Scottish Hospitals Inquiry

Witness Statement of

Professor John Cuddihy

WITNESS DETAILS

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

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

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

OVERVIEW

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

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

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

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

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

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

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

FAMILY BACKGROUND

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

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

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

PERSONAL BACKGROUND

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

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

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

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

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

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

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

INTRODUCTION

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

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

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

PARENTAL RESPONSIBILITY

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

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

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

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

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

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

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

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

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

16 Jan 2018: Molly’s Initial Diagnosis

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

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

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

Molly's Treatment Plan

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

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

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

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

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

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

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

Initial Communication and Engagement - Clinical Care

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

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

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

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

Ward 2A – the Schiehallion Unit: Initial Ward Experience

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

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

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

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

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

Environmental Awareness/Infection Control

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

<u>June 2018 - Hospital Acquired Infection (HAI): Mycobacterium Chelonae</u>

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

September 2018: Closure of Wards 2A and 2B (RHC)

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

October 2018: Molly's surgery

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

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

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

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

October 2018: Admission to Ward 6A

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

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

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

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

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

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

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

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

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

<u>January 2019 – February 2019: Surgery wards 3B RHC</u>

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

February 2019 to June 2019: treatment concluded

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

June/July 2019 – University of Cambridge

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

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

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

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

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

August 2019: Molly Relapsed

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

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

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

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

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

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

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

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

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

August 2019: Surgery – ward 3A RHC

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

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

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

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

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

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

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

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

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

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

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

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

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

5 October 2019: Every Thank You Counts Ball

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

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

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

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

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

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

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

October 2019 – November 2019: Admission ward 6A QEUH

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

December 2019: Make a Wish

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

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

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

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

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

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

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

January 2020: Holiday and preparation for Stem Cell Transplant

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

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

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

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

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

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

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

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

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

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

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

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

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

February 2020 - Stem Cell Transplant

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

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

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

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

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

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

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

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

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

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

February 2019: Admission to PICU

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

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

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

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

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

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

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

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

PREVENTATIVE MEDICATION

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

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

OTHER ISSUES RELATING TO THE CONSTRUCTION OF THE HOSPITALS

Cladding

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

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

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

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

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

Water systems

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

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

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

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

Windows

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

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

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

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

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

Drainage

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

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

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

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

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

Mould

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

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

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

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

COMMUNICATION AND ENGAGEMENT

GENERAL

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

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

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

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

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

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

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

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

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

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

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

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

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

The Independent Review

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

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

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

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

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

Oversight Board: Communication & Engagement Sub Group

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

The Independent Case Note Review

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

DUTY OF CANDOUR

OVERVIEW

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

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

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

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

Duty of Candour - March to May 2018: environmental awareness

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

Duty of Candour Event - June 2019: disclosure of further case of Mycobacterium Chelonae

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

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

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

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

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

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

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

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

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

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

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

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

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

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

Duty of Candour event: February 2020 – Stem Cell Transplant

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

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

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

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

Duty of Candour event: February 2020 - PICU

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

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

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

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

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

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

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

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

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

IMPACTS ON MOLLY AND IMPACTS ON THE WITNESS

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

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

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

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

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

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

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

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

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

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

CONCLUDING REMARKS

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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