**Witness Name:** Elizabeth Brown
**Statement No**: WITN7092001
**Exhibits:** None
**Dated**: 22nd July 2022

**INFECTED BLOOD INQUIRY**

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**WRITTEN STATEMENT OF ELIZABETH BROWN**

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I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 12 May 2022.

I, Elizabeth Brown, will say as follows: -

## Section 1. Introduction

1. My name is Elizabeth Brown. My date of birth is GRO-C 1961 and my home address is known to the Inquiry.

2. I lost my husband in 2017 so I am a widow. I retired last year. Prior to my retirement I was a lawyer working in local government in the areas of regulatory and adult social care law. I have three children aged 29, 28 and 25.

3. I intend to speak about my brother, Henry Allen Titley, who was a Haemophiliac. He is known in our family as "Allen", and his infection with Hepatitis C ("HCV") and potentially HIV after switching from cryoprecipitate to Factor VIII (Hemofil) in 1971/1972. In particular, I will focus on how Allen's illness affected him and our family, the impact of his death and the financial assistance my family received.

4. I can confirm that I have chosen not to have legal representation and that the Inquiry Investigator has explained the anonymity process to me. I do not wish to be anonymous as I wish for my family's story to be known in full.

5. The Inquiry Investigator has explained to me the 'Right to Reply' procedure, and I understand that if I am critical of a medical professional or organisation, they will have the right to reply to that criticism.

6. I wish to acknowledge that naturally as time passes, memories can fade. I have been able to provide approximate timeframes for matters based on life events. However, these timeframes should be accepted as 'near to' rather than precise dates.

7. I have constructed this statement without access to Allen's medical records.

8. My sister, Allyson Edney was present in the room during the process of drafting my witness statement and I have acknowledged her input throughout my statement. I have also read the statement to my 86 year-old father, also called Henry Allen Titley but known in our family as "Harry", and also acknowledged his input throughout my statement. Unfortunately, Harry is too ill to make his own statement.

**Section 2. How Affected**

9. Allen had severe Haemophilia A. His clotting factor was between 0% and 5% and my father used to tell the tale of a young doctor carrying around a file of Allen's blood all day and it never clotted. So we understood that it was closer to 0% than 5%.

10. My mother and father told me that Allen was diagnosed with haemophilia when he was a 3-month-old baby. He had a massive swelling on his cheek but there was nothing inside his mouth that could explain it. A doctor came out to their home and initially could not work out what it was. Various tests and checks

were made, with no positive result. My father asked the doctor if it could be haemophilia because two of my mother's brothers (who had died in infancy, before she was born) had been known to suffer from it, as well as one of her cousins. The doctor went ashen white and then said he thought it was most likely haemophilia, which was duly confirmed

11. My mother was already pregnant with me at this time and my parents feared they would have another haemophiliac child if they had a boy. It was a relief to my parents that both my sister (born 20 months after myself) and I, were girls.

12. My mother GRO-C could not have any more children. The fear of having any more haemophiliac children was too much to bear. Allen was 5, I was 4 and Allyson was 2 GRO-C GRO-C

13. Allen spent a lot of time in hospital and to start with this was at Newcastle General Hospital. My childhood summed up is a colouring book and a packet of sweets in a hospital waiting room, that is how often Allen went to hospital.

14. We were always waiting for something. My mother used to telephone the hospital and advise that Allen had a haemorrhage, an ambulance would be ordered and we would wait for it to arrive. We would wait in the ward waiting room to be seen and often they would have forgotten to phone ahead and order the cryoprecipitate to be taken out of the freezer and prepared. So we would wait for it to be ready (and sometimes defrosted) and then wait for it to be administered to Allen. Then there would be the wait for the ambulance to take us home.

15. Allen was also allergic to cryoprecipitate so had to be given penicillin at the same time.

16. Growing up and having an older brother who was a haemophiliac was difficult. Instead of Allen protecting my sister and I, we had to protect and look out for him. I was always told to look after my brother. My sister and I were told that

we could also never retaliate physically if we were arguing with Allen, as siblings do. This had serious implications as we grew up and Allen could not vent his angst and natural frustrations and aggression in the usual way of play fighting.

17. Allen struggled to release his tension and aggression so he often took out his frustrations on Allyson and I. While I, rather naughtily, would retaliate if Allen hit me, Allyson did not GRO-C GRO-C GRO-C

18. In 1968/1969 when Allen was around 8/9 years-old he sustained an accident in the playground of Cragside Primary School ("Cragside") which he attended, when he was hit on the knee by a football, and spent the following 9 months in hospital. Initially this was in Newcastle General Hospital, which was the place at which he received his treatment from birth. While being treated for the severe haemorrhage to his knee, the hospital staff punctured a blood vessel in his other leg which bled internally, so severely that the whole leg became filled with blood. Allen was very ill and had an awareness of his condition.

19. Allen was on a general children's ward with five other children. My mother stayed with him the whole time. Two children died on the ward whilst Allen was there and he watched a girl's body be wheeled out of the ward. Allen thought he too was going to die.

20. Shortly after the worsening of Allen's condition my mother walked into a bathroom on the ward and saw a young child, who had just had an appendectomy sitting unattended and blue with cold in the bath. My mother was so angry and worried about the level of care on the ward that she demanded that Allen be moved. They said he was too poorly to be moved so she told them they better get him well enough to be able to do so. Allen was shortly moved to his own private room and was subsequently moved to the Royal Victoria Infirmary ("RVI") in Newcastle where a new specialist centre for Haemophilia was being established

21. During the 9-month period Allen was in hospital my sister and I were only allowed to see him twice – on Christmas Day and Boxing Day. Also, our paternal grandmother had to move in and live with us at home in order to allow my father to go to work, as my mother lived at the hospital with Allen. We saw our mother very intermittently during this period when she came home to have a bath and change her clothes.

22. While at the Newcastle General Hospital Allen had to have blood transfusions because of the internal haemorrhaging into his leg. I don't think this blood would have been infected as it was 1968/1969.

23. After Allen was discharged from hospital, following this 9 month stay, he had lost a significant amount of schooling and Cragside would not allow him to return for fear of further injuries. The Local Authority suggested he should attend Pendower Hall School for disabled children but my mother wanted him to remain in mainstream schooling local to our home. She was impressed by Benton Park Primary School ("Benton Park") because of the headmistress who was well ahead of her time. The school, while mainstream, had a specialist deaf unit within it and while Allen did not have trouble with his hearing the headmistress agreed to accept Allen into this unit.

24. Allen had no friends at this new school and didn't know any other pupils as they were drawn from a different catchment area. This was difficult for him and when he transferred to Manor Park High School ("Manor Park") he was still very much behind his peers educationally and was placed into a low set, with children from a different social background to himself.

25. My mother also subsequently moved my sister and I from Cragside to Benton Park.

26. Benton Park was the natural feeder school for Manor Park, which was a split-site school (years 7-9 at one facility and 10-13 at another). My mother sent Allen here because being split-site meant that Manor Park had less children

playing together at lunchtimes and smaller playgrounds which she thought would be safer for Allen.

27. I was at Benton Park for nine months before I went to senior school and I was sent to Heaton Comprehensive School ("Heaton"). This was closer to our home and Cragside was its natural feeder school but the break away from Cragside that I went through meant I was largely friendless at Heaton, until sixth form. Allyson also went to Heaton School. Trying to fit in all the time makes you very resilient but my mother seemed to want to separate us from Allen at this stage so that at least at school we were not impacted by his haemophiliac condition.

28. In 1969, Allen started going to the Haemophilia Centre within the RVI in Newcastle, instead of Newcastle General Hospital. Allen was soon under the care of Dr Peter Jones (known in our family as "Jonesy") and Sister Ferns (known in our family as "Fernsey"). We got the feeling that Peter Jones thought he was a demigod because we understood him, from the staff, who hung on his every word, to be an international leading authority for haemophilia

29. Allen went there very regularly, roughly twice a month (sometimes more) to have his cryoprecipitate administered to him. Allen hated these visits as he was always asked so many questions about how the injury had occurred. When? Where? At home or at school? Did he cause the bleed himself or did someone do something to him? What was he doing when it happened? How long after it happened before he realised he was haemorrhaging? Why did he wait so long before telling anyone? etc etc. My parents would also be asked things like 'How did he get into this state? When did he first mention it to you? Why did you not ring us earlier?' etc etc. The questions were gruelling and intrusive such that significant discussion always preceded any treatment and therefore delayed treatment, which distressed us all and increased Allen's recovery time.

30. The arduousness of all of this distressed Allen significantly. It seemed so unreasonable to me, as I often had bruises on my arms and legs myself but I never knew how I had got them so why should Allen? The occurrence of the injuries that led to a bleed were invariably as a consequence of no more than

normal play, which my parents allowed Allen to engage in as much as his fitness levels permitted. Allen was a young haemophiliac boy; he was going to get bleeds from school and from playing. He couldn't throw a dart with his right arm without having a bleed in his elbow, that's how easily he bled.

31. I have never been able to forget that on one occasion because of the incessant questioning that was occurring Allen simply ran out of the room and attempted to throw himself over the staircase banister. I don't recall if it was my mother or a young doctor who caught and stopped him but it was extremely distressing. It seemed that Allen had reached a point where he did not want to live anymore.

32. An additional distress at hospital visits was the fact that the doctors or nurses were allowed 3 attempts at inserting the intravenous needle before they had to call a Registrar to attempt to administer his treatment. Allen had wasted veins so it was very hard for nurses and doctors to find a vein to use and this again, often led to a delay in the administration of treatment, an exacerbation in the severity of the bleed, increase in pain to Allen, from additional swelling, and a longer recovery period.

33. Allen hated being in hospital and going there at all and he used to downplay how much pain he was in so that he could always leave hospital at the earliest opportunity.

34. I remember around 1971/1972 my family being told that there was a new drug that Allen was going to be put on to. My father clearly recollects that Peter Jones told him that there was a limited supply of cryoprecipitate and so the RVI and other hospitals were looking to source alternative drugs to treat Haemophilia. Peter Jones said that Hemofil was a fantastic new drug and that Allen would be one of the first people to get to use it.

35. The situation as presented to my parents was that if Allen didn't accept the use of Hemofil there would be nothing for him to use when he needed treatment. My parents knew that Allen's pain was so excruciating when he sustained a bleed that he would have to have something to clot his blood and stop it pouring

into his joints and forcing them apart, so for them, the decision was one of Hobson's choice. If there was nothing else available then they would have to consent to Allen using Hemofil.

36. At no point were my parents given the option of Allen remaining on cryoprecipitate.

37. We lived in a very open house. My parents discussed openly what was happening with Allen's treatment. My father is clear that he remembers reading material from the Haemophilia Society, warning that Hemofil was not safe because the blood it was being made from was likely to be contaminated. My father put this to Peter Jones who told him that the product was heated to 60 degrees to kill off any infections and was therefore safe. When my father said that the reports he had read suggested otherwise and that 60 degrees wasn't enough, Peter Jones told him not to be 'ridiculous' and that there was an extensive process the blood had to go through before it reached the hospital and all issues would be eradicated before the blood came to the hospital; it was therefore safe and they knew what was best for Allen and my father should let them do their job.

38. My father still feels he let Allen down by not asking for proof that the bloods were not contaminated with the new AIDS disease that he had read about, or indeed other possible diseases, given the sources from which the American bloods were obtained.

39. Allen was about 12 years-old when he started on Hemofil and was, as we understood it, one of the first haemophiliacs in the North East to be put onto it by Peter Jones

40. Allen must have contracted Hepatitis C and/or potentially HIV as well during the time in which he was given Hemofil, which was from 1971/1972, when he was about twelve years-old, until 1982 when he died on 8th November at age twenty-two.

41. Allen appeared to have faith in Peter Jones. Allyson and I had no respect for him at all, we recollect him as arrogant and condescending. Peter Jones asked us for blood samples when I was eighteen and Allyson was 16, so he could determine if we were carriers of haemophilia or not. When telling us the results he said: "It's like this girls, imagine there are two cakes in the oven, one with self-raising flour and one with plain flour. You both have plain flour in your cakes". Having plain flour meant we were carriers.

42. We found Peter Jones very patronising and insensitive. We were 18 and 16 years old and if we didn't understand by then, the impact of Haemophilia, on the whole family, having lived with Allen all our lives, we never would. Peter Jones' explanation in no way demonstrated an understanding of the extremity of the emotional trauma of knowingly bringing a human being into the world who would have to suffer such agonising and torturous pain as we had witnessed in our brother.

43. It is true to say that Allen much preferred using Hemofil rather than cryoprecipitate, because it was kept in the fridge at home and he could self-administer it, with assistance, in just twenty minutes. He also used a prominent vein on his hand that he would not allow anyone else, including a doctor or nurse, to use.

44. As a haemophiliac Allen's life was impacted in many ways but the implications were particularly heightened with regard to dental appointments and treatment. Bleeds in the head were particularly dangerous, which meant that he would always have to have treatment without pain relief to numb the area, so he simply had to endure the pain. Where treatment was so extensive that pain relief would have to be administered or he needed an extraction, the dentist would refer him to the dental hospital. In such circumstances Allen was given Hemofil beforehand.

45. Allen's educational experiences were not good and he did not like school. Largely this was because of the amount of schooling he had missed due to his 9 month stay in hospital aged 9 and the regularity of his hospital visits, but

particularly when he was transferred from the lower school at Manor Park to the Upper school.

46. For reasons which seemed to be connected to the school's concern regarding Allen getting hurt or bullied by other children, they insisted that he was moved to the top set. No matter how hard he tried he was not at the level of the other pupils in his class.

47. The school nurse was trained to assist Allen with his injections at school once he was using Hemofil, should that be needed. However, Allen refused to admit to a bleed at school and only ever addressed them when he came home.

48. With hindsight, I think Allen self-harmed in order to miss school. There was a pattern over 2 years where he would have a bleed on a Monday morning, come home for lunch (that was normal in those days), have the rest of the week off to let the bleed recover, he would have recovered by the weekend and then the same thing would happen early the following week.

49. Allen wanted to leave school as soon as he could. My mother said he could leave at 16 if he got a job. He stayed at school for a few months after he turned 16 but got an apprenticeship as a scale mechanic, with Avery Ltd, and left straight away. He learnt how to calibrate scales and ensure they were accurate.

50. Allen was clearly well thought of at work as just before his death he had been selected to work on the new electronic scales in which the company was beginning to invest. Avery's were a sizeable organisation and asked Allen to register as 'disabled' but he refused to do so initially although I recollect that he had spoken to my mother in the last year of his life about maybe having to do so and also about leaving work. He loved his job and this seemed very strange but I think, with hindsight, he knew he was more poorly than any of us realised.

51. Allen also had a part time job two nights a week working as a driver for the Doctors deputising service ("Air Call") which was an out of hours on-call GP service. The Doctors often requested the same driver from week to week. Allen

invariably worked for the same two doctors. After Allen's death, the doctors visited my parents and told them that due to the deteriorating condition of his ankles, the doctors were actually driving the vehicle instead of Allen. Both doctors empathised with Allen's condition as they each had been brought up with Haemophiliac relatives and understood the level of pain he endured.

52. At age nineteen, Allen started to have an unprecedented number of bleeds which he could not put down to any injuries. I remember the RVI allowing him to have prophylactic treatment because he was working at the same time as coping with these bleeds. Peter Jones considered him to be something of a success story within his clinic because he had such a severe condition but was holding down a manual job. Allen would usually have a dose of Hemofil before going to work two or three times each week. My sister or I used to assist him with these injections.

53. In June 1982 Allen was very unwell with abdominal pains and was taken into the RVI. The medical staff thought it was appendicitis and decided to perform an appendectomy. However, when they opened him up they found that there was nothing wrong with his appendix but it was removed in any event.

54. They then decided to perform a laparotomy. The operation consent form permitted such additional procedures as the medical professionals deemed appropriate. My father believes that Peter Jones assisted in this operation and that another haemophiliac doctor may have been involved but no general medical specialist appeared to have been consulted or attended.

55. Allen was given several doses of Hemofil before they operated. He was also given a blood transfusion during the procedure. After the operation my parents were advised, by Peter Jones, that Allen had suffered a bleed into his intestinal wall which had caused a blockage. He said that the blockage had been removed.

56. My mother questioned how the removal of a blood clot could be carried out on a haemophiliac without causing further bleeding but Peter Jones assured her it had and that the amount of coagulant in Allen's blood from the Hemofil and the

transfusion had enabled it to occur. Allen was discharged from hospital following this procedure on the GRO-C 1982. I remember this vividly as it was the day of my 21st birthday.

57. Three months later Allen was admitted to hospital again, towards the end of October 1982. I remember this time well as I had my University graduation on Friday 5th November, by which time Allen had been in hospital for almost two weeks. My parents visited Allen daily and reluctantly left the hospital to attend my ceremony.

58. From the first day of his admission my mother felt that Peter Jones was stalling with a diagnosis of Allen's presentation. He had rapidly developed a huge swelling of his abdomen and my parents were extremely concerned. My mother kept asking Peter Jones what was wrong with Allen and he kept changing the diagnosis.

59. At first he said it was jaundice which the family could understand as Allen's skin was very yellow. However, no explanation was proffered as to what was causing the jaundice or how they were going to treat it. My father clearly recalls that Peter Jones then changed his diagnosis, advising that Allen had a thyroid problem. My mother strongly disagreed with this diagnosis as she had some understanding of that condition and couldn't equate Allen's presentation with thyroid problems.

60. Next Peter Jones thought Allen had another 'blockage' in his intestinal wall, as had been diagnosed, and apparently addressed, back in June. Allen was nil by mouth at this time but my mother would go to give him a kiss and would pass him a cube of chocolate from her mouth to his mouth as a treat. My parents queried why, if he had a blockage, they would not operate. Then Peter Jones decided Allen's presentation wasn't the same as in June and therefore declined to operate.

61. My parents continued to press for a clear diagnosis. Peter Jones then advised them that Allen had Hepatitis B. My mother told Peter Jones that if it was just

Hepatitis B she could look after Allen at home. Peter Jones said she couldn't remove Allen from the hospital as it wasn't clear that it was Hepatitis B and they still needed to do further tests. My father has a vivid memory that at this point Peter Jones ordered my mother to leave the hospital as he said that her 'challenges' were upsetting his staff. Peter Jones never mentioned 'Non-A Non-B Hepatitis' as such, but he did go back on his clear statement that Allen was suffering from Hepatitis B and Allen was not allowed home.

62. On the day of my graduation, and after the ceremony I went across to the hospital to see Allen. I recall that Peter Jones entered the room and sat on the bed next to me. Allen was sitting in the chair. Peter Jones very patronisingly asked me, in a voice I thought he must use with small children: "Do you think that if we let you take your brother home you would be able to look after him?" It was quite bizarre. I told him that of course we would, but it was very clear from the swelling I observed of Allen's abdomen that he was not well. He looked about 6 months pregnant. The swelling was so severe it now prevented Allen from moving off the bed without assistance and he could not bend down to put on his slippers when his feet were cold.

63. On Sunday 7th November when my parents visited Allen in the afternoon it was apparent to them that he was continuing to deteriorate further. He told my mother that he thought he was bleeding into his shoulder but she tried to make light of this by saying that they needed to get his tummy sorted out first.

64. Her concern with Allen's abdomen was increased during that visit as she observed that it was visibly larger than the day before. My father recollects that my mother asked the nurses to get a doctor to look at Allen and they were told very clearly that someone would look at him at the end of visiting once they had left.

65. My mother was becoming more and more impatient and annoyed with the hospital because no one knew what was going on and Allen was deteriorating. Her child was in distress and they didn't know what he needed.

66. In the early hours of the morning of Monday 8th November, my parents received a call from the hospital asking them if they could come in as they were taking Allen to theatre to operate. Allen had an additional swelling of his abdomen. My parents arrived only just in time to see Allen being taken off the ward to theatre. They were told by Peter Jones that he was a seriously ill boy and Peter Jones couldn't say what the outcome of the operation would be.

67. Allen had signed the papers himself for this operation. He was asked if he wanted to see a priest prior to the operation and he said yes. Allen was brought up going to church but did not engage with religion much as an adult. It surprised me that he said yes, maybe he knew he was going to die.

68. The operation began at about 2am. Shortly after it began Peter Jones came out of theatre to speak to my parents. He told them that they'd discovered that Allen had ruptured his gut and there was nothing they could do for him as he was necrotic inside so they had sewed him back up.

69. Allen was unconscious after the operation and was never brought back to consciousness. My parents requested that he be kept sedated so that he didn't come round to be told that he would die. While waiting for his passing Peter Jones told my father that: "He's a strong boy, I thought he would have gone before now". My father remained with Allen until his death at around 8.30am Monday 8th November 1982.

70. I was living away from home in a flatshare at the time. My mother was brought by the hospital chaplain to my flat at 6am. I was surprised that she had left Allen in the hospital but she thought that Allen would 'hold on' if she was still there. She left so that he could let go and no longer suffer. She told me that Allen was going to die and that my father would come over from the hospital once Allen had passed. My father arrived at about 9.10am.

71. I go into further detail about the impact of Allen's death on me and my family in a later section, but although the sense of loss was enormous, knowing he was no longer suffering was a relief.

72. Because Allen deteriorated very quickly and died so young, he was never officially diagnosed with either Hepatitis C or HIV or both. I strongly believe he had contracted either one or both of these viruses through Hemofil and that is ultimately what caused his death.

73. Allen had no tattoos and did not take intravenous drugs. Allen lived at home with my parents all his life so someone would have been aware of either of these things. Also, Allen did not like to puncture his skin so he would not have had a tattoo or injected anything other than his medication.

74. After the post mortem, Peter Jones visited my parents at their home. I was not present at the time but Allyson was, as she was home from university. Peter Jones told my parents that there was so much good intestine left in Allen's body that there was a possibility that they could have saved him. Allyson recalls that my mother's response to Peter Jones was; "If I had a gun I would shoot you". Peter Jones replied to this by saying that my parents were entitled to bring a complaint if they wanted to.

75. My mother asked Peter Jones who would lose their job if she brought such a complaint. Peter Jones said it would be the young houseman who was working at the time of Allen's death. My mother said she wanted Peter Jones to lose his job. Peter Jones said that she could potentially get compensation if she made a complaint but she said: "What would I do with that? It won't bring Allen back".

76. I believe if Peter Jones had brought in a general consultant who had knowledge of the possible complications following a full laparotomy they could have saved my brother, by operating at that time. Peter Jones decided not to operate on him and said there was nothing he could do when there clearly was. I am confident now that had Allen not died in November 1982, he would have been diagnosed in 1983 with Hepatitis C, HIV or AIDS.

77. Allen's death certificate records that the cause of death was:

1a. Peritonitis due to

b. perforation of small bowel due to

c. intestinal obstruction

2. Haemophilia

78. I remember going into Allen's bedroom after he died and found the post mortem document in a drawer. It said that Allen had suffered a haemorrhage under his liver. I think this happened because he had Hepatitis C. I think my mother burned this document as I could not find it again. If we had had this document when I helped my father apply to the Skipton Fund I believe he would have received the Stage 2 payment as well.

**Section 3. Other Infections.**

79. As mentioned above, my family does not know and will never know exactly what infections Allen had. The only infection that was officially diagnosed was Hepatitis B. I strongly believe that he had either Hepatitis C or HIV or both too.

80. I do not know if Allen had contracted any other virus.

**Section 4. Consent**

81. As far as I'm aware Allen did not have any treatment without his consent. However, he may have had his blood tested without his consent but I can't be sure. Allyson remembers that the hospital used to take a lot of blood samples from Allen but we never saw any results or knew what the samples were for. Therefore, there is a possibility that his blood was used for research but I can't be certain.

**Section 5. Impact.**

Mental/Physical Impact

82. Allen died in November 1982 without a formal diagnosis of either Hepatitis C or HIV. The only official diagnosis he had was that he was Hepatitis B positive.

83. I think that because Allen died very early on in the AIDS epidemic when very little was known about the disease, he was not affected by the stigma attached to it.

84. The two weeks leading up to Allen's death were horrendous to witness. You could tell that he was in so much pain and so uncomfortable. He was jaundiced too. As I have said before, he struggled to do basic things like put on slippers or dress himself because the swelling was so large. It was a horrible way to die.

85. A long time before Allen was hospitalised you could tell he was unwell and struggling. He would finish his jobs at work in record time so that he could come home and rest in between jobs. The pain in his ankles and feet was more than he could bear. He was tired all the time. My family and I have always wondered if he had HIV and whether this was what was causing his fatigue.

86. He tried to hide the pain from all of us. He wanted to avoid hospital at all costs. He used to put his headphones on a lot, I think he used music to drown out both his physical and emotional pain.

Treatment

87. As mentioned above, Allen died without a formal diagnosis of either Hepatitis C or HIV. This was also before any treatments were available. Therefore, he did not receive any treatment.

Impact

88. Allen's death had a significant impact on all of us in the family. My father blames himself for giving permission for Peter Jones to give Allen Hemofil as a young

boy. My father cannot talk about Allen and his death without getting very upset and emotional.

89. On the first anniversary of Allen's death my father took Allen's wooden crutches to the haemophilia centre at the RVI to a nurse with the message: "Tell Peter Jones they are a present from Allen Titley". He didn't receive a response.

90. My mother was extremely angry with Peter Jones because he could have saved Allen and admitted this to her. As mentioned beforehand, I think my mother burnt the post mortem documents because they were too distressing to read and she didn't believe them. She also thought that what was written on Allen's death certificate for cause of death was a cover up.

91. We as a family have never been given answers, and will never get answers, as to what Allen contracted and what actually caused his death. He was given Hemofil regularly from the age of 12 and at least two, and often three times a month. In the last 3 years of his life he had a minimum of 21 doses in 1981, 29 doses in 1982 and 50 doses in the first 6 months of 1982. I have extracted these latter figures from Allen's diary entries. These were the figures submitted to the Skipton fund and exclude doses he received when attending hospital. There is no way he wasn't infected with Hepatitis C or AIDS.

92. My sister, Allyson, also gets emotional when we talk about Allen. Many years later it is still very painful to talk and think about. Allyson and I were also very wary about having children as we did not want to bring a haemophiliac child into the world and see them suffer in the way Allen did.

93. I got married 18 months after Allen's death. My husband and I wanted children but we agreed not to have them because of the fear of them being haemophiliac and having to be under Peter Jones's 'care'. Peter Jones had told me when I was teenager that I was a carrier. I could not bring myself to try for a baby and then terminate all male pregnancies I may have had so we decided not to try at all.

94. I was recommended by someone I knew to go and see Professor John Burn (now Professor Sir John Burn) who was a national specialist in Clinical Genetics and based in Newcastle at the time. He was the head of the Centre for Life. I was told that he could help my husband and I have children and conduct tests on us as a haemophiliac family.

95. I met with Professor John Burn in late 1987. He said he would test us as his first haemophiliac family but I later discovered he did not have funding. He arranged the tests eventually in Edinburgh and he confirmed that they could identify whether a baby I had was suffering from Haemophilia in October 1989. I was aware that part of the delay was because in Edinburgh they had lost a geneticist and it took three months before they got another one.

96. The results of the test that Professor John Burn initially carried out were that he was 98% certain that I was a carrier of haemophilia.

97. We decided we did want children. But I struggled to conceive GRO-C GRO-C GRO-C I reconciled myself again not to having children. It was a month later that I fell pregnant.

98. Dr Lind, who was my gynaecologist at Princess Mary Hospital in Newcastle, performed GRO-C to enable Dr Burn to carry out tests to identify the sex, and if male, (which he was) the haemophilic status of my baby. When my son was 2 months-old, Dr Burn's genetics team told me that they were now 99% certain that I was not a carrier and that my son did not have haemophilia. I was also told that the tests Peter Jones had carried out when I was 18 years old were "incredibly crude".

99. The member of the genetics team explained that Peter Jones had taken a general demographic of people, not known to carry haemophilia, to ascertain the factor 8 levels in their blood. He then compared this with a graph made up from the factor 8 levels of a demographic of people known to have Haemophilia

in their family. If you were in the middle of the two graphs, where they crossed, he concluded that you were likely to be a carrier. The genetics team were embarrassed to call this 'research'.

100. I went back to Professor Burn to ask him to do the tests again as I had no confidence in the results. How could I go from being 98% likely to be a carrier to 99% sure I am not?

101. He did the test again and I then received a letter to say that there was a laboratory error in the Edinburgh tests, as someone had recorded my grandmother's name under my grandfather's results. He was now 99% certain that I was not a carrier of haemophilia. I subsequently had two more children and neither of them have haemophilia. I almost didn't have children because of information the medical professionals told me.

102. Peter Jones never recalled my sister and I to advise of the crudity of the tests he carried out.

103. Allyson has a son and daughter too. They do not have haemophilia and she has been told that it is likely by 98% that she is not a carrier.

## Section 6. Treatment/Care/Support

104. Allen was not officially diagnosed with either Hepatitis C or HIV and did not live long enough to see the introduction of treatments for such viruses.

105. Allen was never offered any counselling or psychological support. He dealt with everything himself and used music as his escape. He spoke to my mother sometimes about maybe giving up work and registering as disabled, which must have been very difficult for him as he loved working and loved driving.

106. Myself and my family were also not offered any counselling or psychological support.

## Section 7. Financial Assistance

107. I received a letter from the Haemophilia Centre at the RVI dated 1st March 2011 notifying me of the Skipton Fund and recommending that as Allen's next of kin I should apply. I did not know about the Skipton Fund or the availability of any financial support before this.

108. I was also very surprised that I had received this letter and not my father as he was still alive and living at the same address. I persuaded my father to apply for the Skipton Fund and also helped him with the application.

109. I felt that the application was very complicated and particularly difficult for us to complete as we did not have the answers to 90% of the questions, nor could we provide proof that Allen had contracted Hepatitis C.

110. I remember calling the RVI to ask them, as the people who sent it to us, how we were meant to answer all of these questions. I was told to fill out the application with as much information as possible and to then send it to them so that they could fill in any gaps they could before sending it to the Skipton Fund.

111. The final application was not shared with us. The RVI sent it directly to the Skipton Fund and then my father received a lump sum Stage 1 payment of £20,000.

112. I think my father would have received the Stage 2 payment if we still had the post mortem document. This is because it said Allen had a haemorrhage under his liver. I think this shows he had Hepatitis C. Without any further proof that my brother had Hepatitis C my father is not able to claim any further financial assistance.

## Section 8. Other Issues

113. I would like to add that as a result of what happened to my brother and also to me when I was trying to find out whether I was a carrier of haemophilia and could have children or not, I have no confidence in the NHS. The way information is shared is not transparent and is often dishonest.

114. I worked as a lawyer for 37 years, if ever I did not know the answers to questions I would say so and that I would do everything in my power to find out. I did not 'blag' my way through things, I was professional. Why didn't Peter Jones do the same?

115. In my view, no one around Peter Jones questioned him, he was just seen as this God-like figure. I could not trust him and that is why I could not risk having a haemophiliac child as they would be under his supposed 'care'.

116. Professor Burn was a lovely man but he still wasn't transparent and open with me.

117. I know this was a long time ago and the NHS is changing, but it isn't changing enough. We do not have enough doctors or senior medical staff in the NHS that come from different walks of life. We need people who are more understanding and have had similar life experiences to their patients. At the moment we have so many senior people in medicine that cannot communicate properly and therefore are selective in what they tell their patients. If the NHS was more transparent, we would have more answers.

**Statement of Truth**

I believe that the facts stated in this witness statement are true.

Signed GRO-C

Dated 22nd July 2022