Witness Name: Roy Smith
Statement No: WITN0994001
Exhibits:
Dated: 07 September 2021

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF ROY SMITH

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 12 July 2019.

I, Roy Edward Smith, will say as follows: -

Section 1. Introduction

1. My name is Roy Edward Smith. My date of birth is GRO-C 1944 and my address is known to the Inquiry. Now aged 75 years, I have been a resident of GRO-C since 1987 and have lived at my current address for almost 30 years. I am married to my second wife, Kay, aged 78 years. I have a daughter from my first marriage, aged 46 years, who lives in the United States, and Kay has a son from her first marriage, aged 56 years, who lives in South Wales with his family. Kay and I are both retired.

2. I intend to speak about my younger brother Barry James John Smith. In particular, the nature of his illness, how the illness affected him and our family, the treatment received and the impact it had on him and our lives together.

Section 2 How Affected

3. I am the elder brother of Barry James John Smith, born on GRO-C 1948, who had an immediate diagnosis of having Haemophilia, on the evidence of blood-clotting problems at birth. It's clear that our mother was a Haemophilia carrier and there is a 1 in 4 chance of inheriting the disease. Barry suffered from severe Haemophilia A. In his early years, Barry was severely afflicted with conditions associated with the disease, such as swelling and bleeding in the joints, knees, elbows, and he bled uncontrollably, both internally and externally, on many occasions, which often necessitated hospital treatment. He had a number of blood transfusions in these early years. One of the most serious incidents took place at Brean Down, Somerset in 1960, when he was just 12 years old. On this occasion, at the end of our first week of holiday, he ran round a corner of the chalet in which we were staying and hit his head on a protruding fire extinguisher.

4. Barry developed a severe bleed in his head and had to be taken to Bristol Hospital, where he was treated during the second week of the holiday and for at least 2 weeks thereafter. Mum and Dad visited him during the holiday and also made a couple of visits after their return home. When Barry arrived home, he had more or less recovered, but his head, down to his shoulders, was one complete bruise. Barry did not have a continuous and regular attendance record at school, this was often due to spontaneous bleeds, as well as accidents, where a simple knock or cut would leave him requiring treatment. He was largely self-educated, and attended a course in his teenage years in Office Practice, at the Queen Elizabeth Training College for the Disabled, in South-east London, which awarded him a Diploma in that subject on 20 May 1966, aged 18 years. He had an enviable artistic talent, and developed an aptitude for creating original cartoons, examples of which are extant. I helped him to further

himself by sending his work to magazines such as Reveille and Titbits in the 1960s, but, although they were extremely impressed with his work, they decided that they could not use it. He was never able to make a career out of this incredible eye for detail and originality.

5. In 1969, at the age of 21, according to Haemophilia Database Records, he began receiving blood products, from which he was eventually to acquire his infections. He continued to receive them for the next 24 years, until his death on 10 May 1993, aged just 45 years. He was buried in Greenwich Cemetery on 20th May, and my mother lies with him. 20 May 1993 was the day I believe a miracle occurred. During his life Barry had had a keen interest in birds, and he raised Border Canaries for some years in an aviary which Dad had constructed in the back garden. In his final months he would feed a blackbird, which came to collect food from his outstretched hand. At his church funeral, the vicar had told the story of Barry and the blackbird, after which the burial became a very solemn and poignant occasion. It was teeming with rain, and as all the friends and family were standing huddled under umbrellas, we suddenly became aware of the sweetest birdsong. On the roof of a nearby workers' hut there was a solitary blackbird, drenched in rain, and singing its heart out. As we all stood silently agape, the vicar declared: "I do not believe in coincidences any longer!"

6. Barry's Death Certificate shows his passing was due to Bronchopneumonia, Immune Deficiency State and severe Haemophilia. I also demonstrated, via the Skipton Fund, that it was more likely than not that he had also developed cirrhosis of the liver in the years leading up to his death.

7. According to Barry's Haemophilia Database records he received the following products over the course of 24 years, beginning in 1969:

FFP, Cryoprecipitate, Profilate, Factorate, Cutter Factor VIII (Koate), FVIII(BPL), Kryobulin, Travenol/Hyland/Hemofil FVIII, Oxford FVIII.

8. Barry began receiving general treatment at Lewisham Hospital, South-east London in 1956, and this was his main port of call for 37 years. He received his treatment with blood products almost exclusively at the same hospital, but there were 2 visits to St Leonards-on-Sea, which became an inactive Haemophilia centre. His consultant haematologists over the years were Dr. GRO-D, Dr. GRO-D and Dr. J.M. Dudley, MA, MRCP, MRCPath, MD, and the last-mentioned, on 1 June 1992, provided Barry with an information booklet on Hepatitis C, since, at his latest review, antibodies to the Hepatitis C virus were found. This is something that, I feel, should have been discovered in the distant past. This will be explained in the next paragraph. A letter from Lewisham Hospital dated 23 October 1992, advised him to terminate taking his AZT medicine.

9. Infected blood products were dispensed to Barry at some time between 1969 and 1993, over a period of time, and most likely since 1971/72, which is a date generally accepted throughout the profession as the time when infected products were first received. Research documents in my possession show that the date of HCV infection is deemed to be the patient's FIRST exposure to clotting factor concentrate. Before 1985, almost all patients treated in this way have been infected. (See British Journal of Haematology, 1996: "The natural history of chronic hepatitis C in haemophiliacs, pages 746 and 747'). This is corroborated in an email to me from the Skipton Fund dated 7 September 2012. It seems very strange, therefore, that antibodies to hepatitis C were identified in Barry's blood only in 1992, when they had, no doubt, been present for many, many years.

10. Barry received the infected blood products sometime in the 1970s and 1980s. It was probably not by transfusion, although this is possible, as he had to undergo transfusions at various points. He did, however, receive prolific amounts of Factor VIII, which, I imagine, were the main source of his infections, for the treatment of his internal bleeding disorders, affecting his kidneys, and knee or elbow joints. His treatment was carried out at Lewisham Hospital, South-east London. On one occasion, I accompanied

him on a visit for treatment in the early evening and waited for him while he received his concentrate. As we were leaving the hospital, he asked me what his face looked like. I said it seemed to have an orange peel appearance and he immediately took fright. The doctors had not given him his antihistamine, Piriton, which counters the effects of the concentrate. I rushed him back inside and sought out the doctors to give him what was needed. Eventually, Barry was also able to self-medicate at home, which had its own serious implications, about which Barry expressed his own feelings in a letter, which I will refer to later.

11. To my knowledge, no information or advice was given about Hepatitis C or HIV/AIDS. On 29 May 1990, Barry wrote a letter to his consultant complaining that he had not been told of his condition of HIV/AIDS until 1988, even though the hospital knew that he had this condition for about 3 years, according to his Haemophilia Database. I have a draft of that letter and I would testify that it is written in his own hand. I have not found any response to that particular letter, but the sentiments, opinions, concerns, frustration and anger that he expresses in it are of the greatest importance and relevance, and go to the very heart of the matter. This letter is of the most crucial importance in understanding the sequence of events, and the lack of information imparted to the patient. I have no doubt that this letter was sent to Dr. Dudley, aforementioned, but I suspect there was no response in writing, for fear of self-incrimination. What I can say for certain is that sometime in 1991, all the stops were pulled out to ensure that Barry received extra care and support and medicines, such as AZT, to deal with his condition. This really smacks of some kind of subterfuge and I could be forgiven for thinking that the medical professionals expected Barry to die, which would release them from having to divulge anything. What other conclusion can be drawn from this?

12. Barry was infected with both HCV and HIV, and the co-existence of these was a matter of great debate, as I will reveal later.

13. I visited Barry in hospital sometime early in 1991, when he told me that he had Acquired Immunodeficiency Syndrome, after it was confirmed in March of that year (see this in connection with Barry's letter above). In this letter Barry explains that the hospital began monitoring his blood as early as 1983. In 1981, a San Francisco resident, Ken Horne, is believed to have been the very first patient diagnosed with HIV, although it is also believed that the disease had been prevalent since the 1960s. Although, in his letter, Barry does not specifically mention that the annual review of his blood related to HIV, he does talk of "negative" and "positive" results. The conclusion to be drawn from this is that the medical profession was aware of the already existing HIV epidemic since 1981 and were now fearful that it could have arrived in the United Kingdom, via blood which was known to have been imported from the United States. (See Press reports from 1990 and 2011).

14. In 1985, Barry was told that, after tests, he was one of only 2 patients who were HIV negative, implying that there were many patients who were already HIV positive. He did not receive further letters in 1986, 1987 or 1988, telling him that he was HIV positive. The most damning evidence is in the fact that in 1987, his consultant asked Barry if he would want to know if he were "positive" and Barry affirmed that he would want that. Despite this, and the consultant already knowing for a year that Barry was "positive", he still failed to inform them and for a further year, finally revealing to Barry that he was HIV positive on 4th January 1988.

15. Adequate information was, apparently, not given and, on the face of it, this seems to be a deliberate attempt to keep Barry unaware of his condition.

16. The relevant information should have been given to him on 20 January 1986, when it was first known that he was HIV positive. According to his records, the last date he was known to be HIV negative was 8 February 1985.

17. My own view, from the evidence, is that although the authorities knew that Barry was badly infected, they attempted to prevent him from knowing. I

doubt that there was anything altruistic about this decision. The failure to tell Barry that he had already been HIV positive for a period of over 3 years, demonstrates either a complete lapse in communication, which is highly unlikely, but more likely, that there was a need to maintain a silence over what was actually happening, so as not to expose terrible mistakes that had occurred. Since Barry was still alive after those 3 years, the doctors simply had to come clean, which is indicative of the most unsavoury behaviour and cavalier attitude.

18. As far as I know, no information was given on the risks to others of infection, and I and my parents certainly were not alerted to this. If they were keeping quiet on Barry's condition, it would be counterproductive to give advice on risks of infection to other family members.

Section 3: Other infections

19. It is clear that Barry had developed severe deterioration in his liver prior to his death. He had been experiencing continual diarrhoeal; which is a symptom of such a condition, for some time, and was admitted to Lewisham Hospital for the last time on 8 April 1993. Furthermore, from 1991, he had been experiencing some hair loss, and for 2 years he lived with the knowledge that his time was limited. The treatments available now were not available then. This all gave him a feeling of betrayal and hopelessness, from which he knew he could never recover.

Section 4: Consent

20. Although Barry's database treatment records show that he was receiving ONLY those products designed for the specific purpose of containing internal bleeding and he was aware of that, he had no knowledge of the fact that, for almost 5 years, the doctors knew more than they were actually revealing. In essence, he was NOT being treated for a condition which he had acquired, and it was known that he had acquired.

21. Barry did not consent to NOT being treated for a condition which he had acquired and he did not consent to not being told of this condition.

22. Barry did not receive any, let alone adequate, information about his tests and non-treatment since 1983. This is highlighted in his letter to the hospital dated 29 May 1990.

23. I think it may be possible that he was treated as a guinea-pig, to ascertain, knowing he was HIV positive, how the disease would impact upon him, at the same time expecting that he might pass away before the doctors needed to reveal the truth. The whole family was kept in ignorance for the period of 8 years, from the time his blood tests began, until 1991, when he finally found out that he was dangerously ill. According to further records the onset of symptoms was noted on 12 March 1991, when he was diagnosed with AIDS. However, he may have been afflicted with AIDS long before it was actually noted. This is a very cynical view, however, one has to ask the question: why was there a continuous silence over his deteriorating health?

Section 5: Impact

24. Needless to say, finally learning that he had acquired a terrible and, at that time, largely untreatable disease, the impact upon Barry's mental and physical wellbeing was quite devastating. Furthermore, reading between the lines of his 1990 letter, he probably suspected that something was going on behind the scenes, as he would have been aware that the blood tests from 1983 onwards were designed to achieve some results, and he lived in apprehension of what that may have been. He does not specifically mention HIV/AIDS and subsequently, for 5 years he was not aware that he had been infected, but lived in fear of hearing the worst, whatever that may be. After all, there are certain symptoms associated with being HIV positive, and his body would have been telling him that all was not well.

The really devastating blow came when he was informed in 1991 that he had full-blown AIDS.

25. There was no doubt that Barry had developed cirrhosis of the liver. The co-existence of HCV and HIV infection is of great importance in this regard. In an email to the Skipton Fund dated 9th September 2012, I highlighted the result of research carried out at the Pathological Institute of the University of Bonn in 1995 that demonstrated that 50% of the HIV-infected and HCV-positive haemophiliacs have developed post hepatic liver cirrhosis due to hepatitis C. It suggests that HIV co-infection aggravates the course of preceding HCV infection. This premise was eventually accepted by the Appeals Panel of the Skipton Fund.

26. There was the usual deterioration associated with HCV/HIV/AIDS which progressed to Barry's death in 1993. At that time, the drugs available, such as AZT, were largely untested and more effective methods came too late to save Barry.

27. Barry was prescribed AZT, I think, in 1991, when he was told of his condition but in 1992, he was advised to abandon it in a letter from the hospital to him dated 23 October 1992, which also included an urgent request for a blood sample. I believe he had to abandon the AZT as it conflicted with other medications that he was receiving. I have no specific knowledge of what these other treatments were and I am not aware that he was receiving any other treatments for his HIV condition. In any case, his database records confirm this.

28. As far as I know, Barry was given treatment for HIV/AIDS available at that time after 1991, in addition to the treatment he had been receiving for his Haemophilia condition and he never had problems accessing what was required. The problem was that, for many years, he appears to have been denied any treatment which might have been available and which might have had a beneficial effect over many years earlier.

29. I am not aware of any other specific treatments for Barry's HIV, apart from AZT/Retrovir, which was the first drug treatment for HIV approved by the FDA in the United States in 1987, but was not prescribed for Barry until 1991, when he was informed that he was AIDS diagnosed.

30. In the 1980s Barry was able to self-medicate at home with Factor 8 and butterfly needles in his veins. There were times when his blood spilled onto table surfaces and because he was not aware of his HIV condition, he did not realise that this could have been a potentially serious situation for our parents. He makes mention of this in his 1990 letter, intimating that it would be putting their lives at risk.

31. Barry's treatment with AZT had to cease, because it was incompatible with other medications. It is also not suitable for people who have liver disease, pointing to the fact that he had some serious liver problems. I know that he certainly had an enlarged liver and apparently, an enlarged spleen, and this is a point which I pressed with the Skipton Fund. In the final years to 1993, I am not sure if he required any dental treatment, but there is no doubt that he would have taken all steps that he felt were appropriate.

32. An assessment of the impact of his condition on his private life is well documented in his letter of 29 May 1990. His greatest fear was that he would infect those who were near and dear to him, especially during the time when he had no knowledge of his HIV condition. Obviously, with no absolute knowledge of his circumstances, there was a lingering suspicion, especially in 1987, when asked if he would want to know, which made him very apprehensive and he became very careful with his self-medication process. However, in 1990, in retrospect, he was terrified that he could have had such an effect upon his family. Barry was aware that his time now was limited and had he not been infected, he could have expected to live for many more years.

33. This was the case with our cousin, Derek, also a haemophiliac, who lived in Eastbourne, who passed away on 23 February 2018, aged 72 years. He was the son of our mother's sister. He never received any blood

treatments in his life, always refusing to do so, but his body was so weak and distorted that he became totally immobile in the last 2 years of his life. This was the culmination of all those years of pain and suffering.

34. For all his 45 years, Barry lived at home with our parents and never had the opportunity to fulfil his potential and enjoy a family life of his own, although he had a brief relationship with a girl he met at Training College. Our mother effectively put an end to it, because she felt totally responsible for his condition and it was her duty to care for him for the rest of his life. He had few friends and no real social life. Relationships were difficult enough to achieve with severe haemophilia alone, but became totally impossible when he became infected, because of the extra special care that he would require. I would not say that he lapsed into total depression, but he was prone to anger, frustration and total despair. After 1990, Barry's frustrations became more intense and, in the months before his death, he directed his resentment towards myself, who was the brother who had escaped the terrible fate to which he had been condemned. This caused tensions between us and in the time just before his passing, while he was in hospital, I wrote him a letter to try to resolve the problems. My mother told me that he asked if I wanted to have his television set and whether I was going to visit him in Lewisham. I never did and I have regretted it for the last 26 years. I had no car at the time, and my work, managing a convenience store, precluded me from having much free time. The letter I wrote to him was found in his bedside locker and I still have that letter.

35. Emotionally, I was torn apart when Barry told me in 1991 that he had AIDS. It was tragic enough that he had suffered haemophilia all his life, and now he faced the prospect of an even more tragic and ignominious death. For me personally, there is a further dimension to these harrowing circumstances. As I mentioned earlier, there is a 1 in 4 chance of being born with haemophilia. It is all to do with the XY chromosomes. I was one of the 3 fortunate enough not to be affected and when Mum and Dad saw that I was a healthy baby, they decided to have a second child and Barry was born 4 years later. The circumstances were quite different. Now, I do

not know if my mother knew that she was a haemophilia carrier or, if she knew, whether she had informed my father. From what I have discovered, families tended to be very secretive about their affairs in those days and were aware of shame and stigma.

36. Whatever was the case, it created lifelong tensions within the family. My father favoured me over Barry, my mother favoured Barry over me and the problem simply became more entrenched when Barry became very ill. I was the son who was free of disease; Barry was the one affected. I was the son who had an active and fruitful life; Barry was the son who had limited achievement. The point I am trying to make is this: I have been so conscious of this situation all my life and such thoughts have assailed me from time to time almost to the point of utter grief and wretchedness. In the same way that Barry thought: "why me?", I thought very much the same. Why was I gifted such a happy and healthy life? When I have, on occasions, bemoaned my lot, I am suddenly brought down to earth with a crash and I become racked with guilt that I could be so ungrateful. In Barry's final years, I used to weep uncontrollably, knowing that, after 45 years of pain and suffering, he was now to suffer a terrible death. I railed against God and the Saints that life could have been so cruel for him as he suffered his physical pain, but that the final blow would be the cruellest of all and might have been avoided, if the medical profession had acted differently. Knowledge of his terrible disease did not deter me from maintaining contact with him and I made regular visits to the house, as was my wont in years past. I loved him none the less for what had happened. There was a constant sadness with me, knowing that at some point he was going to leave us and memories of our boyhood and youth came flooding back. I felt such bitter resentment at the unfairness of what was to be his very cruel and undeserved death. In the 10 days between his death and his funeral, I compiled an album full of photos of him and the family and of his cartoons and achievements, to celebrate the fact that he was my dear brother and which friends and family members could enjoy at the funeral reception. I was born into this tragedy and the effect of it will be with me forever, in the grief and the tears.

37. Barry's haemophilia was common knowledge with other family members and friends, but knowledge of Barry's HIV/AIDS condition was kept solely within the immediate family circle. I had a great deal of contact with my cousin Derek, but not even he was privy to such details. I did not even tell my wife, Kay, for many years, but it had to come to light when I got involved with the Skipton Fund in 2011. Maybe this was out of shame due to the stigma, but I think it was more about protecting Barry from idle talk. Within the family we tried to avoid talking about it at length and we carried on coping with the situation as best we could. Barry was a son and a brother and we loved him as we had always done. On the morning of 10 May 1993, my father phoned me at work in GRO-C to say that Barry was on his way out. I immediately dropped everything and got someone to drive me to Lewisham. I arrived at 1.10pm, to find that he had passed away just 10 minutes earlier. He would not have known me anyway. He had been in a coma, after intravenous drips were removed from him the night before, which led to his rapid demise. I feel very emotional at this moment, for I remember that I cried my heart out on seeing him lying so peacefully in his bed. I remarked to my mother how perfect his fingernails were, in a body racked with pain and disease.

38. Whilst there was the greatest sadness with my parents over Barry's illness and the manner of his passing, they coped with everything as best they could with their advancing years. Dad was 81 and Mum was 78. They had already devoted 45 years of their lives to supporting him and giving him the best life they thought they could and should give him under the circumstances. However, I think there was a sense of relief that Barry's ordeal was finally over and, indeed, that their own situation would now change. I think they feared that they may not have been able to go on much longer. Mum insisted on Barry being buried. She would not have him "burnt", as "there was not a bad bone in that boy's body." Mum was the more constant in her unfailing responsibility to care for his welfare and upbringing, as she felt the greater responsibility for his condition. If he had

not been born with haemophilia, which she passed to him, he would not have died of AIDS. In all his years, every effort was made to keep him safe and well, even if that meant denying him a relationship that he might have wanted. This entailed numerous visits to doctors, hospitals, and taking him to other places where he needed to be. He never drove, and it was difficult for him to get around. It was incumbent upon my parents to attend to his every need. The effect on their own social lives was such that they withdrew themselves from the company of their own family members. The very fact that Barry had haemophilia was enough to make them feel like outcasts and that feeling was exacerbated when Barry became desperately ill.

39. In his early years Barry attended schools, but very irregularly. If he had a problem with swellings, pain or immobility, he lost a great deal of time during his formal education. Haemophilia curtailed an otherwise active and productive life. He never had a regular job and, consequently, it was never a question of him having to give up work or to find other work. His blood infection precluded him from ever being gainfully employed, even at the age of 38. The situation is different now, as modern drugs can help those infected to cope more effectively with their condition, even though their own lives may be tragically shortened, owing to their utterly devastating disease. With regard to the financial effects, these had a very limited negative impact, since Barry received Disability Benefits, and all his treatment was funded by the National Health Service. As a result, the family had limited outgoings. Furthermore, a government grant in 1991 helped to alleviate any financial hardship that might have arisen. The family did not anticipate any extraordinary expenses or special needs at that time, which probably were not available, anyway.

40. There were no particular work-related or financial effects upon myself. The greatest effect was on my state of mind emotionally, dealing with the most tragic situation that anyone can possibly imagine.

Section 6 Treatment/Care/Support

41. Generally, Barry was given all the care and support required to treat his haemophilia condition, but subsequently, there were clearly serious defects in the mental and physical support given to him for almost 5 years, when he was completely unaware that he had HIV/AIDS. In fact, it was completely non-existent. His letter of 29 May 1990 makes this absolutely clear. When he was informed that he had AIDS in 1991, he received help in the form of drugs and a letter from his consultant Dr. GRO-D dated February 1993, just weeks before he died, regarding extra services to HIV/ AIDS sufferers.

42. Personally, I was never offered any counselling in relation to Barry's circumstances and nor were my parents offered such counselling. The Haemophilia Society supported the family by making a donation of £1000 towards Barry's funeral. As far as I know, Barry himself was never offered counselling or psychological support and I have not seen any correspondence which might suggest that he had. You cannot give this to a person who is unaware of what they are afflicted with.

Section 7 Financial Assistance

43. To my knowledge, Barry never received what might be described as regular financial assistance, in the form of monthly, yearly, or top-up payments, as distributed in later times by Funds such as the Caxton Foundation. This was the case right up to his death and I have not come across any communications which might suggest otherwise. I cannot, therefore, comment further on this issue, but I will deal fully with the matter of one-off grants, payments and compensation payments in the following paragraphs. There were 4 major payments and 3 of these were made to Barry's estate, after he died.

44. I have a copy of a Legal Aid Certificate issued to Barry dated 20 January 1990, in connection with a lawsuit against the British Government for compensation to haemophiliacs who had contracted AIDS. This action had been proposed by the Haemophilia Society since 1986, but the case was not pursued. In December 1990 the Major government announced that compensation would be paid and I believe that Barry received a payment of £44,000 in 1991.

45. At this same time, a further lawsuit was taking place in the United States. I have a series of letters from Panone Napier, Solicitors, of London issued between 8 August 1991 and 12 August 1994, in connection with their association with Law Firm Shrager, McDaid, Loftus, Flum and Spivey of Philadelphia, Pennsylvania, the "American Counsel". The lawsuit was against Armor Pharmaceutical Company, for injuries sustained by Barry James John Smith as a result of the use of Armor HT Factorate (IP). The initial agreement for representation is signed by Barry and dated 4 July 1991. For the sake of brevity, I will simply say that, as a result of this action, Barry was awarded $US90,000 compensation, $US57,000 after fees, which equated to £39,271. This sum was received into Barry's Estate by my parents on 12 April 1994. Therefore, although Barry was aware of the lawsuit, he did not actually live to see the final result, having passed away more than a year earlier.

46. In January 2011, my mother, who was then aged 95, received a communication from the Macfarlane Trust, with whom Barry was registered, stating that compensation payments were to be made to patients who received infected blood and developed HCV/AIDS and who deceased prior to 29 August 2003. She was invited to register with the Skipton Fund by 31 March 2011 to pursue a claim for the 1st stage payment of £20,000. I carried out all the necessary paperwork on her behalf and it became a mere formality to be awarded the 1st stage payment. My mother passed away on 28 October 2011, and that payment was received into her Bank Account on what would have been her 96th

birthday, GRO-C 2011. At that point I had not informed the Skipton Fund that she was deceased. She was then invited to apply to the Fund for the 2nd stage payment of £50,000, if there was evidence that HCV had progressed to any one of 4 other conditions, including:

1. The deceased person had received a liver transplant
2. The deceased person had been diagnosed with primary liver cancer
3. The deceased person had been diagnosed with cirrhosis
4. The deceased person had been diagnosed with B cell non-hodgkins lymphoma.

47. I informed the Fund of my mother's death and told them that I would assume the responsibility of carrying on with the application. To cut a very long story short, the application eventually led to the granting of the 2nd stage payment after more than a year, in February 2013.

48. The process of applying for financial compensation from the Skipton Fund was relatively straightforward, entailing a simple email or postal application, with details of any medical records to support the claim. This should have been the case with regard to the 2nd stage payment.

49. With the 1st stage application, there were no problems in obtaining a result, since it was universally recognised that any person who received blood before 1985 had been infected with HCV.

50. The situation with the 2nd stage application was rather more complicated and problem-prone. I lodged the application with the Skipton Fund on 12 January 2012, without medical records and it was quickly declined in their response to me dated 24 January. The application was declined on the grounds that none of the quoted conditions had been diagnosed. I had no extant medical records, apart from Barry's Haemophilia Database records, which I had obtained earlier. I was told by Lewisham Hospital originally that all his records had been destroyed after 8 years. However, this does not square with the fact that other patients have retrieved their records

from archives in London and I have to suspect that this was yet another attempt to obfuscate the situation with Barry.

51. The Fund stated that I could lodge an appeal with the Appeals Panel, with any further evidence and I duly applied on 5 February 2012, with supporting research evidence, to prove that it was more likely than not that Barry had developed cirrhosis of the liver by the time of his death. I received a letter dated 19 April 2012, informing me that the next Appeals Panel meeting would be on 31 May 2012. In the meantime, I wrote to them again, on 24 April, with further evidence. The Panel meeting of 31 May led to a further meeting on 14 August, which led to a further meeting on 6 December 2012. This was because the Panel needed more time to gather information regarding the effect of co-existing HCV/HIV, and the effect on liver development. In the meantime, I was continuing to adduce more clinical evidence in support.

52. The meeting of 6 December led to a further and final meeting on 7 February 2013, the delay then, resulting from the fact that the Panel needed to "resolve the very difficult question of whether, and, if so, after how long, cirrhosis can be assumed probably to have occurred in a patient also infected with HIV". Finally, I received a letter dated 13 February 2013, confirming that my application "had been approved, following the conclusion of the research into the likelihood of progression to cirrhosis in the absence of case specific information". This means that I was the first person in the United Kingdom to be granted the 2nd stage payment without medical records, demonstrating that it was more likely than not that Barry had contracted cirrhosis. This benefited other people throughout the country, and I had contact from two mothers, via the Haemophilia Society, who had similar cases, wanting my advice on how to proceed. The story of this achievement was published in the Haemophilia Society magazine in 2013.

53. No preconditions were imposed, other than registering with the Skipton Fund by 31 March 2011 and providing further medical evidence of progression to liver disease.

54. I would mention at this point that in 2016, I arranged for financial assistance for my cousin Derek from the Caxton Foundation and they were impeccable in their support and making contributions to his homecare in the final years of his life. My overall view of the Funds is very positive. They did whatever was necessary, according to law, to provide assistance, although it may be argued that, under such tragic circumstances, assistance was insufficient to compensate for the terrible wrong that had been committed. However, their hands were tied by the rules. With regard to the Skipton Fund, I have nothing but praise for them and the Appeals Panel, even though they gave me a very hard time. Over the course of a year, they were prepared to listen to my arguments and worked assiduously to obtain the evidence they required, to enable them to reach their final conclusion.

Section 8. Other Issues

55. All the pertinent issues have been covered in the preceding statement and at this point, I have nothing further to add.

56. I have in my possession all the documents referred to in this statement, viz:

- Barry's medical records, as far as I could obtain them initially, including his Haemophilia Database records, plus all supplementary records received in July 2019.
- Correspondence, Legal Aid Certificate and Solicitors' letters in connection with Government compensation in 1990 and the American litigation in 1991-1994. I have no details of the actual trial against Armor in the United States.
- All the letters and emails to and from the Skipton Fund in connection with 1st and 2nd stage payments.

- Letters between Barry and Lewisham Hospital in connection with his treatment 1986-1993.

  Significant clinical research evidence regarding the case for cirrhosis of the liver.

57. Whilst composing this statement, I received a totally unsolicited and coincidental letter, dated 22 July, from the UKHCDO National Haemophilia Database in Manchester. I had already received some basic information from them in 2011, in connection with the Skipton Fund applications, but this letter informed me that they had recently become aware of a paper archive with additional information, which they were offering to me, if I were interested. I sent an email to confirm my identity and to request whatever further information they had. In reply, a staff member confirmed the necessary documents would be prepared and sent to me and the package arrived on 27 July. They were covered by a letter signed by Professor Charles R.M. Hay, Director of the National Haemophilia Database. His letter explains that paper reporting of medical details by Haemophilia Centres was phased out in the year 2000, but those details were not included in the electronic database, which had been set up. Hence, all this extra information had lain buried for over 20 years, and had only come to light after the database paperwork was scrutinised. This, therefore, begs the question; why was I told in 2011 that all Barry's medical records had been destroyed after 8 years, when all concerned must have known that these records still existed within the Haemophilia Database? As a result, the documents submitted to me contain not only everything in the electronic database, but also all the paper documents submitted by Barry's Haemophilia Centre in former years.

58. Closer scrutiny of these documents confirms and vindicates all that was claimed, surmised or alleged in the previous statement, but the more detailed information regarding Barry's treatment with plasma, cryoprecipitate and Factor 8 from 1969 to 1975 show nothing unusual. What is most important is what is revealed in the remaining documents.

These include an item headed: "Extract from the UK National Haemophilia Database: Explanatory Note". With regards to Barry's personal extract, it states that the period of greatest risk of exposure to HIV infection was 1980-1986. It is already known that Barry's tests began in 1983, but these were samples that were collected and frozen until the HIV test became available in 1985. It was in January 1986, that Barry was first found to be HIV "positive". In 1985, Barry was told that he was still "negative", and one therefore has to assume that all previous blood tests would have had the same result.

59. However, there is now a more precise timing of Barry's "positive" condition. Crucially, there is a letter from Dr. C.R. Rizza, Consultant Physician at the Oxford Haemophilia Centre, to Barry's Physicians, dated 11 December 1986, in which he notes that while Barry was "negative" in 1985, he became "positive" in 1986, defined as a "sero-conversion". He asks for various details about the treatment products Barry received and it is revealed that he received his concentrate almost exclusively supplied by Armor of the United States, who were the subject of the lawsuit described in the previous statement. Dr. Rizza's motive for requesting the information is that "the information is essential if we are going to monitor the safety of the heated blood products." Does this mean that there were lingering concerns for many years about the safety of heat-treated blood products? Barry's first exposure to Armour's heat-treated blood was on 27 January 1985, although it could have been earlier, and he was known to be negative on 8 February 1985, but was diagnosed "positive" almost a year later. At the same time, I find it hard to accept a glaring contradiction. In his letter, Dr Rizza has recorded that there were 2 definite sero-conversions during 1985 with regard to Barry and one other, but he was not declared "positive" until 20 January 1986. From the records, I believe that Barry was first infected soon after 8 February 1985, so there was almost a year when the medics should have been alerted and taken earlier action. However, there still remains the nagging question of why Barry was not told of his condition for a further 3 years.

60. Furthermore, Barry's HIV patient schedule dated 13 April 2011 indicates a date first "positive" as 20th January 1986, and "CONDITION 1", but the latest documents dated 23 July 2019 show the same date but "CONDITION AIDS". Does this mean that Barry was known to have actual AIDS and not just HIV since 1986? HIV and AIDS are not one and the same, where the former can ultimately lead to the latter, but not everyone infected with HIV will develop full-blown AIDS. However, in Barry's case the evidence is unequivocal: Barry was known to have AIDS as early as 1986 and was notified only in 1991. Similarly, whilst the Hepatitis C antibody test became available only in 1992, these new records seem to indicate that being treated with concentrate before 1988, means that he must have been infected with HCV long before that year.

61. The remainder of the documents are Barry's AIDS surveillance records from 1991 to 1994, when he was finally referred to as "DEAD".

Section 9. Anonymity, disclosure and redaction.

62. This is the story of my brother's life, and his equally tragic and premature death. What I have said needed to be said and I have no desire to change it, nor to have it changed. I am not ashamed of the events of the past, and I am not ashamed of what I have written. If the evidence is required, then let it stand. I am adamant that the truth shall be exposed in this totally tragic affair and that proper justice will be done. The saddest aspect of it all is that the authorities in this country have never put their hands up and admitted and accepted the failings which are so glaringly obvious, as they have done in some countries. The total insensitivity and the apparent lack of a sense of guilt and responsibility is an insult to those who have suffered the extreme pain, the grief, the frustration, the heartbreak, the despair, the loss, the broken family relationships and the stigma attached

to this appalling tragedy and I am proud to think that I may have played just a small part in a process of righting that terrible wrong.

Statement of Truth

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

Signed GRO-C

Dated 07 September 2021