Scottish Hospitals Inquiry

Witness Statement of

Colette Gough

WITNESS DETAILS

1. My name is Colette Gough. I was born on[redacted] . I am [redacted]years old.

2. I am the mother of [redacted]. [redacted]'s date of birth is [redacted] . He is 10 years old.

3. I live with my husband, Cameron Gough, and our three children, [redacted], [redacted]and [redacted], in [redacted].

4. I am a [redacted].

OVERVIEW

5. My son is [redacted] [redacted]. [redacted] was diagnosed with a Wilms tumour in his kidney on 30 July 2018 when he was 7 years old. [redacted] was treated in the Royal Hospital for Children ("RHC") and Queen Elizabeth University Hospital ("QEUH") in Glasgow between July 2018 and May 2019 when he finished his treatment. He attended both hospitals as an inpatient and as an outpatient regularly over that year. He still attends at the RHC for six monthly check-ups. I have provided the Inquiry with a timeline which I prepared along with my husband, Cameron Gough. This timeline shows the dates on which [redacted] attended hospital and the wards where he was treated. The timeline is attached to this statement **(CG/01 – Appendix 1)** and I confirm that it is accurate to the best of my recollection.

6. [redacted] spent time in wards 2A and 2B of the RHC which is also known as the Schiehallion Unit. He also spent time on 3B, 2E, 1A, 3C, Paediatric Intensive Care Unit (PICU) and Clinical Decisions Unit (CDU) in the RHC and also in ward 6A in the QEUH. Myself and my husband shared the care of [redacted] during all of his

admissions as an inpatient and as an outpatient. I can speak to the experience and I had on these wards.

7. There are some specific events I would like to mention. [redacted] contracted a serratia marcesens infection, which was a Healthcare Acquired Infection most probably contracted in the RHC. Throughout his treatment there were issues with the water supply, ongoing construction works and issues with fungus which impacted on his experience with the hospital. I will come on to talk about these events on more detail.

FAMILY BACKGROUND

8. I live with my husband, Cameron and three children in[redacted]. [redacted] is ten and he is eldest. [redacted]is [redacted]and[redacted] is [redacted].

9. [redacted] is in[redacted]at school. He was in [redacted]when he was first diagnosed. [redacted]. He is a smart cookie and loves to read, particularly “knowledge” books as he used to call them. Even at a young age he was reading geology books and learning about rocks. Him and his dad love to read science and physics books together. This really helped us during treatment as we could read books with him then.

10. He’s an imaginative wee soul and loves to draw his own comic books and make up his own stories. In fact, one of the things that developed when we were in treatment was the storytelling games that we do as a family. We have these wee dice and we create characters and we roll the dice and that tells them whether or not their character was successful in whatever little trip they were doing in the story. All the kids love making up stories. And that was something that his dad did with him an awful lot. He also loves to build Lego and he is really competent at following the instructions, but also has a great imagination for free-building. At the end of his treatment his wish was to go and visit the Lego Headquarters in

Denmark, which we did, and he met some of the designers. He absolutely loved it.

11. As I am a stay-at-home mum, I am very hands on with all the kids, so is their dad. We spend a lot of time doing fun stuff together and all the kids get on well. We're an outdoor family and do things like walks in the forest, trips to the seaside and going to the park. They don't really go to any clubs, but they do go to Cubs and Beavers and they enjoy that.

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

Admission to hospital: July 2018

12. In July 2018 we were on holiday in England when [redacted] first had blood in his urine. We went to the GP there who thought it might be an infection and gave him some antibiotics. Once we were home he had blood in his urine again and we took him to our own GP who arranged for [redacted] to have some blood tests. They called us and said that the blood work was concerning and referred us for an emergency scan, which was two weeks later. The woman doing the scan told us that we should go home and pack an overnight bag as she was phoning our GP right away and we would be going to the hospital that afternoon. When I spoke to my GP later on that day I told him that [redacted] had actually been sick through the night as he had bumped his side. The GP told us to go straight to A&E as he didn't know which department we could be getting referred to. We still didn't know what was wrong at this point.

13. When we arrived at A&E at the RHC they lady behind the desk couldn't admit us because Dr Ronghe, who was the consultant oncologist in charge of [redacted]'s care was already in his file. He was the first doctor that we saw in the Clinical Decisions Unit ("CDU") which is where we were sent after A&E. When you go into A&E you cross the re-sus corridor into the CDU which is in the part of the

hospital that has curved walls. All the rooms in the CDU are individual rooms and that is where we waited until a bed was ready for us up in Schiehallion.

14. By this point we had read the referral letter from our GP and had seen the word "oncology" so we knew it wasn't good. Dr Ronghe came and told us that [redacted] would be going for an MRI scan and then up the stairs to the Schiehallion Unit, which was ward 2A.

Description of Ward 2A

15. Wards 2A and 2B are both in Schiehallion which is the oncology ward for kids. 2A is the inpatient ward and 2B is the day care ward. 2A is one of the horseshoe wards so it's on the end of the hospital in a big curve. When you go into it, you walk round a big semi-circle and the rooms are all off either side. There were twenty something bedrooms on the ward. As you walk in the door the first rooms are training rooms and then the parents' kitchen. As you walk further along you come to the 'VAC' rooms which are rooms that are set back from the corridor. Those rooms have a double entry system to get in and are for the kids that have had transplants. They are on a heightened level of cleanliness and infection control management. These 'VAC' rooms also had monitors on the walls outside which were pressure gauges, they were negative pressure rooms. I have no idea what this means, it was just something I was told by the staff on the ward. There were maybe four of these rooms.

16. After those rooms was the playroom on the right. It had lovely big windows and colourful pictures. That's you in the curved area now so the rooms are all a funny shape from the outside. They've all got an arched wall. Then there was the nurses' station and behind that there were two bedrooms that were set back. Round the corner was the utilities and the bedding room where you could go and get extra bedding, pillows and things like that, and extra sheets. Then then the

bedrooms carried on round the curve and as you were coming off the curve at the other end there was the Teenage Cancer Trust Area ("TCT") which was the area for older children. They had a playroom that was just for the teenagers, and was set up with PlayStations and gaming chairs and things like that. Then you got to the other end of the horseshoe and there was an exit door out to go back out towards the lifts there.

Infection Control on ward 2A

17. When [redacted] was an inpatient on the ward, we were not allowed in anyone else's room. That was very clear very quickly. We became like parents chatting over the back gate and would stand at the doors, chatting to each other. The children would go up and down the corridor talking to each other and playing with each other. This was all to do with infection control and there were several protocols in place.

18. We had to use hand sanitiser as soon as we walked in. We called it magic hands. There was a restriction on the number of visitors allowed, you were only allowed two visitors in a room, except if it was siblings. The staff said to try and keep visiting to a minimum just for traffic going in and out of the ward.

19. In the parents' kitchen everything had to be cleaned before it was put into the fridge. We had to make sure that everything was single use and you weren't allowed to leave opened food sitting. Edie who was the domestic, they are the staff who wear green shirts, managed the parents' kitchen. When I met her that first morning, she gave me the lowdown on how the parents' kitchen worked and keeping everything clean and the things that weren't allowed in the fridge. You weren't allowed eggs; you weren't allowed seafood. Everything had to be in date. Anything that was out of date was binned. Anything that came in that wasn't sealed from a shop, you had to put the date on and it had to be binned the next day. If you had cooked something at home and brought it in, it had to be used that day. The children had to be given sealed food and if they opened a carton of juice and didn't drink it you had to bin it and give them a new one. We were told not to worry

about the waste. We had to clean everything down in the kitchen after we had used it. We had to use the dishwasher for dishes and if you were washing dishes in the sink you had to use the hot, hot water and the soap and then you had to rinse them with the bottled water. We had to use bottled water in the kettles and bottled water to drink for all of us, especially the children.

20. If we wanted anything we just had to ask because they kept a supply of sandwiches and things like that in the staff kitchen. We didn't want to put the kids at risk, so if you give them a ham sandwich and they don't eat it, it would be binned after an hour and we could go and get a fresh one. It shouldn't be left sitting there in the heat of their room. The rooms were warm, especially in the summer. It was about keeping everybody safe.

Description of bedrooms

21. In terms of the bedrooms themselves, they were all standard. You walked in and there was a sink on the right hand side, then a bedside cabinet, then a bed for [redacted]. There was another bedside cabinet and then a wall unit which had a fold down bed for the parents. It had to be put away during the day. There was a big purple reclining chair which you had to move out of the way to put the bed down. There was a wardrobe unit and a chair with two arms and the high back. There were also stacking chairs that you could bring in if needed. We had one of them in the room as well so there was a chair for us all to sit on, so we weren't sitting on the bed. We were told by staff that visitors shouldn't sit on the bed, for infection control. As his parents, we were allowed in his bed and we spent a lot of time in his bed with him sleeping and comforting him. Then there was a bathroom off the bedroom with a toilet, a sink, and the shower area.

Description of parents' kitchen

22. The Parents' kitchen had two big kind of American-style fridges, a sofa, a TV on the wall, which the remote was never there for, and a wee circular table and four chairs to sit at. There was a microwave and two instant hot water kettles. So you pushed the button and it spat out a cup of boiling water. There were a few cupboards, another, smaller larder fridge and a dishwasher. There were zip seal bags and labels and pens in the cupboards so that you could label everything. Edie looked after the room and she was the one who knew where everything was. She was like a granny to everyone and looked after us all.

23. We did use the parents' kitchen. It was the only place you could go for a break really. That first day I went along a bit tentatively and I collapsed in a heap on the couch. There were two other women in there and they immediately comforted me. It was the first place that I cried because I couldn't do that in the bedroom. You were often in there by yourself, but it was a place to speak with other parents and get to know them. You could also leave things on the table in the kitchen and other parents could help themselves to it, for example, if you had fruit that you weren't going to use, or the charities would leave gifts for the kids. I really feel for parents who didn't have that space once we moved to 6A.

Description of Playroom

24. We quite often used the playroom when [redacted] was an inpatient and we would often go there to find something for him to do. He wanted to colour in and play board games. It also meant that he could meet other children. There were simple toys like cars and dolls, building bricks and that sort of thing. There was a big cupboard full of arts and crafts that the play worker would bring out and there were always different craft activities every day. It was all easy stuff. There was also a cupboard full of board games and a whole selection of books and DVDs. One night, we had a cinema night in the playroom and all the kids watched a DVD. It was lovely to hear them all laughing.

25. I have mentioned the play workers. One of them, Anne, was funded by the hospital charity and was there nine to five during the week. There was also Linda who was a CLIC Sargent play therapist. She had a slightly different role and helped us with things like dealing with [redacted]'s aversion to needles and what tactics we could use to help him.

26. Anne was in the playroom on a day-to-day basis and she would also come into the bedroom if [redacted] was too ill to go to the playroom. She would bring some activities along for him to do, or would sit and play with him for a while to let me go and get a cup of tea. There were also volunteers from the Children's Hospital Charity who would come in and go round the rooms as well and be in the playroom. That was maybe two or three times a week.

27. Only patients and their parents were allowed in the playroom. Siblings weren't allowed. Everything was wiped down constantly; anything that you played with. We got into the protocol very quickly where you finished playing with something, wiped it down and put it back on the shelf.

28. There weren't officially any facilities for siblings, but if you gave the play workers a heads up that they were coming then they would bring along the activities that they were doing in the playroom. We were told just to keep it in the room and even to leave it sitting and they would wipe it all down before they would put it back in the playroom.

Facilities

29. There were big TVs in the bedrooms. They had these flat screens that were on a big arm that would come out from the wall and sit wherever you wanted it to sit and they were touch screen so the children could operate it themselves, the ones in the children's hospital were quite big. The ones in the adult hospital are probably the size of an iPad. The children's ward ones were much bigger, maybe so the child and the parent could both watch. We noticed that difference when we

were transferred to the adult hospital, that it was all the wee screens that you were using then.

30. Quite often on Schiehallion the TV wouldn't work and the staff would just say "ah, well, TV doesn't work". It would be reported, and quite often it just needed a hard restart and a tech support guy who worked in the hospital would come and unscrew everything off the wall and hit a button and then it would work again after that. If your TV didn't work, there was nothing the staff could do about it. They would just bring you a PlayStation in so you could watch DVDs instead.

31. There was patient Wi-Fi that you could log into, but you would get booted off it every hour so we'd use our phones to log into it. It wasn't great and at busy times during the day it was very poor. Probably due to the number of people trying to access it.

32. We were also gifted an iPad from one of the children's cancer charities. The CLIC Sargent social worker arranged it so that [redacted] could play games if he wanted.

Staffing

33. There were a lot of nurses on the ward. I don't know if we were on one-to-one with a nurse, it was maybe one nurse looking after two or three children, but the staff did tell us the ratios were much higher in Schiehallion because the children did need more care. There was a nurse near us whenever we needed them. When you pushed the buzzer, it was the same nurse that came in every time. There was a specific nurse keeping an eye on our buzzer in our room. There was always someone available to help us out if we needed it.

34. In those early stages, the nurses were teaching us a lot. They were also managing and noticing how he reacted to things and what his preferences were. They were very reassuring and very quick to help. That first night when he started being sick, I didn't even need to buzz the nurse because she was standing outside and she

could hear it so she came in straightaway and noted that the doctors had reduced one of his anti-sickness medications so she arranged for that to be increased. They would come in and check him over and they learned his little routines such as he liked to have his temperature taken on a particular side. He was the driving force. They didn't force anything on him and they would always look to us for reassurance before they did anything. [redacted] was the leader of his own care which was lovely to witness. They were very reassuring all the time and kept calm all the time and the ward was a fun place to go. [redacted] was always happy to go in and see them all. They were a wee family. It was a positive place and the staff made it as easy on the kids as they could.

35. The nurses were also very strict in their timing of [redacted]'s observations and the timing of his medications. They were almost ahead of the game in knowing when his next dose of medication was needed. In one particular instance [redacted] was spiking a temperature. When a child spikes a temperature, they rely on paracetamol as ibuprofen is not a great drug to use along with chemo. On this occasion the paracetamol had taken the edge off but he was still above 38 degrees and he was due paracetamol at, for example, seven o'clock. The nurse was standing ready with it at three minutes to seven. We didn't need to chase them for medication or anything.

36. There were also specific nurses that were chemo nurses and it had to be one of them that gave the chemotherapy. There were always some on a shift who could do it. There were also the advanced nurse practitioners who were trained to a higher level so they could prescribe medication.

37. The consultant would come and do a round every morning. They would also come in and out at other times too. I suppose with [redacted] at that early stage, they were more attentive because they'd be checking on him to see how he was doing. There was the consultant, Dr Ronghe; Senior Registrar, Caitlyn, Registrar, Anne-Marie; and then the junior doctor, James, who rotated onto the ward just as we started.

It was his first week on Schiehallion that we were there. James was there I think for three months. He then rotated out and someone else rotated in. When we asked for a doctor, he would be the first one that would come. He would then refer us up the line if we needed it. During out-of-hours there wasn't a doctor on the ward, it would be the A&E doctor that would have to come and prescribe any medication that was required. So there was one night, for example, [redacted] was really itchy and he was having an itchy reaction to something and they had to get a doctor to come and prescribe Piriton so that he could get it. He had to wait until the doctor came up from downstairs to do the prescription for it. So no doctor would only be there for overnight; it would be a downstairs doctor. For weekend cover, consultants took turns. If you needed a consultant over the weekend there were four of them that would do every four weeks. There were no first year doctors in Schiehallion and part of that is because they need to have a certain level of training to be there. Our first experience of first year doctors was when we went into the surgical unit and we realised then why they don't have first years in Schiehallion.

38. The nurses were supported by an auxiliary team who wore the kind of light blue shirts and quite often if you pushed your buzzer, it would be an auxiliary that would come to you first because more often than not an auxiliary could do what you needed them to do. If you were pushing your buzzer because we were finished with our food, they would take the tray away or if he'd been to the toilet, they would take the bedpans away. As they walked into the room they would always put on gloves and a disposable apron. It was a much higher level of infection control going on and we saw the difference when you went to other wards; there wasn't that same level of infection control protocol.

39. There were also the cleaners on the ward. The bedrooms would get done once a day unless there was extra which sometimes there was if there had been a spillage or something. We got to know the cleaners quite well because they would be in your room often. When we were in old Schiehallion they would stick their head in

and ask if it was okay to come in and we'd go along to the playroom and let them clean. When we were in other wards there was nowhere else for us to go, so we'd just have to sit there while they did the cleaning. The standards of cleanliness were high. We never noticed anything dirty. We were asked to keep surfaces clear and we were given a book when we first came into ward 2A which told us all about infection control and the importance of cleanliness and keeping the bedrooms free of clutter.

Diagnosis of Wilms Tumour: 30 July 2018

40. On the evening of 30 July 2018, the doctors confirmed that [redacted] had a tumour on his kidney and he was to get a CT scan the following day to see if it had spread. At that stage no one was saying the "C" word, just that there was definitely a mass on his kidney. I asked Dr Anne-Marie, one of the Registrars if it was "that", meaning cancer, and she nodded. They were very careful about the language they used in front of the children.

41. The next day [redacted] went for his CT scan, to see if the cancer had spread and to help the doctors stage it. Later that day, Cameron and I went to one of the consulting rooms with Dr Ronghe and he showed us the scans. He said they could assume it was a Wilms tumour given its presentation so they didn't need to do a biopsy to confirm. The CT confirmed it hadn't spread into his liver or lungs. Once they knew what it was, they started treatment straight away.

42. The next day [redacted] had surgery under general anaesthetic to have a Hickman line, inserted into his chest. They made an incision in his neck and put the line in. There were then two access points going into his central vein and that became the access point for all the medications. This was better than working with cannulas which can fail quickly and mean the kids have to get jags which is traumatic for them. Getting the Hickman Line is a good thing because it immediately means treatment is easier on the kids and it's not as traumatic.

43. The day after that, which was a Thursday, [redacted]'s chemo started. The plan was that he would get four weeks of chemo to try and shrink the tumour and then there would be surgery scheduled to have his kidney removed. He was in room 10 on ward 2A and that was where he stayed during this admission. The plan was that they would start the chemo as an inpatient so that they could manage his reactions and symptoms and then hopefully let him go home and attend for treatment as a day care patient. It was also an opportunity for us to be educated about his condition and get as much insight as possible.

44. [redacted] was given vincristine (vinc) and actinomycin, which are the two standard chemo drugs for treating a Wilms tumour. The vincristine was more regular than the actinomycin. The actinomycin was fortnightly. To begin with it was a double (vinc and actinomycin), then a single (vinc), then a double, then a single. We kept that rhythm going for a good two months and then it became a single, a double, a week off, a single, a double, a week off. The kids are only allowed a certain amount of all of the drugs within the course of treatment. Dr Ronghe explained that they try and give them the smallest amount of chemo that they can because of the side-effects and the long-term effects of it and also keep some "in the bag" for if there is a relapse. If [redacted] were to have a relapse but has had the maximum amount of a particular chemo, he couldn't have any more of that drug and a different treatment protocol would need to be used which comes with its own long-term side effects and risks.

45. Dr Ronghe was very good at giving us background information on Wilms tumours and how it manifests and develops. We were also given information sheets about the chemo and the related possible side effects and risks. The problem with [redacted] is that he was older than most children who present with a Wilms tumour; typically, they are about three years old. As he was the top of the age bracket, there wasn't a lot of data to help the doctors project what his treatment plan would be. No one knew how [redacted] was going to react to the treatment and all the doctors could do was treat him based on what they knew and had worked previously in other children.

46. [redacted] did suffer from some side effects once he started getting chemo. He had no appetite and stopped eating. He “took to his bed” and just wanted to sleep. On the first night after the chemo he was sick, so they upped his antiemetic (anti-sickness medication) to stop that, he had a temperature, and he just felt rubbish. This lasted two or three days before we then managed to coax him to eat a bit, coax him to drink a bit. If a child has a reaction to the chemo, the medical staff are carefully monitoring the ins and outs of their fluids. We had to report everything that [redacted] was eating and drinking and they were measuring everything that was coming out. He was on IV fluids all the way through because he just wasn’t keeping anything down. Or wasn’t putting anything in to begin with and anything that did go in, he was being sick again.

47. After that first round of chemo [redacted] was discharged on 8 August 2018 which was a Wednesday and we were to come into ward 2B the following day as a day care patient so that he could get his chemo. His day for chemo was going to be every Thursday. We were given a tour of 2B and told where to go to report in and then where we would wait and where the chemo would be given. The staff were very good at prepping the kids so that none of it was scary.

48. In the run up to [redacted]’s discharge we were also being prepped by the medical staff in relation to how we would manage [redacted] and his symptoms at home. The plan was that he would get his chemo as a day care patient and then we would manage him at home unless he spiked a temperature. That’s the magic word that they kept on using, a “spike”. A spike means a temperature spike. So if [redacted] had a temperature over 38 degrees, it’s classed as a fever and we had to get to the hospital as quickly as we could. If we couldn’t get there under our own steam within half an hour we had to ’phone an ambulance’.

49. The “spike” protocol was that we had to ’phone the ward and tell them that [redacted] was spiking. If it was during day hours, then we would go straight to day care and they

would then start antibiotics. We had to be there and have antibiotics started within an hour if possible. If it was out of hours, then the ward would ’phone down to A&E to let them know we were coming and we would be taken straight into CDU and they would start the antibiotics. It was a very slick process and the system meant that all the worry of getting to hospital and being seen was gone.

50. The reason that it was treated with such urgency is because the medical staff were treating any spike as a potential line infection and that was serious. By that I mean the Hickman line. If [redacted] had a temperature of 38 degrees at the house, then we were to give him paracetamol before we left and get to the hospital as soon as we could. Even if his temperature was 36 by the time we got to hospital that didn’t matter. The staff always erred on the side of caution and wanted to see him.

51. Unfortunately, [redacted]’s pattern was that he would spike a temperature in reaction to the chemo and so we were in and out of hospital all the time during his treatment. This doesn’t seem to be something that happened with other children. I think he is just a child who gets a temperature when he is not well. Some other children might vomit, or get a headache, but [redacted] gets a temperature, which meant that we had to treat it like a line infection every time.

52. At the time of his first discharge we were also given information by the nurses. I didn’t keep it. This was an A4 sheet of paper with a table that was pre-filled. A nurse went through the list with us and signed a box to confirm that everything had been explained to us. It was things like infection control, line management, what to do if [redacted] spiked a temperature. It was a standard form, but if there were things specific to [redacted] they were handwritten in. They went through it with us and made sure we understood everything that we needed to before we took [redacted] home. This included the medication that we were to give him and the hygiene protocol. We were told that we were not to touch the line. The line came out of [redacted]’s body and had two white lines, very similar to an iPad charger, and on the end of it there were two access ports with green caps on them. We weren’t allowed to touch the green

caps. Each time [redacted] had his line accessed, the medical staff put a new sterile green cap on once it had all been cleaned with sterile wipes. We hadn't to touch that or go anywhere near it, and if it came off, we were to go straight in to the hospital because the staff had to deal with it. It was okay to shower with it on, but then when he was dressed you could actually get a wee bag to keep the ends of the line in. [redacted]. This stopped them from dangling around or getting caught on clothes.

53. When I knew [redacted] was coming home, I'd gone around the house so it was spotless. Although the nurses did say to us, don't keep the house too clean. Don't be bleaching everything because the bugs that he's used to will help his immune system. They told us to keep surfaces clear and that washing hands was really the biggest thing. We were to make sure that anything that goes in his mouth, like the syringes that they used for giving medicine, were new every time we gave him anything.

[redacted]'s ongoing treatment: 8 August 2018- 3 September 2018

54. [redacted] was discharged on the 8th of August and we were back in on the 9th in day care in 2B. 2B is a straight ward rather than on the curve of the building. When you walk in the door, there is a reception desk and then a waiting area/ playroom. There was a play worker there, Alison, who gave the children some activities to do and there was a PlayStation for the ones that wanted to do that. Then you would be taken round to where the bell was. This is the bell that the children ring when they are finished their treatment. There was also a set of chair scales so each time the children came into day care, their height and weight would be measured. The staff were monitoring weight loss because of loss of appetite due to the chemo. There was a magic ten per cent that we had to watch for and if fell below a certain weight, that would mean he would have to get a NG feeding tube placed to then up his feeding and you would be giving him feeds through the night and things like that. [redacted] managed to avoid having to get an NG tube. He managed to avoid this because we heavily encouraged him to keep eating. We

would motivate him with rewards, things he wanted and it worked. It was hard for him, but he managed.

55. There were maybe four treatment rooms with consulting rooms down on the right-hand side of the ward and on the left-hand side, a larger bay that had maybe four beds in it. We were never in there because that would be where the kids that needed to get chemo through an infusion would go. [redacted]'s chemo was called a push where they would just push it in through [redacted]'s Hickman line and that would be it. His only took two or three minutes, but some of the other kids could be in there all day getting chemo infusions and other things like blood transfusions.

56. There was a door at the end of the ward which we learned later was a door that you walked out straight across the corridor into 2A if you were being admitted there.

57. The plan for [redacted]'s treatment was that he would go to ward 2B every Thursday and he would get his chemo. He would get one every week (vinc) and two every two weeks (vinc and actinomycin). He was due to get four treatments, although it actually ended up being five due to surgery scheduling. So this equated to five weeks of treatment. His first week he got vinc and actinomycin, the next week he got vinc, the third week he got vinc and actinomycin, the fourth week he got vinc and then he got an extra round of vinc on the fifth week, then he got his surgery to remove his kidney.

58. Every time that [redacted] attended day care he would have to go into clinic three, which was not in ward 2B, but which is one of the outpatient clinics on the bottom floor of the RHC in the big atrium, and get a thumb prick. The nurse puts a wee bit of Vaseline on [redacted]'s thumb and they puncture it and do little drops of blood into a tiny little vial that then gives them a quick blood count and white cell count. It would give them four magic numbers: white count, haemoglobin, platelets and neutrophils. These were the four numbers that they would then report for him

and if the numbers weren't right, he wouldn't get chemo. Or if the numbers weren't right, he might also need a blood or platelet transfusion with his chemo. It would dictate the treatment for the day.

59. On that first day on the 9 August, 2B told us just to go straight there and they would do the first thumb prick as [redacted] was a bit scared about it. We said, no, as we wanted to get [redacted] used to what we needed to do each week. We bribed him with the promise that, every jag he got, he would get a Lego mini figure and that worked.

60. After the thumb prick had been done, we sat in the waiting room in 2B and waited for that result to come back. It only took about 20 minutes. Then [redacted] was taken in and weighed in one of the consulting rooms. As soon as we got the okay that his blood work was okay, the call went to the pharmacy that his chemo could be prepared and someone would go from the ward to collect the chemo. Because he was getting vincristine, which is one of the really nasty ones, it had to be collected from the pharmacy by a nurse. Once the nurse had the chemo she would glove up and put on cuffs to protect her arms and she would flush the line. When they first connect the line, they make sure that it's flowing properly because you can get blood clots in the line so they'll draw from it to make sure that they can draw off and then they'll flush it with saline to make sure that it's flowing well. Then they would give [redacted] the vinc. After the chemo has been administered, they flush it again and then put a lock in it so that it's not sitting empty. Then they'll put a new clean green cap on. There was an awful lot of double and triple checking that the chemo was right and then they would watch the chemo go in. Later on in his treatment, there was one instance they had to give the vinc through a cannula post op after [redacted] had his Hickman line removed, and they had to watch it so carefully because it can burn the arm as it's going in which is why they prefer to give it into the central line. It does less damage. I learned that day that people have lost arms because it's done so much damage. If it doesn't go deep enough and get flushed away quickly, it can cause there to

be burns to the limb, bone. Awful, absolutely awful but it does the job. So they're watching it go in and they're watching all of the skin around about the site to make sure that it's going in and getting flushed away into the body straightaway. Then you have to wait 20 minutes or so to make sure that there's no reaction or anything and then that's you free to go. When you were leaving they would reinforce what to do if he spiked a temperature.

61. That was the process for every round of chemo and, after his first round as an outpatient, on 9 August he did spike a temperature. It was early in the morning of 10 August. We didn't sleep and had been monitoring his temperature. It was creeping up and up and once it hit 38 degrees we phoned ward 2B and they told us to make sure we gave him paracetamol and bring him in. Because it was out of hours, we had to go in through A&E and then to CDU to then be transferred up to Schiehallion. When we got into CDU we were put in a room and a nurse came along and took cultures from the line. This meant blood was taken from the line and then antibiotics were administered through the line. It had to be done by a nurse who had had some training in working with the lines. They started giving antibiotics, I think it was tazocin on this occasion, just in case it was a line infection as they have to wait 48 hours for the culture results to come back.

62. On 10 August, [redacted] was admitted back onto ward 2A, back into room 10 and we had to wait for the results of the cultures. He was given paracetamol to manage his temperature and I think his culture results were clear. He had to be 48 hours without a temperature before being discharged, so we were discharged on the 13 August.

63. As time went on with [redacted] the staff got a bit more lenient with letting [redacted] go home after a spike as this was just his pattern. If his culture had come back clear but he was still spiking a temperature they wouldn't make him stay for another 48 hours. His pattern seemed to be that he would get chemo on a Thursday then

he would be back into the hospital on the Friday or Saturday with a temperature spike. It only seemed to happen when he had the vinc chemo on its own. When he got the two doses of chemo together he was more sickly and nauseous but temp would be generally okay.

64. After he was discharged on 13 August he was back in day care on 16 August. He didn't spike on that occasion although he did get a black tongue. It was very strange. No one knew why it happened and It never happened again.

65. On 23 August [redacted] was back in day care in 2B to have the vinc chemo. He spiked a temperature on 24 August. This time it was during the day so we went in through 2B. We didn't give him paracetamol before we took him into hospital and that was a mistake we never made again. When we went in to 2B, we waited for a long time to be transferred into 2A, so we were left in a room in day care while he was fading. He was getting warmer and warmer because we hadn't given him paracetamol yet. The ward was really busy and eventually a nurse came in to say we could go through to 2A. By that time, he was in rigor which is when you start to get shivery. At that point, the nurses jumped into action and realised that he hadn't had any paracetamol. They gave it to him immediately and then watched him closely to see if his temperature came down. There were five or six people in the room at that point because they were worried about him as rigor is a sign of sepsis. He had been given the antibiotics when he got into day care, and we did tell a nurse that he hadn't had paracetamol yet, but that didn't seem to register. The nurse came along later and apologised.

66. On this admission, [redacted] was in one of the VAC rooms. This was one of the rooms with the double doors that are used for kids getting transplants. We were only in there because it was the only room available. It had a double door entry so you go through the first door which is from the corridor and there is a sink and there's a place to hang your coat and you've to wash your hands there before you can then open the second door to go into the room. That didn't need to happen for

us because we weren't there because we needed that extra level of infection control. Although, when we were on other wards that did not have the Schiehallion levels of infection control, we were put into a VAC room because that was an extra level of infection control.

67. This VAC room was number 20 something and it was in on the left just before the nurses' station. This was one of the rooms that I had been told by the nurses had negative pressure, where there is no air being brought in from outside. We didn't need it, so I didn't find out any more about what that meant, but it did mean that the air conditioning worked in that room.

68. [redacted] was being monitored closely by the nurses on this occasion to make sure his temperature came down, but also because he had a reaction to the antibiotics they gave him, Tazocin. They gave him another kind of antibiotic (meropenam) and then they had to monitor him to make sure he didn't have a reaction to that. They were in taking his blood pressure and temperature constantly. He had also had cultures taken and they came back negative after 48 hours and his temperature stabilised and he was discharged on the 27 August.

69. This room was the only room in the hospital that we stayed in where the air conditioning worked. In any other room we were in, it was rubbish. There was a little bracket on the wall where you could control the heat in the room. The first thing we would do when we would go in would be hit the negative number because it would be sitting at 25 degrees and the wee light would come on to let you know that we had interacted with it. The light came on and it would click down to 19 degrees, but the temperature would never actually change. The general temperature was 25 degrees all the time. In this VAC room we could lower the temperature to 21 degrees, so it was positively cool. We hadn't been told by any of the staff that the air conditioning worked in that room, we just discovered it for ourselves. We had mentioned to the nurses that, in other rooms we were in that it was very hot, but they never said much about it, they just told

us that the air conditioning doesn't work. It was just accepted that the air con didn't work. The wee bottles of water that you would get would be in the freezer to become ice blocks so that you could have them in your room at night and they would gradually melt overnight so that you could get a cold drink. That was the standard. Everybody had frozen bottles of water in their room to try and get a cold drink because it was always so warm. Once the condensation from the frozen bottle frazzled my phone.

70. We had issues with water drainage whilst we were in this room. [redacted] was nervous about cutting his hair, which it had been suggested that we do as his hair was going to start falling out with the chemo, so Cameron said he would shave his first. We let [redacted] have a go of the clippers and Cameron was sitting on a chair in the shower cubicle so we could clean it up easily. [redacted] had a great time. Afterwards we cleaned up the hair and I left Cameron to have a shower. I was sitting in the bedroom and I saw water came out from under the bathroom door and all the way through the room and out into the corridor. I had to dash and grab towels and clean up and buzz the nurse to ask for a mop because the water was everywhere. The nurses just rolled their eyes and said that sometimes the water goes everywhere and they would report it. From what they were saying, it wasn't the first time it had happened. I don't know how it had flooded. It wasn't clogged with hair as I had picked all that up. It looked like the water wasn't running into the drain. It seemed like the angle of the floor meant the water didn't run the right way. No one came to look at it or tried to fix it while we were there. Cameron wondered how it had passed inspection. This was the only time this happened and it didn't happen in any other rooms we were in. There is a diagram of this in the appended timeline **(CG/01- Appendix 1)**.

[redacted]'s admission for surgery: 3 September

71. On 3 September 2018 we went to 2B and [redacted] got some blood taken to check everything was okay and then we had a consultation with Dr Ronghe, and then the surgeon, and then the anaesthetist. We were told to come back later in the

afternoon and go straight to the surgical ward to get admitted. The plan was that would get admitted that day and the next day he was going to have the kidney removed and then he would go to the PICU that night. The surgery was scheduled when there was a PICU space available. He would be in the PICU overnight and then back to the surgical ward and then recovery and home. We were told he would be in hospital for about a week.

72. The surgical ward was in ward 3B of the RHC. We had chatted about this ward with some of the nurses from Schiehallion and they had warned it was quite different. They said Schiehallion is first class and 3B was definitely not first class. I'm sure there's a bit of competition between the wards and between the nurses but they said that there were not the same facilities for the families. We had been warned that we needed to be "on it" and pay attention to [redacted]'s medication and his fluid balances, which was monitoring how much fluid he was ingesting and what was coming out, to ensure he didn't get dehydrated, as the nurses in 3B would not pay as close attention as the Schiehallion nurses. We were also told that they didn't have the same number of nurses. We had heard stories from other parents whose kids had had temperature spikes and been put into other wards about how they really had to pay attention to the fact that the kids were needing their medicine. They were phoning down to Schiehallion asking why nobody was coming. So we were a wee bit anxious about going into the other wards.

73. When we arrived on ward 3B, [redacted]'s room wasn't ready so we were told to wait in the playroom. 3B is a big long straight ward and when you walk in, you're in the middle so the nurses' station and the clerk desk are there and the playroom is straight ahead of you. Then there are rooms along each side and a bay with four beds in it. There is also a kind of kitchen area. It was a staff kitchen so the door was open all the time, and that's where you would go and help yourself to breakfast for [redacted]. We were given a bit of a tour and then sat in the playroom. I was immediately aware of all of the other children in the playroom who were

snotty nosed. At this stage we were very conscious of [redacted] getting infections and we wiped everything before he touched it. Eventually we gave him his iPad and told him not to touch anything. It definitely wasn't the same level of cleanliness as the Schiehallion playroom. All the cupboards were open and the kids could go in and touch anything and put anything back. There was no member of staff in there. So I was a wee bit apprehensive and I just sat there and wiped everything. There were some kids in there who were cystic fibrosis patients and they were being looked after by the nurses, their families weren't there with them. So there were little kids playing in the playroom by themselves and it was a bit of an eye-opener. I couldn't imagine leaving [redacted] on his own in hospital, but it was totally normal for these little kids and they were used to it.

74. Once [redacted]'s room was ready we were taken round and the nurse told us that they were really busy. I think that's because there were two cystic fibrosis children who were staying on the ward and needed the nurses to care for them, which I totally understand, but we immediately felt we weren't getting any care. By the time the nurses came to actually do [redacted]'s admission, where we sit down with the forms and actually admit him, it had been a good couple of hours. In Schiehallion you never had to wait that long to get admitted.

75. As we were putting [redacted] into bed we pulled the sides of the bed up and noticed that they weren't clean at all. They were covered in something brown. I don't know what it was. It could have been surgical wash. Cameron was annoyed and told the nurses that the bed wasn't clean. My initial reaction was to clean it but Cameron wouldn't let me. The nurse came along and was mortified. She organised for a new bed to be brought in straight away. Then we set to clean the room from top to bottom with wipes we had brought from Schiehallion because we didn't trust that anything was clean. We really didn't feel safe, and we were already thinking, that this really wasn't first class.

76. The room we were in was nearest to the nurses' station and I think the protocol was that the kids that were going into surgery that needed the most care were closest to them, but there was a VAC room on this ward and, with hindsight, I should have told them we should be in that room. That would have meant we had some added infection control protection and were away from the other children. At this stage [redacted] was neutropenic; neutropenic is the word that they use when you have no immune system. There was no acknowledgment that he was neutropenic, or a Schiehallion patient. After this stay on ward 3B, I spoke with Wendy and Jane, the advanced nurse practitioners from Schiehallion, who had come to help [redacted] in ward 3B and they were not happy with what they saw in ward 3B and seemed upset about it, but they couldn't criticise nurses on other wards. None of the nurses on Schiehallion explicitly said that [redacted] should have been in a VAC room in ward 3B, but we learned from later stays in other wards, when he was put in a VAC room, that this is what we should be asking for if we had to go to a ward other than Schiehallion. Nobody actually sat down and told us that is what we should be expecting and asking for. I made sure that I put this, along with other advice about what we'd learned, on the Facebook group for Schiehallion parents which was set up by Schiehallion parents. This was maybe November 2018. I said that we seemed to be jumping in and out and going to lots of different wards and we've learned that when you go to another ward you really should be in a VAC room. I also gave my experience of which playrooms were clean in which wards, where you had access to a kitchen and what the rules were on each different ward for things like hot drinks, as some of the wards didn't allow hot drinks.

77. The facilities on ward 3B were not as good as Schiehallion either. The playroom was there but wasn't clean. We were shown the staff kitchen and could go and get a cup of tea and that's where we got breakfast for the children. There was a fridge in the corner with sandwiches and wee yogurt pots and wee juice pots because they recognise that children don't want to always eat at lunchtime especially if they've been fasting for surgery. So we could help ourselves to

those things, which was good to have access to. Every time I went into the kitchen, I had to clean it. There were always mugs from the staff in the sink. We had been taught in Schiehallion that leaving stuff on the draining board is a breeding ground for bacteria and I thought that these nurses must surely have known that.

78. I don't want this to sound dramatic, but usually if you told people that [redacted] was a cancer kid then, from anybody in the outside world would give quite a strong reaction. That didn't go with us to other wards. What I mean is that the Schiehallion kids should have got different treatment, preferential treatment, if you like. As soon as the staff were aware that someone on their ward was immunocompromised, they should have upped their game. Even if normally they left their kitchen in a riot, there's somebody here that's immunocompromised, so they should have recognised they would need to bring it up to scratch. That's what I was fighting against when I said this umbrella of Schiehallion should have gone with us wherever we went. I shouldn't have to be washing nurse's cups.

79. After this experience, it became our standard that, whenever we were admitted to a room that wasn't in Schiehallion, the first thing we did was clean. This wasn't something that the Schiehallion nurses told us to do, it was something we were doing off our own back, although when we told the Schiehallion nurses what we did, they said they would have done that too.

80. [redacted] had his surgery on 4 September under general anaesthetic. It all went well, his kidney was removed cleanly and the surgeon was happy. We happened to meet the surgeon as we were walking onto the surgical floor and she took us to the recovery room to see [redacted]. He didn't look great. He was pretty pale, very small and desperate for water, he was asking for sips of water, which he threw back up immediately. His bed had to be stripped and he had to be changed, which was very painful and quite traumatic for him. He was then transferred round to the PICU so we had to wait in the PICU waiting area while they got him

established. Because it had been such a big operation he went into PICU for constant monitoring as there's one nurse per patient.

81. PICU has very restricted entry, there are only two of you allowed in to visit. As you go in, there's a whole area which is the family area where you have to leave everything. You're not allowed to take anything with you into the ward. We didn't have to gown up or anything but you weren't allowed even to take a cup of tea in and sit beside him. There was a little family room with lockers with stuff in it so that you could leave your jackets and your bags and things. When we went into the PICU, [redacted] was in a bay with four beds and each of them had a complete space around about them and a nursing station at each space. It was a very dark room, no natural light, no windows. There were individual rooms along the corridor but I wasn't really aware of them because I just went in and turned right, into [redacted]'s bay. We had to wash our hands on arrival. There was a sink right beside him to wash our hands and we weren't allowed to stay overnight. We had been warned that we wouldn't be allowed to stay overnight because there is no facility to put a parent bed but you can stay as long as you like. We could have gone to the family suite, but he seemed comfortable and we stayed until about eight o'clock that night and then he had settled into a sleep so we were encouraged to go home and get a rest ourselves.

82. He was attached to loads of IVs and cannulas and he was heavily medicated. We weren't in control of anything, we could only sit and watch him. This was only overnight and he was discharged back to ward 3B the next day.

83. Whilst he was in PICU he spiked a temperature in the middle of the night, but they didn't panic about that because a high temperature is quite a common reaction to general anaesthetic. They started an antibiotic protocol anyway and they did cultures and we were told when we arrived the next morning that he had a bit of a temperature. He seemed okay and he was managing to build some

Lego which is a measure of how well he was. Nobody seemed too concerned about him, but then the cultures came back that there was a line infection.

Serratia Marcesens infection

84. [redacted] returned to ward 3B on 5 September 2018. Once [redacted] was back in ward 3B, Dr Ronghe told us that there was a line infection so [redacted] was going to get some more antibiotics. This was quicker than 48 hours after the cultures were taken. They wait 48 hours to see if anything grows, but it in this case, something had already started growing. Dr Ronghe didn't know what the infection was at that point. had antibiotics administered in his Hickman line. Although [redacted] was not in Schiehallion at this point, Dr Ronghe still came to see him, along with the surgeon, Ms Brimley.

85. On 6 September I think the doctors knew what the infection was as they were going to give him antibiotics for it, but we were never told the name of it. We were just told he had an infection that needed to be treated. Once they knew that there was an infection, they checked to see if the infection was anywhere else in his body or just in the line. This is called a peripheral culture. These are the blood draws that the first year doctors attempted to take from [redacted] and made a real mess of. They also check the levels of where else it is in the body so they can give him an additional antibiotic. I remember that the A&E doctor who came to see [redacted] after he had gone into septic shock on the 7 September looked at [redacted]'s chart and told us that he had a "poo bug" so the name of the infection must have been noted on the chart for her to know that.

86. So on 6 September, before they could give [redacted] the antibiotic, they had to get a peripheral draw from the line and elsewhere on his body. The first year doctors were sent to do this and because [redacted] was so dehydrated after his operation, it was like getting blood from a stone. Blood was drawn via the line and it took a bit of time to do. They were going to have to come back and take blood from elsewhere on his body, so the doctors put EMLA cream on his hands to numb it.

[redacted] realised he was going to have to give blood through a needle which he did not like doing.

87. Minutes after the doctors had taken blood from the line, [redacted] went into septic shock. At the time we didn't know it was septic shock. His temperature spiked, he had rigor and he started vomiting and grunting. That's something that we'd seen in as a wee baby, when his temperature was really high, his breathing would become different. So that told us he had a really high temperature. At first we thought he was just anxious and panicking because he was in so much pain from the operation. He had a wound right across his torso. Cameron said to get someone so I pushed the buzzer. An auxiliary came and said she would get someone but nobody came. The fact that it was lunchtime meant that there was nobody floating around the corridor to deal with it at that moment. I pushed the button again and no one came. By this time, I was starting to panic a bit and I went out to the desk. I was finding it difficult to speak at that point because I was getting quite panicked and so I just said to the clerk at the desk, that [redacted] was "going down fast, somebody needs to come". I was starting to imagine the worst and it was suddenly getting a bit scary. The first year doctor came running. It was a first year doctor that we'd only seen once, hadn't even been on our service. He said he was there to help and said he would do some obs and check [redacted]. He agreed that [redacted] was definitely not good, but that they needed to get the peripheral draw of blood before they could do anything. The whole time I was just concentrating on [redacted] and trying to keep him calm, thinking this was just a panic attack. He was vomiting and his temperature was through the roof but he'd already had paracetamol so they couldn't give him anything else for the temperatures, so we just had to manage it. The first year doctor tried three or four times to get a needle into [redacted]'s hands to get the blood draw. They had injured him. It was all a bit chaotic and they then moved on to his feet and were trying to get a blood draw from there. After a while the surgeon arrived, Dr Hettle, or "Hettle" as we knew him. He totally calmed the room down. He sat down, took

[redacted]s' foot and started talking to him about dinosaurs. He was American so had an accent which was exotic for [redacted]. [redacted] was being sick but was trying to talk to him and as he was interacting with him, Dr Hettle managed to get the blood draw. He totally took control and gave instructions for [redacted] to be started on antibiotics. Within about 20 minutes or half an hour, [redacted]'s heart rate started to come down and everything calmed down.

88. That was the day I had to leave the room. I was upset because I stepped out of the way to let the nurses and the doctors get in at [redacted]. I recognise now, that I lost my grip on him. I lost my anchor that was keeping me calm. I was just kind of standing at the edge of the room watching the chaos around about and thinking, "oh, this is not good", but it was quite traumatic for us, that whole episode. I was the only one who left the room that day. I don't know how much of it [redacted] remembers because I've never asked him about it. I don't want to ask him about it. He's never really talked about it. I don't think he remembers a lot of that first couple of days because he was so heavily drugged. He had an awful lot of morphine kicking round his system. The hindsight and the aftereffect of that particular episode, that's the one that I keep dealing with and had to go to a bit of therapy for afterwards. I keep remembering the panic and I get panicked and emotional talking about it because I really feel that I failed [redacted] in that scenario because I left the room. I really did feel in that moment that they were about to turn round and say that there was nothing more that they could do. He didn't lose consciousness at any point. They didn't have to do CPR on him at any point, but I was already at that stage.

89. The septic shock itself was caused by the infection. They used the term "septic shower" because they had accessed the line to take blood out of it and part of any access to the line is they flush it. This means, they connect the syringe to the line with a wee screw and they draw from it first to make sure that blood comes out. It's a syringe with saline in it, and they'll pull back and you see a wee bit of blood going into the syringe and they push the saline through to flush the

line. So in doing that they flushed more infection into his blood. So anytime that line is accessed, it's flushing infection into his blood and so his body went into shock because of all of the bad stuff going into his blood.

90. The way that the situation was handled definitely made us aware of why there are no first year doctors in Schiehallion because when kids get sick there, they get sick very quickly. We definitely felt that the doctors didn't have a grip on the situation and that it was out of control. As soon as the more qualified surgeon arrived everything calmed but it took half an hour or so. When we compared this incident with the episode that we had witnessed in Schiehallion when [redacted] had rigor, that they had caught quicker, we felt that there wasn't the same panic. It definitely wasn't the same panic for me. I had seen [redacted] with rigor before but at that moment in 3B it wasn't the rigor that I was worried about, it was the operation. It was the fact that he had just had major surgery. It was the fact that he couldn't move. It was the fact that sitting up to vomit was painful for him and witnessing that hurt. He was just so small and so delicate, so fragile. Even when he wasn't well before he was never fragile.

91. Having discussed this incident with Professor Michael Stevens as part of the Case Note Review, I think there were an awful lot of things that could have been better and had been ill timed. Ward 3B is a surgical ward and [redacted] was there so his wound from his surgery could be managed. They were maybe less experienced in that ward in dealing with line infections and that inexperience is perhaps why things happened the way they did. If they had experience of dealing with line infections, the doctors and nurses may not have worked on the line and then left the room and gone for their lunch. They would perhaps have stuck around and monitored [redacted] for a while. This may not have happened in Schiehallion as they were more experienced in dealing with line infections and this is a situation where the Schiehallion umbrella was not over us. I didn't know this at the time, this is all with the benefit of hindsight.

92. The following day (7 September) word came from microbiology that they knew what the bug was and that they wanted to put what's called a block in the line. A block is where this little tube area in the line is filled with solid antibiotic. Dr Ronghe came round and talked about microbiology asking for the block to be put in and he explained it to us that it would be a very specifically measured amount of antibiotic that would be put in to fill the length of the tube so it was very accurately measured. That would then hopefully kill the bug in the tube and he described the infection as a very sticky bug. It likes plastic so it's a difficult one to clear and that's why microbiology had recommended that the block be put in to try and save the line. We weren't told what the bug was at that time.

93. Putting the block in had been discussed in the morning and it didn't happen until four o'clock in the afternoon. Dr Hettle and Dr Ronghe were in the room telling us this in the morning and we laughed and said, don't leave it until five o'clock. Do it early so there are plenty people here to deal with it if something goes wrong. Of course, it happened at four o'clock and the septic shock happened at 4:40pm and there was nobody in the building. Dr Ronghe had finished for the day and Dr Hettle was in surgery. By this time on a Friday afternoon, the staff had changed to the weekend shift and there were less staff on duty. I don't know why it was left until the last minute.

94. The delay in the instruction from microbiology and the block actually being put in the line is something we raised with Professor Stevens when dealing with the Case Note Review. He said there was a long gap between microbiology's instruction and it actually happening and that's something that was getting highlighted as it took too long. If microbiology ordered it at ten o'clock that morning, it should have happened at 10:10am. It just took time, I suppose, for the antibiotic to be drawn up or to be sent up from the pharmacy but I'm not sure, we weren't part of any of that discussion. There's also a question of at what point it was noted in the medical notes, because when we were asking questions about this, the Case Note Review came back to us confirming the exact times that

things had been written down in the medical notes. The medical notes say that the antibiotic was given before lunchtime, but we know that is not true as we were carefully noting when it was given and when [redacted] took a reaction. It was given at 4pm and he had a reaction exactly 40 minutes later. Professor Stevens commented that the notes could have been written in hindsight because going by our timeline of events, it doesn't quite marry up. They're more inclined to think that it was noted retrospectively. The medical staff were busy dealing with a patient, they weren't standing writing notes so that's fair enough, we've no issue with that, but the exact time that microbiology sent their instruction, I don't know.

95. [redacted] went into septic shock exactly 40 minutes after the block went in. Our first recognition that something wasn't right was that [redacted]'s heartrate went through the roof. Cameron told me he saw it was above 200bpm at one point. He was vomiting and he was in rigor and at that point we knew that this was because the line had been accessed to put the antibiotic block in. We knew he wasn't well and we were much quicker to get help in the room. The nurse, Jenny, who put the block in, was brilliant. She reacted very quickly and started monitoring him and doing obs constantly. She had a student stand and just constantly taking his obs. A junior surgeon came into the room, Dr Kamal. I think he was called in by one of the nurses. Dr Kamal was Hettle's junior; Hettle was in surgery at that point. Hettle and Kamal weren't our surgeons, it just so happened that they were the surgeons that were on that weekend. Our surgical team were on their days off as they had just done a big surgery.

96. Dr Kamal started a bolus, which was a rapid fluid infusion to flush his system and to help with this kind of scenario, and he gave [redacted] ibuprofen to try and manage his temperature. He'd already had paracetamol and had already maxed out his morphine clicker so the decision was made to give ibuprofen. That was given orally and within two or three minutes [redacted] had vomited it back up again. Officially, he'd had ibuprofen so they couldn't give him any more and they were desperately trying to manage this temperature and stop it spiking. I'm sure he was up above

40 degrees by that point. I did not feel that Dr Kamal was fully in control of the situation.

97. Around this time, Wendy and Jane, nurse practitioners from Schiehallion arrived. I think one of the junior doctors had gone to them for some advice. They came running in out of breath and started examining [redacted] and talking to him and trying to calm him. They told Dr Kamal not to give him anymore ibuprofen. We didn’t know at that point that you don’t give ibuprofen to chemo kids because the chemotherapy itself stops the blood from making red blood cells and ibuprofen kills red blood cells and it can stop recovery from chemo. After that it was just a waiting game to see if the bolus would work and his temperature would come down and he would stop being sick. There weren’t really any other interventions they could do at that point and all the medical staff were standing back while the nurses kept taking obs.

98. At some point another doctor came in. She was a female A&E doctor; I don’t think I got her name. She must have been the on-call A&E doctor and had been responding to a call to come and assist. She didn’t stay long. When she first came into the room she didn’t speak to us. She spoke to the other medics in the room, looked at a chart and they stepped outside the room and had a conversation and then came back in and asked us some questions about the antibiotic block. She asked who had said it should go in. When we told her ‘microbiology’ she said she could understand that. She then told us that she was an A&E doctor but also a consultant with infection control and that is when she told us that he had a “poo bug” in his line. She told us that it wasn’t a good one and so she could understand why microbiology had put the block in. Then she and the other doctors disappeared out the room again. I think Dr Hettle had arrived by that point. Whoever she was talking to, I think it was Dr Hettle, came back in and told us that [redacted] was getting surgery the next morning to take the line out. So the conversation they had outside must have been that it was better to

pull the line rather than continue trying to save it. We weren't given any more information about the "poo bug" or how [redacted] might have contracted it.

99. When Dr Hettle came into the room, he definitely calmed the room. I was right beside [redacted] and had moved as far up as I could so I could keep a hold of him and so I was right beside Dr Hettle and Dr Kamal at the bedside. I noticed that when Dr Hettle came in, the first person he looked at was Dr Kamal and the look was "are you alright?". It was interesting to see the interaction between them as there was definitely seemed that things weren't going the way they wanted as quickly as they wanted. After that, it seems that the bolus started to work and I think the physical impact of the septic shower started to wear off. The decision was made that the line would get removed the following morning. This meant that the easy access point for treatment would be lost and all the treatment would have to be given through cannulas, which are reliable but don't last as long and mean more needle sticks for [redacted].

100. During this incident, the doctors were in the room quicker; it was the junior surgeon, Dr Kamal that was in the room managing the situation. I didn't let go of [redacted] that day. I held his hand but moved back to let people get in and access him if they needed to but I didn't leave him because I knew that I needed to keep hold of him to keep me calm. I can definitely say that there was a fear in Dr Kamal's eyes that he wasn't in control of the situation because I was looking at him and he was biting his nails and surgeons don't bite their nails. So there was definitely a feeling of things weren't good. Whether we would have felt like that in Schiehallion, I don't know and we'll never know. [redacted] was part of the Case Note Review and one of the questions was why he was in a surgical ward after the surgery and not Schiehallion. The answer was: that is the protocol for that surgery because the surgical ward has the skillset to deal with the wound and the treatment of the wound. Schiehallion may have the skillset to better deal with the line infection but the fact that he got a line infection was a fluke. If he hadn't had the line infection, he would have been in the best ward for the care being a

post-operative patient. It was noted as part of the Case Note Review that perhaps the neutropenic aspect of it wasn't given a high enough priority. That is what left him open to a line infection and if he had gone to Schiehallion we'll never know if it would have been dealt with better. We don't know whether the Schiehallion staff would have been as good at dealing with the pain management and the wound management; probably not, because that's not what they do every day.

101. [redacted]'s line was removed on the 8 August 2018 under general anaesthetic. The lead surgeon, Mr Davies came round to see [redacted] afterwards and see how he was doing after both the line surgery and his big surgery. I was concerned that the line infection might have damaged his heart as the central line is a fast-track to the heart. Mr Davis said that we didn't need to worry about that. He told me that the antibiotics that [redacted] was on were very strong and would kill everything. He told me that the antibiotics he was on were Meropenem and gentamicin. They were the go-to antibiotics that were used in Schiehallion whenever there was a suspected line infection. During this admission, [redacted] had been given prophylactic antibiotics when he was in surgery and then, when he spiked a temperature afterwards he was started on intravenous antibiotics in line with the protocol. When it was confirmed that he had an infection, he remained on those antibiotics intravenously for the remainder of his admission and when he was discharged home he continued to take the antibiotics orally for a further 4 or 5 days. I don't know if the infection was gone before [redacted] was discharged, although he was constantly getting his blood drawn. He was discharged on the 13 September and we were asked by Dr Ronghe to come in to day care on the Monday which was the 17 September.

102. The other side effect of surgery for [redacted], was that it became evident that he was allergic to something and we still don't know what that something was. When he'd had his first line placement, we noticed that he had a rash where the ChloraPrep, the antibiotic wash that they put over the skin, had been. After he

had his kidney surgery, the area where they superglued the outside shut, a big strip an inch wide all across his torso, became red and inflamed and it was an allergic reaction to the glue or to the ChloraPrep under the glue. We're not entirely sure but the whole area, the whole surgical field became intolerably itchy, where we had to lie and hold his hands at night to stop him scratching it because if he was scratching at the wound he was going to make it infected. He then had to be sedated so that we could pick the glue off. We still don't know what it was he was allergic to. That, plus the infection on top of the big surgery meant that it was a really difficult hospital stay for a few days because he was so uncomfortable, he was so itchy, he was so sore.

Meeting with Dr Ronghe and Dr Inkster: 17 September 2018

103. When Dr Ronghe asked for us to go in and see him on 17 September, we thought it was just for a check-up, to talk about how [redacted] was doing. Dr Ronghe came in and sat down asked how [redacted] was doing. He was being very cagey and wasn't chatting the way that he normally would. We now know that that's because he didn't know what he was allowed to say without Dr Inkster being there, he told us that after the meeting. We formed the view that he was angry and upset about what had happened and that the building was not up to scratch, although he didn't say that to us. Dr Inkster was an infection control doctor. When Dr Inkster came in, I got her name after the fact, she told us about the infection and she said that they now had to apologise to us because it came from the drains. We weren't given any more information about the drains, or which drains they thought the infection had come from. We were just told that it was a hospital acquired infection and they were very sorry. She said it was an ongoing situation and they were addressing it. She said it shouldn't have happened and they were now working to try and make sure it didn't happen again. She told us that [redacted] was one of six children who got ill that same weekend and they were looking into it and trying to solve it and they were going to close the whole Schiehallion unit and move it somewhere else. It was only the Schiehallion unit

that was being moved. Angela, the staff nurse in the Schiehallion day care unit, later told me that they were closing Schiehallion as a precaution as there were immunocompromised kids there who were at risk if there were bugs. The rest of the children's hospital didn't need to be shut as kids elsewhere in the hospital weren't immunocompromised and could fight these bugs. The doctors didn't know where the unit would be moving to at that point, they were working with estates management to try and work something out. They thought potentially somewhere in the adult hospital. We were told what the bug was, serratia marcescens, and they described it as a biofilm. They said it's a build-up that happens in drains and it's in your drain at home and it's soap that causes it. They described the pink stuff you might find in your bathroom on the side of the bath. The bacteria grow and eats the soap. They said they had been having problems with it in the ward and had been trying things to get rid of it but [redacted] was infected with it. We sat in stunned silence and really just said "oh okay". We made light of the issue and said that, compared to the surgery he had just gone through, the infection was not our biggest concern. The doctors' response to this was that this infection was the most concerning thing about [redacted]'s stay in hospital, not the removal of the kidney, the removal of the cancerous growth or the stay in PICU. We weren't expecting that and we didn't ask any questions about it. To be honest it went right over my head as I was just thinking about what was coming next. We now know he had this infection, but he was okay and I was focused on what the outcome of the surgery was and finding out the staging of the tumour so we could deal with the next stage of treatment.

104. When the Case Note Review was being carried out, we asked whether it was possible to pinpoint when [redacted] had contracted this infection. We were told he could have contracted it up to two weeks before it manifested itself. He could have caught it in 2A, but he could also have caught it in surgery or 3B, we just don't know. It is possible that he could have caught it when the bathroom flooded in the VAC room in 2A as it is within that timeline. We just don't know.

[redacted]'s ongoing treatment and announcement of decant to Ward 6A: September 2018

105. After this meeting, [redacted]'s treatment continued. As a result of his infection [redacted]'s treatment wasn't delayed, but the doctors did have to change the way his chemo was administered. When [redacted] had his surgery, they removed the tumour from his kidney which went to pathology for analysis. The results of that analysis were discussed at a "tumour meeting" between radiography, pathology and the Schiehallion team. The feedback from that would then dictate the next course of treatment depending on what the staging the tumour was. If it was stage one which is completely contained in the kidney, no spread at all, then he would get four more weeks of chemo and that would be the end of his treatment. If it was stage two, then it would be six months more of chemo and that would be the end of his treatment. When the pathology report came back, the entire tumour was necrotic which meant everything was dead and there was nothing left to test, so they were unable to stage it. Because of [redacted]'s age, it was unusual that he would have this type of tumour and because they couldn't give a decisive staging, the decision was to err on the side of caution and go with six months' treatment. It took them two weeks to come to that decision and in the intervening week, [redacted] was to come in and get either the first chemo of either a four week or six-month plan. Dr Ronghe said that, if he was only getting four weeks of chemo, it could all be done through a cannula. If it was going to be six months, then they would insert a port-a-cath. As the decision on the six-month treatment hadn't been decided by the time of his first chemo session, he had to get it through a cannula. When went in that Thursday, which was the 20 September, he had to get his entire chemo treatment through cannula. So his chemo wasn't delayed as a result of the infection and the line coming out, it was just given differently. It also meant he had to undergo another surgery under general anaesthetic to get the port-a-cath inserted.

106. That appointment where they had to give the chemo through a cannula was one of the most traumatic day care appointments that we had because

Cameron and I both were pinning [redacted] down while two nurses were pinning his arm down to keep it completely still. That was hard going. That was a really difficult one. [redacted]'s fear of needles had built up through the course of the surgery and the infection, because it wasn't really that big an issue before. He had just had so many needle sticks, and so many failed needle sticks, during that time. He is usually a very logic-minded boy, he doesn't let emotions override him, but I think that this had all been too much for him and it took him a long time to get over it.

107. When the decision was made that [redacted] was going to get six months of treatment, he was booked in on 26 September to get his port-a-cath fitted. This is a subdermal access so the line is put into the vein the same as a Hickman line but there's a little device, with three lumps, shaped like a triangle, that is inserted under the skin. To access it, the nurses come and they feel the three bumps and then they insert a needle through the skin into the port and that's the access point. So it's a jag every time but when you're not using it, the skin is closed which means there's less risk of infection so that was the preferred option because of the issue that they'd been having with the Hickman lines.

108. [redacted] had chemo on the 20 September and he had to have his chemo through a cannula. He then spiked, which was a reaction to his chemo, and he had to be admitted to ward 2A on 21 September. He had to have all his treatment through a cannula on that occasion too. It was during this stay that we were told that ward 2A was definitely moving to an adult ward and when we found out that was going to have his surgery for his port-a-cath on 26 September, we were told that was the day Schiehallion was moving. We were being told all of this information by Angela, the day care manager staff nurse. All we were told was that the whole ward would be moving and taking up a unit in the adult ward and it would be for us only. There wasn't any reassurance given that the Schiehallion protocol would be moving with us but we didn't really ask for it; we were just assuming that everything would be fine. Angela told us that it would be for a few

weeks because they needed to do work on the drains and pipes so everyone needed to be out of the way. Dr Ronghe told us the same as Angela when we saw him, just that we were moving upstairs and it will just be the same except in a different bit of the building.

109. There had been informal chat about the move and bits of paper handed out. We got a letter dated 18 September 2018, a copy of which is attached to this statement **(CG/02 – Appendix 2)** telling us about that there was a new cleaning process being introduced on ward 2A and that we would be moving to one of the adult wards to allow some work to be carried out on 2A which was linked to the infections.

110. On this same date we also got a letter dated 7 September 2018, a copy of which is attached to this statement **(CG/03 – Appendix 3)** telling us that we should access the hospital via the discharge lounge of the adult hospital. At this time a window had fallen out of the adult hospital and smashed on the pavement so there was scaffolding at the main entrance to the adult hospital and there was no entry whilst they carried out the work. At the same time, there was work on the cladding being carried out at the main entrance to the children's hospital. I don't know if this was anything to do with what had happened at Grenfell. This letter told us that the work that was being done on the cladding could cause dust which could affect the air quality so, as a precaution for all the immunocompromised kids, we should not use the main entrance to the children's hospital and should instead come in through the adult discharge lounge. This meant quite a walk as when you came in that entrance you had to walk into the adult atrium then through the link corridor into the children's hospital then upstairs to ward 2B for day care. That entrance was always crowded with smokers as well so it wasn't great. We used that entrance until the decant to 6A at which time I queried why we had to use it and I didn't like it because of all the smokers and we were told that we could use the main entrance to the adult hospital.

111. The move to 6A happened on 26 September 2018 and we were initially told, informally, that it would be for 4-6 weeks. At some point, I can't remember when, Angela told us that the decant would be more like 3 months and we would probably be in 6A until after Christmas. Then, on 6 December 2018 we were told that the decant would be for another year. We were told that when they were looking at 2A, it wasn't just the pipework that was an issue but actually the air conditioning units weren't up to scratch when the building was first built so they were going to retrofit something whilst the ward was shut. This was all informal through Angela and we weren't given any formal explanation about the ward closure, or an explanation about what work was being carried out in 2A, or given any updates on progress.

Admission to ward 1A in the RHC for surgery and decant to ward 6A in the QEUH: 26 September 2018

112. [redacted] went into ward 1A in the RHC on 26 September which was a surgical ward to have his port-a-cath inserted. We hadn't been in this ward before. It was a day ward, so the children would go in and go into bays and then would go round to surgery and come back to a bay. We were immediately given gold standard treatment. They knew we were Schiehallion and we got a wee VAC room in behind the nurses' station. The standard procedure was that when your child went to surgery, you then had to go and wander about and wait in the waiting room outside, but because [redacted] was in a VAC room, I could sit in his room and wait for him. That room was very clean. In fact, when we got there we were told they were just finishing cleaning the room, so I did feel confident that the room was clean. Then the doctor that came to do his pre-op admission was one of the juniors from the surgical ward that we had just been discharged from so she knew us and she was very pleased to see [redacted] looking well. He went away for his surgery and I stayed in his room until he came back so I was with him as soon as he came back. That unit only stays open until seven o'clock at night because usually the children that have been in for their tonsils out, or whatever,

are either sent up to the surgical ward to be admitted or sent home. We were then transferred up to ward 6A, which was the "new" Schiehallion unit in the adult ward, in order to stay overnight for [redacted] to be monitored as he had a general anaesthetic. We had a good experience in 1A.

113. When we got to 6A everyone was rushing about trying to find a place for everything. They didn't stop. The auxiliaries were in and out of each room asking if we had what we needed. No bed had been put into our room yet, so they had to go and find one for [redacted] and one for me. They were full of apologies because there was no kitchen for the parents. There were no facilities and they were just so apologetic that it wasn't up to their usual standard. They looked after us as [redacted] hadn't had dinner yet and there wasn't much left so they got him a sandwich from the staff kitchen. They really were very kind even though not one of them stopped the whole time we were in.

114. Despite how busy they were, there was absolutely nothing we could complain about. [redacted]'s obs were done on time, his medication was given on time. The next day he had to wait all day for his chemo, as the day patients get priority, but he got his chemo about 5pm and we were discharged.

Description of 6A

115. The adult hospital looks like a square in the middle, this is where the big atrium is, and then there are 4 legs that come off the square at each corner so it looks like a X. Ward 6A looks a bit like a Y shape. There are two corridors on the square part of the hospital that meet at a right angle at the corner of the square and then the main part of the ward is on one of the legs of the X that comes of the square centre. The entrance to the ward is on one of the corridors on the square part of the building and there are rooms to the left hand side of that corridor as you come into the ward. The right hand side looks out onto the atrium. You then go right round the corner and onto the other corridor which is on the square part of the building. There are rooms on that corridor too which

look out onto the car park. There is an exit door on this corridor, but this was only accessed by staff. The main part of ward 6A is on the leg of the X that projects out from the square centre and there were rooms on both sides of this corridor with toilets, facilities and storage rooms down the centre. At the end of the ward is day care. At the very end of the ward there was a big window which gave great views over Glasgow. All the day care patients had to walk right through the ward to get to day care and it meant the ward was always busy and had loads of through traffic. On [redacted]'s first admission in 6A we were in a room right up at the entrance to the ward and right next door to us was a store room and there was somebody in there the entire night shift putting stuff in, tidying, finding homes for things.

116. The rooms in 6A were still single rooms with en-suite bathrooms, but they did not have the fold away parent beds which had memory foam mattresses. We just got a “z-bed” which had mattresses that folded in half. They were rubbish and didn’t have the proper support. They were okay for one or two nights but if you’re in for anything long-term then it’s an absolute waste of time. Then, of course, when it’s folded up, there’s nowhere to put it because the rooms in the adult ward are not designed to have a space for a parent or for a fold-down bed so there wasn’t even a bit of wall long enough or square enough to sit it against.

Facilities

117. There were no kitchen facilities for parents in 6A. We would bring our own kettle and flask so we could get a hot cup of tea. It was only post-event when I went to Jak’s Den and got some counselling to help deal with some of the traumas of it the counsellor was aghast when I explained that we took our own kettle in and we took our flask to have a hot cup of tea in the middle of the night. She said we were effectively camping in the hospital and that was not okay. But we did what we had to at the time. We just found a way to get through it.

118. There were no play facilities for the kids. They improvised a wee plastic table and two chairs, like an Ikea-style wee plastic chairs in the corridor. This had colouring in stuff, but there were no toys. The play team, at that point, didn’t even have a cupboard up in ward 6A, so if somebody wanted something, they had to go all the way back to the children’s ward to get it. Part of the remit of the play workers was to manage a scheme called the Beads of Courage. The children are given a string when they start treatment and for every single thing that happens to them in the hospital; so every needle prick, every x-ray, every meeting with a specialist is a specific little bead. These beads then get threaded on and its part of a counselling thing for the children to be able to represent their treatment. At the end of it, they have these big long strings with all these beads on it that show their journey. We would get a sheet and fill in what beads we were to get and the play team would get them for us. When you handed the sheets in up in 6A, they would run all the way to the children’s ward to get them and bring them back to you, but loads of kids didn’t get their beads for months and months and months because that was the lowest priority. For some children that really was a reward and really important they were able to put the beads on their strings.

119. The TVs were smaller generally in 6A. and the Wi-Fi was as sporadic as it was in the children’s hospital. The auxiliaries would come into the room asking if we had all that we needed and if the TV was working. At that point they were still getting to know the ward and at that point there were a lot of breakages and a lot of things not working. They were on it. They got an awful lot of things fixed as quickly as they could but obviously the PlayStations and Xboxes were in high demand at that stage.

120. In terms of the staffing and the protocols, that was all the same as ward 2A, it was the same staff team. There were some rooms in 6A where you felt quite isolated, like you were on island because no one walked past your door,

but you always had your buzzer and your assigned nurse would come and see you if you buzzed them.

[redacted]'s ongoing treatment: October –December 2018

121. [redacted]'s chemo continued as a day care patient and he would attend day care in ward 6A. He had several times throughout this period when he spiked a temperature in reaction to his chemo. If this happened, then we would be admitted through the CDU unit in the RHC to ward 6A if it was out of hours, or through day care in ward 6A if it was during the day.

Stay in ward 2E in the RHC: 13 November 2018

122. There we some occasions when we had to be admitted to other wards in the RHC when [redacted] spiked a temperature, because there was no room in 6A. The first time this happened was on 13 November 2018.

123. We were admitted from day care to ward 2E in the RHC which was a cardio ward. We hadn't been told by anyone at the hospital that it was a possibility that we would have to go to other wards, but we had been told by other parents that it might happen.

124. When we got to ward 2E were given a VAC room as [redacted] was a Schiehallion patient. The cardio ward was heavily staffed and they were on top of all [redacted]'s observations and there were actually monitors showing the obs on the wall outside the room because it was for cardio kids, so he was well monitored. We really rated that ward. Because it was a VAC room, the staff had to adhere to the VAC room protocols. This meant that the staff should wash their hands in the room outside the bedroom before and after they came in to the room and they should wear gloves and an apron. All of the VAC rooms we were in had double doors with the room in between where the sink was for washing hands We were actually in isolation; we didn't come out of the room. That was to protect [redacted]. We were advised by the nurses not to take him to the playroom as

there were lots of "snotty" kids there and we were advised it was safer to just keep him in his room. So he could have used the playroom if it had been safe for him. There was also a staff kitchen that I had access to and because we were back in the children's hospital, there was a parent's bed for me in the room, not a "z-bed". We were in for two or three days just for him to be monitored and then we were discharged.

Stay in ward 3C: 7 December 2018

125. The next time that [redacted] spiked was on 7 December. This time it was out of hours and he was admitted through CDU to ward 3C in RHC because there were no beds in 6A. Cameron had major issues with the nurses in CDU accessing [redacted]'s port during this stay. The port is harder to access and fewer people are trained in that than the Hickman line. On this occasion, they were trying to access the port but would miss, so when they were sticking the needle in it wasn't going into the port, but it was sticking into [redacted]'s skin. After five failed attempts, Cameron said, "enough already" so they started a cannula to get the antibiotics going.

126. [redacted] was then admitted to ward 3C is an orthopaedics ward. This was a hard stay, although it was mainly Cameron who dealt with it as he dealt with the admission. [redacted] got a VAC room, but it was not a good experience in terms of the care that [redacted] got. Cameron was phoning me at home and telling me that he was having to shout to get attention. He felt the nurses weren't attentive at all and they weren't properly monitoring [redacted], whose temperature was continuing to spike. He found it really concerning as we'd witnessed how bad a line infection could be and we didn't know that it wasn't that at this stage. The experience was so bad that Cameron put in a formal complaint to the hospital using their complaints procedure.

127. In ward 3C they worked with the cannula for a while. The nurses there did not make any attempts to access the port and said they would try and get

someone from Schiehallion day care to come and access the port. Dr Ronghe came and said that he wanted to make sure that the port was okay as he was worried that there might be a reason that the CDU nurses had had difficulty accessing it. When he said this, Cameron was worried that [redacted] had a line infection and that was why he was spiking. As no one had accessed the port yet, no one knew if it was compromised or not. So Cameron put [redacted] on his back and ran him along the corridor and up to 6A. Rather than someone from day care coming to us, he took [redacted] to them and they accessed the port first time as they do it all the time. They took the cultures and it came back that it wasn't a line infection so it had just been another reaction to the chemo. I wasn't there for any of this. By the time I got to ward 3C it was the night shift. Everything was timely and the staff were great. The spike had ended and the fever had broken. I took over to do the night shift and Cameron was pretty broken. That's the worst I've seen him because he didn't sleep at all. He couldn't relax at all because he didn't feel that he could. He just didn't feel [redacted] was being cared for

128. The next day, [redacted]'s skin had started to react under the dressing. If you can imagine they've put the access point through the port and then they've put a big sticky dressing over the top of it to stop the line that's in from falling out, to give it a bit more purchase. His skin started reacting underneath that dressing. I told the day shift staff about the inflammation, but because they weren't trained in dealing with a port, they didn't want to touch it. I kept asking for someone to come and nobody came. Their answer was to just put another plaster over the top so that didn't help treat the allergic reaction that was happening. Finally, someone from Schiehallion came down at nine o'clock that night to change the dressing and give him Piriton. I had been saying from about one o'clock that afternoon that there was something going with the dressing. The nurses in 3C had phoned someone in Schiehallion but they hadn't told me that they had done that. I only knew once they arrived. So when we were discharged from that stay, he was on steroids for four days to try and treat the skin reaction.

129. We then had a referral to dermatology that following Monday on the 10 December 2018, which was a referral that had been put in post-surgery because of the reaction he had to the dressing. That's one of the worst appointments I have ever had with [redacted] because he just wouldn't let that doctor touch him or look at him. He wouldn't even lift his t-shirt. He was just so uncooperative. I was getting irritated with him, but then the calmer person in me was saying that he doesn't want anybody to touch him because he's just fed up of being poked and prodded. The Holy Spirit was with me that day because I didn't shout at him. I just gave him a big hug and when we were finished we went for doughnuts. He had had a rubbish weekend because it was a particularly bad spike as well. He didn't sleep well and he was just feeling terrible. The knock on effect of all these little things that didn't need to happen meant that he became difficult to engage and work with; this was all knowing that we still had another five months of treatment to go.

Complaint about stay in ward 3C

130. On our next visit to day care on ward 6A on 11 December we told the staff there about our experience in ward 3C. We were saying that, although we didn't want [redacted] to be in hospital over Christmas, after the stay on ward 3C we had gone from saying, "I really hope we're not in over Christmas" to just, "I really hope we're not in orthopaedics". I don't care if we're in Schiehallion over Christmas, just don't put us back in ortho again because it was just grim". The staff in Schiehallion told us that we should put in a complaint because otherwise nothing will change. They knew about what had happened because they were getting the phone calls about accessing [redacted]'s port. They wanted to come down and help but their seniors wouldn't release them to go and help. They were pleased when Cameron showed up with [redacted] on his back and were relieved that they could help. So it was after that conversation that we decided put in a complaint. We took a few days to do it as we took a bit of time to write it without trying to be vindictive and without trying to be just angry, to take the emotion out of it.

131. We went through the official hospital procedure for complaints. We didn't hear anything for weeks and weeks and weeks and then Cameron prompted them to say nothing had come back. We got a reply saying they were very sorry and that they would respond in “x” number of days. Those days came and went and we didn't hear anything, so we sent another email prompt. Someone from the official complaints department, I don't know who they were, had a meeting with the nursing team and it was all discussed with the nurses in question. We then got a response dated 7 February 2019, and they were full of apologies and said extra training will be put in place for any gaps and they recognised that the failings that we pointed out should not have happened. We were satisfied with the way the complaint was dealt with as long as the changes would be made. When we did return to 3C a few months later it was a better stay.

132. After this stay in ward 3C on 7 December 2018 [redacted]'s chemo continued as a day care patient. He had another spike on 28 December and was admitted to ward 6A. Again this was just a reaction to the chemo, not an infection.

133. During this whole period when we were moving around between wards, there were filters on all the taps and as Schiehallion patients we were drinking bottled water.

Fungal Issue on ward 6A and decant to CDU: 17 January 2019

134. Once we got into January 2019, [redacted]'s chemo continued and he spiked on 17 January and was admitted to 6A via day care. At this time there was a fungal issue on the ward which was being blamed on pigeon poo. We had only heard about it on the news and saw it on the chat among the parents on the Schiehallion parents' page. We thought “what now?” and that this was ridiculous. There was a lot of anger on the Facebook page that we hadn't been given any information about this from the hospital. When we went into the

hospital on that occasion, there were HEPA filters in the corridors and in every room. We were given very little information from the nurses on the ward about what was going on. We were not told anything official by the hospital at this point, we were only being told by Angela, the day care staff nurse that there was a fungal issue in the hospital and the filters were there as a precaution because the kids were immunocompromised and were too precious to risk. She was the person who was giving us all the information at this point and the poor woman was in the firing line every time. It was about a week later that we got a letter from the hospital telling us about the pigeon poo. This letter is dated 23 January 2019 and I have a copy which is attached to this statement **(CG/04 – Appendix 4)**. I think we only got this as the parents were so angry about the lack of information and what we were hearing in the press. That was the first instance of the hospital deliberately making sure everyone got a copy of a letter. January 2019 was the point that they started giving us formal headed notepaper letters. We got a copy at day care and it was also posted to us so it had obviously been posted out to every patient on the unit. This letter said that people had been infected. This is what it said: "*I write to you to personally offer reassurances that we are taking these issues very seriously and we apologise for any anxiety it may have caused. We're focussed on ensuring a safe environment for all our patients and are actively managing this instance. As you will have seen from the news reports, we're investigating two isolated cases of an unusual fungal infection, Cryptococcus which is linked to soil or pigeon droppings. These were identified in December and the likely source detected and dealt with immediately*." It is basically saying that there's nothing left to worry about so stop worrying about it.

135. Around about this time, we were starting to see orange seals around some of the bedroom doors, and they were closed for repair work to be carried out in specific rooms. We saw that happen on a couple of rooms up on ward 6A, but never when any of us were in them, obviously. They did it while the rooms were empty. During [redacted]'s admission for a spike on 17 January, I think he was moved

rooms because there was work being done in the room next door. Cameron was with him at this time so will know the details better. They had just moved and got settled into their new room when they were told they were getting moved to the CDU.

136. On 19 January, the whole ward was decanted down to CDU for a week and a half or two weeks while they were repairing flaws in the bathroom seals. We noticed that some of the bathrooms in ward 6A weren't up to scratch. Some of the flooring was peeling off the walls and some of the seals weren't properly sealed so there was bacteria and fungus growing and it needed to be fixed. We took over that ward. It was no longer CDU. It was now Schiehallion in CDU and CDU were moved up to ward 2A to allow the work to happen in 6A. The day care unit moved to ward 1A in the RHC.

137. There had been an awful lot of chat on the parent's page about how the Professor, that is Professor Gibson, had been having meetings and information sessions with families about the issues on ward 6A at that time. There was an awful lot of panic among a lot of the families at that point. We weren't at these meetings as she wasn't our consultant, she was the consultant dealing with the kids with leukaemia. From what I heard on the Facebook group, these meetings consisted of a lot of discussion around the anti-fungal medication that the kids were being given. Professor Gibson was on the ward on 19 January and I don't know whether it was her that came and told Cameron that they were moving but he got very upset and very angry that they were having to move rooms again. He had arrived in with [redacted] spiking, he got no sleep for the first 24 hours while the temperature was being managed and he'd unpacked the basics of the suitcase, in which he'd had to bring his own kettle and flask, and he now needed to pack it all up again to move room again. He had had enough, he was knackered. So that was difficult. I wasn't in the hospital at that time, but he was on the phone telling me what was going on so that I knew where to go to when I came in to do my shift change.

138. When [redacted] was in hospital on this occasion, Dr Ronghe came to visit, doing his usual daily rounds with us when we were in and he told us what was going on and what would be happening next. He told us that there were repairs being done to the bathrooms up in ward 6A and that when we went back to 6A the filters would still be there. He also mentioned that there was an antifungal medication that they were prescribing for a lot of boys and girls that were on the ward but [redacted] wouldn't be getting it because it can react with the vinc. He reassured us that, because [redacted] was in and out of the hospital, because he wasn't staying for any length of time, then he wasn't at such a high risk of contracting a fungal infection, so he was satisfied that, we were better off not giving him it because if he did, he would need to change the vinc protocol and, they were better off continuing with that. All he said about it was that it was a fungal thing and that they were giving prophylactic treatment to all the children to protect them, but as he had explained why [redacted] was getting it, it didn't impact us. I had also heard through the Facebook group that the anti-fungal medication might have had some side effects so I was quite happy that [redacted] wasn't getting it and I didn't ask Dr Ronghe anymore about it.

139. When we were decanted to the CDU all the staff came with us and it was back in the children's hospital so there were parent beds and there was a playroom for the kids so they got to mix again. It was actually great for us because it was on the ground floor. My mother-in-law is disabled and on a wee scooter but was claustrophobic so couldn't go in the lift. She hadn't actually been to visit [redacted] in the hospital because she couldn't get up to his room. So when he was in CDU, she could come and visit.

140. [redacted] continued to have his chemo during the decant to CDU. He had a couple spikes where he was admitted there, on 1 February and 9 February and then the next time we went in on 21 February, we were back in 6A for day care.

Return to ward 6A: 21 February 2019

141. As I say, [redacted] had chemo in day care on 21 February and then was admitted with a spike on 27 February to ward 6A. I didn't notice any improvement in the bathrooms in ward 6A when we returned after the decant to the CDU. At this time, it was kicking off with the parents about why the kids were on these prophylactic drugs. It was building up in February and March and finally the hospital started having meetings with the parents in April/May time.

142. The HEPA filters were still on the ward and we weren't told anything about what was happening. We were just told to come to 6A if you have a spike.

143. After this admission, [redacted] had a couple more chemo sessions in day care and then had his last spike on 26 March 2019 and that is when we went back to ward 3C as there was no room in 6A.

144. We had a much better stay this time. The nurses who we had complained about stayed away from us and we were given a different nursing team, but it was definitely an easier stay. Everything was timely and he wasn't as unwell.

145. The Cleaners were also amazing. I had met the cleaner coming in, she was also the cleaner in Schiehallion. She asked me what I was doing there and told me that the room we were in had been gutted from top to bottom, so we knew it was clean.

146. There was one thing that happened with water during this stay in ward 3C. I went into the kitchen to get [redacted] a drink because I had left the suitcase in the car until I knew where I was taking him. We didn't have any supplies and he was thirsty and wanted a drink so I went into the kitchen, to get some water. The chief nurse of the renal unit was there, half of 3C is ortho, the other is renal. She told me to take a jug and get some water, but I told her that we were Schiehallion and would need bottled of water. We ended up using the tiny, wee

sterile bottles that are used for babies just so that he could get a drink until I brought in our supply from the car. Apparently by that point the water was fine to drink, although I was never officially told that by anyone. Across the board in the hospital the water issue had been solved but Schiehallion still weren't taking any chances.

147. That was [redacted]'s chemo finished. He had an ultrasound and an x-ray on 27 March 2019 which was us getting started on a three-month regime of ultrasound and x-ray. We went every three months from then for an ultrasound to check that his other kidney is functioning properly and that everything's still as it should be. The x-ray is to check for any spread in the lungs. We had a day care meeting with Dr Ronghe on the 4th April 2019 and that was to tie up treatment, to discuss the three monthly consultation which was just for keeping a check on [redacted] and to reassure us. He said that hopefully [redacted] will be okay and when he turns 18 he would be transferred to adult care and be monitored every five years. He'll be monitored his whole life because he's had chemo and this puts him at greater risk of various different things.

148. On the 8th April he had day surgery under general anaesthetic to get his port removed and they sent us home. We were allowed to then care for him because if he had a spike at that point, we didn't need to worry about a line infection so we were given back control.

149. He has been having his three monthly checks ever since, and since two years have passed, we have just moved on to six monthly checks.

WATER: EVENTS INVOLVING WATER SYSTEMS

150. There were some specific incidents that happened involving water when we were in the RHC. When we were admitted to ward 2A in July 2018, we were told that there had been issues with the water.

151. We were told to use the bottled water for drinking. When we first went on to the ward there weren't any filters on the taps, but they appeared at some point in the first month. We were told by the staff that there had been issues with the water at the start of the summer. It was on the news apparently, but we didn't pay attention to it and weren't aware of it. When we did mention it other parents they told that there had been an issue and that's why the filters were on the taps and why we're using bottled water. It was very much played down by the staff. Whenever you asked about it they said to use the bottled water and the filters are on the taps and not to touch them, or interfere with them. And that was it.

152. We were allowed to use the water for washing, although there was a sign in the bathroom telling you to run the water for three minutes before you use it in the shower every day. We were also told by staff to run the water before we used it. I assumed that was for Legionnaires. There was also a sign saying "for handwashing only" at the sink in the bed area so we did tooth brushing and stuff in the bathroom. We used the water in the bathroom to brush our teeth and nobody told us we shouldn't.

153. In August 2018 there was the incident in one of the VAC rooms in ward 2A. The water flooded out of the shower and ran right through the bedroom and into the corridor. The nurses did not seem surprised by this and said it had happened before.

154. We weren't aware of any rooms ever being sealed off, or work being done whilst we were in ward 2A. We were in and out though so it is possible it was happening but we just never saw it.

155. When [redacted] was in ward 3B in the RHC in September 2018, before he got his kidney operation there was no filter on the tap in that room. When we were in

the second room, after the operation, Dr Ronghe came in and noted that there were filters on the taps this time. It was only after the fact, in discussion with him, that he said, yes, those filters should have been on the taps in the first room you were in. The filters on the taps and stuff wasn't really on our radar at that point. We were just eyes on [redacted] the whole time

156. Once we were decanted to ward 6A, the issues were not so much with the water, but with the conditions of the bathrooms and that is the reason we were decanted to CDU for a few weeks in January 2019.

Water: Communication

157. We were not told very much about why bottled water was being used and why the filters were on the taps. We just assumed it was for infection control. All we had been told was that there had been an issue with the water at the start of the summer in 2018. We were not aware of what that issue was, or whether it was still ongoing.

158. When [redacted] had his line infection in September 2018 we were told what the infection was, that it was a Hospital Acquired Infection and that it had come from the drains. At that point the hospital were aware that there had been other instances of infections so we knew that they were planning to close ward 2A to allow the issue to be sorted.

OTHER ISSUES RELATING TO HOSPITAL CONSTRUCTION

Air conditioning

159. The air conditioning did not work in many of the rooms in ward 2A. There were control panels on the walls, but they didn't do anything and more often than not, the rooms were incredibly hot, which wasn't great if [redacted] was spiking a temperature. The only place the air conditioning worked was in the VAC room that we were in that one time in August 2018. The staff just seemed to accept

that it didn't work in most of the rooms and that was it, nothing was ever done to fix the problem that we were aware of.

Issues on ward 6A

160. There were issues on ward 6A once we were decanted there. The bathrooms were not in a good state. In quite a few of them at the corners where the materials met, there was seal and that seal was broken in a lot of places and there was also a black rubbery seal between the floor and the wall and that would be degrading at points as well I was quite surprised at the state of disrepair that it was in, given that it was a brand-new building. It shouldn't be that degraded already because this stuff's built to last and it's built to be used regularly. It's built to be washed and disinfected regularly so I did wonder why it was already falling apart. There were quite often bedrooms closed off in ward 6A for remedial work to be carried out, although we didn't know exactly what was being done.

161. There was the issue with fungal infection related to the pigeon droppings that led to all the HEPA filters appearing on the ward. All the parents were very worried about this, but it was very much played down by the hospital and were told not to worry and that they were dealing with it.

162. As far as we were aware, the decant from 6A to the CDU was for the bathrooms to be fixed. I don't know if the clinical staff or the hospital board were being up front about this. We were told as little as possible. I'm assuming it's for self-preservation. I feel that the board only told us what they had to tell us in case we would sue them. You really did feel that they were being very protective of their position, and the clinical staff didn't know what information they were allowed to tell us so they just told us nothing.

HOSPITAL ACQUIRED INFECTION

HAIs: events and impact

163. [redacted] had one healthcare associated infection. That was the Serratia Marcesens infection he contracted in his line in September 2018 when he was in getting his kidney operation. I have described the circumstances of the infection in more detail above. The infection and the additional surgery where the line was removed, slowed his recovery from his kidney surgery. However, he was very unwell after the kidney surgery. We have photos from that time and he was so skinny, so drawn looking and weak, very, very weak but you would expect that after a major surgery. We'll never know the physical impact the line infection caused on top of that. The physical recovery was perhaps a bit slower because of the infection but we're not sure. I can definitely say there was an emotional impact for him with regards to needles and that was an ongoing impact. That was very apparent. Bribery with Lego mini figures wasn't going to cut it anymore.

HAIs: Communication

164. We felt that the communication surrounding the infection was adequate in terms of telling us what had happened to [redacted], but we weren't given any wider context. Dr Ronghe and Dr Inkster didn't explain that there was more than one issue with the hospital and when they said there were six children who got sick they didn't say that all of those children were sick with different bugs. We didn't know until we did the Case Note Review that, actually, [redacted] was the only one who had that particular bug. These six children all got sick from different things that came back to a water issue or a drain issue which, to me, means there's more of a problem. It wasn't just one bottle of Coke that everybody drank from and got sick. It was multiple points of contact. They also didn't explain to us the wider concern about the ventilation systems in 2A either. The first we knew

that there was an issue with the ventilation was when we were told, informally, by Angela that there was to be a retrofit of the ventilation system in 2A whilst it was closed. This was when we had already been decanted to 6A. We weren't told anything about what the issue was or why there needed to be a retrofit. They weren't upfront about any of it.

165. We were very, very surprised reading the case note review about the number of line infections that there were. It wasn't made clear to us how common it was. It wasn't made clear to us that for most children who get chemo, they will get a line infection at some point or most children who get chemo will get more than one-line infection. In fact, we're very lucky we only had one. That was quite scary that that was the norm, that it was normal for children to be in that state of ill health.

166. It's hard to quantify whether the issues with the water or the issues with the ventilation had a physical impact on [redacted]. Whenever we were spiking he was in a room that was 25 degrees but we'll never know if it would have been different if the building had worked. The water issue was there and we dealt with it. The ventilation issue, where the air conditioning wasn't working and the rooms were all really hot, was there and we dealt with it because ultimately the chemo was harder for us.

167. I think the issues with the hospital which led to the decant to ward 6A compromised [redacted]'s safety and care because the nurses were constantly having that extra level of anxiety, that extra level of hard work. They're already doing a very complicated job and then the ward as moved and they don't know where anything is. Their system that they had set up so brilliantly in 2A has suddenly disappeared because they don't know where the stuff was. The extra levels of cleaning that was going on always astounded us from the nurses. The nurses cleaned absolutely everything that they touched and used and then when they'd finished using it, they cleaned absolutely everything again. To have the extra

strain of all the building issues on top of them is something you can't quantify but it must have been something that wore them down. I would love to know the turnover of staff before the decant and after the decant because I'm sure there were a lot more leaving. It must be hard to retain staff through that. I'd say there was an extra level of anxiety for them all. They were the frontline for all the abuse from parents and also especially after the line infection stuff, their professionalism was getting questioned because if there's a line infection then it's the nurse that did it who is at fault. The nurses were getting questioned and their ability was getting questioned. To work with that level of anxiety on top of your job, that's unfair. It's unfair that they took the brunt of it when in actual fact it was the drains and it was the taps. Their protocols were robust.

OVERALL EMOTIONAL IMPACT ON [redacted] AND HIS FAMILY

Overall emotional impact on [redacted].

168. [redacted] became institutionalised. We all became institutionalised. He became isolated because he was in isolation all the time and after he'd finished treatment we really had to work hard to remind him how to play with other children because he spent time only with adults. That probably would have happened anyway, but not to the same extent because he wasn't even interacting with his peers on the ward once we moved to ward 6A. Had he been playing with other children on the ward then that would have made a big difference to him. The fact was, he had one-to-one attention from adults all the time and when treatment stopped we had to reverse all that, remind him that he's not the centre of the universe. I think this was a direct consequence of the decant to ward 6A where there were no facilities. We were just in isolation all the time and it wasn't just him; it was us as well. We were in isolation all the time because once we were moved to ward 6A there was no facilities for us to use or anywhere for us to socialise with any other parents. We weren't allowed

to go into other people's rooms so we were stuck in our room the whole time. We forgot how to interact with normal people.

169. There was also the issue of [redacted]'s fear of needles and that was really exacerbated by the experience he had when he had the line infection when several different doctors were trying to take blood from him unsuccessfully. We had to work really hard with him to get over that fear.

170. I think that the decant, the frequent moves, having to be in different wards and never really knowing where you were going to be if you came in for a spike had an effect on [redacted]. If nothing else, the impact on the family had an impact on him. That element of it was the bit that drained us. It wasn't the fact that [redacted] was getting chemo. It was the fact that we never knew where we were going and having to pack the bag ready for whatever eventuality, that was wearing on all of us. For him, he very much felt as though he was part of the Schiehallion family and the fact that he got to know the nurses so well and they knew him so well was a massive bonus to his treatment. So when he wasn't in that ward and it was people that didn't know him, that made it harder. It made it harder for him to be relaxed and comfortable.

Overall emotional impact on witness

171. The drip, drip, drip of not knowing where we were going to end up when we were admitted, especially after the ortho stay on ward 3C, and the anxiety about whether or not the nurses would be on it meant we didn't relax. We were like a cat on a hot tin roof whenever we were admitted. We had to clean the rooms and we didn't feel safe in the building when you're supposed to feel safe.

172. The rooms themselves in 6A weren't user-friendly at all. The furniture didn't fit. It was just harder at a time when you don't need anything to be harder. At the end of it, when [redacted] rang the bell at the end of his treatment I went to the GP and said, I'm supposed to be joyous but I'm just broken. I just don't want

to do it anymore. I'm still on medication. I'm still on anti-anxiety medication and still have issues. Any time we take him back to the hospital for scans, I find it really hard. "Scanxiety" is definitely real in our house and I don't know if it would have been as bad as this but I definitely know that the PTSD was because of the line infection scenario. That's what I kept reliving. That was the bit that I needed counselling for and it really was a stumbling block. So I'm still not back at work. Although I'm a full-time mum, I'm supposed to be job hunting right now and I'm doing anything to avoid it.

173. The charity, Jak's Den also helped me with counselling. I felt that I needed it as I kept reliving the incident with the line infection. It was readily available and they were advertising it, so I went in and asked and was in within 3 or 4 days. They were amazing.

Overall emotional impact on other members of the family

174. The girls, [redacted]s' sisters, were definitely impacted by the isolation. I loved watching and seeing photographs that people were sharing within the ward and within the unit of when their siblings would come to stay and come to visit. We just stopped taking the girls in because it was too hard because there wasn't a space that they could play easily because we were stuck in a hospital room in ward 6A and when we were in the other wards when there wasn't room in 6A.

175. Another issue was that we never knew what ward we were going into and it was easier to leave them at home. One of us took [redacted] and one of us stayed at home with the girls. Then, ultimately, rather than taking them into the building, because you never knew where in the building you were going to be, we would do car park swap overs. If Cameron took [redacted] in, then the next day he would come down, meet me in the car park, I'd give him the car keys with the two girls in the back and he would take them home and I would go in and be with [redacted]. This meant we were separated as a family for most of that treatment

time. We lived as two separate units and didn't do things as a family because there was always one of us with [redacted] and one of us with the girls. They missed him and missed playing with him and the wee one in particular barely knew him because she never saw him as he was always in the hospital. We didn't take them in to be in hospital because it was easier just to keep them at home.

176. I think it would have been different if all the treatment had taken place in ward 2A. We would have known the unit and the staff would have got to know them the same way that they did other families. When we first went in, there were families there and you got to know the siblings because they'd be playing but we couldn't do that when we were jumping about wards and 6A just was not set up for bringing the family in at all. There was nowhere for them to go. The play staff kit was at the bottom of a flight of stairs two buildings over so even to have the play staff come in and give them something to play with in the room, that wasn't feasible. Our emergency bag had stuff in it to entertain the girls. We took colouring pens and that kind of stuff for them and anything that would keep them contained in the space in the room. That was just so hard, so we just didn't bring them in. It was easier just to keep [redacted] isolated which meant he was on his own getting one-to-one adult attention and it ended up he got more and more plugged in to his games consoles. From having to Google how to switch on the PlayStation when we first went in, by the end of it we were asking for a PlayStation so he could sit and play it.

Support from Charities

177. There were several charities that supported us while [redacted] was getting treatment. CLIC Sargent was one of them. Cancer and Leukaemia in Children is what it stands for. Cancer and Leukaemia in Children merged with Sargent and that was named after the man that set it up. We'd never heard of them. But they fund the social workers, there's a social work team. So on our second day after [redacted] was first admitted, we were introduced to our CLIC Sargent social worker. They were then the person that did things like applying for disability for

[redacted], getting us a disabled car pass, getting us grants and things to support us while we were off work, care for [redacted], things like that. [redacted] was registered as disabled after three months of care, because you had to be in treatment for three months before that happens. He was registered as disabled and I was registered as a carer for him.

178. They also got things like grants from other children's cancer charities to do things. We would get passes to go to Blair Drummond for the day or things like that. And other charities were donating so they managed the distribution of a lot of that stuff. The social worker was the go-to for help that way, to support the family. She would come and visit us in the hospital, she'd come and visit us at home as well. Just to see how we were doing and see if we needed any help or support with anything. She would also do counselling for the children if we needed it. And she liaised with the school as well to support [redacted] when he was going back to school. Or to support the girls when they were going back to school.

179. We also had some support from charities like Team Hamish, Jak's Den, Love Oliver, Logan's Fund, Abbie's Sparkle Fund. But once the decant happened, a lot of that support disappeared. Jak's Den, for example, fund a music therapist to be in the ward. They're in the ward one day a week. When the decant happened, they weren't given access anymore so the music therapy stopped. [redacted] had been part of the music therapy programme. Jak's Den would do activities with the children. They weren't allowed in once the decant happened, so they couldn't go in and do activities with the children and things like that. Some of the support charities would send in stuff, like treats and sweets and toys and they were told to stop. The Christmas that we were in 6A, one of the other mothers started a bit of a campaign to get wee Christmas presents put together for the children that they knew already were going to be on the ward; that's the other thing, if you're in the ward, you can't go Christmas shopping. There was a bit of a pushback from the hospital charity because they

said they provided presents to the children, but they couldn't as they weren't allowed to come up to ward 6A. Even the clown doctors, who entertain the kids weren't allowed in. They just shut the door saying, infection control, nobody's allowed in.

180. Usually there would be visitors. For example, the charities would arrange for some footballers to come at Christmas time. There's three or four days in one week where Celtic come one day, Rangers come one day, the rugby team come the next day, and they do the rounds, saying hello to all the children. They weren't allowed into 6A. The charities also arrange for actors dressed up as Disney princesses to come in and they weren't allowed in because the princesses wore gloves. They said they would take their gloves off and use hand sanitiser but it was just a "no". The hospital wasn't even willing to find ways around it, just we've been told access is off, that's it. So things that would have meant a lot to the children on the ward, like getting a visit from Cinderella would have lifted their spirits, for Spiderman to come into the room would have lifted their spirits. They could go anywhere else in the hospital but they couldn't go into Schiehallion in 6A.

181. There were other things that happened in the RHC that Schiehallion didn't get to go to once the decant happened. In our first week in 6A there was a magic week run by the play team in the atrium in the children's hospital and children that were able would go down and people would go up into the wards where children couldn't go down. There was also the medi-cinema, that happens two nights a week where children are taken from their ward into the wee cinema that's in the children's hospital. Well, Schiehallion couldn't go to those things because they were in another building and it meant that the children were excluded from lots of things. The reason given was Infection control, although I was never part of those conversations.

COMMUNICATION

The decants

182. We had no issues with the communication surrounding [redacted]'s treatment and we never felt that it was being compromised. There was maybe a bit less communication about where we were to go if we went in with a spike, but you really did feel that everybody was trying their best, especially when we were in the Schiehallion unit.

183. After the decant, we would phone in when [redacted] had a spike and they would tell us where we had to go. If it was out of hours we knew we were going to A&E. If it was within hours, we knew we were going to day care. And we would be told what ward day care was in. Then if Schiehallion was full then you'd be sitting in day care waiting or you'd be sitting in CDU waiting to then be transferred to wherever there was a bed. You were never told why there wasn't a bed, you were just told which ward you were going to instead. So the communication about the decants and why they were happening and what the background to all of that was wasn't really shared with us. We just took everything at face value.

Schiehallion Umbrella

184. If we had a negative experience in another ward, I would tell the nurses in Schiehallion about the complete contrast in care that [redacted] was receiving and they would roll their eyes and say "oh for goodness sake". They would encourage us to complain as they were telling us that it takes a parent to put in a complaint for something to be done.

185. We were never told that the Schiehallion protocols should be following us and, other than the nurses saying that it wasn't right, we didn't get anything official about it. It was only once we had had negative experiences that we started asking for particular things, like being in a VAC room and only drinking bottled water.

Remedial work

186. We weren’t told anything about any of the remedial work that was going on in the hospital at the time it was happening. It was all just going on round about us and you almost felt as though you shouldn’t ask. I didn’t think it was my place to ask, why the big orange thing was on a bedroom door, or what was going on in the next room. It wasn’t our place to question them and there was no information being volunteered.

187. The first time we got an in-depth explanation about what was happening was at the meeting at with the board in 2019 and the first time we got anything in writing concerning the impact of the issues with the building was when we got the Case Note Review.

Safety of the hospital

188. Throughout we were being told that everything was okay. When the issue with the fungus arose, the hospital was saying that the HEPA filters were there just as a precaution and saying, “it’s fine, don’t worry about it, it’s only for the most vulnerable patients”. But we were the most vulnerable patients. The hospital was downplaying the issues to us, so we were immediately downplaying it to my extended family. I was getting text messages from my sister who lives up north asking what was going on as she had seen stuff on the news about the pigeon droppings and we were telling her everything was fine as that is what we were being told. It was poor Angela in day care who was on the frontline of all of this communication because she was the one that was sent in to take the flak from all of us. It did get to the point where the parents were saying that it wasn’t fair to send her. Where are the management? Where’s the PR team? I think that was when the grumblings of all the parents got to the point where they couldn’t ignore it anymore and that was at the point where there was the meeting with the Health Secretary and

then the meeting with the Board and then the Facebook group with Professor White was set up.

189. But that was only after parents really kicked up a fuss. Because we were hearing stories in the press about people dying unnecessarily and we didn't want our children to become one of those statistics.

190. Another issue that I never thought about at the time [redacted] was getting treatment was the proximity of the water treatment centre to the hospital. I was aware of the smell, but I didn't really think anything of it. Having spoken with some of the other parents I do now have concerns. At the meeting with the health board, the facilities manager spoke and told us that a new water filtration system was being put in. Why was this only being done? Does that mean the water wasn't safe when [redacted] was an inpatient? He also said that they didn't know how safe the water was as they hadn't been testing it. I think that was highlighted in the Case Note Review; why the water wasn't being tested. I am concerned that the issues with the water were caused by the water treatment facility being so close. If it is flooded, for example, does that then impact the supply of the water that goes to the hospital? I would still not drink the water if I was in the hospital now, in fact I think I would be even less likely to having heard all the stories from all the other parents.

Meetings

191. It was all kicking off on ward 6A among all the parents about the fungus and the fact that we weren't getting information from the hospital but were finding out from the BBC that something's going on. Parents were getting phone calls from reporters asking us to comment which we weren't happy about. One of the other parents, became a flagbearer and started calling for a public inquiry and saying that it was ridiculous the level of care that the kids are receiving at the time they should be getting the best care in the best hospital and it really wasn't.

192. In response to this, there was a meeting which the health secretary held in a hotel in Glasgow. I am not sure when this took place but it was after [redacted]'s treatment had finished so it was after April 2019. Speaking with the health secretary, you really did feel that she was shocked at the stories that everyone was sharing. The fact that then led onto there being a public inquiry validated our emotions and validated the fact that we were all feeling something ought to be done. So those meetings were very helpful.

193. After this meeting Professor Craig White was appointed to spearhead the Oversight Committee and he became our point of contact for communication. He would send us regular emails with updates. He also arranged for the meeting with the health board and we were all invited along to that. Again, I am not sure when that took place, I only know it was after [redacted] had finished his treatment in April 2019. There were maybe about 20 or 25 parents at this meeting. That was the first time we had met the Board and some of the things that were talked about were pretty surprising. I can only relay my own story and our own treatment story but some of the parents were very, very angry at the lack of communication and the lack of forewarning about what was happening and then finding out about it on the news. I think Craig White actually facilitated that meeting, he was there and it was after this the Facebook group was set up.

194. At this meeting we were given a break-down of what work was being done on ward 2A, and when it was expected to re-open. I did feel as though we all got a chance to speak and we were suggesting what needed to be changed and fixed. Members of the board which included the Nursing Director, the Chief Executive, the Clinical Director, and Professor Craig White, were frantically scribbling and reacting to what we were raising. I know that a couple of the things that I mentioned then, have been changed so it was worthwhile, having this meeting. One of the things I raised was, for three months after treatment,

you're still considered immunocompromised so there's certain protocols you have to follow, so if you're exposed to the chicken pox, you have to go and get an antiviral. So [redacted] had chicken pox exposure at school and I had to take him into day care and we had to walk the length of ward 6A to get to day care. It was the first time I had realised that he might be infectious and he was in a ward where there are people that could be infected. I raised that saying, that wasn't such a clever idea. I also raised the fact that there wasn't a playroom and there wasn't a parents' kitchen and these things were all then rectified which is great.

195. At both these meetings I raised the issue of the Schiehallion "umbrella" and how it wasn't fair that the care wasn't following us, and that extra level of anxiety that was put on the families could have easily been removed had that Schiehallion "umbrella" gone with us. There were then subsequent, regular meetings with the health board, but John Cuddihy attended those meetings as a representative for the parents. We could ask questions that he would ask at the meetings and then he would report back. I did ask questions through him and we did get answers, but I can't recall what those questions were.

CASE NOTE REVIEW

196. We were not involved in the Oversight Board that was set up, but [redacted] was one of the children who was involved in the Case Note Review. We received a copy of the report and it was quite substantial. I went at it with my wee yellow stickies and saw there was only one case of serratia marcescens, so I was guessing that it was [redacted], but I didn't know, so I sent the Review team an email asking them to confirm this and they sent us a specific report on [redacted], which then answered my questions and I did feel that it answered my questions fully. I was very surprised because one of the questions that I asked was, is it possible to be told if our son's case falls into the "highly likely caused by hospital environment" category? They said, we have answered this question above that, yes, [redacted] is in the group described as most likely to have been associated

with the environment. Really, that was me just looking for clarification for the purposes of the Public Inquiry so that we could say that [redacted]'s infection was caused by, or it is most likely to have been caused by the environment.

197. In the report they gave us there were a few errors in the information. It said that he went from surgery back to 2A and he didn't, he went to 3B. So we requested a meeting with the Review Team and that meeting was very informative because we were speaking to a consultant, Professor Michael Stevens, whose background was tumours and he actually worked with Dr Ronghe. He was able to answer questions about why [redacted] had gone back to a surgical ward and not Schiehallion. He said he was in surgery for the surgical management of the wound, rather than for line infection management and that is the protocol for that procedure. That's what happens in every hospital so it wasn't just Glasgow specific. So that was really helpful to have that background. They then followed up with another email, dated 10 May 2021 answering and commenting on the questions that we talked about in that one-to-one with them. Really, the upshot, again, was the umbrella of Schiehallion and how we felt that it didn't follow us into surgery. I don't know if there have been any changes made as a result of the issues we raised, but Professor Stevens said they would feed it back.

198. We were satisfied with the Case Note Review and felt it answered all of our questions. I'm not aware that there have been any changes as a result of [redacted]'s review, but in our conversation the team alluded to the fact that they would be making recommendations based on [redacted]'s case where antibiotics weren't given in a timely fashion and they should be, so that has to be part of the protocol. They have to make sure that there's enough staff trained in Hickman lines and port-a-caths because that was a failing for [redacted] that he had to wait for somebody that knew how to do it. They also said there has to be better training for the staff to deal with the children that are presented to them and that the umbrella should travel with the children.

FACEBOOK GROUP

199. By this I mean a Facebook page which was freely advertised on the ward as a means of parents communicating with each other and supporting each other. This was a parent-only group. You quite often get questions like, "what's the number for day care again?", and "my child's got this symptom, is something I should be phoning about?". It was a way of getting a bit of reassurance. This was a closed group and no doctors or anyone from the hospital had access. It was different to the Facebook Group that was set up by Professor White and run by the NHS. I did use that when it was established. All the parents were invited to be part of it. It was used to disperse information about the Case Note Review and the fact that the public inquiry was on the horizon. This Facebook Group started once we had finished [redacted]'s treatment.

200. I was aware of the Oversight Board and I know that Professor Cuddihy was representing us at that and he would put feedback through the NHS Facebook page of meetings he'd been attending and minutes of the meetings and recommendations that he was making on our behalf. He seems to be a very good spokesman and we could send him questions to ask, which we did do. I can't remember what our questions were, but I do know that they were answered and Professor Cuddihy provided very eloquent reports of what happened at these meetings.

CONCLUDING COMMENTS

201. I think, now, if [redacted] were to relapse and we went back into the hospital, I think I would have a bit more confidence than I had two years ago because of this process. I feel that we have been listened to and that there have been changes made. I feel that we are better educated to be able to go in and say, "no, that's not acceptable". I would be more of a "gobby" parent if I was back in again which is not my personality.

202. The anxiety that we have of [redacted] relapsing is always going to be there, I think. When we finished treatment there was very much an element of, “oh, God, I really don’t want him to end up back in here” and if he ended up relapsing, would we want to go to Edinburgh because we really didn’t have confidence in Glasgow anymore, especially having heard all of the other horror stories. I thought ours was an isolated case. I still had faith in the system but when I read the Case Note Review and spoke to a lot of the other parents in the meetings it was horrific that these families were having to suffer because the building was broken. Meanwhile, the hospital is being held up as a wonderful flagship, yet it’s rubbish. The fact that whenever there’s any fundraising happening for any of the hospital charities, there’s a wee bald-headed child that draws the money but that money’s not getting spent on the wee bald-headed children, that is a kick to the teeth. Once the decant happened, the Schiehallion kids were not getting the benefit of any of the money raised by the charities as they were not allowed to come on to ward 6A. They are the ones who should be getting the diamond service because the treatment that they’re going through is horrific, but it felt like they were the poor relations who were not getting the same input from these charities as the children who were still in the RHC were getting.

203. I got a bit of a shock when I was talking to my dad about the hospital because my dad is the meekest man you’ve ever met. He is a retired carpenter who has built and worked on many a building site, many a house build. He got so angry about what was allowed to happen in the hospital. He said it was ridiculous that the shower was allowed to leak all over the floor and why had the clerk of works not come in and said it wasn’t up to standard at the time before the hospital opened? That would never have been acceptable, but now it is acceptable and the company that built the hospital will be into receivership and nobody will have to foot the bill? His view was that, even if a finding by the Public Inquiry says that the hospital was at fault or the builders were at fault, nobody’ll pay for it because it’s the way that it works now. Substandard is

acceptable now. It shocked me to hear my dad being so cynical because he's not like that at all. It does worry me that the board of directors went home and slept fine in their beds, not worried about what was happening. One of the questions one of the parents asked of the chair of the board was, "if your grandchildren were sick, would you bring them here?". They said that, of course they would, but really, them knowing all that they know, that we have not been party to, I'm not sure they would. The hospital is not a safe space to be in and that's the worrying bit, that the kids were safer at home and yet when they were spiking, we had to take them in.

204. I do have ongoing concerns about the safety of the hospital. [redacted] had to go in about seven months after [redacted] finished his treatment [redacted] and it was hard work. It was hard being in with her and taking her in and also taking her in and not being a Schiehallion patient because she didn't get a room to herself. She didn't get the same level of diamond care, and that was really hard because I was sitting with a critical eye on everything. I was cleaning everything around her and being the manic, cleaning mother because at that point I really didn't feel that the hospital was up to standard. I was really concerned taking her in for something as simple as that and she's a very healthy child, not immunocompromised at all but we just wanted to get her out of there as quickly as possible. I became a bit OCD. I didn't let her drink the water, I didn't let her got to the playroom. I didn't trust infection control and I just kept her isolated as best I could.

205. I don't know if is there anything that the hospital could do to address my concerns because when we were in it we just accepted and trusted them because we had to trust them and I think it's a good thing that the parents weren't able to talk to each other on the ward because we riled each other up a bit. There were some more vocal parents than others and I was very grounded in the fact that [redacted] got through it and he is well. He got through the line infection. We got a good outcome and it was only in all the meetings we

had that we then realised he could so easily have not had a good outcome we met the parents that have lost children and saw their anger. Having those meetings feeds that anxiety.

206. But I do think that the families forcing the board to have meetings, which then led to the Facebook group, has had made the board communicate better with the families. It is forcing them to be more transparent. Although I think COVID has been a catch-all for any failings that have happened in the last year. It's a nice wee peg they can hang everything on just now. But when it comes to questions about whether the water is safe, that's frightening. Will it ever be safe because of where it is sitting, because of the position of the hospital compared to the water treatment? Have they put a better cleansing unit in? Have they put better facilities in to keep it safe? We have to trust that they have but ultimately until something goes wrong we won't know about it because they haven't been transparent. It is only because of everything which has come out that they are being forced to be more transparent.

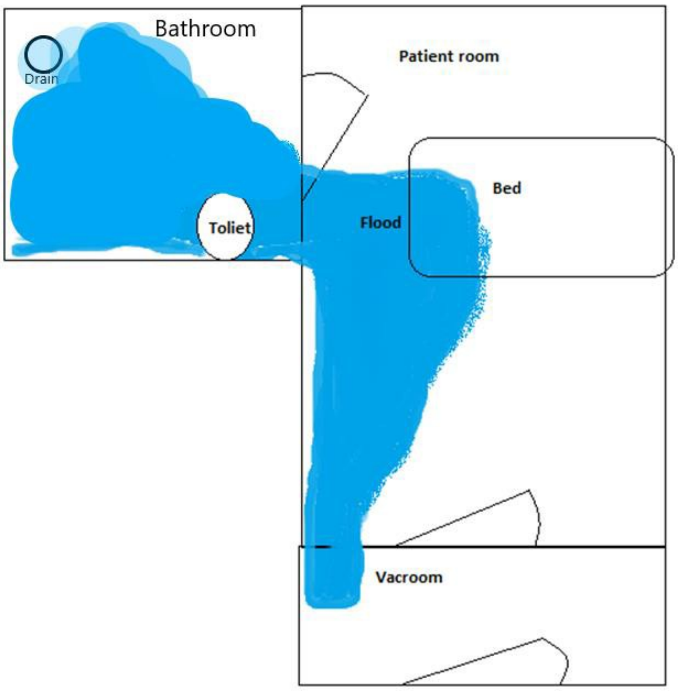
207. I believe that the facts stated in this witness statement are true. I understand that this statement may form part of the evidence before the Inquiry and be published on the Inquiry's website.

CG/01 – Appendix 1

[redacted]'s Illness TimeLine

2018

- 04/07 Discoloured Urine – thought from eating beetroot
- 05/07 Blood in urine – Alnwick out of hours – Antibiotics given and urine culture taken
- 09/07 Phone Alnwick GP – Culture clear advised to follow up with own GP
- 13/07 Urine sample to our GP and 2nd antibiotics given with bloods booked for Monday
- 16/07 Bloods taken, Urine cultures clear.
- 17/07 Bloods showed anaemia – scan and renal referral made.
- 24/07 Blood in urine more prevalent (now scarlet)
- 25/07 GP call – Scan date is booked - nothing more can be done until scan appointment
- 29/07 Bumped abdomen while playing and went green, low appetite for the rest of the day then vomiting through night.
- 30/07 SCAN RAH : Scan revealed mass on kidney – referred straight to oncology. MRI confirms Kidney tumour, Wilms. Dr Ronghe now on board. Tumour 12cmx8cmx8cm. Admitted via CDU to Ward 2A room 10
- 31/07 CT and X ray confirms containment in the Kidney area. Plan to start Chemo asap.
- 01/08 Surgery to fit Hickman Line
- 02/08 Chemotherapy protocol started, Vincristine (Vinc) and Actinomycin
- 08/08 Discharged
- 09/08 Day care 2B - Chemo, Vinc
- 10/08 Spike re-admitted to 2A room 10 via CDU
- 13/08 Discharged
- 16/08 Day care 2B - Chemo, Vinc and Actinomycin
- 20/08 Day care presented with a black tongue – told to monitor.
- 23/08 Day care 2B - Chemo, Vinc
- 24/08 Spike admitted through Day care 2B to Ward 2A room 2? Our first Vac Room also first room where air con actually worked. Went into rigor for first time, and we were communicated how serious his was, Nurse Kat waited outside with meds to get best overlap.
- 26/08 Showered in room and flooded the room as drains did not function properly. Water pooled along wall, under toilet, into room, and out into vacroom. Reported to staff – response was eyes rolled "yes loads of the drains are dodgy"



- 27/08 Discharged
- 30/08 Day care 2B – Chemo, Vinc
- 03/09 Day care 2B - Blood work and pre- surgery meeting with anaesthetist and surgeon Ms Brinley.
  3.30 at surgical ward 3B for admission. Room not ready so had to wait in playroom until room was ready.We cleaned the surfaces down and on lifting the bed guard found it to be covered in brown/red dried matter. Not sure if blood, faecal matter or chemicals from operation. Bed was replaced. Not in room appropriate for immunocompromised patient i.e. protocol/procedures is for vac room. No filters on taps. Also different general failing of protocols i.e. reduced cleaning regime/dirty; all play equipment/areas accessible to everyone and not just patients (also cleaning of play area and equipment not as stringent) therefore unable to access these spaces/facilities due to risk of infection. Patient care different to chemo wards. Chemo wards do not have yr1 (1st year doctors) as these doctors do not have the experience and practical skill necessary for care of chemo kids. In both prep and post-surgical we had YR1 doctors.
- 04/09 Surgery. Kidney and tumour removed then into PICU
- 05/09 Temp spike through night – line infection suspected and antibiotics started.Transferred back to 3B – no vac seal doors, no water filters, yr1 doctors, different cleaning protocols for rooms as described above
  [redacted] had epidural still in place, morphine via PCA, and was on regular doses of antibiotics.
- 06/09 Line infection confirmed Serratia Marcesens Blood drawn via the line at 11.45. Emla cream applied to hands and feet to get peripheral bloods. (this is usually left for 30- 60mins to work) 40 mins later toxic shock. Taccacrdic (heart exceeding 200bpm); temp spike, rigor, vomiting. Had to go to front desk

for help as no one around. Two YR1 docs arrived to help. – tried to get the peripheral draw. [redacted] very distressed by this point.
The nurses on the chemo ward would meticulously inspect the site and find the vein before applying the anaesthetic then come back later to take the blood – so they knew where to look. This YR1 doctor just put 4 patches on and came back later and started jagging. After multiple attempts to get the blood they stopped trying. This left [redacted] with a real aversion/fear of needles, which required extensive work with the play team to reduce the impacts to a point that they could use a needle without me having to physically restrain him. Additional nurses also in the room. Colette Panic – had to leave.
Dr Hettle – surgeon on call arrived and the room calmed. Line was ordered out of bounds. He got the blood draw first time while calmly talking with about dinosaurs. Antibiotics were pushed, bolus was started and after an hour things settled down.

- 07/09 Visit from Dr Ronghe. Microbiology advise to place an antibiotic block in line (which required accessing it). In conversation with Dr Hettle, I raised concern this should not happen late afternoon on a Friday due to people leaving the building if care required. Dr Hettle agreed – not on a Friday afternoon 16.10 block put in. 40 min later toxic shock again due to toxic shower from line. Same symptoms as before. Duty docs call in Dr Kamal – jnr surgeon starts a bolus and gives ibuprofen to help manage temp. Consulting doctor from A and E (also on infection control) called in said “it’s a poo bug”. Wendy and Jane,Nurse Practicioners from schiehallion, arrive and advise no more ibuprofen due to the dangers of ibuprofen for chemo-kids. Takes 90 min to stabilise, Kamal considers readmitting to PICU. Dr Hettle arrives (who had been in surgery) and makes plan to pull line.
- 08/09 Surgery Line out. Visit from Mr Davis Head surgeon on rounds. [redacted]’s skin has become inflamed and itchy around the entire surgical site. Dermatology referral made
- 13/09 Discharged
- 17/09 Day care 2B Meeting with Dr Ronghe and Dr Inkster (infection control). Apologised for line infection and they confirmed it was hospital acquired and should not have happened, and it came from drains. I made light of the issue saying that compared to what he went through in surgery this was not our biggest concern. The response to which was that the infection was the most concerning thing that happened during [redacted]’s stay. Not the removal of a kidney, or removal of a cancerous growth, or stay in ICU.
- They confirmed one of six children ill at same time, part of ongoing issue with water system and they are planning to close ward
- 19/09 Day care 2B antibiotics for sore on [redacted].
- 20/09 Day care 2B Chemo, Vinc via cannula. Had to be pinned down and restrained by mum, dad and two nurses.
- 21/09 Spike admitted via 2B into ward 2A room 10 – all treatment via cannula and had to be pinned down again.
- 24/09 Discharged
- 26/09 Admission ward 1A Surgery - port fitted

Transfer to 6A – adult ward ‘New Schiehallion’ with no facilities, fold down adult bed, no play room, no play team, no facilities for adults to get food/drink bar bottled water (Scheihallion had parents room with fridge, freezer, kettle and microwave). It was like going into full isolation with no contact/support from other patients, carers or play team.
Not having general facilities like proper bed, access to kitchen, etc made a difficult experience much worse for the carer, you can’t just leave a child to go and get a hot drink if it takes you 40 minutes.
We travelled with insulated picnic bags with ice blocks to keep snacks cool, thermos flasks, snack noodles etc.

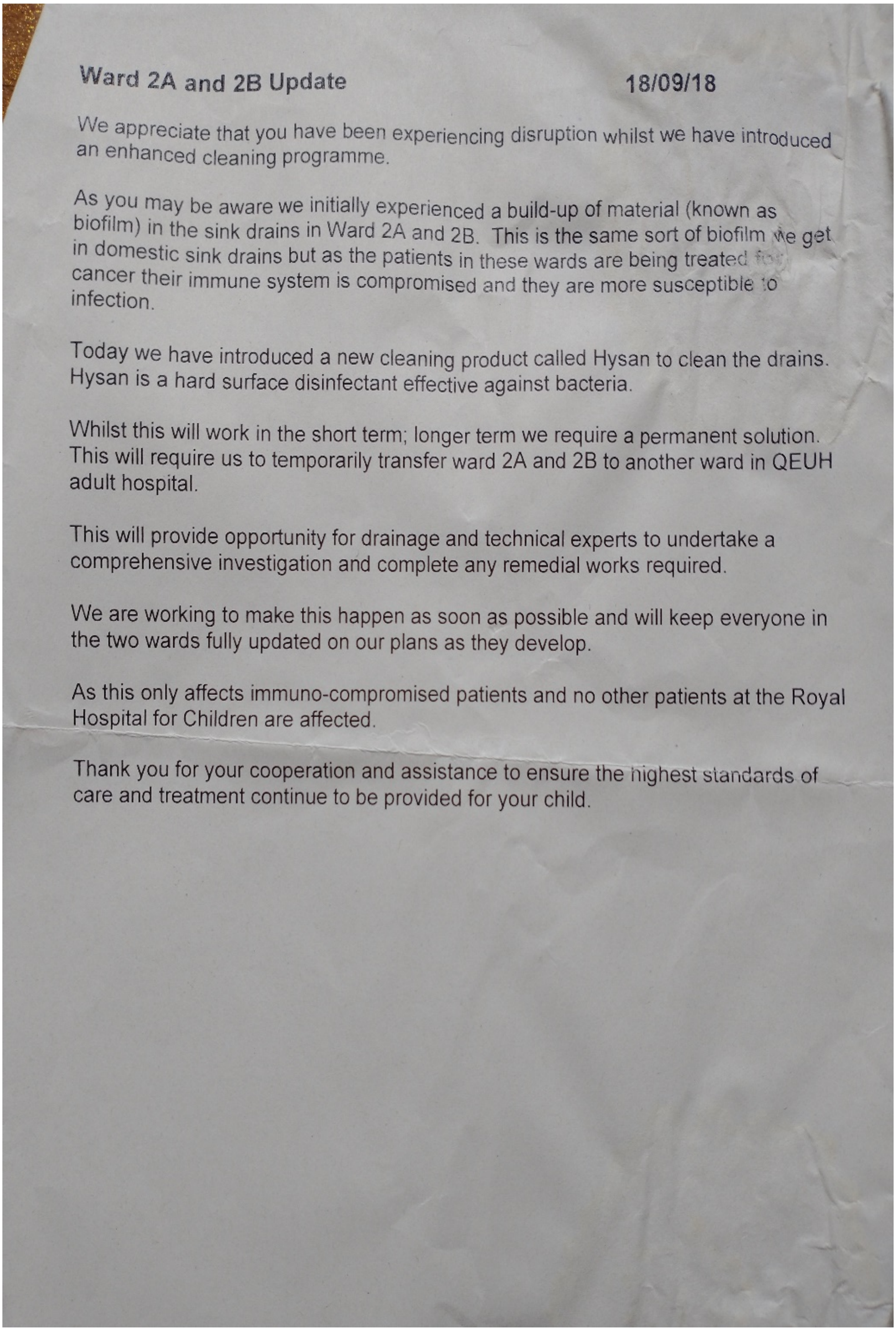
- 27/09 Chemo Vinc and Actinomycin and discharge
- 01/10 Day care 6A infection neck wound site – given cream
- 04/10 Day care 6A chemo Vinc
- 05/10 Spike admitted to 6A via CDU room 4
- 07/10 Discharged
- 08/10 Spike admitted to 6A via day care room 21
- 11/10 Chemo Vinc, transfusion and discharge
- 13/10 Spike admitted to 6A via CDU room 23
- 16/10 Discharged
- 18/10 Day care 6A- Chemo Vinc and Actinomycin
- 25/10 Day care 6A- Chemo Vinc
- 1/11 Day care 6A- Chemo Vinc
- 8/11 Day care 6A- Chemo Vinc and Actinomycin
- 13/11 Spike 2E (cardio) admitted via Day care 6A
- 22/11 Day care 6A – bloods and dressing check
- 06/12 Day care 6A - Chemo Vinc. Sciehallion confirm decant for another year X-ray and ultrasound.
- 07/12 Spike admitted via CDU to 3C Orthopaedics. 5 failed attempts to get port access. Cannula fitted to allow antibiotics to start. It was not until one of oncology Day care’s excellent nurses saw [redacted] that they could get line in. While struggling to get line in this was raising concerns with us in case of line infection like previously rather than standard chemo temperature spike. Very poor care in orthopaedics (especially considering heightened concerns due to issues accessing line). Failure to do observations at correct times, failure to respond to temperature spikes in timely manner (let’s not forget his last line infection in 40 minute he went from ok to a room full of consultants discussing if he should be going to PICU), failure to administer medicine at correct timings causing discomfort and distress to the patient, and general lack of interest by the nursing staff (too busy standing round the nursing station chatting about the Christmas night out). I put in a complaint due to my concerns
- 09/12 Discharged
- 10/12 Dermatology – skin reaction to dressing a very difficult visit with being uncooperative due to the trauma of most recent stay. Wouldn’t let Doc examine him, didn’t want to be touched, poked or prodded.

- 11/12 Day care 6A sore [redacted] again therefore antibiotics
- 20/12 Day care 6A - Chemo Vinc and Actinomycin
- 27/12 Day care 6A – Chemo, Vinc
- 28/12 spike- admitted 6A
- 31/12 Discharged

2019

- 10/01 Day care 6A Chemo, Vinc and Actinomycin
- 17/01 Day care 6A Chemo, Vinc
  Spike admitted 6A via Day care
  Fungal issue on ward had been identified now HEPA filter installed in corridors and every room
- 19/01 Transferred with ward to CDU rm 19
- 20/01 Discharged
- 31/01 Day care 1A Chemo, Vinc and Actinomycin
- 1/02 Spike admitted via Day care 1A into CDU rm 19
- 4/02 Discharged
- 7/02 Day care 1A Chemo, Vinc
- 9/02 Spike admitted via 2A (temp CDU) to CDU
- 12/02 Discharged
- 14/02 ENT follow up appointment
- 21/02 Day care 6A Chemo, Vinc and Actinomycin
- 27/02 Spike admitted via Day care 6A
- 3/03 Discharged
- 4/03 Day care 6A Chemo, Vinc
- 15/03 Dermatology
- 18/03 Day care 6A Chemo, Vinc and Actinomycin
- 24/03 Admitted 6A sore [redacted].
- 25/03 Chemo Vinc – last dose
- 26/03 Spike admitted via Day care to 3C
- 27/03 Ultrasound and x-ray
- 29/03 Discharged
- 4/04 Day care Dr Ronghe meeting
- 8/04 Day Surgery 1A port removal surgery
- Date not noted May/Jun – Day care visit – chickenpox exposure – had to walk length of ward 6A to access Day care. Raised potential infection risk at hospital board meeting.

CG/02 – Appendix 2



Ward 2A and 2B Update **18/09/18**

We appreciate that you have been experiencing disruption whilst we have introduced an enhanced cleaning programme.

As you may be aware we initially experienced a build-up of material (known as biofilm) in the sink drains in Ward 2A and 2B. This is the same sort of biofilm we get in domestic sink drains but as the patients in these wards are being treated for cancer their immune system is compromised and they are more susceptible to infection.

Today we have introduced a new cleaning product called Hysan to clean the drains. Hysan is a hard surface disinfectant effective against bacteria.

Whilst this will work in the short term; longer term we require a permanent solution. This will require us to temporarily transfer ward 2A and 2B to another ward in QEUH adult hospital.

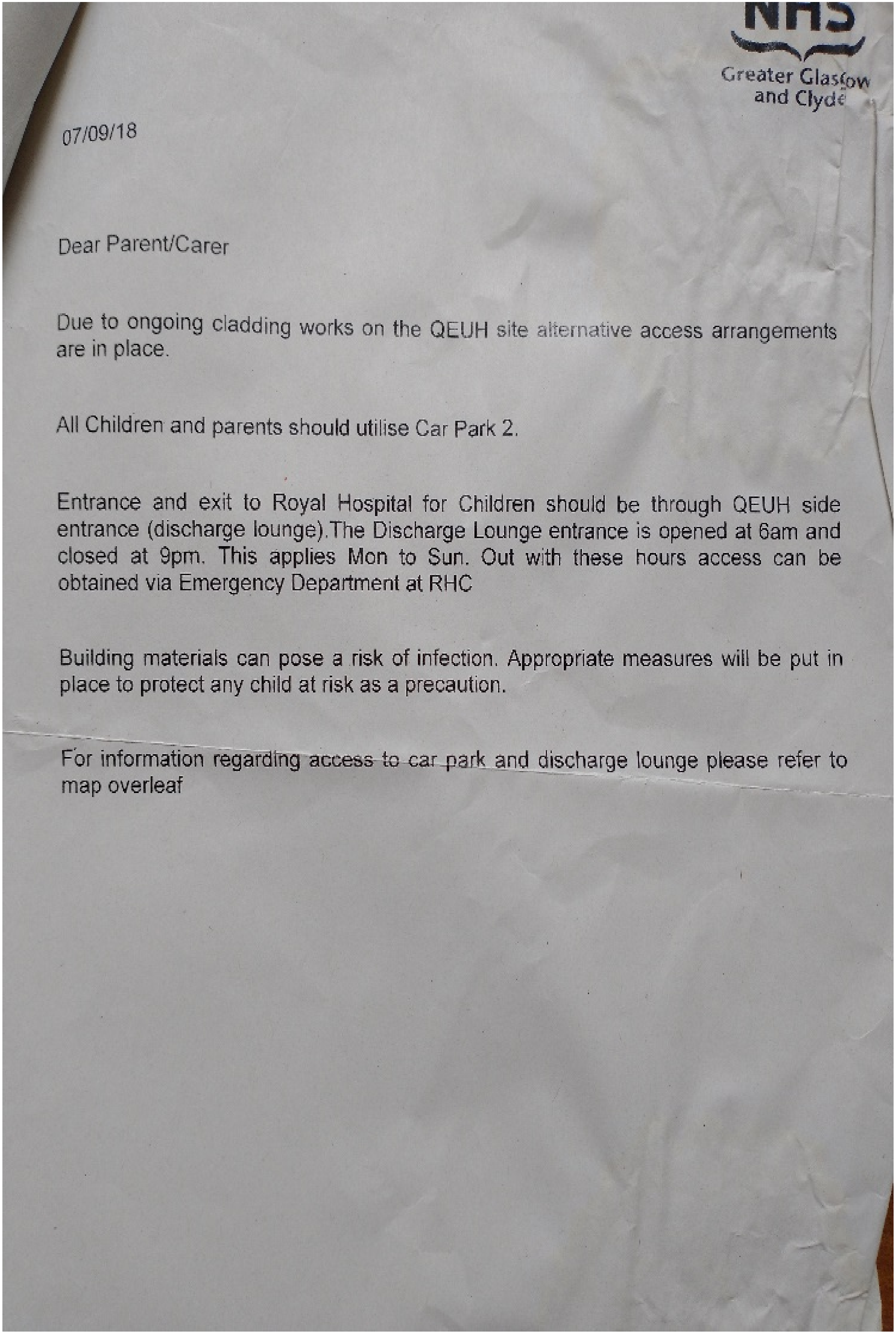
This will provide opportunity for drainage and technical experts to undertake a comprehensive investigation and complete any remedial works required.

We are working to make this happen as soon as possible and will keep everyone in the two wards fully updated on our plans as they develop.

As this only affects immuno-compromised patients and no other patients at the Royal Hospital for Children are affected.

Thank you for your cooperation and assistance to ensure the highest standards of care and treatment continue to be provided for your child.

CG/03 - Appendix 3
Part 1



NHS
Greater Glasgow
and Clyde

07/09/18

Dear Parent/Carer

Due to ongoing cladding works on the QEUH site alternative access arrangements are in place.

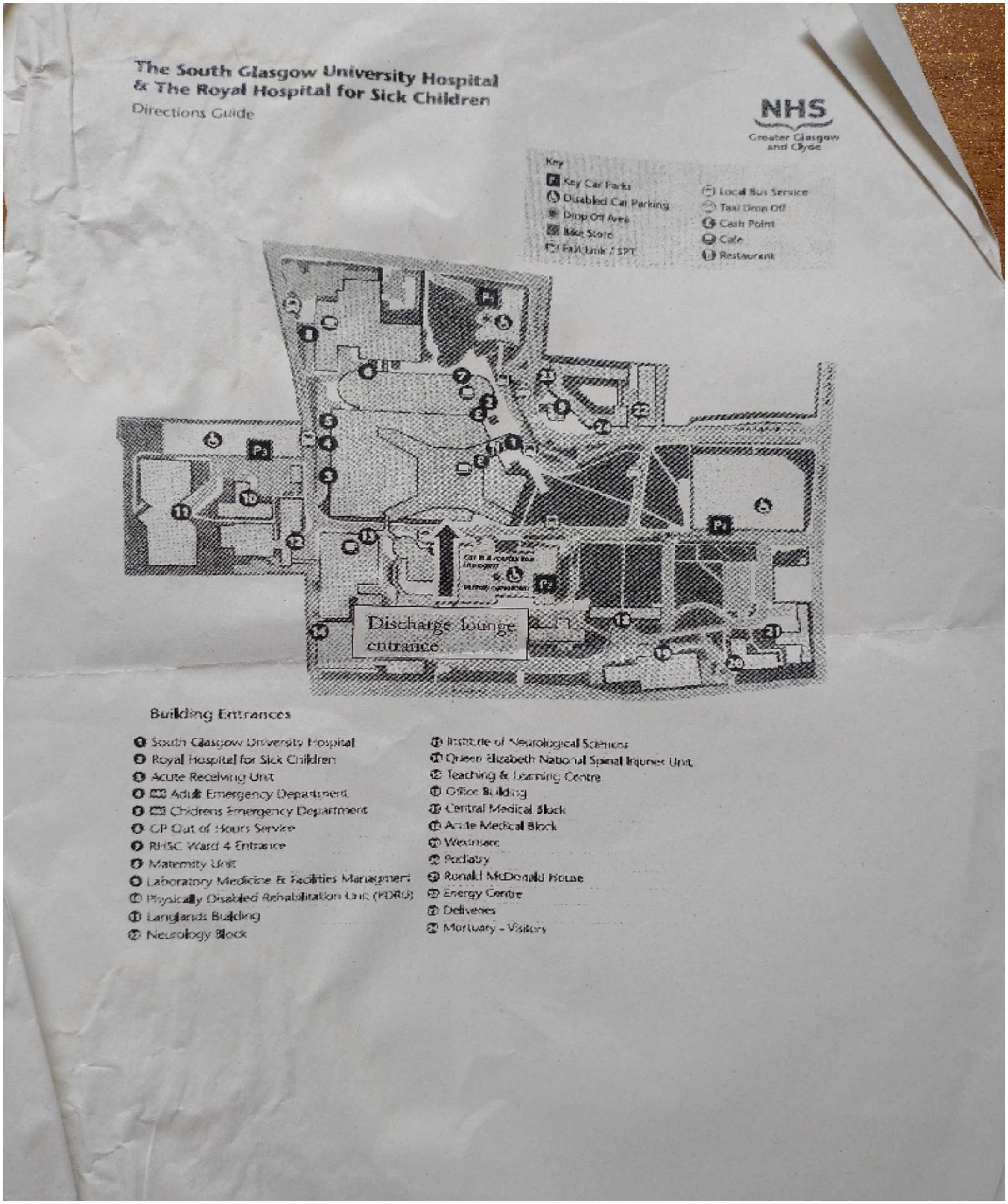
All Children and parents should utilise Car Park 2.

Entrance and exit to Royal Hospital for Children should be through QEUH side entrance (discharge lounge).The Discharge Lounge entrance is opened at 6am and closed at 9pm. This applies Mon to Sun. Out with these hours access can be obtained via Emergency Department at RHC

Building materials can pose a risk of infection. Appropriate measures will be put in place to protect any child at risk as a precaution.

For information regarding access to car park and discharge lounge please refer to map overleaf

CG/03 – Appendix 3
Part 2



The South Glasgow University Hospital
& The Royal Hospital for Sick Children
Directions Guide

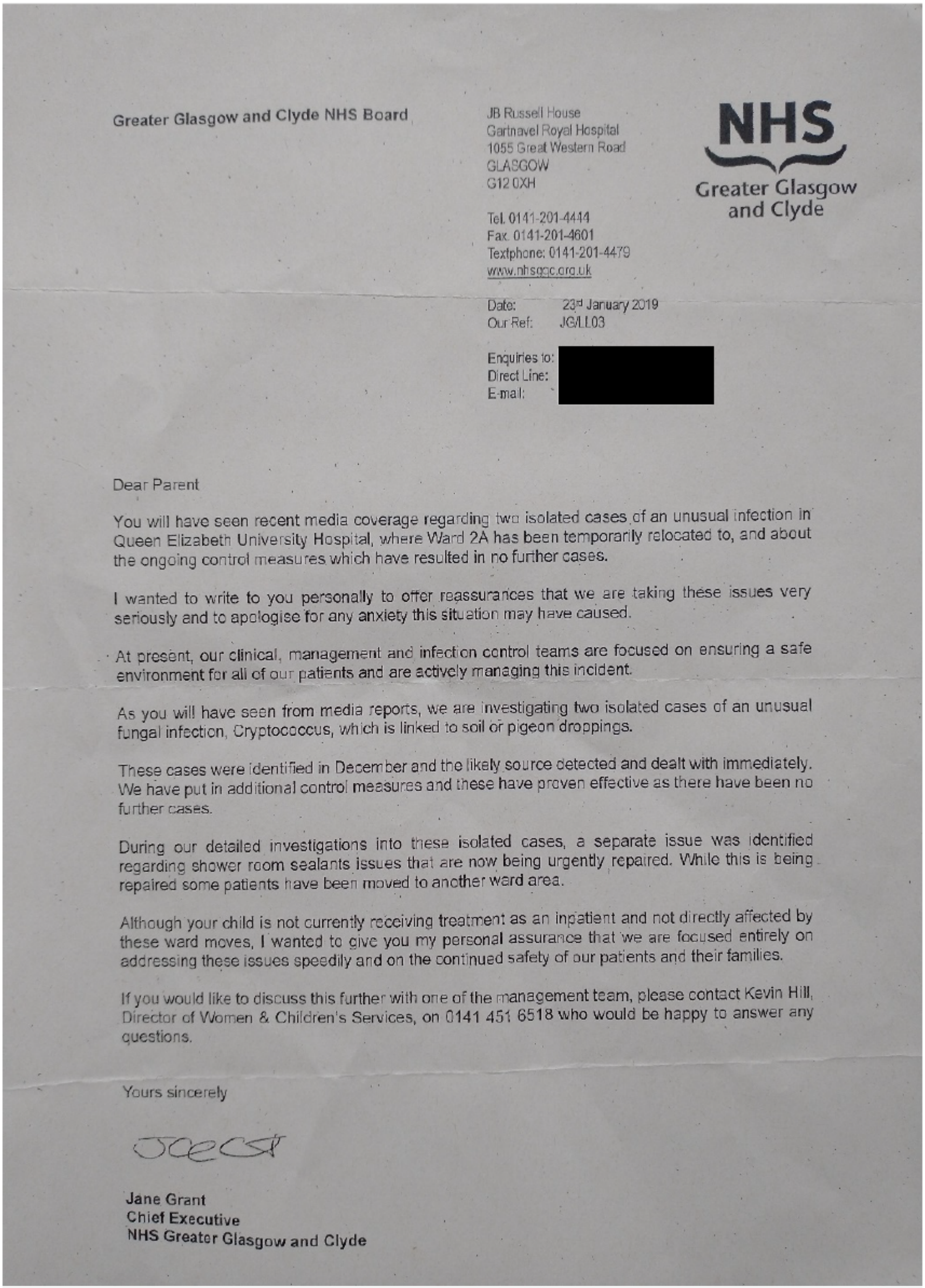
NHS
Greater Glasgow and Clyde

Key
- P Key Car Parks
- Disabled Car Parking
- Drop Off Area
- Bike Store
- Fastlink / SPT
- Local Bus Service
- Taxi Drop Off
- Cash Point
- Cafe
- Restaurant

Building Entrances

① South Glasgow University Hospital
② Royal Hospital for Sick Children
③ Acute Receiving Unit
④ Adult Emergency Department
⑤ Childrens Emergency Department
⑥ GP Out of Hours Service
⑦ RHSC Ward 4 Entrance
⑧ Maternity Unit
⑨ Laboratory Medicine & Facilities Management
⑩ Physically Disabled Rehabilitation Unit (PDRU)
⑪ Langlands Building
⑫ Neurology Block
⑬ Institute of Neurological Sciences
⑭ Queen Elizabeth National Spinal Injuries Unit
⑮ Teaching & Learning Centre
⑯ Office Building
⑰ Central Medical Block
⑱ Acute Medical Block
⑲ Westmarc
⑳ Podiatry
㉑ Ronald McDonald House
㉒ Energy Centre
㉓ Deliveries
㉔ Mortuary - Visitors

CG/04 – Appendix 4



Greater Glasgow and Clyde NHS Board

JB Russell House
Gartnavel Royal Hospital
1055 Great Western Road
GLASGOW
G12 0XH

Tel. 0141-201-4444
Fax. 0141-201-4601
Textphone: 0141-201-4479
www.nhsggc.org.uk

NHS
Greater Glasgow
and Clyde

Date: 23rd January 2019
Our Ref: JG/LL03

Enquiries to: [redacted]
Direct Line:
E-mail:

Dear Parent

You will have seen recent media coverage regarding two isolated cases of an unusual infection in Queen Elizabeth University Hospital, where Ward 2A has been temporarily relocated to, and about the ongoing control measures which have resulted in no further cases.

I wanted to write to you personally to offer reassurances that we are taking these issues very seriously and to apologise for any anxiety this situation may have caused.

At present, our clinical, management and infection control teams are focused on ensuring a safe environment for all of our patients and are actively managing this incident.

As you will have seen from media reports, we are investigating two isolated cases of an unusual fungal infection, Cryptococcus, which is linked to soil or pigeon droppings.

These cases were identified in December and the likely source detected and dealt with immediately. We have put in additional control measures and these have proven effective as there have been no further cases.

During our detailed investigations into these isolated cases, a separate issue was identified regarding shower room sealants issues that are now being urgently repaired. While this is being repaired some patients have been moved to another ward area.

Although your child is not currently receiving treatment as an inpatient and not directly affected by these ward moves, I wanted to give you my personal assurance that we are focused entirely on addressing these issues speedily and on the continued safety of our patients and their families.

If you would like to discuss this further with one of the management team, please contact Kevin Hill, Director of Women & Children's Services, on 0141 451 6518 who would be happy to answer any questions.

Yours sincerely

Jane Grant
Chief Executive
NHS Greater Glasgow and Clyde