the single rooms, the ward had only had one bed bay, which consisted of four patient beds, but [redacted] was really only in there at the beginning, and then she was always put into one of the single rooms, especially once the infections began. So that meant that she was more or less alone. All of this made us anxious because we had concerns about [redacted] safety.

17. [redacted] was in several different single rooms. They were all pretty much the same, so it’s hard to remember the numbers, but I think she might have been in rooms 11 or 21 at some point. When she first showed signs of an infection, she went into the room that was opposite the one with a hepa filter in it. I believe that The hepa filter room was a specialised air conditioned/air purifying room.

18. We were never really told why [redacted] was moving rooms. I assumed it was maybe to allow them to go in and do a deep clean. Rooms were cleaned daily, wiping of sinks and floors etc, however, some patients were sensitive to cleaning fluids and easily disrupted, so deep cleaning of rooms was a bit more awkward. A lot of patients had several pieces of medical equipment and these took up a lot of space. Deep cleaning would have only have been possible if this equipment was removed.

19. We did discuss these concerns but were told by the nurses that it was important for [redacted] to be isolated because of infection control.

20. From when we arrived in ward 3A in [redacted], we were told not to use the taps, other than those in the ward kitchens. Each patient bedroom had a small sink that was next to the patient's bed and we were told not to drink from those at all. There was a main kitchen on the ward and we were told if we wanted a drink of water we were to go into the main kitchen to get it. I think the advice also applied to the four bed bay as well because there was a kind of communal sink and you were requested only to wash your hands at it. I don't recall being offered bottled water in 3A, though we did have this previously sometimes in the maternity unit.

21. We didn't really stay over in the hospital at that time because we needed to look after [redacted].

22. Though the rooms had TVs in them, it was common knowledge that the TVs would never work. Some of the nurses would say that when the hospital first opened, the TVs worked for about six months and then they all stopped working. We never saw anyone trying to fix them during our time there.

23. Not having TVs that worked did have an impact on us because we had the toddler, [redacted], at the time. So if the TVs had been working, it would have meant we could have probably put a wee cartoon or something on to entertain [redacted] while we administered to [redacted]. There was nothing to keep her entertained.

24. There was nothing else apart from a little playroom that the ward had at the very end of the ward but it meant that one of us had to leave [redacted] room to actually take [redacted] down there. That meant that the attention that [redacted] was having was halved and the parent that was left in [redacted] room would have to administer all those medical cares themselves while the other parent took

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

25. The urn in the staff kitchen was out of order so that presented a problem because you had to then leave ward 3A to go away down another corridor to get a cup of tea to bring it back and then stand outside the door waiting for somebody to let you in the door. So it all compounded itself. If something was out of order, it just exacerbated the whole thing and made it more frustrating.

26. Ward 3A always seemed to have major works being carried out. Some patients' bedrooms were completely closed off for deep cleaning and maintenance works. In fairness to the contractors, they tried to keep the noise and mess to a minimum. There were about two bedrooms going on at the one time. Ward 3A always appeared to be in demand for bed spaces and these works would only have added to the pressure.

27. There were big orange, zipped plastic bags over the doors and I presume this was to stop any dust and noise from escaping into the main ward. You could see through the glass panel into these rooms and there were machines going on inside. I don't know what the machines did, they were some sort of generator and I can only presume that they were maybe decontaminating or something. Sometimes workmen weren't present at all inside the rooms but these machines would be on all the time as if they were doing something to the rooms in the background. So I'm not too sure what was going on inside those rooms. We never asked and we never got told what was going on.

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

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

29. We were told Robin House was fun for the family, with lots and lots of staff to care for [redacted] which meant that we could, as a family, enjoy the garden and the wee play areas without having to worry too much about medical procedures. So it was kind of sold as a wee light-hearted, fun-filled family time together. It was also trying to give the parents a break. If staff there felt the parents were getting kind of exhausted, they were there to help.

30. Robin House was absolutely fantastic. The noticeable thing for me was I felt little [redacted] knew that she was out the hospital and she was enjoying all this attention that she was getting. They were coming over with musical instruments and giving her art therapy. I could really see her happy for the very, very first time. She was coming out her shell.

31. It was kind of a Friday to Sunday thing because on the Monday, [redacted] was then scheduled back at ward 3A to go through with her orthopaedic surgeries, so they wanted her back. So they cut her wee holiday short because of this big, major operation that was getting carried out on the Monday.

32. On [redacted] [redacted] got her orthopaedic surgery on her knees and ankles. This was pre-planned and they were waiting until she was slightly older, which was around nine months, before they carried out this procedure. She had a wee leg that didn't bend and she had ankles that didn't move, so they

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

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

Plans for discharge from QEUH

34. On [redacted] [redacted] became eligible for the discharge home and phased discharge plans were drawn up. The doctor said that for her bone progress and development [redacted] would be much better off in a home environment. They believed that they couldn't do any more medically to improve her situation; it was just a case of taking her home and us administering medical cares to her to give her some quality of life.

35. I have a copy of the discharge plan and can provide it if required. So it would be something like Monday – put [redacted] in her pram, take her outwith the hospital grounds for an hour and then bring her back. And then Tuesday would look like – take her out for two hours and then bring her back. So when you got to the end of the week there was a gradual exposure to more and more responsibility for [redacted]. There was no definite timeline. They said they would be guided by us and how well we could adhere to the phased discharge plans and how well we felt.

36. When they were talking about the discharge plans, it was relayed to us that we would have to just take [redacted] home and everything would be ok. You would have to sleep beside her and if she choked you would automatically wake up. There was to be no medical machinery provided and we wouldn't get a bleeper or anything like that. Realising that a baby relies on somebody not risking going into a deep sleep, we started to voice our concerns with the staff. We felt we were being pushed out before we felt

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

37. The Ear, Nose and Throat (ENT) team and Dr Louisa Pollock, the Paediatric Consultant, would argue with us that as parents we would just wake up whenever we heard [redacted] in distress, and I would explain that I was also on sleeping tablets, and I still am, therefore, there is a tendency to go into a deep sleep. Could they guarantee me actually waking up? So [redacted] and I thought that bringing [redacted] home would be more risky from her point of view because we felt that we didn't have that backing to be able to look after her and keep her safe. The medical staff would argue with us all the time and would say, "Och, it's nonsense, you're lacking in confidence – plenty other families have done it, why can't you do it?" They'd be really, really rude and putting us down like that and that was hurtful. We had a meeting with the social services and the woman was quite upbeat and optimistic about the amount of help that would be forthcoming. I don't know whether she was quite new in her post, but then one of the girls or nurses in the hospital said "You're not going to get half of what she's telling you, you'll be lucky if you get one night a week. The problem with that is they're relying on carers but if the carer doesn't turn up, you have a problem because it's your responsibility."

38. As it happened, [redacted] was never able to leave the hospital. On [redacted], we were there and the nurse told me that [redacted] had been unwell for most of the day with vomiting and diarrhoea. The nurse mentioned tachycardia, which is rapid heartbeat. [redacted] had presented most of the day with a rapid heartbeat, so her heartbeat had been accelerated by something that they weren't sure of. They suggested maybe teething. The nurse administered paracetamol and ibuprofen to relieve [redacted] symptoms. [redacted] and I said goodnight to [redacted] and left the hospital at 10:30 pm to go home.

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

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

40. The Doctor, Alastair Turner, took us in to a side room and expressed that there was major concern that [redacted] was deteriorating and not doing well. He said he couldn't quite explain the reasons why but he mentioned her kidneys.

41. All of a sudden, soon after we got there, [redacted] monitor just went to dead. The doctor started administering CPR. It was stressful watching[redacted] getting compressed but I appreciate he was doing his best. But eventually one of the nurses came and said, maybe it might be better not to see what was happening and to allow the staff to get on with their jobs. Then it was all hands on deck. I mean, there were lots of staff in the room at the time. There must have been about eight or ten people all around doing their different procedures. So we were then taken away to a side room.

42. We were then alerted that [redacted] was vomiting as well. I think it was just all the stress as she'd been woken quickly and taken over to the hospital. So we were trying to cope with that too. However, they stabilised [redacted]. But they then came and told us that they thought there was possible brain damage because of the seizures and that it would most probably be best to terminate her life support. So it was agreed with me that I would sit with her in a chair and hold her and they would then switch off the life support machine. And that's how [redacted] passed away.

43. My daughter [redacted] was also hospitalised in Ward 3A for a few days in [redacted] after being diagnosed with Respiratory Syncytial Virus (RSV).

Building issues in ward 3A

44. In addition to the water problems, on [redacted], the door entry system to ward 3A became out of order. Other than a few hiccups before then it had been fine but then they just didn't seem able to fix it. It remained broken until we no longer needed to go to the hospital after [redacted] died in the [redacted].

45. To gain access, a telephone number was provided, but, it usually rang out. I have provided a picture of the notice on the door to ring the number **[Picture SF/01 – at Appendix 1]**. We could wait in excess 30 mins to gain entry to ward 3A, unless we were lucky enough that a member of staff was going in or out of the ward.

46. You could have made your presence an awful lot more vocal to gain access, but you're not wanting to be thought of as standing and banging on the door or kicking on the door or things like that. You did realise that if you called the phone number you could be taking a nurse away from maybe doing a medical procedure. If somebody was, say, maybe doing a medical procedure on [redacted] you would have hated to think that they would have to stop doing that just to simply go and open a door, and you just felt that was impacting on the staff. The nurses were quite rushed off their feet as it was and you just felt you were imposing on their valuable time banging on the door. So you tried to ring the bell a few times but you would ring it and then wait for maybe, three or four minutes and you'd maybe ring it again, you know, three or four minutes later. Or you might land lucky and find somebody who had permission and a pass. By that time we knew most of the staff and a lot of the time they knew we were entitled to go in. On

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

47. We spoke to the staff several times about this and they just kept saying there was nothing they could do, that there were complaints that had been put forward to the contractor and it was outwith their control type thing. They said they'd reported it. I think they must have been embarrassed at the amount of people that were complaining at the time, you know, standing outside. There were other parents waiting with you to try and get into the ward. We would all stand out there like a bunch of pigeons waiting to get in and we would all be saying how ridiculous this was that they had to put us through this type of thing.

48. There were always barriers up outside the hospital due to scaffolding above because of loose cladding in the main external structure. Some entrances were periodically blocked off which meant you had to take alternative corridors or routes to get to 3A.

49. The main adult hospital is connected to the children's hospital via link corridors; they've all got these link corridors, so there's all different entrances all around the actual site. So it means if one's blocked off that day with the men up the scaffolding and the cherry-pickers, whatever you want to call them, you would have to take a detour and go through a different entrance. You would then need to find the link corridor to take you down to the children's hospital and then find your way from there up.

50. We kind of accepted that with a building of that size you're always going to have constant maintenance and stuff but I'd have said this was maybe more

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

51. Sometimes a lot of the problems were compounded because of a lack of parking. Sometimes you could park fairly near to the children's hospital but other times you had to park away at the far end, which was quite a distance away. Then you would have to go in to maybe one of the side entrances to the main hospital and then you would work your way through to the right area, which wasn't always easy.

52. When [redacted] was in Ward 3A in [redacted], at the same time as [redacted], because she had an infection, my partner [redacted] opened the blinds of the hepa-filter bedroom she was in. I think this room had a different air filtration system but I'm not sure. Through the window there is a ledge overlooking the children's atrium. This ledge was covered in grey clumps of tumbleweed, like balls of fluff you'd get if emptying a hoover, visible from the hepa-filter room. We didn't speak to the staff about this but it seemed that the nurse kept closing these blinds as if to conceal the dirt.

53. On a separate occasion after [redacted] died, we had to go to A&E at the QEUH on [redacted], when [redacted] had jammed her finger. We were sitting in a clinical bed bay area of A&E when grey fluff was blown out of the overhead ventilation and the aircon. It was like clumps of dust particles and more dust clumps were witnessed by another family there. This was similar to the kind of stuff that [redacted] saw on the ledge outside the hepa-filter room in 3A.

54. I thought it was a feather at first when it came down and then [redacted] said, no that's not a feather, that's a big clump of dust. It looked as if it landed on my shoulder but it was actually just caught in my peripheral vision. We were

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

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

INFECTIONS AFFECTING FAMILY IN RHC

56. On [redacted] [redacted], [redacted] first presented with Rhinovirus, which showed as flu-like symptoms. She had a runny nose and she was dribbling more from her mouth. Her oxygen would de-saturate quite often, therefore, the medical team knew that she was struggling with something, there was something underlying going on. I think they conducted blood tests at the time and I think it came back as Rhinovirus and we were told at that time that Rhinovirus was very common around the winter months and it was almost expected in a wee tracheostomy baby. So they kind of played it down, "Och, she'll get over it, she'll be fine, a couple of weeks and she'll be fine", that kind of thing.

57. It was the children's coordinator, Jacqueline Riley, who told us this. She would often come in and visit us a couple of times a week to let us know how [redacted] was getting on and she would tell us a wee bit about the Rhinovirus and the background to it and that kind of thing. I'm not exactly

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

58. I can’t recall what treatment [redacted] was given for this virus, or whether it involved any antibiotics being given.

59. Around [redacted] [redacted] contracted her second virus, this time the Enterovirus, in ward 3A. This wasn’t long after the Rhinovirus; it was put to us that it was just a routine little virus that is normal and quite accepted for babies at this time of the year to contract it. I can’t remember if they gave her any antibiotics at that time or whether it was just a case of keeping her comfortable, keeping her safe and letting her own body repair itself. But she did require a wee bit of oxygen support – that was quite apparent, and it kind of coincided with this Enterovirus. But they could never wean her back off this oxygen; she kind of needed it and demanded it, so we got the impression that she never, ever regained her full strength from this Enterovirus, that kind of knocked her immune system a bit.

60. We weren’t sure whether the Rhinovirus had cleared by this point or whether [redacted] had two infections. There was very little discussed with us.

61. So [redacted] was on oxygen support, yet they were still saying she remained eligible for discharge home. They were talking about releasing her home despite her having at least one, and possibly two viruses at this stage. We argued with them and we asked if the fact that [redacted] was now on oxygen would make her more eligible for additional social support at home. The

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

62. From around [redacted], [redacted], [redacted] and I all started to become unwell. I think I was the first one to start off a wee cough. Then it wasn't long after that until

[redacted] became unwell and [redacted] became unwell. We didn't all become unwell on the [redacted]. It was maybe staggered over days after that.

63. I went to my GP and was diagnosed with Haemophilus influenza. The GP couldn't say how I acquired that. However, I do remember having three courses of antibiotics, so it was quite resistant to treatment. It was quite bad whatever it was I had.

64. [redacted] was actually diagnosed with respiratory syncytial virus, RSV. Because she was weaker, it had a far, far greater effect on her. In early [redacted], she was actually hospitalised as a result of this as well and ended up in ward 3A for a few days herself. So you had both your girls in 3A at that point. They were in different rooms, both single rooms. [redacted] was nearer the entrance and [redacted] was much further in, deeper down the corridor. Nurses said "It is strange to have two sisters in at the same time. We'll try and accommodate you as a family, so we'll try and make sure that [redacted] gets admitted to 3A to reduce the inconvenience to the family." That was good of them to do that, to put the two girls in the one ward. And it meant we could leave and one perhaps go and visit the other one, type thing. [redacted] was in there for five days before being released.

65. I can't recall [redacted] room number but like the others, the TV didn't work. She made do with a tablet and we'd bought a DVD player and a CD player to keep her amused.

66. We weren't told a thing about the infections. We normally keep very well as a family. Both [redacted] and I keep very well and so does [redacted]. So it was very unusual at that precise time for all three of us to come down with something so debilitating.

67. Ironically, in her final pathology report, the pathologist mentioned that was more susceptible to these infections because of her long hospital stay. So we actually had it in writing by the pathologist that the reason [redacted] picked up these infections was the fact that she was in hospital for such a long, long time. So there's a correlation there. There's a relationship there. I think that's partly why they seemed so keen to get [redacted] out of the hospital, even when we didn't feel able to take on her care.

68. Given that [redacted] was hardly ever out of hospital, other than the few days in Robin House, it can only have been in hospital where she picked up these infections.

Overall views about the hospital building

69. I think patient safety should be the top priority. I believe that there were some things in the design of that building that maybe compromised patient safety, especially in our situation with a wee child that couldn't press buzzers or cry for help or move. [redacted] couldn't move properly like any other baby. So the overall design impeded her welfare and issues like the nurses not having direct line of sight to her when she couldn't cry for help made me worried and anxious about her safety.

70. The issue for me was the shape of the 3A corridors. It was all in crescent shapes, circular shapes. That didn't lend itself to good staff observations. I

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

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

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

OVERALL EMOTIONAL IMPACT ON FAMILY

72. As you can imagine, losing our daughter before her first birthday had a huge impact on me and on [redacted]. We still don't know why she died or from what, despite there even being two post mortems.

73. On the morning [redacted] died on [redacted], Dr Alastair Turner was perplexed as to why her demise was so rapid and sudden, even though it was that Doctor who advocated the termination of [redacted] life support machine. I understood that it was his duty was to report [redacted] death to the Procurator Fiscal for investigation. [redacted] post mortem examination was conducted by

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

74. We are wanting answers from the medical staff to try and explain their side of the story.

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

COMMUNICATION: GENERAL

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

[redacted]and treated us.

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

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

COMPLAINTS

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

OVERSIGHT BOARD / CASE NOTE REVIEW / REPRESENTATIVE GROUPS

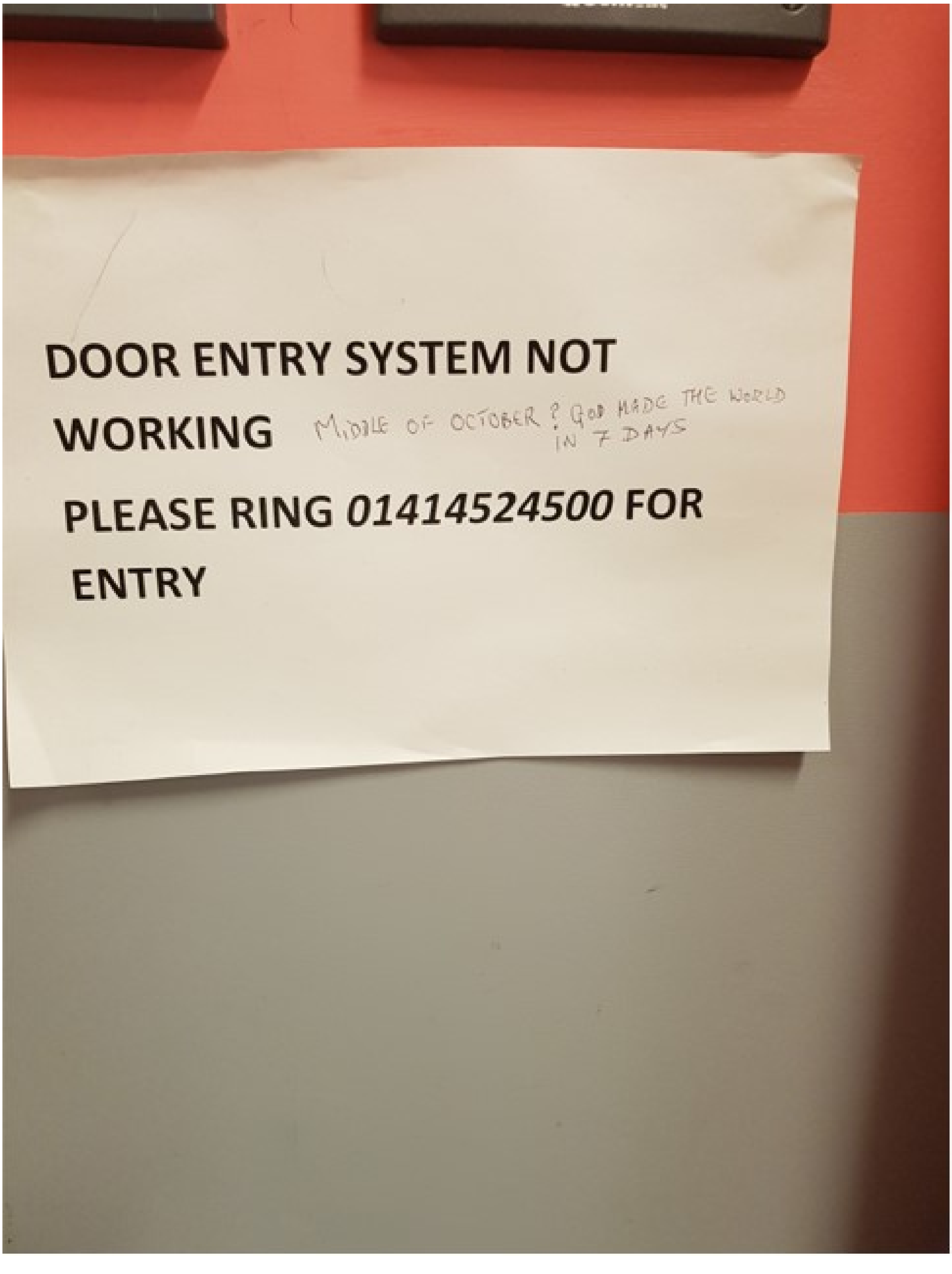
79. We had heard of the Oversight Board and the Case Note Review but we were not involved with either of them. We heard mixed stories about the parents' Facebook page but we haven't been involved with that either. We were told that there was a Tracheostomy Group on Facebook but the ENT at the hospital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

CONCLUDING COMMENTS

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

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

SF/01 – Appendix 1



DOOR ENTRY SYSTEM NOT WORKING

MIDDLE OF OCTOBER ? GOD MADE THE WORLD IN 7 DAYS

PLEASE RING *01414524500* FOR ENTRY

SCOTTISH HOSPITALS INQUIRY

SCOTTISH HOSPITALS INQUIRY

Hearing Commencing

20 September 2021

Bundle 6 – Witness Statements for Week commencing 25 October