SCOTTISH HOSPITALS INQUIRY

WITNESS STATEMENT OF

MS SANDIE ARMSTRONG AND MS BETH ARMSTRONG

WITNESS DETAILS

1. Our names are Sandie Armstrong, date of birth: [redacted] and Beth Armstrong, date of birth: [redacted]. We live in [redacted].

2. We are the daughters of [redacted] who was born on [redacted] and passed away on [redacted]. Our mum lived in Glasgow with her [redacted]. Mum was a patient in Ward 4C at the Queen Elizabeth University Hospital ("QEUH") in Glasgow where she contracted cryptococcus neoformans while she was undergoing cancer treatment.

3. During the period when these events unfolded, I (Beth) was living in Glasgow and would be regularly attending the hospital to see Mum, and Sandie was regularly [redacted] Scotland to see her.

Background

4. Our mum [redacted] was full of life. She was [redacted] but was very young for her age. She was active and lived life to the full. She travelled the world even after her cancer diagnosis and would regularly travel to [redacted] to visit Sandie and other family members. She was young in spirit, bright, intelligent and happy and would have continued to be so, had it not been for what happened. We exhibit a photo of our mum as 001. **(A50616103 - Photograph of [redacted])**

5. Mum was diagnosed with angio- immunoblastic T Cell Lymphoma in June 2016 and underwent six cycles of chemotherapy treatment from October 2016 – July 2017 as part of a Chemo-T trial. Unfortunately, she relapsed 8 months after completing this treatment and commenced on oral cyclophosphamide chemotherapy treatment in December 2017. This treatment was intended to continue indefinitely to control progression of the disease.

6. Mum was responding well to treatment until she became unwell on a trip to see Sandie in [redacted] in October 2018. She was admitted to [redacted] on [redacted] October 2018. Blood results showed that she had pancytopenia. Her oral chemotherapy was stopped and she was treated with IV antibiotics to increase her blood cells.

7. She was transferred to [redacted] for continuing treatment where a bone marrow biopsy showed findings consistent with her having a relapse of lymphoma. Steroids were commenced on [redacted] October. It was recognised that Mum needed ongoing inpatient care. She was given the choice to stay where she was or go closer to home. She told them she wanted to go back to Glasgow, so they transferred her to the QEUH on [redacted] November 2018 by ambulance and admitted her to Ward 4C which is a specialist ward for cancer patients. This was the first time Mum had ever been to the QEUH. Prior to this her regular treatment was at the Queen Victoria hospital in the haematology clinic on an outpatient basis. Mum was never transferred to any other ward during her time at the QEUH.

8. When Mum was admitted she had a continuing fever but had no further indications of having an infection. She remained on antibiotics due to her fever.

9. We recall that when she was admitted she was put in a specialist negative pressure room, which had double door entry access. We would have to put on full PPE and scrub up before we could see her.

This was because she was neutropenic. We can't recall what room number she was in. She was decanted from that room shortly after she was admitted but we can't recall dates now. We also recall that there was one point in November that she was decanted from her room on ward 4C because there was a blockage and stagnant water was sitting in the shower room.

10. The main room that mum stayed in was very near to the nurses' station, as you walked into the room the bathroom was on the right. There was a window which she couldn't open that looked out onto the flat roof outside. The roof had a lot of vegetation on it, which Teresa Inkster later told us was attracting pigeons.

11. Apart from the incident with the bathroom, the rooms Mum stayed in looked very clean. They would be cleaned daily and we didn't see any obvious red flags.

12. The medical records show that on the ██ November, Mum was showing signs of confusion.

13. On the ██ November her test results showed that her Liver function Test results (LFTs) were worsening, so her medication was stopped.

14. On the ██ November Mum started saying she was feeling better but by the ██ November her fevers had returned.

15. On the ██ November blood cultures were returned and we were advised that she had tested positive for cryptococcus neoformans. Antifungal treatment, Ambisome commenced and was soon combined with Flucytosine. By early December we were told her blood cultures were negative.

16. Sandie was travelling up to see Mum during the weekend that Mum was diagnosed and I (Beth) recall that ████, one of the Senior Staff

nurses who was excellent at keeping us informed when we weren't there, spoke to me. ███ asked if Sandie was coming up soon. I told her that she was on her way at that moment and █████ said that ███ wanted to speak to us both together because there had been a serious meeting with Dr Inkster, Dr MacDonald, our Mum and her █████████. █████ was concerned that we had not been present. ███ told us ███ was not clear how much of the meeting Mum and ██ had taken in.

17. When Sandie arrived █████ clarified that ███ couldn't emphasise the seriousness of the conversation that had happened. ███ told us that Mum had contracted a hospital acquired infection, this was how it was described to us. We were told that the infection that Mum had caught was a very unusual infection. ███ said that this was a very serious matter, and Mum should not have caught it. ███ told us we had a right to request a meeting and advised us to get in touch with management to request an official meeting to tell us what was going on.

18. On Thursday ██ November or Friday ██ November, the Registrar informed us (Beth, Mum and ███) that the source of the infection had been identified as Cryptococcus and that the infection was known to originate from pigeons. We can't recall ██ name – ██ seemed very nervous. █████ told us that the anti-fungal medication, Flucytosine which Mum started taking on ██ November, cost ████ for each box that would last 5 days of treatment. Mum was on the medication for 10-14 days, after which she was told that the infection had cleared from her blood (they were no longer able to grow the cryptococcus bacteria from her blood) but said that the fungus could hide in her system for up to a year so she would have to continue to take an anti-fungal medication in oral form for the next 12 months.

19. We think but we can't be sure that it was the Registrar who told us that the infection had cleared from mum's blood.

20. Mum's records show that Staph epidermidis is also indicated in the blood cultures but this was also showing as being negative in early December. We were told that Mum was showing as no longer having Cryptococcus in early December. We don't have any recollection of being told about the Staph epidermidis.

21. Mum's health deteriorated quickly during this period - she lost the use of her legs, was having nightmares and hallucinations and at some point she was unable to speak coherently, getting her words mixed up. During this time Dr Hart [REDACTED]. This was a supportive conversation, and he was trying to reassure us.

22. I (Sandie) have looked up AmBisome that mum was taking. Online information advises that side effects of this drug can include confusion, abnormal thinking, chills, dizziness, nausea, vomiting, renal function abnormalities, respiratory failure and seizures amongst many others.

23. Mum recommenced chemotherapy cycle 2 on [REDACTED] December. Several years after Mum died, we saw in the records that on the [REDACTED] of December Mum's test results showed that she was antigen positive which was never discussed with either of us.. We were just told continually that her blood cultures were negative. We have also never been told what possible impact being antigen positive might have had on her health. It raises the question of why they stopped the treatment for Cryptococcus and put her on a more general anti-fungal maintenance of Fluconazole.

24. The Cryptococcus knocked her back and unfortunately she never recovered from that. She had a physio coming in every day because since contracting Cryptococcus she had lost the use of her legs. She was told that she would only be able to go home for Christmas if she

was able to walk unaided. She was determined to get home for Christmas. She tried to regain some limited mobility and ██ was taking her for walks in the corridor every day with the aid of a walking frame. She was trying to get up and about, this was what our Mum was like. She wanted to be told what she had to do to get better and she would do it.

25. The chemotherapy treatment stopped on █ December 2018 and she was allowed to go home for Christmas day. She was quite weak at this point but was well enough to get dressed, put make-up on and have Christmas dinner with us.

26. We attended a meeting with Dr Inkster – we are not sure of the date, it may have been on 27 December. Dr Inkster explained her role and what infection control entails. It was explained to us that when there is more than one incident of an unusual infection close in time and place it would trigger an investigation, and that she would be leading the investigation. We were told that Mum had a hospital-acquired infection that comes from pigeon droppings and that they had discovered a hole in the roof on the 12th floor where pigeons were roosting in the ventilation machine room. There was also some conversation about the flat roof outside Mum's room on ward 4C that had vegetation growing and was attracting pigeons. Dr Inkster said that all of this would be looked at in the investigation. We asked about the other patient who contracted cryptococcus and she told us she couldn't discuss any details due to patient confidentiality. When we asked if the hole in the roof had been fixed, we were told that she didn't know and she would have to ask Estates.

27. We were advised she would provide us with the results following air testing they were conducting, but we never received these. I (Beth) once received a phone call from Dr Inkster to discuss the air tests while I was on a bus home from work. It was a very technical conversation so I asked if it could be put in an email. I also wanted this information in

writing so I could share it with the family, but I never received anything in writing. We read in the press that the test results were returned on 16 January 2019.

28. Mum returned to hospital on Boxing Day and her health continued to deteriorate. A meeting was organised for 9am on 1 January. Sandie was in so it was just me (Beth) and . picked me up at 8.30am and we drove to the hospital and attended a meeting with Mum, Dr Hart and Dr McDonald. We were advised that there had been a clinical deterioration and that Mum was no longer responding to chemotherapy. Her treatment would stop and she would move to palliative care. Mum was stunned by this news – we all were. She was very quiet but she did ask how long she had to live – it was a big shock.

29. I knew that Mum had to process the news with privately, so I gave them some space and left. I don't drive, I ended up in tears in the forecourt of that hospital. There were no buses running because it was New Year's Day. I had just been told my mum was going to die. I remember thinking, why did they build the bloody hospital in the middle of nowhere and beside a sewage plant? Who was going to be awake on the 1st January at 9am to help me get home? I didn't know who to phone and didn't have my purse on me to pay for a taxi. I was stranded and just felt totally helpless.

30. There were 2 subsequent meetings on 3rd and 4th January with Dr MacDonald. Dr Inkster was at one of them. When we spoke to Dr MacDonald and Dr Inkster at one of these meetings Dr MacDonald mentioned the other case near Mum's ward. I (Sandie) asked if this patient was alive or dead. They said they couldn't tell us because of patient confidentiality. So I asked if there was a problem, why was she not moved out of the ward? There was a big silence and told us that it would have been too difficult because she wouldn't have the specialist equipment for her care. also said that she was in a

different ward to the other patient. So I (Sandie) then said, oh right so it's not just her room, its possibly the whole ward that's been infected or maybe other wards or the whole hospital? [redacted]. We were very confused about the fact that they knew something was happening but they kept her in the same room. There was a note-taker in at least one of these meetings. We asked for the minutes after Mum's death and we were told there did not appear to be any minutes taken.

31. After the meeting on the 4th January Dr MacDonald said he wanted to talk to Mum and the family. We had to wait for Dr Hart to arrive and we had a meeting with Dr MacDonald, Dr Hart, Mum, [redacted] and both of us. At that meeting they confirmed the previous conversation from 1st January that she would be moving on to palliative care and explained what this meant. There was a discussion about whether she wanted to go to a hospice or to die at home. She was adamant she wanted to go home. They told her that they would not resuscitate her if she required it. This seemed to come out of the blue, and Mum was looking at us puzzled and asking us what we thought about this. It was the most horrific conversation we have ever had.

32. Mum passed away in hospital on [redacted].

33. Mum was never out of ward 4C despite having sustained the Cryptococcus infection. We put it to the doctors that she ought to be moved as there was a fungal infection going around, but she never was.

The Building

34. Having never been in the QEUH before, we were quite shocked by the building. It was so large and overwhelming.

35. I (Beth) would spend a long time just wondering how on earth they would keep it clean. I remember looking down on the atrium when we were waiting for the lifts. There were three lifts and quite often one of them would be out of order so you would spend a long time just staring down at this atrium waiting for the lift. I remember looking down at the atrium where coffee and tea is served and seeing these offices that look like boxes that jut out into the atrium above the food court areas. You would need a crane to come and clean those areas - it was such an odd design for a hospital. The top of the boxes were thick with dust and grime and I would wonder how on earth are they going to clean them? It makes you wonder what was in the dust that the ventilation system must have been circulating.

36. I (Sandie) remember seeing flocks of birds in great numbers circulating the waste processing plant next to the hospital on many occasions and pigeons flying around the outside area of the hospital. The foul smell from the waste processing plant was often overpowering.

37. I (Beth) recall reading a social media post where a pregnant lady posted a video of a pigeon flying around in the atrium. This was shocking as there would be no way of catching it due to cavernous nature of the space. It looked more like an airport hangar than a hospital. Also, there was often no hand sanitiser in the dispensers.

38. ██ would take Mum out for walks every day down the corridors to try and get her strength up, as advised by the clinical staff. Mum wanted to do everything she could to get better so remained as active as possible.

Anti Fungals and Treatment

39. We were alarmed by how fast Mum deteriorated. She started speaking nonsense, having terrible nightmares and hallucinations. This was after

she started the anti-fungals. She lost the use of her legs, she had to use a catheter and was completely bedridden. She knew she was talking nonsense but couldn't express it. We wondered about the toxicity of the drugs she was being given and whether it was causing this reaction. She had a relapse, was neutropenic, on steroids, had an infection and then she was hit with these heavy-going anti-fungals. It seemed to us that the Cryptococcus and the anti-fungal treatment significantly reduced her quality of life during this time. The chemo had to be stopped so we were asking questions about the drugs and no one gave us coherent answers. Was it dangerous? Was it going to reduce the chance of success of the chemo? We had all those questions. We also asked these questions after the SCI report **(A50257415 – Beth and Sandie Armstrong – SCI report 003 – Bundle 27, volume 13, page 26)** and after our meeting of 30/09/2020 **(A50256349 – Beth and Sandie Armstrong – Meeting with [redacted] [redacted] family 30 September 2020 – Bundle 27 volume 13, page 41)** and felt we never received a straight answer.

40. The doctors were due to administer a lumbar puncture (spinal tap) but explained that Mum was not well enough to endure this so they couldn't say for certain what was going on but the cultures were negative. At the time we weren't sure why a lumbar puncture was so important but we now think they might have been looking for evidence of cryptococcal meningitis.

41. For me (Beth) there were two phases, the first phase when Mum was alive and she was going through the cancer journey. Had Cryptococcus not happened all the conversations would have been about the cancer and the treatment options. Even if the treatment was going to fail again, Mum would have had options, for example to be cared for at home where she could have been surrounded by friends and family in her final days. We would have had space to say goodbye, but instead all of the conversations were about what was going on with the

Cryptococcus and dealing with the fallout of the infection and the treatment.

42. There were all these new doctors that would come in every day and check her eyes and send her for scans. We now understand that meningitis is a condition that can follow on from Cryptococcus. We were never told that they were looking for meningitis we just suspected it later, however it was clear that Mum had symptoms of some sort of brain infection. Unfortunately, because no spinal tap or post-mortem was carried out, this is inconclusive. They told us they couldn't do a lumbar puncture because she was too weak and no post-mortem was offered or discussed. In the SCI, which we describe below, it was never explained to us that Cryptococcus could be linked to developing meningitis.

43. Mum's specialist consultant, Dr Hart, advised that she had a choice of three cancer treatments in November 2018. It was decided that she ought to go with treatment option A which was three courses of chemotherapy which go in 3-weekly cycles with a rest week in between. This started on █ November 2018. Treatment was temporarily stopped because she was not well enough when they had just confirmed the cryptococcus infection on █ November. Once her blood cultures showed negative she recommenced chemotherapy on █ December and had 3 courses ending on █ December. On Jan 1st we were told that the treatment had failed so she would go into palliative care. We asked about the other cancer treatments that had previously been discussed but were told that there were no longer options. It was a shock when we were told that the options had disappeared suddenly. A few weeks ago there were 3 different options for cancer treatment, now there were none.

44. Dr Hart was very kind and he had a good rapport with us when Mum was in hospital. The communication at one point was also very good, I (Beth) recall that they would talk to us about results coming back and

that the results would be available on a Friday morning because samples would need to grow on the petri dishes for the right amount of time. This was when Dr Hart and other senior consultants and registrars would visit so I started to take Friday mornings off work so I could be updated.

Events after 7 January 2019 - Communication

45. Mum sadly died on [redacted] [redacted]. Our stepfather, [redacted] signed and collected the death certificate. The death certificate noted the cause of death as being Lymphoma. [redacted] asked the doctor whether Cryptococcus should have been included on the death certificate. The [redacted] said it should not as the cause of death was Lymphoma. We wanted to challenge this, but [redacted] was very upset and just wanted to get away from the hospital.

46. It transpires that the presence of an active Cryptococcus infection in her blood at the time of death could be conclusively proven or disproven with a post-mortem – a fact we did not know at the time. We had just been told that her blood cultures had turned negative, but we now know that the Cryptococcus antigen was still in her blood. There was no discussion or offer of having a post-mortem when [redacted] went to collect the death certificate.

47. Dr Hart reassured me (Beth) that Mum's case had been raised at a weekly haematology department meeting and that there had been a long conversation with all the Senior Consultants about the matter where it was agreed unanimously that the cause of death was lymphoma.

48. The day after our mum was cremated, the QEUH issued a press release on 18 January which told the public that a child [redacted] in the

hospital as a result of Cryptococcus, and that an "elderly" woman had also died, but her death was not linked to Cryptococcus although she had contracted the infection. This was the first we heard about the child [redacted]. [redacted], and we were annoyed about the press release describing my mother as elderly. She was certainly not elderly, she was very young for her age. She was active and travelled around the world even after her cancer diagnosis. It felt like there was an agenda at play, describing her in this manner. It also felt like odd timing – as the information was released to the press about the [redacted] the day after mum's funeral.

49. The day after Mum was cremated, Dr MacDonald contacted [redacted] to tell [redacted] there was going to be a press release coming out that was going to talk about Mum. This was the point that everything switched for us from being this terrible unfortunate incident to something more sinister. The moment she was cremated and the press release came out, it felt like the hospital's sole focus became about disproving a link between Mum's death and cryptococcus neoformans and later on this developed into disproving a link between the building and the infection. That seemed to be their only goal.

50. A couple of things happened after the initial press release that we would like to share with the inquiry to help illustrate how the hospital began to take control of the narrative to our detriment and, we believe, to the detriment of the search for the truth. Firstly, the then Health Minister Jeanne Freeman made a statement to the Scottish Parliament which was recorded and published on the BBC website stating that an elderly woman had contracted cryptococcus at the QEUH and had subsequently died, but her death was not related to the infection. The description of our Mum as 'elderly', we believe, was designed to minimise the interest in the cause of her death and to discourage questions to be asked concerning a second instance of Cryptococcus at the hospital. It was shocking to us that a definitive statement was made ruling out any possible connection to the other patient who had

cryptococcus before any investigations, including the SCI, had been concluded. We can only imagine this briefing came from the health board. I wrote to Ms Freeman to ask about this, but never received a reply.

51. We were contacted by a BBC journalist, , who was making an investigative documentary about the infections contracted by children and adults at the QEUH. I (Beth) met with her and her producer at my workplace, along with my , . had brought along photographs of Mum as he was so upset about how she was being portrayed in the press. When we showed the photographs to the BBC journalists they were visibly shocked. told us that had called the press office the day that the press release had been issued to ask about the second case of cryptococcus and had been advised that the lady who had died was very old and very frail. could not believe that the woman in the photographs could be described in this way – this is why introduced our Mum's story with the photograph that we have submitted to the inquiry as exhibit 001. **(A50616103 - Photograph of)**

52. In response to the concerns we raised about what happened to Mum, we received a letter from Jonathan Best dated 10 May 2019 which we exhibit as 002 **(A50257408 – Beth and Sandie Armstrong – Letter from Greater Glasgow Health Board in relation to concerns raised following the death of – 10 May 2019 - Bundle 27, volume 13, page 22).**

53. This letter was presented as a response to a formal complaint that in actual fact, we had never made. We had been asking the hospital questions about our mother's death which became a formal complaint without us being advised or given information about our rights. We never received any letters that indicated a complaint procedure was underway until we received this letter from Jonathan Best. We think our questions must have been lodged as a complaint by Jennifer Haynes,

the Board's Complaint Manager, because it says in the letter that if we were unhappy with this response to our complaint, we could meet with them to discuss it and if we were still unhappy we could take the complaint to the ombudsman. The reason we did not take it to the ombudsman was because we were uncertain if a complaint had been submitted and we were dealing with grief.

54. We asked if we could be assigned a Family Liaison person who could help us understand more about what had happened and answer our questions. They assigned us Jennifer Haynes, the Board's Complaint Manager. We were never signposted to any family support services at the hospital by anyone.

55. Jennifer Haynes had previously been in email touch with us and we asked how to lodge a formal complaint about how we were being treated. Mum's [redacted] wanted to as well. [redacted] had been sending emails and was creating an e-mail trail, and at one point [redacted] said [redacted] wasn't happy with the communication and wanted to know what the formal complaint procedure was. Jennifer said [redacted] complaint had already been lodged, assembled from their communications. In a phone call with Ms Haynes, [redacted] said [redacted] was not happy with that and wanted to lodge his own complaint, and Jennifer said [redacted] couldn't because once you lodge one complaint that's it. We were never told about the process and procedures for complaints. A leaflet was sent to us by Jennifer Haynes but there was no discussion about how it works – no one said to us there should have been Stage One and Stage Two.

56. I (Beth) compiled a list of questions from our family that we wanted to ask before we lodged the complaint and sent the questions to Ms Haynes. Ms Haynes said she didn't know the answers to the questions but would get back to us. She then asked if she could use our questions as a basis for a complaint. We replied that she would like answers to our questions before the family got together to compile the complaint. This back and forth continued without resolution. Our

questions were very clearly not our complaint, and this was repeatedly ignored. We never received any letters that indicated a complaint procedure was underway until we received the letter from Jonathan Best as a response to our ‘complaint’. This ongoing refusal to listen to us and answer our questions and the submission of a complaint without our agreement or knowledge was hugely distressing to us at an already upsetting time. I exhibit this e-mail chain as 003

57. In this letter Jonathan Best also says that an SCI investigation was already underway and would look to understand the root causes of her death. It said they would engage with us throughout this process. This did not happen.

58. We exhibit our copy of the Significant Clinical Incident Investigation Report that took place into Mum’s death as 004 **(A50257415 – Beth and Sandie Armstrong – SCI report 003 – Bundle 27, volume 13, page 26)**. This report created more questions than answers.

59. The SCI states that it was commissioned on 11 March 2019 and finalised on 6 April 2020. It was not sent to us until 28 April 2020, 3 weeks after it was finalised, and 1 year and 3 months after our mother's death. The guidelines state an SCI should be completed within 3 months of the incident.

60. We believe that the hospital failed in its duty of candour to us when producing and communicating about the SCI and we will explain why, later in the statement.

<u>Sandie’s View – SCI</u>

61. The SCI concludes that the cryptococcus infection was not thought to have made a significant contribution to mum’s deterioration and death,

rather, this was as a result of her underlying lymphoma. It concludes that issues were identified but they did not contribute to the event.

62. Antifungals: The SCI report states that clinicians noted Mum's worsening liver function on ██ November 2018, so she was taken off the standard anti-fungal Fluconazole. This was before they knew she had the cryptococcus infection. The review team considered whether another anti-fungal should have been considered but that *"there was an extremely low risk of such an organism infecting a patient such as ████. Whilst clinicians now may be sensitized to the risk of this recurring and are more likely to consider secondary antifungal cover".* This seems like they were saying that mum did not have adequate anti-fungal protection against contracting the Cryptococcus infection, but the doctors did not think she would contract such an infection so, on balance, it was decided to take her off the anti-fungal protection because of her liver function. This may be the case but we don't understand why the SCI concludes with such certainty that *"Issues identified but they did not contribute to the event.'*

63. Side effects of antifungals: There was no discussion of the possible side effects of the cryptococcus antifungals in the SCI report. We go on to discuss this later in the statement.

64. Scans: The SCI mentioned Mum's CT and MRI scans to the head (13/11 and 16/11) because of her confusion but said no findings of concern were noted. However no mention is made of her extreme confusion after these scans were carried out. We particularly remember her speaking incoherently, making no sense at all, and having hallucinations, later on, in the week beginning ██ November 2018. There is also no mention of what they were specifically looking for when they did the scans, and the possibility of cryptococcal meningitis is not mentioned in the SCI.

65. Investigations: We were not given any details of investigations that had been carried out as part of the SCI , except a list of actions in the Review Process which were: review of patient records; construction of timeline; review of any relevant policies, procedure, literature. In particular, we are concerned that the construction of a timeline was not disclosed in the report, to give us an overview of mum's treatment and care.

66. Presence of infection: There is no mention that mum was antigen positive for cryptococcus when she died, although her blood cultures were negative.

67. Scope change of SCI: The SCI did not address the root causes of the infection or the source of the infection. We had not been informed that the scope of the SCI had been changed to no longer include the source of the infection. Jonathan Best said in his letter (exhibit 002) that they would look to understand the root causes in the SCI. When we received the SCI report it had changed its terms of reference and it said: "*Section 1: Terms of Reference: The initial terms of reference included consideration of the potential source of the organism but this was revised as the Board commissioned a specific review of these matters."* We were never given any further information about what the Board's specific review of these matters" was. In *Section 4 'Key Issues Identified & Lessons Learned',* it states: *"The findings from the accident causation model should be included here. What was the source of the Cryptococcus infection? Estates and Environment Considerations. The presence of Cryptococcus in the hospital environment is subject to wider review by the Board and Scottish Government."* That is all we were told - we were not given any more information about what the wider review by the Board and the Scottish Government was. They did send us the QEUH Independent Review of June 2020 but we were not told whether this was the wider review mentioned in the SCI as they did not communicate any connection with the SCI when they sent it to us. When we read the Review in June 2020 we found out it had been

commissioned in response to the two cryptococcus cases and another case at QEUH. However, the Review did not mention Ward 4C where mum was, in any of its pages and it also threw up more questions than it answered.

68. Duty of candour: We believe that the hospital failed in its duty of candour to us when producing this report, for a number of reasons: We were not notified about the SCI until it was already underway. We were not included in any conversations about the SCI process and the investigations. Details of the investigations they carried out were not disclosed in the SCI. The scope of the SCI had been changed without our prior knowledge or discussion, and investigating the source of the infection became out with the scope. The way we were told about the scope change we believe was also evasive and misleading, as we note further on.

69. In his letter of 10 May 2019 (exhibit 002) **(A50257408 – Beth and Sandie Armstrong – Letter from Greater Glasgow Health Board in relation to concerns raised following the death of [redacted] – 10 May 2019 - Bundle 27, volume 13, page 22)** Jonathan Best told us that the SCI was already underway, and when we received the SCI it states it was commissioned on 11 March. No one had contacted us in March to tell us about it or explain what it was or how the process worked, this happened only by letter two months after it had been commissioned. Contrary to his assurance in his letter that they would engage with the family throughout, no-one contacted us about the investigation until the report was sent to us on 28 April 2020. We have since found out that the report was referred to the Commissioner at some point but we were never notified about this or contacted by the Commissioner.

<u>Beth's comments on SCI report</u>

70. When we received the report it was distressing. We felt as though we were being blindsided. The SCI report was a whitewash, a deliberate attempt to mislead us . No one wanted to put anything in writing before we received this. When we received the agreed terms that the report would consider it was presented with the title “draft”. I questioned this but felt everything was smoke and mirrors.

SCI – Communication

71. We exhibit our copy of the cover letter from Jonathan Best of April 2020 which accompanied Significant Clinical Incident Investigation Report as 005 **(A50622700 – Beth and Sandie Armstrong – Cover letter from J Best – 28 April 2020 - see appendix)**.

72. In his cover letter with the SCI report dated 28 April 2020, Mr Best states that the purpose of the SCI report is to establish the root cause of the incident, and that is why clinical language is used. However, he then goes on to say, *"In addition, as you will see, the SCI report does not consider the source of your mother’s infection. This is because the role of an SCI investigation is to establish if there was anything related to care and treatment that had a detrimental impact to the patient. For this reason, establishing the source of the infection was out with the scope of the SCI."* We find this wording very misleading, because the purpose of an SCI is to understand root causes, not just to investigate care and treatment. Establishing the source of the infection was not out with the scope of the SCI until the scope had been changed without our knowledge, consultation or any prior notification whatsoever. In addition, we have only now discovered that, according to Dr Inkster's oral evidence to the Inquiry, the drafts of the SCI reports had been changed so they did not include any information about the ventilation system plant room.

73. We asked in 2020 why the ventilation system had not been discussed in the SCI. Jonathan Best replied in his letter (October 2020) **(A50256343 – Beth and Sandie Armstrong – Letter re SCI investigation – 13 October 2020 – Bundle 27, volume 13, page 46)** *"Although ventilation systems have received negative publicity, I can confirm that despite extensive review, no link has been found between ventilation and infections in the Queen Elizabeth University Hospital".* He then goes on to summarise Dr Hood's hypothesis which attempts to rule out a link between our mother's cryptococcus infection and one ventilation system plant room. We strongly dispute this reason for omitting a discussion of the ventilation system in the SCI. We also strongly dispute Dr Hood's hypothesis.

74. The SCI report threw up many unanswered questions for us, it had inaccurate information in it and it did not address many issues about either our mother's care or the source of the infection. We put these questions to the hospital and received a response letter from Jonathan Best in October 2020 which he sent to us after meeting with the hospital in September 2020 as exhibit 006 **(A50256343 – Beth and Sandie Armstrong – Letter re SCI investigation – 13 October 2020 – Bundle 27, volume 13, page 46).**

75. We had a Zoom meeting on 30/9/20 with senior management and clinical staff from the QEUH to discuss this report:
Scott Davidson (SD) – Deputy Medical Director, Acute Services
Jonathan Best (JB) – Chief Operating Officer, Acute Services
Alistair Hart (AH) – Consultant Haematologist
Teresa Inkster (TI) – Consultant Microbiologist
John Hood (JH) – Consultant Microbiologist
Jen Haynes (JHaynes) – Board Complaints Manager

76. Ahead of this meeting, I (Beth) prepared an agenda to try and find a way to get clear answers, which we exhibit as 007 **(A50256399 – Beth and Sandie Armstrong – Meeting with QEUH on 30 September**

2020 – Bundle 27, vol 13, page 34). At the beginning of the meeting, I read out a statement on behalf of the entire [redacted] family. The response to our statement in the meeting was that they were sorry for our loss.:

We would like to reiterate our gratitude for the excellent care mum received from the doctors, nurses and health support staff throughout her care both as an outpatient at the [redacted] and an inpatient at the QEUH. She always felt well cared for and in good hands. Our complaint is not with them, it is with the senior management of the QEUH and health board who we feel have acted in their own interests and not in the interest of patients. A lack of transparency from the hospital has damaged our confidence in them. we feel that the hospital and the SCI report has taken the approach of downplaying the seriousness of the Cryptococcus infection, its link to the known building issues and its impact on our Mum's treatment and death. We do not believe that the priority has been to investigate the source of the Cryptococcus infection to ensure that the issue is resolved so that it never happens again. Rather we feel that the priority has been to protect their own reputations.

77. At this meeting John Hood downplayed everything. We felt we were being manipulated. We had believed that in an NHS hospital, the only motivation would be to resolve the problem to prevent others from becoming sick and in our view that's not what happened. The main focus seemed to be about disproving links rather than finding out the truth.

78. At this meeting we asked if any special measures had been implemented because of the substandard ventilation. Dr Hood argued the air was fine and even if pigeons were accumulating on the roof, the spores from the droppings could not find their way in through the ventilation system. He went into great detail about a test that he had done himself with a sheet of paper that conclusively proved this. This

seemed ridiculous to us. He said there was no way we could prove that the Cryptococcus came from pigeons roosting in the hospital, and our Mum could have contracted this in the park opposite her house. This seemed highly unlikely to us, particularly as we knew that there had been two cases in close proximity in time and location in the hospital. Dr Inkster was very quiet at this meeting and did not seem to support Dr Hood's hypothesis which dominated the meeting. The notes reflect that she could not say with certainty but it was her opinion that mum probably had an acute infection, which she felt was linked to the pigeons on the QEUH site.

79. When discussing his hypothesis with us in the meeting (30.09.20), Dr Hood was basing his theory on one ventilation plant room which he said did not serve areas of the hospital that our mum or the other case were in. However, Dr Inkster told us in the same meeting that she and other colleagues had been into the plant rooms and that pigeons had been in all four of the level 12 plant rooms.

80. Since this conversation with Dr Hood we have been very upset to read other reports about the ventilation system including papers submitted to the Inquiry, that strongly dispute Dr Hood's hypothesis. In addition, since this conversation with Dr Hood, a number of expert reports have been published which point out that the air change rate and the air pressure in the rooms in Ward 4C and other wards, did not meet Health and Safety regulations.

81. I (Sandie) tried to discuss the improvement notice on Ward 4c but they denied knowing what I was talking about because I never specifically referred to the 'improvement notice' instead I referred to "special measures". When I asked about this, there was an awkward silence and everyone looked at each other. They all said they had never heard of special measures. What I had meant was the Improvement notice and I do believe that they knew that. The improvement notice has been in force since January 2019, and as a result, they were legally obliged

to install upgraded air ventilation systems, which appeared to be evidence that there was, in fact, an issue with the air. We had never been informed about the Improvement Notice on Ward 4C by the hospital so we were only vaguely aware of it and at this point we hadn't seen it **.**

82. We requested minutes of this meeting to be sent to us. What we eventually received were not accurate minutes. It was a document named 'final version' and contained additional information on Dr Hood's hypothesis that was not part of the meeting and it skimmed over much of what we had said. We complained about this and have never received a satisfactory response. This increased our mistrust of Dr Hood and the senior management of the hospital. We exhibit a copy of the meeting notes that we received after this meeting as 008 **(A50256349 – Beth and Sandie Armstrong – Meeting with ██ ████████ family 30 September 2020 – Bundle 27, volume 13, page 41)**.

83. After the meeting we once again had more questions than answers. One area was the SCI report which we decided to send written questions about to get them to respond in writing. After the meeting Jennifer Haynes sent us a letter from Jonathan Best which attempted to answer some of the questions we had raised about the SCI report.

84. Antifungals: There was no discussion of the side effects of the cryptococcus antifungals in the SCI report and we asked what they could have been. In his response letter Jonathan Best says: *"Whilst I realise you are worried, please be assured that her clinicians do not think these 3 medications had any specific side effects that had a significant effect on your mother. Of note, Ambisome is particularly well tolerated for a patient's overall condition in terms of side effects".* We strongly dispute that Ambisome is well tolerated, but we also want to point out that the SCI report itself says that a side effect of Fluconazole is liver toxicity, and that is why mum was taken off it on Nov ██ yet

Jonathan Best contradicts this and says clinicians do not think these medications had any side effects that affected our mother.

85. Negative blood cultures: His letter changes the focus of our question which was whether Mum could have still had cryptococcus in her system even with negative blood cultures. He said a *“significant part”* of her infection had been treated which changed from us being advised it was absent after treatment. This is what they had implied verbally to us by saying the blood cultures were negative.

86. During the meeting of 30/09/20 Dr Hart showed us a timeline of Mum’s care and her journey. We don’t know whether this was the same timeline that was mentioned in the SCI because that timeline was never disclosed to us. The first time we saw Dr Hart’s timeline was when it was flashed up on screen. It said Mum was ”antigen positive” on December █ but this was not discussed and we didn’t notice it because it didn’t mention the word Cryptococcus so we didn’t know what it meant.

87. Jennifer Haynes sent us Dr Hart's timeline afterwards with the letter from Jonathan Best of 13/10/20 **(A50256343 – Beth and Sandie Armstrong – Letter re SCI investigation – 13 October 2020 – Bundle 27, volume 13, page 46)**. In his letter Jonathan Best, when answering the question of whether cryptococcus could still have been in her blood when she died, still did not mention that she was antigen positive. Mr Best turned it into a discussion about whether the infection was latent or acute which was not what we were asking. Mr Best, wrote in his letter of 13/10/20: *"Negative blood cultures: As you know, we discussed in the meeting we had with you the difference between a latent infection (lies inactive or dormant in a patient) and an acute infection (a ‘live’ infection, where symptoms are present). We unfortunately do not know with certainty whether your mother’s Cryptococcal infection was latent or acute, but we do know her blood cultures were initially positive, then became negative, which suggests*

that a significant part of the infection had been treated through the aforementioned antifungal medications". We had been led to believe up until this point that Mum had shown no signs of a live infection because her blood cultures were negative, hence she had been taken off the targeted cryptococcus antifungals and the cause of death was recorded as lymphoma. However, Mr Best was now saying that they did not know if her infection was live/acute or dormant/latent. He also says in this letter that mum's deterioration was not thought to be specifically due to her infection and its treatment …"*although this will have been part of it".* This was the first time it had been inferred that mum's infection may have been part of her decline. In addition. We were being told different things by different people and it seemed liked the narrative was constantly changing.

88. We asked if the cryptococcus could have contributed to Mum's death and Mr Best replied: *"Her blood cultures were not of concern at this time. For these reasons, [redacted] colleagues do not feel Cryptococcus contributed to your mother's death, and this was also the conclusion reached by the SCI investigation team based on their review of your mother's case, including her medical records."* He is again referring to the blood cultures being negative, and no mention is made of her being antigen positive for cryptococcus in her medical records.

89. If we had been told she was antigen positive we would never have agreed to have the DNR conversation with Mum but would have demanded a treatment plan. With hindsight, we should have been advised properly so we could have requested a post mortem as to establish the true circumstances into her death.

90. As we have outlined in detail in this statement, when we got the Significant Clinical Incident Review we asked a lot of questions about why was it commissioned and why was there a delay in it being released. Why were the authors not named and we pointed out that the

dates were wrong. We said we were not happy with the SCI - it was full of inaccuracies and it looked as though it had been put together at the last minute. It looked as though they had forgotten to do it and had quickly put it together. It took over a year to be written, and guidelines say it should have been written in 3 months. It included a statement that the family had been kept informed about its delay which was not true. Other questions we asked about the SCI report related to reasons it was commissioned, why it took so long and why the ventilation system and root causes had never been discussed in the report.

91. In summary, communication with the hospital has been appalling. We were put in contact with Jennifer Haynes, the Board's Complaint Manager but we never felt like we ever got answers to our questions. It felt like she was just a gate keeper and it seemed like we were not being supported to put our own complaint in. We felt like communication from Jonathan Best and others, was at times evasive and misleading. We believe the hospital failed in its duty of candour to us, particularly in terms of the SCI report and the ensuing meetings and letters. We became very fatigued by the whole process, we became burned out, hence why we did not engage with the public inquiry to begin with.

92. We have been very distressed to learn recently that there have been other cases of cryptococcus with links to the QEUH that we were never told about before. This only came to light in May 2024 in the Expert report prepared for the Inquiry by Sara Mumford and Linda Dempster. This report states that, in addition to our mum and the child, there were 5 other cases between 2015 and 2020 that suggested links to the QEUH. The fact that this was never disclosed to us is deeply shocking and distressing. It further compounds our deep distrust in the senior management of the QEUH and their evasive communication with us throughout the years since our mum's death.

Impact

Sandie

93. I believe that our mother's life was shortened by the cryptococcus infection and possibly also her treatment for it. We will never get that time back with her. In addition to feeling that loss, the rapid decline in mum's health was extremely difficult to cope with. We were advised in November that she would be back on track but at the end of December, we were told nothing else could be done. I was unable to really talk and be with my mother prior to her death, she was unable to have conversations. A lot of people would turn up to say their goodbyes, it was a chaotic time. We never had that time with her, at the end. To really talk to her and say goodbye. It was just so sudden. We never had that time with her, at the end.

94. Mum never even wrote a will until two days prior to her death.

95. We can't grieve properly and all the investigations seem to just go on and on and keep being brought up so publicly. On top of grief and loss, when you feel you are battling a system and you don't know what is true and what is not, it is disturbing and very difficult to cope with. It felt like we were being manipulated and that has added so much to our upset and strain. It's just awful.

96. Ever since Mum's death, [redacted]. It has been difficult. The pandemic followed one year after as well. Mentally, it has been the toughest time of my entire life.

97. I had to see a counsellor for over a year. [redacted] [redacted].

98. I was starting a counselling diploma course in 2021 and had to drop out due to the stress of everything, keeping up with the expert reports and

developments in the media and processing the often contradictory and confusing information.

99. Dealing with evasive communications from the hospital and their subtly changing narrative around the circumstances of mum’s death has been extremely upsetting and confusing.

100. Contact with the media has also been stressful. For example, I was on my way to a friend’s wedding and I received a text from a journalist asking me to attend a 6pm press conference that day. I was unable to do this and it completely threw me off kilter.

101. I am a single parent and a self-employed freelancer. The stress and time-consuming nature of dealing with everything since 2019 has impacted on me in many different ways and at times I have felt completely overwhelmed.

102. I just do not consider I have had time to grieve. I really miss my mother, it has been terrible. It happened too quickly, and she suffered so much.

103. I feel terribly sad for the other families who have had to endure the pain of not knowing the truth and having to fight for answers, on top of dealing with their tragic loss and the grief.

Beth

104. As well as the grief we are experiencing, every time another report appears we are having to read it over again and again.

105. I have worked for a charity for over 15 years and I loved my job. I was the creative director of a film charity in Glasgow and was very committed to my job. During this period my health deteriorated because

it was so stressful. I was working during the day and visiting the hospital at night, arriving home late every night. The hospital is not very accessible to people without cars, and I spent much of my time waiting on buses.

106. After my Mum died I was the main point of communication for my family with the hospital. I was dealing with the press releases and emails and trying to push for answers. It felt like we were being run around in circles by the hospital. [redacted]. [redacted]. I believe this to be a result of the incredible stress that I experienced attempting to deal with the aftermath of my Mum's death and the appalling communication from the hospital.

107. I realised that if I continued dealing with all of this I was [redacted] [redacted]. I decided to stop working and moved to Spain to try to get better. I was not aware of the adverts relating to the public inquiry when I was abroad and largely ignored what was going on as I had become burnt out by it all.

108. When I went to Spain, Sandie took over the communications and that resulted in her having to drop out of a counselling course that she was undergoing because it was too stressful to do it all.

109. It's not unusual to lose a Mum to cancer, it's not even unusual to catch an infection while in hospital, but what we were experiencing here was at another level. It felt as though the hospital was deliberately trying to confuse us and wear us out – it was like an episode of the twilight zone. The smoke and mirrors, the lack of trust, never getting a straight answer, feeling like we were being fobbed off, feeling like a cover-up was going on and feeling all the time like we have to get to the bottom of this for our Mum. That's entirely different from grieving for our mum.

110. We are very pro-NHS and until this happened we trusted in the NHS to protect the interests of its patients and staff. The clinical and support

staff that cared for our Mum were amazing in caring for her, and also for us, as my Mum went through her cancer journey. They were compassionate and kind. However, once we started dealing with the senior management we were met with obfuscation and disrespect. It felt as though they were taking advantage of our grief and distress to avoid any accountability for what happened to our Mum. We are appalled that these people are representatives of the NHS and they undermine the wonderful work that the clinical and support staff do every day in extremely difficult circumstances.

Hopes for the Inquiry

111. Is it appropriate to build a hospital with contractors competing to win the contracts at the cheapest price? Is it appropriate that those in positions of power have the authority to make the questionable decisions that they did regarding the quality and specifications of the building and ventilation system that was installed? Why did they accept the keys in the first place? If they need to shut down the hospital to resolve the problem then they must do that to save lives. There are no checks and balances when playing with people's lives – it's a false economy. The NHS is paid for by us and from what we have found out over the past few years, patients haven't been put first and they still aren't.

112. The senior management of NHSGCC need to be held to account for this appalling tragedy. The people at the top, the buck stops with them. We hope the Public Inquiry will remind them that they are here to serve the people of Scotland and they cannot play with peoples' lives in order to balance their budgets. If they are shown to have been negligent or to have obstructed the search for the truth they must be removed from their positions for which they have substantial salaries, paid for by the people that they were supposed to protect.

Final Comments

113. We understand that our Mum had a rare form of cancer. . Her final days should have been spent somewhere safe, with her family, not fighting a rare environmental infection that shortened her time with us. Instead, she was fighting a serious infection and undergoing invasive treatment on top of her cancer treatment and wasn't well enough to spend time with the people she loved or to properly say goodbye. This has never been acknowledged by anyone at QEUH, and we hope that the public inquiry will finally recognise the impact that this had on our Mum's life and the quality of her death.

114. We hope that this inquiry will be a force for good so that the hospital and the Health Board addresses the extremely concerning built environment issues that are still unresolved today in order to avoid any further terrible consequences to patients and their families in the future.

Declaration

115. We believe that the facts stated in this witness statement are true to the best of our knowledge, information, and belief. We understand that this statement may form part of the evidence before the Inquiry and be published on the Inquiry's website

115. The witnesses verbally introduced or provided the following documents to the Scottish Hospital Inquiry for reference when they completed their statement (Appendix A).

Appendix A

A50616103 - Photograph of

A50257415 – Beth and Sandie Armstrong – SCI report 003

A50256349 – Beth and Sandie Armstrong – Meeting with [redacted] family 30 September 2020

A50257408 – Beth and Sandie Armstrong – Letter from Greater Glasgow Health Board in relation to concerns raised following the death of [redacted] – 10 May 2019

A50256343 – Beth and Sandie Armstrong – Letter re SCI investigation – 13 October 2020

A50256399 – Beth and Sandie Armstrong – Meeting with QEUH on 30 September 2020

A50622700 – Beth and Sandie Armstrong – Cover letter from J Best – 28 April 2020

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NHS
Greater Glasgow and Clyde

Private and Confidential
Ms Beth Armstrong

Via email:

Date: 28 April 2020

Enquiries to: Jennifer Haynes
Direct Line:
E-mail:

Dear Ms Armstrong,

I am writing to you following the completion of the Significant Clinical Incident (SCI) investigation into the death of your mother, , and I have enclosed a copy of the SCI investigation report with this letter.

Firstly, I would like to apologise unreservedly for the inordinate delay in completing the SCI report. This delay was unacceptable, and I deeply regret any added distress the lateness of receiving the report caused you and your family. We recognised the importance of the issues, and wanted to make sure that we obtained all of the information required to consider and address the serious and significant concerns, but even with that being the case, it should not have taken the length of time it did to complete the investigation and report, and for that, I am truly sorry.

I would also like to highlight to you that the purpose of an SCI investigation is to establish the root cause which led to the, in this case, very sad outcome. It is therefore written in a very factual and clinical way, so that the findings are clear, and lessons can be learned. This is therefore not the same approach we would take, for example, when writing a letter to a bereaved family, where we would still wish to be clear and factual, but would also put a lot of consideration into ensuring the tone and language was compassionate.

In addition, as you will see, the SCI report does not consider the source of your mother's infection. This is because the role of an SCI investigation is to establish if there was anything related to care and treatment that had a detrimental impact to the patient. For this reason, establishing the source of the infection was out with the scope of the SCI. Please be assured that does not mean that this matter is not very important, and is being looked at as part of a separate external investigation.

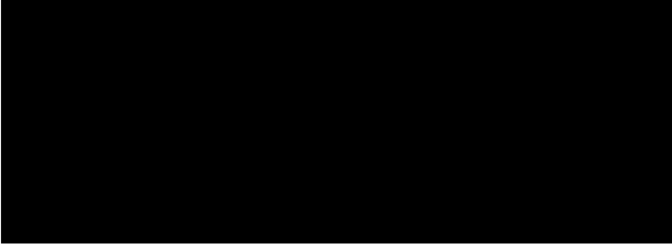
The reason I have brought these points to your attention is to assure you that despite the factual nature of the SCI report, we have not lost sight of all that you and your family have been through. I realise that some time has now passed since your mother died, and whilst time can make grief easier to cope with, I am very aware that losing a parent is a significant event in anyone's life, and this must have been even more difficult in your case, given what happened. My sincerest condolences therefore remain with you.

In normal circumstances, I would invite you to come to meet with us once you had the opportunity to fully consider the SCI report, if there was anything that you wished clarification on, or wanted to discuss. At the moment, however, such a meeting would not be possible due to the unprecedented COVID-19 pandemic, and the social distancing measures in place to help protect us all. Once the pandemic is over and some of these measures have been lifted, we would welcome the opportunity to meet with you, if you would wish to do so. Alternatively, if, once you have read the report, you wish to speak to us and feel you cannot wait until the pandemic is over, we could look at using

technology to allow for a video conferencing style meeting. If you wish to pursue either of these options, or have any questions, please do not hesitate to contact Mrs Jennifer Haynes, Board Complaints Manager, whose details are at the top of this letter.

My kindest regards go to you and your family.

Yours sincerely



Jonathan Best
Chief Operating Officer – Acute Services
NHS Greater Glasgow and Clyde