Scottish Hospitals Inquiry

Witness Statement of

Stevie-Jo Kirkpatrick

WITNESS DETAILS

1. My name is Stevie-Jo Kirkpatrick. I was born on [redacted]. I am 17 years old.

2. I am a pupil at [redacted], [redacted], [redacted] and have recently started S5.

3. I live with my parents, Steven and Annemarie Kirkpatrick in [redacted] , [redacted].

OVERVIEW

4. I was diagnosed with Acute Lymphoblastic Leukaemia (ALL) in 2014 when I was 9 years old. I was originally treated in the old Yorkhill hospital in Glasgow until it transferred over to the new Queen Elizabeth University Hospital (QEUH), where I was treated as an-outpatient until 2015. I relapsed in 2017 and I was treated in the Royal Hospital for Children (RHC) and the QEUH between July 2017 and March 2019 when I finished my treatment. I still attend at the QEUH for check-ups.

5. I was treated in ward 2A at the RHC, which is the Schiehallion Unit. It treats children with cancer. I also spent time in ward 3A at the children's hospital. After the Schiehallion Unit closed in 2018 I was treated in ward 6A in the adult hospital; this was where the Schiehallion ward was moved to. I was treated there as an in-patient and an out-patient. Both my mum and dad stayed with me in hospital when I was there but it was mostly my mum as my dad was working. We also stayed at CLIC Sargent house too.

6. There are some specific events that I would like to mention. I contracted a line infection in late 2017 when I was an inpatient in ward 2A. I also contracted listeria meningitis in December 2018. I contracted another line infection in February 2019, not long after being discharged as an in-patient from ward 6A. I contracted a mycobacterium chelonae infection in March 2019 after surgery to remove my line in February 2019, at the RHC. There were issues with the water supply throughout my time at both hospitals. There were ongoing construction works at the hospital throughout my time there which, in my view, impacted my experience. I will talk about these events in more detail.

FAMILY BACKGROUND

7. I live with my parents, Steven and Annemarie Kirkpatrick near [redacted].

8. I am a pupil at [redacted], [redacted] , [redacted]. I have recently finished my S4 exams and have moved up to S5. One of my hobbies is football. I support Celtic and I also play for [redacted]. I play the bass guitar. I taught myself because I can't get lessons in [redacted]. I like listening to music, I like 80s, 90s and more modern music, a real proper mix.

9. When we do things together as a family we'll go to football matches or the cinema. My dad plays golf so we do things together whenever that is not taking up too much time!

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

Initial diagnosis and treatment: Yorkhill and transfer to RHC: 2014 – 2017

10. I was diagnosed with ALL (Acute Lymphoblastic Leukaemia) in 2014 when I was 9 years old. I was treated at Yorkhill Hospital in Glasgow up to 2015 and

then I moved over to the new Royal Hospital for Children (RHC). I was an out-patient there for a couple of years at the RHC.

11. I attended at the clinic, down in the atrium, when I was there. The clinic is for the patients in the children's hospital and it's where you go when you're on maintenance which is when you get tablets and a monthly check-up from the Doctor. Day care is when you're still on IV chemo and things like that. The same Doctors that work in the clinic and day care in ward 2B of the RHC. I went to clinic once a month. I went there to get my chemo tablets, a check over and get bloods done. I was in maintenance at that point.

12. The clinic had a really big waiting area. All the clinics are together so everybody is mixed in the waiting area and there could be three or four different clinics on at the same time, and the patients all sit next to each other. The clinics serve lots of different departments in the RHC, there was the heart one that was often there but I can't remember all of the other clinics. There were usually three or four Doctors from the Schiehallion clinic there. Pharmacy is down there as well.

13. There are two rooms for bloods but they cover two or three clinics. We would usually try and get there for 10am in the morning when it was quiet but you would still have to wait for three or four hours for the bloods coming back. A lot of the time the bloods in the samples were clotted because you were waiting that long for them to be tested. That was really quite annoying especially because of the amount of time we had to travel from [redacted] to get there. If the bloods were clotted, you would have to get them done again and then you'd have to wait another three hours on them coming back. The bloods would get sent through the chutes to the labs and a lot of the times the chutes would break down which would make it even worse and make the wait longer. Sometimes the staff had to draw 3 or 4 times due to bloods sitting for a long

time and clotting. For young kids who were scared of needles this was really bad.

Relapse and admission to ward 2A, RHC: July 2017

14. My blood had never recovered after the first time I had ALL. We always knew there was something there. In July 2017 I started getting really bad shooting pains up my legs and I was getting tonsillitis a lot. I was also tired quite a lot, which was usually one of the first signs; it was one of the first symptoms.

15. On the 3 July 2017 I went up to Dumfries hospital for a routine check. Nothing was showing up on my routine blood checks. My Doctor, Jean McKnight, took my bloods and she made sure the film of the bloods was checked as well. A film is a deeper look at the bloods. Because she did that, that's how we found out I had relapsed.

16. I was transferred by ambulance to the Royal Hospital for Children in Glasgow. I got admitted to ward 2A at the Schiehallion Unit. Professor Gibson was my consultant, when we arrived she took my mum and dad away to discuss my treatment plan. The doctors started my chemotherapy treatment straight away to see if they could get me into remission. It was intense chemotherapy treatment. If they couldn't get me into remission, then I would need a bone marrow transplant. After my first round of chemo I did go into remission so that was fine. I remained an in-patient in ward 2A for about 6 to 8 months and I received chemotherapy treatment during that time.

17. I got the treatment through IV which went in through a central line into the right side of my chest. I had to get surgery under general anaesthetic to get that fitted. The central line is used to take bloods and give chemo and medicines through it too. There are two separate lines, one is white which is

for chemo and the other is a red one for getting bloods put in and taken out. The medicines can be antibiotics, platelets and bloods. The line has a dressing over it. I have always been really bad with cannulas with my veins, and I was going to need too many treatments, so I needed a central line.

Experience on ward 2A of the RHC: July 2017 – December 2017

18. The first thing I noticed about ward 2A was that it only had a single door whereas the old Yorkhill had double doors to ensure the air on the ward was purified. After you went in to ward 2A, the ward was in a curve so you couldn't see what was coming which I found quite weird. There was quite a small playroom for the little ones but everybody was in their rooms. There were not a lot of patient rooms; less than Yorkhill. The nurse's station was right in the middle of the ward. In the old Yorkhill all the kids were out of their rooms, up and down the corridors or in the playroom, or in and out of each other's rooms.

19. Being 'in source' is when patients are kept in their rooms for infection control purposes. At Yorkhill the only time you were in source was when you had a cold. In the new hospital you were never out of source because you were always getting infections.

20. I was in the TCT (Teenage Cancer Trust) unit on ward 2A and it is funded by the Teenage Cancer Trust. I think I was in room 3 which is a TCT bedroom. There are about five rooms in the unit. It's a separate unit away from the younger ones and it's just for teenagers. In my room there was a bed and there was a small TV above the bed that never worked. There was a three-drawer unit, a fold down bed for my mum or dad to stay and some of the rooms had a big wardrobe. There was also the bathroom which had a shower, sink and plastic drawers, which were brought in later. I stayed in that room for

the first year I was there. My mum or dad could stay over with me and use the pull out bed.

21. The unit has a common room which is like an adult version of a playroom. It's got a pool table, a TV, X-boxes, a full Sky package, and quite a good mini kitchen. There are comfy couches and board games; it's a pure chill out area which can be used by teenagers and their parents.

22. The TCT coordinator, Ronan, got a few people in to do things with us. There was pyjama making, guitar lessons and he would come in and play board games and the X-box with us. There wasn't too much going on and I never had a teacher the whole time I was there. Some people did get a teacher but I didn't and it wasn't until I was getting ready to leave that he decided to come round. The teachers were all primary but I think there was a secondary teacher. I was in S1 at that point.

23. One day I was sitting in the unit and I was talking to the TCT coordinator. We were talking about the ventilation and how it felt different. He told me that it was only up to 30% standard for a normal person and 70% lower should be for what it was for us. It was really humid and stuffy in the unit. It didn't feel right or what it should be. You were warm anyway, you were spiking temperatures and the thermostat in the bedrooms didn't work; it was horrible. It was boiling in the patient rooms but at night it went freezing, it was either one or the other and there were no windows to open. If you were warm, you stripped down and if you were freezing you got all the covers. The old Yorkhill had a bit of a breeze and it was quite cold and different to what it was like in the rest of the hospital. In Yorkhill we had Dyson fans to keep cool, when I first arrived in Ward 2A we had Dyson fans. Then one day they took them away; they randomly disappeared and no one told us why. We were not allowed to use the fans and the rooms were too hot. It was not nice.

24. My first lot of treatment lasted six months. I had chemotherapy every day, the whole time I was there. Sometimes it was stopped when I got infections and I would then get antibiotics in place of the chemo, for however long it took for the infection to go away. The first sign of an infection was when I had a temperature, which was above 38 degrees, and then they tested it through my bloods and swabs. That's when I would get started on antibiotics. I had infections a good few times during that admission but they could never find out what they were.

25. I was in isolation during my time in ward 2A. There was 'isolation' and there was 'in source'. Isolation was when you weren't allowed to leave your room and the nurses would bring everything to you and 'in source' was when you had a temperature or a cold or cough and you weren't allowed out the room. You tended to be 'in source' if you had an infection. I was mostly in source rather than isolation but that was later on though. I wasn't in isolation during my first admission but I think that it was in 2018 when I got the RSB virus that I was in isolation. I was more annoyed in source, I was really lonely and things play on your mind and there's no escaping it when you're in source.

26. The water coolers were like rectangular white boxes with a blue bottle on top. There was one in the parent's room in ward 2A. I would use it a couple of times a day and I was drinking quite a lot of it. I would stand and chat to the nurses. There was one week in December 2017 when I drank a lot of it and by Thursday or Friday I had to go on oxygen because I couldn't breathe properly. I had x-rays and it showed up a bit of cloudiness so I had to go to surgery for suction to get whatever it was, out. I stayed on oxygen for quite a while because it was really low, around 93 or 94 and sometimes when I was sleeping it was around 91 or 92. It never really recovered properly and they never understood how or why it was like that. My oxygen should be around

98; that was the lowest it should ever be sitting at. One or two months after that all the water coolers started disappearing from the hospital. The doctors were never able to work out what caused the cloudiness in my lungs.

27. There were never enough sockets and the nurses told them when they were putting them in that they needed at least eight. I was hooked up to at least six machines that were bleeping all the time and they never held charge so when I got up for the toilet I would switch all the plugs around. The machines were for chemo, bloods, platelets, morphine, ketamine and antibiotic fluids. If you were already ill and not sleeping then you had all the bleeping on top of that, it wasn't good. The bleeping came from the battery packs, it didn't matter how long they were on charge, they just didn't hold it. It wasn't very good if you were halfway through bloods or chemo and the battery runs out.

28. My mum and dad didn't really use the parent's kitchen much in the ward. It had a microwave, a kettle and a coffee machine too. It also had a fridge, a freezer and a table. It also had daylight from a window. We used the TCT room instead.

29. The TCT facilities in ward 2A were all internal, including all the bedrooms. My room, (room 3) was also internal. If you turned off the lights it didn't really make a difference because the lights never went off in the main atrium and the blinds were always broken. They were internal so you couldn't get in to the window to fix them. The cleaner would come around at 4 o'clock in the morning to clean the atrium, pulling all the chairs that were squeaking on the ground and then there was the cleaning machine screeching and squealing. They had the out-patient adult clinic down there as well so weekends were stressful with adults walking about the hospital and kids screaming. They had a 24 hour, out of hours thing, with drunk folk entering in the atrium. This was all near to my room window and because the atrium is so big it echoes, so

you're up all night basically. I was always wondering if I would manage to get a sleep.

Discharge from ward 2A, CLIC Sargent and day care, ward 2B: January 2018 – November 2018

30. I got out in approximately January 2018 and went to stay at CLIC Sargent for a few days a week. I had to keep going to day care in Ward 2B for chemo every day I started a treatment plan of 3 days inpatient chemotherapy treatment at the hospital and was allowed to go over to CLIC in between times. I was still in 2A officially and had to stay very near to the hospital.

31. Over time at the weekend I would get home to [redacted] and then back up on the Monday to go again. I think that lasted for a couple of months but a few times I ended up spiking a temperature so I ended up getting put in the ward.

32. CLIC Sargent is a two minute drive from the hospital grounds, it is two minutes around the corner. It's kind of classed like being a little bit of an out-patient. It's a little house and there's a couple of families that live in it. There's a kitchen, a living room and your whole family can stay there. It's got a drier, a washing machine and a wee garden. You can make proper meals and you can have it as long as you need. It's like a home from home and it's only Schiehallion patients that can use it and you can talk to other families. It's not like Ronald MacDonald house, because that is for the whole hospital and that's always busy. That is why CLIC was good, it has communal areas and we could talk to other families who had children who were Schiehallion patients. I could stay there with my mum and dad.

33. I went to day care for my IV but sometimes I spiked temperatures so I ended up getting put back into ward 2A as an in-patient. That happened three or four

times during that period. I also remember towards the end of that, I had a problem with my eyes and I had to get admitted to get eye drops every two hours, day and night. It was because of the chemo that I had problems with my eyes. We were still staying at CLIC Sargent then.

34. I was never told why I spiked temperatures but when I got them my chemo had to be stopped. Professor Gibson wouldn't let me home to [redacted] because I had too many infections and a relapse so she wanted to keep a close eye on me. It's an hour and half drive from the hospital to my home. She was just over-protective of me.

35. Maintenance treatment lasts for two years. It's a treatment and is basically chemo but in tablet form. You also get vincristine through a cannula although I still had my line in. You get regular check overs from the Doctor and get your bloods checked as part of it. I got home kind of half way through maintenance treatment but not at the start of it because I was still in CLIC.

November 2018: PICU and admission to ward 3A in the RHC

36. In June 2018 I began the maintenance phase of treatment. I started getting really, really bad headaches and my eyes were flickering. The treatment can cause headaches but I told Professor Gibson and she told me to take some paracetamol and I would be fine.

37. This lasted up to November 2018 when I had been at home for a short time. I woke up the morning of 19 November 2018 and couldn't lift my head off the pillow. I couldn't handle the pain at all so we went straight up to Dumfries hospital. I stayed in overnight and in the morning it looked like I had a stroke. I couldn't talk and I couldn't swallow.

38. My Doctor at Dumfries hospital gave me a CT scan and I got taken straight up to Glasgow. That night I went into PICU in the RHC and spent two days there. I had loads of steroids pumped into me. I then spent three or four weeks in the neuro ward which is 3A. They were trying to figure out what was wrong. I started picking up after they put me on a high dose of steroids which reduced inflammation in my body. During this time they did a lumbar puncture, which is a surgical procedure where they drained fluid from the spine. I started receiving high dose chemotherapy and was released home again around the start of December 2018.

39. I was mainly under the care of the neuro Doctors and it was only once a day one of the Schiehallion Doctors would come up to see me on Ward 3A . My maintenance treatment stopped while I was in 3A. My mum thought that I had leukaemia in my brain. One of the doctors thought it might be a neural disease. The steroids made my headaches mild, my eyes were still squint and I couldn’t speak properly. My balance was off and it never really went back to normal. Some of my face is still numb and I’ve still got scarring on my brain. Sometimes I can’t see too many people, my sight is a bit blurry. My mouth is squint, I still can’t chew on the left side of my mouth.

December 2018 – January 2019: PICU and the move to ward 6A QEUH

40. I got let out in the middle of December 2018 and I came home but a couple of days later we went back to Glasgow because I had really bad headaches again. My mum and dad took me up in the car. We went to day care which was now in ward 6A in the adult’s hospital, and one of the neuro Doctors and Professor Gibson came to see me. They had a look at me and said that it was fine because they had been reducing my steroids. We went back home to [redacted] . My chemotherapy was still stopped during this time.

41. On Christmas Eve the same happened again. I couldn't lift my head off the pillow; it was even worse than before. We went back up to Dumfries hospital where I saw Doctor McKnight and they did a CT scan. I went straight back up to Glasgow by ambulance again and was admitted to ward 6A in the QEUH.

42. I can't really remember much about the night of that admission. I remember watching TV that night I was admitted but that's about it. A couple of days later I was in PICU, ward 1B.

43. It's quite hard to get to PICU from ward 6A. When I was going down, I had the crash team with me. It's a team that has resus, a defibrillator, oxygen, medicines and adrenalin, that kind of thing. It's a lot of kit, it's huge backpack. The medical staff had their staff cards for the lifts but some of the lifts were broken down or full of people so they had to put me in the public lifts and take me the long way round the whole of the adult hospital to the children's side. I then had to go all the way round the children's side to get to the ward. It could take 15 minutes to get through it all. If I had been in the children's hospital, it would have been nearer, down one floor, instead of down six and up one floor. The staff had to make a plan of what to do and where to go if I crashed during the journey to PICU from ward 6A.

44. The resus teams for kids and PICU for kids is on the children's side of the hospital. So if I crashed and needed my resus team, they had to run from the children's side of the hospital. When they got the adults hospital they had to run up flights of stairs to get to the 6th floor where we now were. It is not suitable to provide care like this when the children are in the adult side of the hospital. That's where the problem came in for the resus team, if there was an emergency in 6A, it would take them too long to get there and then to try and resuscitate somebody. They were always saying that, with all their equipment

to carry that it was dangerous. It was tiring, and they probably wouldn't have been able to resuscitate a child once they got to ward 6A. Only the resus team for kids can resuscitate kids; adult resus teams cannot resuscitate children. It is just too different.

45. At that point they didn't know what was wrong with me. It wasn't until 27 December 2018 that they could actually figure out what was wrong. The first thing Professor Gibson said was not to give me any steroids whatsoever because that would mask whatever I had. My maintenance chemo treatment was still on hold at this point. When I was in PICU they took a lumbar puncture and Professor Gibson ran it to the labs herself. When it came back my mum and dad were told that I had listeria meningitis. I got treated with IV antibiotics for eight weeks. I had a cannula in because I had my line removed half way through my maintenance treatment, which was more surgery in late summer 2018. Because the antibiotic treatment took so long and my veins were so bad from my previous treatment, they put another central line back in, at the start of January 2019. That was also surgery under general anaesthetic and I was in ward 6A.

46. Connor Docherty is an infection disease Doctor. I started to see him the second time I went to PICU which was in December 2018. It was Professor Gibson and Connor Docherty who were not too sure what it was and they thought I got the meningitis through something I had eaten.

Experience of ward 6A

47. I stayed in 6A until the end of January 2019. That's when they started bringing in the HEPA filters and all the Cryptococcus happened with the pigeons and the ventilation. The microbiologist and the Professor were also coming around at 9 o'clock at night to the patient bedrooms to check the drains in the shower.

48. The Schiehallion team from both wards 2A and 2B are on ward 6A in the adult hospital. Ward 6A is in two parts. You go through two doors and there are five or six rooms on the left hand side. The nurse’s station is on the right hand side at the corner, it was like a triangle. There were another seven rooms and then you go through a door to day care. You had to walk through 6A where all the in-patients were, to get to day care; it was quite a long ward. The transplant patients were not in the ward though, they were in ward 4 in the QEUH. That was the children who were getting bone marrow and stem cell transplants.

49. I was in room 5 when I was in 6A. It’s in front of the nurse’s station, at the corner. The room had a bed, a unit and a bathroom but I don’t think it had a window. It was really basic, a lot more so than the rooms in the children’s hospital. There was a fold down bed for my mum or dad to sleep on. There was no kitchen for parents; they had one but it was only for staff. You weren’t allowed to use it all, if you wanted a cup of tea or coffee, you had to get one of the nurses to make it. You didn’t have a fridge and the only place you could heat up food was in the adult’s atrium, in the communal microwave, but you couldn’t use it until after 3 o’clock because it was for the staff for their breakfasts and lunches. Whilst we could use the microwave in the Atrium, staff and members of the public passed through that area and used it. It was not good for an infection prevention point so we didn’t use it.

50. In general the food was not nice in the hospital. They had stuff that I liked but it was cold. When I had meningitis, I was on a soft diet, and it was actually better than the solid diet. I was given burnt soup at one point though. The canteen food was not good, and it was such a shame as the Yorkhill food was good. We got food at Marks and Spencer and it was expensive. Lidl is across the road but it is difficult to get out to the shops.

51. The ward didn’t have a playroom or a TCT (Teenage Cancer Trust) facilities. The only room it had was a meeting room for teenagers to play a game or something like that but sometimes you couldn’t use it for a couple of hours. All the younger children had was a table and two chairs, in the middle of the ward corridor outside one of the rooms. That was literally their play area.

Emotional effects of move to ward 6A QEUH

52. It was a depressing and lonely experience in ward 6A. I found that with all the teenagers, they were all on anti-depressants and they didn’t even want to leave their room. One of my friends was anxious, it was really bad. The TCT staff could come to your room if you weren’t in source, but it was very limited. Before moving to 6A I knew all the other teenagers but when I was on ward 6A I never knew any of the other ones that were in at the exact same time as me. I ended up seeing a psychologist later on in [redacted].

53. When we moved to Ward 6A, we had nothing. We lost our community. We were isolated because we had nowhere to go meet each other, and that was a hard thing. We didn’t have a place where we could just meet and talk about stuff: where somebody else is going through something and they tell you, and you’ve went through it and you can talk with them. Even if all you want to do is talk about something completely irrelevant, and try and take your mind off it. Or if somebody is upset, there wasn’t any place where we could do that, where we could meet and speak to each other. It was hard, especially if you're just starting treatment. I'd already been through that but if you're just starting treatment it can be a really daunting time anyway, and then adding that on top: it's just hard.

Ward 6A QEUH and Dumfries Hospital: Late January 2019 to March 2019

54. In January 2019 I was made aware of the Cryptococcus in the ward and the possible ventilation issues by one of the nurses. I would rather not say what the nurse's name was. We already knew there were things going on around the hospital anyway and we were being told quite a lot of things from the nurse. We were talking to the nurse about HEPA filters that had been brought into ward 6A. We asked what they were for and she said it was for the Cryptococcus that came from the pigeons and the ventilation in the hospital. It was in the main ventilation for the whole hospital.

55. At that time it started coming out on the news and infection control were in and investigating what was going on in the hospital. Anytime my mum tried to find out what was going on from hospital management they, just didn't tell her anything.

56. In January 2019 I went to a meeting with my mum, Professor Gibson and the microbiologist whose name I cannot recall. This meeting took place in a room in ward 6A. There were also two other patients and their parents. The meeting was a chance for us to ask questions, but every question we asked the microbiologist, she just averted away from answering it. We were asking if it was safe for me, and she said "yeah, it's fine". We asked if the building was safe, if the patients were safe. The microbiologist never really had an answer, to be honest. The microbiologist came down to clinic to have these meetings, and everybody that wanted to talk to her went and spoke to her. The meeting came about because everybody was up in arms about what was happening throughout the hospital. The Cryptococcus in ward 6A was in the news at the time, and the news reported that two patients had died from it.

57. At the end of January 2019 my mum and dad had a meeting with the microbiologist and Professor Gibson and my mum asked if I was safe in the hospital and they said “yes”. I wasn’t at that meeting. My mum was also told that there was mould in the showers by Professor Gibson and the microbiologist. I don’t know the name of the microbiologist but it was a female.

58. After that meeting, the next day Professor Gibson came to my room and said she was driving home that previous night after that meeting, and she was thinking of how she could keep me safe. She said the best way to keep me safe from all the infections in the hospital was to transfer me down to Dumfries hospital. I wasn’t surprised to hear that to be honest, and I was relieved. My mum was with me when she told me that. We packed up my things and my mum drove me down to Dumfries hospital that day. The reason I was moved to Dumfries was to take me away from the QEUH and the issues there.

59. At the end of January 2019 I was transferred down to the hospital in Dumfries and was there for five or six weeks until the end of February 2019. I was fine. I was still getting my antibiotics and my chemo was on hold. I felt safe in hospital because I knew I wouldn’t catch any weird infections in there and that their water was clean. They had good ventilation as well because they’ve got a special isolation room for me with proper double doors and purified air. It had a door, a sink then doors again. You could feel the difference; it was very cool, their windows open and you can see outside.

60. The skin around my line had already begun to go red before I'd left ward 6A in January 2019, but we never really thought anything of it at the time. It wasn’t until I was in Dumfries for a couple of weeks and the line started to come out, this was about mid-February 2019. I went back up to Glasgow and was admitted to ward 6A in the QEUH. I saw one of the general doctors on the ward and the decision was taken to remove my line, he just looked at the line

and didn't do any other tests. The next day I was down in surgery in the first floor in RHC for a line removal. I had a general anaesthetic and the line was removed and scar stitched up.

61. As I didn't have a central line I continued to get my course of antibiotics by cannula. I was in Ward 6A for about a week until the scar scabbed over and then I was transferred back down to Dumfries. I finished my course of antibiotics at Dumfries hospital and when I finished the course I was able to home around about the beginning of March 2019.

62. Around about this time which was the end of February 2019/start of March 2019 I was starting to get a red lump on my right arm, at the top of my forearm. I didn't think too much about it at the time.

63. After I was discharged, I was back to school for a bit. In March 2019 not long after I was discharged from Dumfries, I went up for a routine check-up at Hospital. Where my stitches were, it looked like something was happening. It looked like one of my stitches were still left there and the area turned red again. I had a little pocket of pus where my line had been removed; the area was really sore.

64. I was sent immediately back up to the Glasgow hospital again and was sent straight to day-care in ward 6A. One of the nurses took out a bit of stitch and the whole area just blew up into like a big ball; it was just like a huge ball of pus. I was then admitted as an in-patient to the cardiology ward in RHC as there were no beds in ward 6A. The area of pus just kept getting bigger and bigger.

65. I stayed overnight and then the next day I went to surgery to get the area cut out. It was a surgery under general anaesthetic and the surgeon removed an

area about the size of a 50 pence piece. I was in hospital for a couple of days. I was then transferred back to Dumfries Hospital for a while, because the area had to be packed every day. I was in Dumfries hospital until the surgery scar healed a bit more and then I went home.

66. After I was discharged from hospital I gradually got more lumps on my arms, my legs and chest. The lumps were sore. They would burst and bleed, there was pus coming from them. It was sore to touch. I ended up with ten altogether and they appeared gradually over one to two months.

67. The lumps were at the worst about two to three months after they began to appear. It took about six months for the lumps to actually stop bursting. Only then did they finally start to heal a bit.

68. I had a routine clinic appointment in March 2019 at Ward 6A in QEUH. At the appointment I showed Professor Gibson the lumps on my body. She sent me straight over to the old Yorkhill hospital for a biopsy on them. At Yorkhill hospital they took a biopsy from a big lump on my arm. The lumps were bad at this point. They were bursting and bleeding all the time.

69. I was given a dressing for the bleeding but it just made it worse. I went back home to [redacted] after the biopsy and nothing really happened for a while.

70. A couple of weeks after I had the biopsy, Professor Gibson phoned to say that they biopsy results were back and it that it was TB. She asked us to go back up to Glasgow. Me and my mum went back up to Ward 6A and met with Professor Gibson and Conor Doherty. They explained that my immune system was so low, and they said that I had to come off chemo to let my body recover. They told me that I couldn't have an IV antibiotic, the side-effects were so severe that they didn't want to put me through that on top of

everything else. At that point the doctors decided to stop my chemo for now, and hope that my body can fight the infection itself. They didn’t tell me how I might have contracted TB. We went home and we thought that was it about the infection.

March 2019 – June 2019: Confirmation of Mycobacterium Chelonae infection and impact on treatment

71. A short while later we got another call from Professor Gibson. She asked to speak to the family. On the 29 March 2019 we all attended a meeting with Professor Gibson and the microbiologist whose name I cannot recall, in Glasgow. The microbiologist confirmed that the infection that I had was actually mycobacterium chelonae. It is related to TB but is not TB. She told us that she had traced it back to the water in surgery when I had my line removed in February 2019. She apologised and said she was sorry. I had caught the infection in the hospital. We went back home to [redacted] after the meeting.

72. Around June 2019 I was going for a bone marrow and lumbar puncture to Ward 6A. One of the main Schiehallion consultants called Annamaria came and spoke to me and mum. She told us that the doctors had decided to completely stop my cancer treatment altogether. At that meeting she told me, her and Professor Gibson and doctors from all over the world had discussed my infection. They agreed that the best option would just to be to stop my chemo altogether, so I finished treatment six months early. They said this was to try and keep the mycobacterium chelonae infection gone by allowing my immune system to recover.

73. The doctors were worried that I was getting so many rare infections, and they didn’t know what they were or how to treat them. They were worried that one

day I might get an infection that they might not be able to treat and that would reduce my cancer treatment options. Whereas, if I were to relapse again now, I've still got bone marrow, stem cell, and CAR-T therapy: I still have options open for cancer treatment should it be needed. It was a safer option just to stop my chemo for the time being and let my body recover.

74. After this I began to see a psychologist in [redacted] to help me given my experience at the hospital.

WATER: EVENTS INVOLVING WATER

Water incidents in RHC and QEUH: 2017 to 2019

75. For the first couple of months in ward 2A there was never anything said about the water. That was in 2017. I was drinking from the water cooler but not the taps. I was taking showers and brushing my teeth with tap water. After that first two months they came round and said that we weren't allowed to use the showers because there was a problem with something in them and they had to put filters on the taps in the shower. A lot of people didn't have a shower for about seven weeks and we were given some sort of foam spray to clean ourselves with. There was nothing we could really do, it is not like we could go home or go to CLIC and get washed. I was lying on a hot bed, the mattresses are covered in blue plastic and I couldn't wash unless I used bottled water. I think it was the nurses who told us not to use the tap water. After that it all went back to normal and then it happened again around August/September 2017.

76. Around November 2017 they were coming round and putting bleach or something down the sink at night so you weren't allowed to use the sink or the

toilet for a couple of hours. That was never explained; what they were doing or why.

77. They brought in portaloos for the Doctors and nurses and put them outside the hospital so if they needed the toilet they'd have to go all the way outside because the water was turned off. They were there for a couple of days. I remember the nurses saying they would go in a group because in the middle of the night in Govan, it wasn't exactly safe. It was obviously taking a lot of nurses out of the ward which was bad if an emergency happened in the ward.

78. Around about that time they brought in bottled water and we used it since then; it was constant. I still use my own bottled water and bottled water is still used in the ward now. Around this time I noticed they put filters on the taps and showers.

79. Being on chemo I had to keep my fluids up. I mentioned that I drank a lot of water from the water cooler. Not being able to drink the water in the ward, we had to buy bottled. Families had to find time to go to the shops. If I was ok and feeling up to it, I could go if I was allowed out and if I was not in isolation. If not it was my mum who would have to find the time to go down to the shops in the atrium for it. If we ran out someone had to go get it.

80. In 6A there were the same issues with 2A, with the showers and the water. You weren't allowed to use the water in 6A either. I think they still drink bottled water now. You were only allowed to use bottled water to drink, and I used it to brush my teeth. I did go for a shower in ward 6A because my mum asked if it was safe to go for a shower and the staff on the ward said it was.

Zone 12 flooding: 2019

81. In 2019 I was up in ward 3A, the neuro ward, between the teenagers and the kids bit. I was in zone 12. It was like TCT (Teenage Cancer Trust) but for younger people. I remember the tiles from the ceiling fell in overnight and all the water flooded the room.

HEALTHCARE ASSOCIATED INFECTIONS

HAIs: events and physical impact

82. At the end of 2017 it was all happening with the water and everyone was getting line infections. Infection control said it was the nurses fault and that they weren’t using the central lines right, which was a complete lie because they did it the exact same way as they always had. They introduced the green caps to keep the lines clean. Every time it got taken off to get whatever done, they would give it a clean and put it back on, and it had to stay on the whole time. Nobody had ever seen them before, they didn’t have them in the old Yorkhill and Dumfries (hospital) had never seen them before, so that was quite a weird thing. I had a green cap on my central line from the end of 2017 and it stayed on for the rest of the time I had a central line. They didn’t help as everyone kept getting infections anyway.

83. In the old Yorkhill I barely ever changed my dressing. I would leave my dressing on my central line for about a month until I went back up to Glasgow and got it changed because they could give it a proper clean and I never got a line infection from it. It was when I went to the RHC and got my line put in, every couple of days they wanted to change the dressing. The green caps got changed every time the line got touched, and then the green cap was disposed of. I think they cost quite a lot of money. I got told by the nurses that

the reason for the green caps was because there was so many line infections. I had never had a line infection until I was in with Meningitis.

84. When I contracted the mycobacterium chelonae infection it gave me lumps on my arms, legs and body. These burst and have left me with scars. As I mentioned the lumps were at the worst about two to three months after they began to appear. They were sore, they burst and bled constantly. It took about six months for the lumps to actually stop bursting. Only then did they finally start to heal a bit. I cover up my arms and legs now.

85. I did see a few doctors about the scars on my arms and legs, but even with all the doctors opinions about what to do, nothing was really happening. It was just a case of waiting, and letting my body heal itself.

HAIs: Emotional Impact

86. For half a year I was going between Glasgow and Dumfries constantly, with infections and I think they were related to either water or soil. Some we know about, others we don’t know the causes. We didn’t always know what the infections were. It got to the stage that I didn’t want to go up to the hospital in Glasgow: I was having anxiety and panic attacks as I didn’t want to go up.

87. I felt annoyed that I was getting infections and they were getting harder and harder to treat. When I was told that my treatment was stopping early because of the mycobacterium chelonae, I felt worried and anxious about that. I caught an infection so rare that I cannot get my cancer treatment.

88. When my mum was at one of the meeting with the microbiologist, she asked if I was at risk in the hospital. The response from the microbiologist was that my

body would cope outside. But I was inside the hospital, I should have been safe in the hospital. I was being treated inside that hospital.

89. I still see the psychologist and I've still got all the scars from the mycobacterium chelonae. It's made me feel self-conscious and I get panic attacks when I go up to Glasgow. I still go up to the clinic every two weeks because Professor Gibson keeps an eye on me but since Covid I've not been up for a year, which is not a bad thing. I now only go to Dumfries hospital for routine checks, every three months. I still have contact with Connor Docherty, we don't meet but he checked on my progress at the end of last year.

HAIs: communication

90. When the microbiologist discovered I had mycobacterium chelonae, I think the communication of that issue was probably alright. They didn't leave out anything. When the doctors found out about it they told us, and they didn't really have to do that.

91. Prior to that I was hearing things about the water, the ventilation, the infections. Parents and staff were saying the hospital wasn't safe. The staff were getting fed little bits of information and they were telling people. The staff were trying to get us to talk to the media because they obviously couldn't. Everybody was talking about the infections and then the Cryptococcus came to light. They were talking about the infections constantly occurring and how they were weird infections, and if someone went to day care, how they got an infection from there. People would talk about how they picked up infections and others would say how they got them as well. I knew the infections were coming from the water because when I was on the oxygen I had been drinking the water. All the infections I got were linked to the soil and the water environment and they all had the same links to that so that was the reason.

92. I only found about the Cryptococcus through one of the nurses, otherwise I wouldn’t have heard about it apart from through the news. Any time you asked the hospital about what was happening, they never gave you anything. We would ask the Doctors, infection control, the microbiologist.

OTHER ISSUES RELATING TO HOSPITAL CONSTRUCTION

Hospital build issues: impact of construction works

93. In 2017, when I had relapsed, the window panels on the outside of the hospital were falling out. A few of them fell out and they put scaffolding over the main entrance of the hospital. There was a net also so they wouldn’t land on somebody. At the children’s side, they took out all the window panels and replaced them.

94. The shape of the main QEUH building is like a star. When you’re walking up to the entrance of the hospital, there’s an unbelievable amount of wind that flows in your face. It doesn’t matter the time of the year, it can be a really nice day but it can still be the same. I think it’s because the shape of the building that drags the air in. They had to put up a false wall inside the doors to try and break the wind a bit. At reception they were sitting with heaters underneath the desks to try and keep them warm. Later on in 2017 there was one day when the doors swung open and smashed so the entrance got shut and you had to go the long way round. In December 2019 the roof in the adult’s atrium came off. It blew off and left a gap.

95. The lifts in general were always breaking down, they were really dodgy. When we got moved to the adults you’ve got to share the lifts with the general public,

like drunks, folk out their face and coughing their lungs up. If you're neutropenic it's not a good place to be.

96. The hospital was next to the sewage works and that's all you could smell walking up to the hospital. On a windy day it's worse but then on a hot day it's terrible. That's all you could smell throughout, even on the wards. You could go as high as you want but you could still smell it. When I had the RSB virus I was in 2A for a week. I was stuck in source and the only place I was allowed out was to the park but even at that, you couldn't go to the outdoor park. I was up there for five minutes and I was just about sick. It's not nice, you're feeling sick anyway and then you add that onto it as well, and then you're trying to eat and all you can smell is that, it's not pleasant. They had a problem as well, in that the sewage was coming up through the ground. My mum saw that in the atrium, in the corridor between the adults and the children's hospital.

COMMUNICATION: GENERAL

97. When I was down in clinic I had heard from the TCT coordinator, and from other people, that they had moved all the patients out from 2A to 6A, to try and fix the ventilation in the ward. More problems kept on occurring with the likes of the water, the move back to 2A was delayed about four times. The communication aspect of it was pretty poor. After the move to 6A happened, when I was sitting in clinic in 6A, there were still people going up to ward 2 because they hadn't told anybody about the move.

98. The communication around the water and other issues was terrible, there was none whatsoever from senior management. If it wasn't for the nurses we wouldn't have known about half the stuff that was going on in the hospital. When my mum emailed infection control about general issues, they wouldn't

reply or they would give you as short answers as they could or something that was completely irrelevant to what you were actually asking.

99. The staff were getting blamed for a lot of things, like the line infections. It was really taking its toll on a lot of them, the stress in general. A lot of them were seeing psychologists for it. With all the Cryptococcus coming out, it was really getting to the staff, you could see that but they couldn't speak out about it because they worked within the NHS. They were constantly pushing for us to try and speak for them. We were already sick of what was going on anyway so that gave us all the more reason why to do it.

100. My mum contacted the media, the newspapers and BBC as well. I think we were on Reporting Scotland. We talked about the hospital in general, like all the problems with the water, because the hospital wasn't doing anything about it. If we brought more things to light then they couldn't deny as much as they were. It had an impact; a lot of people started coming forward and a lot of things were brought to light and the hospital weren't holding onto as much information as they had been doing, and they started talking to people. It improved communication with us but not drastically, but it changed a little bit. The Health Board started giving us bits of information and didn't deny as much as they were. They then promised we would find out information before the media. A lot of my friends were only finding out things from the media or the news before that.

101. I feel that communication between us and the hospital has changed a little bit for the better. They could be more honest about it, even now they're holding back information about issues in the hospital.

102. I don't use the closed Facebook group. The press coverage hasn't impacted me at all.

Meeting with Cabinet Secretary for Health and Sport

103. I went to the meeting with Jeane Freeman. I went with my mum and dad and there was about six different families there who were all asking questions about why so many things had happened and why were there so many problems with the hospital and why it had opened so early. Everyone was sharing stories and saying things like, “that’s happened to me too”. We never really had that many answers at all. We were promised the world but it wasn’t a long meeting. It lasted about half an hour and took place in the Central Hotel in Glasgow but I can’t remember when it was.

OVERSIGHT BOARD / CASE NOTE REVIEW / REPRESENTATIVE GROUPS

104. I don’t know anything about the work of the Oversight Board and I’m not a member of any of the representative groups.

105. My medical notes were part of the Case Note Review. I don’t think I had contact with them but I think my mum did.

CONCLUDING COMMENTS

106. I don’t like the hospital building at all. I don’t know what I feel about the Health Board, but I think there’s too many problems to solve. I think they should knock it down and start again. You’re never going to get rid of the sewage for a start which means you’re never going to get rid of the water problem.

107. The experience has had a really big impact on me. I still have scars. I still have panic attacks when I go up to Glasgow. I still see a psychologist. I didn’t

mind going to the hospital before but now it’s a fight to try and get me to go. I get panic attacks every time I go there. I don’t know what I’m going to catch next. The stress and the anxiety from it impacted me quite a lot. From the scars, I’m very self-conscious, I wear jeans and a hoody when I leave the house; it doesn’t matter how hot it is.

108. 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.