ANONYMOUS

Witness Name: GRO-B

Statement No: WITN3940001

Exhibits: **WITN3940002-WITN3940020**

Dated: 25/7/2022

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF GRO-B

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 5 March 2019.

I, GRO-B, will say as follows: -

Section 1. Introduction

1. My name is GRO-B My date of birth is GRO-B 1962, I live on GRO-B North Wales and my full address is known to the Inquiry. I have been previously known by the name GRO-B when I was married to GRO-B: H and my maiden name was GRO-B I live with my second husband and our youngest daughter. I have recently finished a Masters and I am self-employed providing admin, design and web design at GRO-B

2. I intend to speak about my late husband, H who was born on GRO-B 1960, and his infection with HIV, Hepatitis C (HCV) and Hepatitis B (HBV), which he contracted as a result of being given contaminated blood products to treat his haemophilia. H died on GRO-B 1993 at John Radcliffe Hospital, Oxford.

3. In particular, I intend to discuss the nature of H s illness, how the illness affected him, the treatment he received and the impact it had on him and our lives together.

4. I obtained H s medical records from the Churchill Hospital, Oxford, which I have submitted to the Inquiry. H s medical notes includes a death summary letter which give a number of causes for his death including HIV, HCV, and Haemophilia A (**WITN3940002**) but his death certificate records his cause of death as 1a. Retroperitoneal Haemorrhage, b. Haemophilia. **(WITN3940003)** and does not include HIV and HCV as causes of his death.

5. I was grateful that HIV and HCV were not listed on the death certificate as I had to send copies to so many places. However, they did not do an autopsy on H after his death due to his HIV status, so it would have been impossible to precisely ascertain his cause of death. Having read H s notes, I have learned that a liver sample was either taken or used after his death without my knowledge or consent.

6. I confirm that I have chosen not to be legally represented and that I am happy for the Inquiry team to assist me with my statement.

7. The investigator explained the 'Right to reply' process, should I make any such criticisms of individuals or organisations. I am aware that there is an existing agreed procedure that will be followed in such an event.

8. I have chosen to be an anonymous witness in order to protect the identity of my family.

Section 2. How Affected

9. H was diagnosed with severe Haemophilia A 0% factor VIII shortly after birth. He was the first in his family to be diagnosed with Haemophilia. His

brother GRO-B: BIL born one year later, was also a haemophiliac. He also had another brother and two sisters.

10. During his childhood, H suffered many bleeds into his joints, which affected his elbows, knees, and ankles, making mobility at times difficult. He attended GRO-B School, which was a special needs school and at the time, it did not offer qualifications. H wore a knee brace until late teens. He also wore ankle splints to strengthen his ankles when standing or walking and continued to wear these throughout his life.

11. H then attended GRO-B college and studied O' Levels intending to work in an office, but left before finishing the course due to health issues. H s home life was not ideal, and he left home after his parents split up. By the time I met H he didn't have a relationship with his father. I met his father, GRO-B, twice in 7 years, once when our car broke down near his house and we used his phone and the second time was at H s funeral.

12. Around 1984/85, H was advised by Dr Joan Trowel to cut down on his drinking because what might be a normal amount of alcohol for other young men was not suitable for haemophiliacs. I think the medical profession already knew that hepatitis was a problem by the 1970s, but this was never mentioned to H or linked to the advice they gave him to stop drinking.

13. H had stopped drinking all together by the time I met him in 1986, and he never drank alcohol again, not even at our wedding reception. He used to drink pints of orange and lemonade when we went out and in the early stages of our relationship when I was coming to terms with H s HIV status, he often joked that I was 'drinking for two.'

14. I have noticed in H s medical records that he has been described as an 'occasional drinker' or 'social drinker', which is an absolute fabrication. I never

saw H drink as much as one drop of alcohol in over 7 years of our relationship. In the time I knew him he didn't drink, smoke or take any kind of recreational drugs.

15. When I accessed my own medical records, I noted that they had mentioned that I was an 'occasional drinker', even though I had told my doctor I did not drink any alcohol and had stopped drinking many years before this. This mislabelling about alcohol consumption is more common than you would think, as it happened to both H and I.

16. In a Histopathology report in relation to H produced by Dr Trowell at John Radcliffe Hospital, Oxford dated GRO-B 1993, it says 'This liver biopsy could be accounted by alcoholic liver disease; however, the portal tract changes raise the possibility of large bile duct obstruction and this should be excluded. Furthermore, the presence of focal portal lymphocytic infiltrate, cholestasis and occasional acidophil cells could also represent hepatitis C.' Knowing H s background, I don't know why alcoholic liver disease would even be mentioned in relation to his liver. (**WITN3940004**)

17. Having checked H s medical notes, the earliest positive HIV test in his records is from 1984. There is no record of when or how he was told about his HIV diagnosis. There is however, a detailed, undated letter from Dr Rizza to H which says that they have been able to carry out blood tests in Oxford, which show whether there has been contact with an AIDS related virus.

18. In this letter, Dr Rizza says that due to variation of results, they take several samples from the patients before they take a report. He says that they have 7 test results for H and asks H to contact him or Dr Matthews if he wishes to know the results. I do not understand how patients could elect not to

know their HIV status, as this seems quite unsafe as there are precautions you need to take in day to day life when you are HIV positive.

19. In this letter Dr Rizza says, "it should be emphasised that a positive test does not mean that one has AIDS or will develop AIDS". It also gives advice to all haemophiliacs, regardless of test results, about precautions to take including cleaning blood stained areas with anti-septic and using a condom during sexual intercourse. (**WITN3940005**).

20. I have also located a letter from Dr J.M Matthews to Dr GRO-B H s GP, enclosing his AIDS antibody results which were positive. Although the test is undated, he appears to have tested positive for HIV in November 1984. The letter says that some patients do not wish to know the results of the tests but those who do wish to know will be told and 'will be encouraged to discuss the significance of a positive result with us'. **(WITN3940006)**

21. There are detailed notes about the Factor VIII doses H was given. H adamantly believed he was on the English Factor VIII until HIV testing began and then switched to American Factor VIII, but the medical notes of his that I have seen indicate that he was on American Factor VIII throughout.

22. A note in his medical file shows he was given Armour products in June 1985 and Koate products in 1983. He was under the assumption that he was only changed to American Factor VIII a few months before his diagnosis. He was not aware of what the extra blood tests he was having were for, until he was diagnosed with HIV.

23. Around the time he thought he had changed Factor VIII blood product, H suffered from a bout of what he thought was food poisoning followed by a dramatic weight loss. He required an overnight stay in hospital at this time.

24. H told me that he was informed of his HIV diagnosis over the telephone. This was on a public telephone in a block of flats where he lived, which was very inappropriate. I do not believe he was given any information about HIV at this time or support in relation to how he should go forward living with HIV.

25. Despite this, H never became angry or self-pitying about it at all and he wasn't resentful. He did not blame the doctors treating him including Dr Rizza, and instead he blamed people higher up. He believed that cost influenced the decision makers and that using blood products from a large pool of donors at a cheaper price was not the doctors' choice.

26. I have seen in H s notes that he was sent a letter with a form that he sent back on 16 February 1986, which said that they wanted to make sure all patients who wish to know the results of the HTLV III antibody testing have been informed and given the results. The attached form asked H to section one of 3 options - I have been told the results, I have not been told the results and DO want to know and I have not been told and DO NOT want to know. H ticked that he had been told the results, which showed he would have received the phone call informing him of his diagnosis before then. **(WITN3940006)**

27. The consultation with Dr Trowel and the HIV diagnosis he received changed H s life; he gave up his interest in the mobile disco he ran with two friends from college and gave up drinking around July of 1985. The downside of this is that by the time I met him, H had given up all hope of having any kind of normal life.

28. After H s diagnosis, he lived a very isolated life. He lived in a studio flat on his own and felt let down as he had no support from the haemophilia centre. I know he was very frightened of dying there on his own and no one even

realising he was gone. H was phobic about dying alone and when we were first together, he would make me promise that I would not let him die alone. Before we met, he had no support and no social life apart from weekly visits to his family, and it is a miracle he did not go mad. It is hard to forgive a system that allowed that to happen to him.

29. I first met H at his future sister-in-law's house. I was invited over for coffee on the first Sunday in March 1986 by GRO-B who was engaged, and later married, to H s brother BIL We went to the pub for the evening along with another couple of their friends. H offered me a lift home, as he didn't drink, and dropped me back at my parent's house. According to GRO-B H staying more than an hour or two was unusual and he almost never accompanied them on nights out.

30. The following week I was invited again, and when H took me home, he asked me out on a date. GRO-B had warned me that H was an incredibly shy, quiet person, but he took me to the cinema, where we saw Commando, and then we went for a drink and we just talked and talked. We continued to see each other every day. I moved into his studio flat almost immediately and we got engaged later that year. We were married on GRO-B GRO-B years after we first met.

31. When we met, I knew H had haemophilia but had no idea that he was also HIV positive. I think he held off from telling me partly from a misunderstanding that GRO-B had already told me and partly because he was sure I would stop seeing him.

32. H told me of his status in late March 1986, and I moved in with him the following day. I have never regretted my decision for a moment. I am not, by nature, a romantic person, but from the very beginning of our relationship, I had

no interest in living my life without H I have included as exhibits some photographs of H and I, to show us as a couple. **(WITN3940007; WITN3940008)**

33. I attended all of H s hospital appointments with him and was very involved in his care after I learned about his HIV status. Because he struggled to keep weight on, I learned to cook. I asked questions of his doctors and read as much as I could about HIV, although at the time so much rubbish was written in the press about how it could be caught from toilet seats or sharing crockery. Without the internet we relied heavily on what we were told by the Haemophilia department at the Churchill Hospital.

34. Although I chose to stay with H I was still scared about the risk of HIV to myself and I did drink excessively in the first couple of years to cope with what was happening, but after that I didn't drink much at all and eventually gave up drinking when I had some issues with my liver some years ago.

35. In 1999 when pregnant, I caught the flu and then developed a chest infection and then broke a rib while in hospital, I was given regular doses of paracetamol. My liver function tests showed very high numbers and it was suggested that I had HCV and was tested. I can't find the words to tell you how this affected me. A couple of days later a nurse casually mentioned that the test had come back negative.

36. I have found a letter from Mary Fletcher to myself, confirming that my blood test from the 31 of August 1993 was negative for HIV and that all my tests have been negative for HIV and HCV since I was first tested on 15 October 1986. **(WITN3940009)**

37. Early in our relationship I received a letter from the Churchill Hospital addressed to my parent's address, asking me to attend an HIV test. I seem to remember that all the wives and girlfriends of those who had HIV were invited for an HIV test every 6 months, though it may have been every 3 months.

38. We had told Mary Fletcher (She was originally Dr Rizza's researcher, but she acted more like an outreach worker. Her role wasn't clear as her job title seemed to change on different correspondence she sent out) not to send any correspondence in relation to HIV to my parent's address. I could not receive any post at H s studio flat where I was living, as it was for single occupancy and I technically could not live there, so I was still using my parent's address to receive any post. I didn't want to give them my parents' address but they insisted and assured me that it was for their records only and wouldn't be used.

39. My mother opened the letter believing it was an appointment for my annual orthopaedic appointment at the GRO-B. I was born with hip dysplasia and attended regular appointments from the age of two. I had numerous surgeries as a child and like H I was no stranger to lying in bed while other children were out playing.

40. This was when my mother learned of H s HIV status for the first time. I can only describe the subsequent telephone conversation as 'upsetting' for both of us, and it resulted in my mother giving me a choice between my family and H I did not see or speak to any members of my family, except for one phone call from my eldest sister, until August 1988.

41 H and I were both very angry that this had happened and made a complaint about this letter, which I have seen in H s medical notes. I remember that Mary asked why my mother was opening letters addressed to

me, when this was none of her business and completely beside the point. My mother had always opened my medical letters.

42. Following this incident, we had told Mary never to come to the flat again, and it did affect our relationship with her for some time. However, we did not really have much choice in relation to who treated H and dealt with us as Mary was the only support offered, which made things difficult. We gradually improved our relationship with her; I have never been one to hold a grudge and H certainly wasn't.

43. I have since found a note in relation to this incident on a document in H s medical notes from Oxford Haemophilia Centre's follow up clinic from 22 March 1988. In the comments section it says that MF (Mary Fletcher) sent a letter to my parent's house which was opened by my mother, and that my parents have since shunned both H and I, and do not want to see us again. The note says that we do not want to be seen by MF again. **(WITN3940010)**

44. I have seen a letter from Mary Fletcher dated 25 May 1988 addressed to both H and I, regarding a short survey for wives and girlfriends to enable them to give better advice in the future. She says that Dr Rizza had suggested asking me about this. **(WITN3940011)**

45. In the spring of 1992, we were told that H also had HCV. I was also tested around this time, but I don't remember being told the result or what precisely they were testing me for. Although H s liver disease and deterioration is attributed to his HCV, we never knew to take the HCV seriously. No one told us that his combination of HIV and HCV was a big worry. If he had not been HIV positive too, he may have been able to survive with HCV for many years. I know lots of people who lost haemophiliac partners actually lost them to HCV rather than HIV, even though they had both.

46. When I looked through H s medical records recently, I saw that his mother had applied to the Skipton Fund in 2011 and Dr Paul Giagrande had not supported this application as apparently H had received a negative HCV RNA test before he died. He ticked the relevant box on the Skipton Form to indicate this. I didn't even know that Dr Giagrande was at Oxford at this time and as I had no communication with H s mother after his funeral, I had no idea that she had made this application.

47. We had never been told that H had received an RNA negative HCV test and I have no idea how H would have been able to clear HCV naturally with such a poor immune system. It could have been a false negative, but there is no way to go back and verify this which is why it seems unfair. RNA sample storage is critical to whether the sample degrades and from looking at the label it appears H s sample was tested quite a while after collection. (**WITN3940012**)

48. H s medical notes since this negative RNA test have shown that he was HCV positive on 01 October 1992 (**WITN3940013**) and 19 April 1993 (**WITN3940014**). His death summary (**WITN3940002**) also includes HCV as a cause of death, so it seems unfair that the Skipton Fund rejected her application on this basis. However, I feel that as H s widow, I would have been the most appropriate person to make this application. It later transpired when I contacted EIBSS, that they had awarded funding to H but that his mother was not eligible to receive it, however, I was never informed of this decision.

49. I was also tested for HCV 3 months after H had died at the Churchill Haemophilia Centre in Oxford, and I don't know why they would have continued to test me if H was apparently HCV free before his death. Clearly this was incorrect on behalf of the Skipton Fund.

50. As far as I know, I was never asked to be tested for HBV, although H did have antibodies for that too. We were only informed of this when I asked Mary why H and I had not been offered the HBV vaccine, and she told me we did not need it as H had shown to have HBV antibodies for years, although this was the first we had heard of it. We were in the Haemophilia Centre waiting room where there was never any confidentiality, and I overheard a conversation between Mary and another haemophilia patient which mentioned this vaccine, and this is the only way I even knew about an HBV vaccine. All haemophilia patients were treated like a big family since everyone was in the same boat, and you would often overhear medical discussions in the waiting room.

Section 3. Other Infections

51. I am not aware if H contracted any other infections other than HIV, HCV and HBV as a result of blood transfusions or Factor VIII he received. At the end of his life there were some issues and as you will see from his notes they did a CT scan but could not do a lumbar puncture because of his Haemophilia. If his symptoms were caused by another infection we will never know.

Section 4. Consent

52. I do not know if H was treated without his knowledge or consent, however, I do believe the medical staff worked on a need to know basis sometimes.

53. We felt at the time and I still feel that Dr Rizza was doing research on how HIV spread, but how that influenced H s treatment or if it did, I couldn't say, and the medical notes I received are incomplete. If it were possible to get hold of any papers Dr Rizza either wrote or co-authored, that might be of interest.

54. The letter that I referred to above (**WITN3940005**) from Dr Rizza to H indicates that they were testing his blood for 'AIDS-related virus' without his

knowledge or consent. He mentions that they have 7 test results for H so far, but this letter appears to be the first time H is being informed his blood is being tested for it.

55. I have seen a letter from Mary Fletcher to H dated 30 April 1985, saying that Dr Rizza had asked her to get in touch with H about donating an extra blood sample to help with work being done on heated Factor VIII. I don't know if H was ever given more information about this or what exactly research this was for. **(WITN3940015)**

56. Another letter from Mary to H dated 23 October 1987 asks H whether he would give them a blood sample, but does not mention what this is for. She asks whether she can come and speak to him about this. **(WITN3940016)** These letters indicate that some research about HIV was ongoing, but how H fitted into this is unclear.

57. I can't know for a fact that my blood was tested without my knowledge or consent. However, I had a conversation with Mary which indicated it was. As I mentioned above, in the haemophilia centre waiting room I overheard a conversation about someone getting an HBV vaccine. I asked Mary about this and whether H and I should have it. She said I had not got HBV but H had HBV antibodies for years. I thought it was odd because the only blood I had given was for HIV tests and HBV had never been mentioned, and I had not consented to this. My memory surrounding testing for Hepatitis is vague because HIV was such a threat we almost couldn't take in that there was yet more life threatening infection to deal with.

58. After reading H s notes I discovered that after his death, a sample of his liver was taken for testing purposes. I was not asked to consent to this before

it was done. This biopsy must have been post-mortem as I was with him 24/7 until his death and the sample date is after his death,

59. I have listened to some of the Infected Blood Inquiry hearings and because I had been introduced to Dr Paul Giangrande when Dr Matthews retired, although I have no memory if he had ever treated [redacted] I listened to his testimony. I did not like a remark that he made, whereby he said that he did not believe his wife would have allowed a blood test to be done if she did not know what it was for. I was made to feel foolish, but like most wives and girlfriends I had regular blood tests for HIV but these samples could have been used for anything. According to a letter written by Mary Fletcher, I only had 6 HIV tests in 7 years all of which were negative and a negative Hepatitis C test, but I believe I had far more tests than this.

Section 5. Impact

60. At the start of our relationship, [redacted]s health was good considering he was living with haemophilia and HIV and although we didn't know it, he also had HBV and HCV. We only attended appointments with Dr Rizza or Dr Mathews at the Churchill Hospital every three to six months. [redacted] had known both these doctors for most of his life and trusted them both completely. He never believed they had a personal agenda and thought they were only following government policy. We lived in constant fear of people discovering [redacted]s HIV status. Although we were later also aware of [redacted]s HCV, we were less concerned about this, as I discussed above.

61. When [redacted] started working at the Job Centre, he was given Sceptrin as a prophylactic measure. However, he was never offered any HIV treatment like AZT because, as Mary Fletcher explained, the side effects might make him feel ill and because at that time he was happy and non-symptomatic, it was better to wait.

62. He had recovered well from the bowel operation that he had, and he had apparently needed this due to a genetic predisposition for his bowel to twist. We were told that his bowel issue was not linked to his other health problems. He had a few bleeds on and off and I would help him inject Factor VIII, but overall, his health was in a good place. Early in our relationship I had been shown how to administer Factor VIII as H s veins had become scarred from regular treatment and he also had difficulty due to the damage to his elbows.

63. As H was working in a public facing role, Mary suggested to me that H should have a pneumonia vaccine and that she would bring a dose to the house when she next visited. H said he would think about it, but I convinced him to take it. H was given the pneumonia vaccine and reacted very badly to it. He had a reaction at the site of the injection and an extremely high temperature, as well as symptoms such as night sweats, lack of appetite, cough and just an overall malaise. He was so unwell that I even had to call out the GP to come and see him. This reaction was so massively severe that I was very frightened at the time.

64. I later repeatedly asked various medical professionals at the Churchill Haemophilia Centre if the vaccine had contributed to H s death, but didn't receive any answer. It is probably only a coincidence that H s health downward spiral started at the same time as his reaction to the vaccine, but it would have been nice to have been assured of this as I talked him into having it. I am in no way an anti-vaxxer, but I had read that vaccines can accumulate in the liver, and I was worried if this had worsened the condition of his liver, which had already been damaged by HCV.

65. Not long after his initial HCV diagnosis and the pneumonia vaccine, H started to feel unwell long-term. It began with extreme tiredness, passing black stools, passing white stools, food tasting of saccharine, and finally, his eyes and

skin started to take on a yellowish hue. H was given an appointment to see Dr Trowel, and she took him off the Sceptrin antibiotic tablets (given as a prophylactic to protect against pneumonia) as she thought that they were maybe causing the symptoms. H didn't improve but was getting worse, and Dr Rizza told us it wasn't the Septrin but he thought the HCV was causing the symptoms, which indicates that H had not cleared the HCV or that the damage had already been done. I have subsequently read those co-infected and immunosuppressed patients are at high risk of reoccurrence of symptoms.

66. In GRO-B 993 H was admitted to the ward 5F John Radcliffe Hospital for tests. He had been feeling a little better in the days before he went in and I asked him to cancel, but he desperately hoped they would find the reason he had been so ill and be able to improve his long-term health. H had even been able to eat a meal and taste the food properly instead of tasting saccharine the day before he went into hospital, which was a big thing for him as he had become a bit of a foodie. Because I hadn't been able to leave him to do any shopping his last meal was the emergency meat pie and tinned peas left in the cupboard.

67. I know tha H had given his consent to having various tests, but I think that is something his doctors should have also discussed with me present, as H had severe liver disease and was not capable of making those decisions. It is only when I read his medical notes more recently that I even learned how invasive these tests were, including an ERPC. He was also put on nil by mouth when he was admitted to hospital, and never ate again.

68. By the time H was admitted to hospital for these tests, he had been living with full blown AIDS for many years and you could count his T-Cells on your fingers. However, Mary told us that AIDS is only called so in America for financial aid purposes, and HIV does not actually become AIDS. I believe we were told this to placate us, given H had been infected by contaminated

blood. We were treated like mushrooms - we were kept in the dark and only fed bits of information when they felt they needed to give us something.

69. H and I were not scientifically knowledgeable and neither of us had good education at the time to do our own research about his conditions. We had to believe what the medical professionals told us. I think they told us what we wanted to hear and to a level that they thought we could understand, which was very patronising. I managed to get some additional information from my own GPs, who were different to the ones that treated H I know that at the time I told them to keep any information about H out of my notes as one day my life would change, and I have seen in my notes that there is no mention of H

70. While H was being admitted or had gone to the bathroom, Mary Fletcher and Dr Trowel took me into an office and gave me what I can only call the 'get ready for widowhood talk'. It was a pep talk on making new friends and finding a hobby or pastime that didn't include my husband, as they knew H and I were inseparable.

71. Dr Trowel said that she had a husband with chronic illness herself and tried to be kind, but I thought it the height of stupidity myself and terribly patronising. It was obvious that I was with H because I wanted to be, and H had always said no one could make me do something I didn't want to. I was not a child, I was 30 years old when H died and we had been together for over 7 years. I knew what I was doing and realistically, I knew I would not have him forever, but our time together went by too quickly.

72. After this talk, I left H in the hospital with some trepidation. I needed to leave as I hadn't been able to find someone to look after the dog and cats. In our time together, H and I had only spent a few nights apart; the one

before our wedding and the first night when he had been rushed into hospital for emergency bowel surgery and a couple of times when a bed in the hospital could not be found for me. I really didn't want to leave him there, but he believed that they could do something for him to give us a little more time.

73. Less than 24 hours after I left him at the hospital, they phoned and told me to get there as soon as possible. H had developed pancreatitis after the ERCP, and they couldn't calm him down; he was literally screaming for me every time he was conscious. I phoned a member of H s family and told them they needed to take care of the pets and left a key with a neighbour for them and drove to Oxford. I did not leave the hospital again until just before midnight on GRO-B 1993. H died at 10:58 pm. A nurse and I packed up H s and my belongings, this was one of the hardest things I've ever done. I left the room and left with my father who had been sitting in the ward's common room on the last day waiting to take me home.

74. At the beginning of his hospital stay, we were told his prognosis was good as his bloods had shown that his liver counts were improving, but after the pancreatitis he then developed an acute bleed from his oesophagus, I believe this was as a result of varices. I can only describe what followed as terrifying. H began to projectile vomit blood at the same time as blood was literally running out the other end. This happened with no warning, one minute we were talking and the next he needed the commode and a bowl to be sick into.

75. I pressed the buzzer while trying to hold H on the commode and shouted for help. The matron and another nurse came running, and the matron sent the nurse to ring for emergency blood, get a doctor to do the surgery and find a cleaner, as by this time the floor was covered in blood. It looked like a scene out of a horror film.

76. While we waited for a surgeon, H needed 12 units of blood; they only had 19 units of H s blood type in the hospital at the time. The matron asked if I would stay and help or she could get two nurses off the main ward to replace us. I knew why she asked me - with H s HIV status the sheer amount of blood must have been off putting. I stayed, and the matron kept putting intravenous drips up and I held him while calmly talking to him and keeping him upright, so he didn't choke on the blood. I have never been able to forget that room, the smell and the blood covering everything. The sheer panic in H s eyes.

77. Finally, he was taken to the theatre where they stopped the bleeding. I was waiting for H to get back from the theatre when one of the nurses decided to tell me that I should be wearing gloves and a mask when touching my husband. I remember thinking, as I thanked him for the advice, that people just love to state the obvious, but the whole reason I stayed with him is so that he would have some human contact.

78. Initially, we were told the procedure was a success, but a couple of days later H had his first seizure and started to see things that weren't there. After that, he was given an X-ray and then a CT scan which showed he was haemorrhaging from a blood vessel in his abdomen. I stayed with him during both as he would panic if he couldn't see me.

79. A houseman for the ward took me into a small room just off the nurses' station and told me that the prognosis was not good, at that stage. However silly it might have been, I still hoped. Having now read H s notes, I have seen that Dr Trowell had said on GRO-B 1993 at 14:00 that H had a poor prognosis and he was not for ventilation, which had not been discussed with me. (**WITN3940017**) His death summary also says that they had decided to treat H conservatively, which was not discussed with me either. (**WITN3940002**)

80. Later that day, H s family came to visit him, and so I took a moment for myself and went to the dayroom. It wasn't long before his sister GRO-B came and found me because he was asking for me. When I got back to the room the rest of the family were saying their goodbyes and promising to come back soon.

81. I heard the doctor stop them on the way out, but as I had told him not to tell H s family that he wasn't going to recover, I wasn't worried that he'd ignore my wishes and hoped that they'd visit again. I was wrong, and they had been told, and so that was their last visit to H I spoke to GRO-B H s sister-in-law on the phone the next day and she confirmed the doctor had told the family and that they were all too upset to see H again. This I think was for the best as staying positive around H would have been impossible for them. To this day I still think that the doctor's highhanded actions were wrong.

82. The day he died, I believe the staff phoned his mother, but she and his brothers and sisters could not bring themselves to face being with him when he died. This was not their fault, and H had never had an expectation that they would be with him and in fact expected this. He expected me to be there, I made this promise right at the very beginning when I moved in with him.

83 H s pain levels began to get intolerable, and as they increased his dose of morphine he lost consciousness, as his abdomen slowly filled with blood. He was just left in bed with this slow bleed, as all his internal organs were crushed by the accumulation of blood in his abdomen. His stomach was very distended by this stage.

84. At no point did I tell H he was dying. I was in dispute with at least one of the nurses over this as she wanted me to agree to them lowering the dose of

morphine so I could tell him he was dying and say goodbye. H died on GRO-B 993 at The John Radcliffe Hospital.

85. Reading through H s medical notes has been very difficult for me and made me hysterically upset at times, especially when I saw that they had said they were treating him conservatively for this abdominal bleed. I had never been given the opportunity to decide on whether H should have further treatment, and I was always under the impression until recently when reading these notes that there was nothing else that could be done to treat H The injustice of it all is unforgivable.

86. My husband was the bravest person I have ever met. He lived with HIV without showing his fear or sadness. He made the best of his life and never ever said 'why me' or felt sorry for himself. It is hard to get across what a wonderful person he was. He always had smiling eyes and a great sense of humour. He was just an incredibly kind person. He did not gossip and if there was nothing nice to say about someone, he wouldn't say anything. He was a much better person than me.

87. In a part of H s medical notes that I have read recently, I have seen that Mary Fletcher had commented that I did not take the risk of becoming infected with HIV seriously enough. This is absolutely untrue as the worry that I could contract these infections really did impact my mental health and completely changed my outlook forever. I am sure I have made my daughters' lives difficult at times as I was obsessed with them not getting HIV. I took this risk to be with H because he was such a special person and I could not live my life without him.

88. The judgement in H s notes makes me very angry. I have also seen some quite GRO-D comments made by Mary. For example, I would cook for H

but she had written that he lived on snacks, which was completely untrue. A lot of his appointment notes are also missing; he had so many hospital appointments but there are only a few notes in relation to this although they appear to have listed all the Factor products he was given. I also do not like how these notes give no indication of the wonderful person H was, and have no humanistic side to them. He was so bright, lively and intelligent but you just cannot see that from these notes.

89. The haemophilia H suffered from was bad enough as he had bad joints and bleeds, but adding HIV, HCV and HBV to that was so unfair. He would still get up every day and get dressed, bring me a coffee in bed if we were on different shifts and get on with the day, all while smiling. I really don't understand how he did it.

90. The last conversation we had was about renting a house by the sea and taking the dog for a walk on the beach every day, and I hope and believe that this would have been his last conscious thought. H was such a kind and wonderful person and I am grateful for the short time I had with him. Looking back, we should have seen what was to come but when you love someone you get caught up in the emotion.

91. After H died, I found it very difficult to find a funeral director to arrange his funeral. I was calling around to many different funeral directors and when I explained Hs situation, everyone told me they were busy. My father encouraged me to get dressed and go and visit the different funeral directors in person, as he said they would find it harder to say no to my face. I decided to do this and I visited another funeral director who was very understanding and kind, and said that Hs situation was not a problem and they would deal with it. I explained that his body would come in a bag with a hazmat seal on it, but thankfully they agreed to do his funeral.

92. H and I tried for a baby for several years, but we were unsuccessful. During that time, we received visits at home from Mary, who advised us to use protection when not ovulating, it was a little like stating the obvious as that was our plan. I believe H felt guilty for putting me at risk. We talked about it often and it did put an extra strain on our relationship at times. H wanted so much to have a normal life, nothing special just normal and I tried so hard to give it to him.

93. H s life ambitions to many might seem small; he wanted to be married, have a job, to own a house, have a child with me and to be happy. I am grateful that we achieved everything we did, apart from the baby, which was a great sadness to both of us. At that time we were not offered any fertility treatment or counselling, just enough condoms to fill our spare room!

94. We saw on television about donor insemination and contacted Mary to ask about it. We were surprised that it had not been offered to us. We started fertility treatment on 01 June 1991, which we paid for because it was not available on the NHS, a couple of months later. It took us six months to finally conceive.

95. Unfortunately, I miscarried at about 16 weeks pregnant in April 1992 and by the time I was ready to start again, H was rushed into the John Radcliffe Hospital in Oxford with an obstructed bowel. He had a section of his lower intestine and appendix removed. The day after the operation the hospital provided me with a room, and I stayed with him. The 90 mile round trip was too much for me physically and mentally.

96. After his initial recovery, he was moved to the infectious diseases department which had a new HIV ward. As this was a new ward, the Actor Ian McKellen had been invited to open it. We had to bundle H up and go for a drive to make sure he wasn't seen on camera, as they videoed the opening of the ward.

We stayed there for around a week then transferred to a nearby hotel while H healed. We intended to restart fertility treatment, but by the time H got over the surgery and we had been back to work for a while, we had waited too long and his health had started to decline.

97. Although we did have another round of fertility treatment booked, deep down we knew we would never have a baby and unfortunately, we were unable to proceed with this second round of treatment. By this time, we had our dog, GRO-B and cat GRO-B, who was a thirtieth birthday gift from H and each other, so I started a degree course with the Open University and H decided he wanted to learn to play the piano. We were sad, but we knew we had each other and our life together, if anything, we got even happier. H was the most resilient person. I really don't know how he picked himself up and lived a normal life despite everything that was going on, but he did.

98. It took me years to realise that I was suffering from Post Traumatic Stress Disorder (PTSD) following my experiences of staying with H in hospital during his final weeks. Incidents such as seeing H projectile vomiting blood were very traumatic. I could have done with counselling twenty-eight years ago. There was no support offered to me after H s death.

99. Looking back, I think I was probably completely 'nuts' for a while. I'm certain that I went to our doctor to get sleeping tablets and uncertain as to why. I was completely not myself. Unfortunately, being around H s family made me sadder, we'd never been close, and H did feel that they didn't really understand him. This meant I didn't really have a support group after he died. My Mum and Dad loved H when they got over the first panic about his AIDS status, they treated my widowhood a little like an illness.

100. It was a very difficult and strange time. People would say things you just did not want to hear, widows are targeted for well-meaning advice. There was no one from the haemophilia centre or Macfarlane trust keeping in touch with the wives of those who had died. We were just left struggling with an empty hole we could not fill. I had also cared for [redacted] as he became more and more ill towards the end of his life, and I felt like I had lost my purpose. Our GP wanted to have a nurse come in, but [redacted] did not want this, he was paranoid about people where we lived knowing

101. There was a great deal of stigma associated with [redacted]s HIV diagnosis. None of my family attended our wedding. We had planned to have a bigger wedding than we did but decided only to invite those who already knew [redacted]s HIV status, which was one friend on my side and [redacted]s family and two close family friends that he had run the mobile disco with. We tried so hard to have a normal life, his HIV status infiltrated everything we tried to do.

102. Before [redacted] joined the civil service, we had both worked in a photographic lab together, and we had a lot of friends from there. We wanted to have a big reception for them to celebrate with us, but we could not take the risk of people finding out about his HIV diagnosis. We told them we had to have a small wedding due to our finances, but this was not actually the case.

103. There was a lot of pressure at the time from the constant scare articles published by trashy tabloids, and it was hard just to forget about [redacted]s situation when there were endless adverts on TV. There were headlines like "put them all on an island" and there were warnings not to drink out of cups people with HIV had used, share cutlery, use the same bathrooms and so on.

104. The need for secrecy coupled with the fact that at any point I could have been infected brought us closer together as a couple. Unless you have been involved in it, it is impossible to understand how it felt. When we received the first ex-

gratia payment, we had thought about travelling or going on a cruise, but H s HIV status made this difficult and impossible for countries like America and cruises banned people with HIV from boarding.

105. There was so much hate attached to those living with HIV, we were very worried about anyone finding out about H s HIV diagnosis. There was also a vilification of homosexual men at the time, which was just awful. My own mother had made a comment before she knew about H s diagnosis that AIDS is God's judgement on certain types of people. She came from a very conservative, middle class background and a lot of people in her position held those views at the time, but she later really regretted this. I don't think she would ever have guessed H had HIV if she had not seen the letter that came to the house.

106. I feel now like I have been a coward in relation to talking about what happened to H as I didn't want people to talk about it. However, I want him to have his say. It took me a long time to come forward as obviously cowardice was winning out. I just don't trust people enough to talk about H Even my best friend where I have now lived for 28 years has no idea that H was a haemophiliac, and believes he died of liver cancer. That shows how closed off I have become. I don't think anyone can understand unless they have lived it.

107. When I went to the bank in order to get a mortgage with my second husband in 2002, I had to apply for life insurance. The life insurance form had a box to tick if you had ever had an AIDS test. I had to go into the bank and speak to an advisor in relation to this, they said it should be okay, but I should speak to the life insurance people too. I was upset by this experience and for weeks I worried that people would be talking about it behind my back. Sounds silly I know, but I live in a small community and my experience of people's attitude is set very much by what happened in the 1980s.

108. I spoke to someone else at the life insurance company about this who was not satisfied with my explanation as to why I had an AIDS test in the past. As a result, I had to provide a negative AIDS test result, a written statement and a copy of H s death certificate, to show the blood test had been taken after he died. I had to wait quite some time for them to come back to me and could not proceed with the house purchase even though we had a mortgage offer, as we needed to show we had life insurance. I was worried if I told a fib I could be caught out, so I was honest throughout, but it made the process more stressful.

109. As I mentioned above, I moved into H s studio flat very soon after we started going out in 1986. We moved into a bigger council flat in GRO-B GRO-B later that year and H started his first-ever job. We were happy, and I changed my job to become a temp, so I could take time off whenever he needed me without having to give detailed explanations to an employer.

110. H was a member of the Haemophilia Society from very early on and had a good relationship with the local representative. At one point both ended up out of work for some time and we were struggling with rent arrears. It was one of the worst periods for us. H told the Haemophilia Society representative he knew about this, and I recall he came over and paid our rent for us, which was so helpful at the time.

111. We had been living in this flat for some time when we were able to buy the flat, using the 'right to buy' scheme that the council offered, which gave us a discounted rate and didn't require life insurance. We used the first £20,000 ex-gratia payment we received to update this flat. At first, the flat was a lovely place to live. However, when the old lady next door to us moved out, the council moved a woman with a small child into the flat who was completely unsuitable to live there. When her partner came out of prison he came to stay with her, things became awful in the block and lots of unsavoury characters would spend time

there. By the time we finally were able to move out the couple, fought all the while, had three children in a tiny one-bedroom flat.

112. The couple who lived above us wanted to move as a result of these unsavoury people and sold their flat to someone who worked in London, who used the flat for parties all weekend. We had to contend with being disturbed by all night parties, rough sleepers, violent altercations on the stairs and cleaning up ripped rubbish bags full of dirty nappies. It had gone from being a quiet cul-de-sac to hell on earth. This had a negative effect on both mine and H s mental health and he blamed my miscarriage on our living circumstances.

113. When we complained to the council, they placed a security door on the front of the block. However, this did nothing to help as the woman in the flat next to us would keep it propped open. Things became even more challenging when one of our neighbours discovered H s HIV status. The neighbour was on the ward when I had my miscarriage and must have overheard something one of the doctors said to me. Looking back, we were lucky in a way that she just started to ignore us instead of spreading rumours about H as that could have been very dangerous for us.

114. We asked the council to release us from the repayment of our right-to-buy mortgage. The council forced us to jump through hoops, asked invasive questions at face to face meetings and then turned us down. The Council also refused to move us because none of H s doctors could predict how long H would live for.

115. When my parents realised how ill H was becoming and how bad the flats had become, they purchased the flat off us so we could move. We could not sell the flat for any value due to the poor housing market at the time, and if not for my parent's help, we could not have moved.

116. Despite H s poor health, he had managed to go back to work and we got a mortgage to purchase a bungalow in GRO-B Thanks to my parents we spent our last Christmas together in the bungalow. We had seven happy months in our new home before he passed away. We felt let down by the council but thankfully we were able to move on from this terrible time.

117 H s last job was with the civil service working for the employment service. He loved his career on the frontline H was quiet but also a people person in that he liked to help and was always popular with people he worked with. The Civil Service job was amazing and came at the right time for him.

118 H had been doing some temping work but he had suffered a haemorrhage while at work, and felt he could not go back there. When he went to the job centre to look for work, he saw they were actually looking for staff and he was encouraged to apply. Although he felt he did not have the relevant experience, they said that he had empathy for those on the other side which was the most important thing.

119 H told his employer about his HIV status when he applied for the job because he'd had a couple of problems with his teeth which had caused spontaneous haemorrhaging. He thought it would be unfair to put other people like the first aiders at risk, if they did not know about his HIV status.

120. Previously H and I had worked together at a photographic lab so we felt we could manage a situation between us if anything happened to him and our employer did not know about his HIV status. In this role, I would not be there to help so I think this was also a reason to inform his employer about the HIV. This did not affect his job or the relationship he had with other workers, and he was extremely happy working at this time.

121. Although he was initially hired to work in the GRO-B office, we had bought a bungalow in GRO-B and he transferred to that office. They were just as lovely in that office too. When H died, so many of his colleagues came to his funeral, it was absolutely packed. As we were a very insular couple, it was surprising to see how many people came to pay their respects.

122. I still feel H s death acutely even now. It changed my life and it made me a different person. I had to put one foot in front of the other and just get on with it and 30 years later I'm still doing the same thing. I have never been able to move on. I have never made peace with what happened, and I never will, but I would like to find some sort of closure and justice for H

123. I was lucky to remarry someone we both knew and someone who would never begrudge me my first marriage. I always have a picture of H up in our house and when things come up I am always happy to talk about H with my new family.

124. With the new treatments that are available now, H would have lived into old age, which is what really upsets me. H always believed his HIV infection was down to money, which is why he apparently didn't blame Dr Rizza for all the things that happened to him. He felt that the decisions came from higher than Dr Rizza's pay grade.

125. I felt sorry for some of the clinicians involved in this; although they did not always do a great job, they were thrown into something they were not capable of dealing with. I truly believe this because I know Dr Rizza was still making all the decisions for haemophilia patients living with AIDS until very late in H s treatment. Our contact with infectious diseases consultants was minimal.

126. H did not see anyone from the communicable diseases ward regularly and everything was done through the haemophilia centre who took advice from them on how to treat specific things. When H had to have emergency surgery on his bowel and he couldn't go home, he had to convalesce on the AIDS ward, and I stayed with him. The staff were lovely.

127. By the grace of God AIDS was not airborne, but still so many haemophiliacs were infected which is why there should have been a full inquiry about what happened at the time. In my opinion, you can't think of budgets for good healthcare and always try to use the cheapest option. This type of thinking killed a whole generation of haemophiliacs. Looking back, I just loved someone who had got caught up in this problem and I just wanted to love and support him. I don't think attitudes to public health have changed and that successive governments have learned nothing from HIV, Hep C and CJD infections.

128. H s HIV and HCV infections and his experiences have affected me a great deal psychologically. I had my first daughter in 1994 and I suffered a haemorrhage following her birth, but I refused a blood transfusion due to the fear and psychological trauma I had about contaminated blood.

129. I went on to have my second daughter in 2000, and I had problems with my liver while I was pregnant. They suspected that I had HCV. I had an HCV test when I was 7 months pregnant. I did not tell the hospital about the fact that H had been diagnosed with HCV, and I let the nurse explain to me what HCV was. I felt sheer panic at this time as I had not received any transfusions myself and I had always had negative tests when I was tested previously. It turned out that I had cracked a rib while I was pregnant and the amount of paracetamol I had been taking had affected my liver. The trauma of what happened to H has followed me and I have absolutely no confidence in the medical profession.

Section 6. Treatment/Care/Support

130 H s HIV status always made things more complicated even in hospital, like having to ask for a volunteer cleaner and nursing staff who understood there was some risk of infection from H s blood. This, I think, is why H didn't want any home visits from our GP practice.

131 H died before they even started using interferon, and no treatment was offered to him. He was also never offered any treatment for HIV, as he was considered 'too well' to require AZT treatment.

132. Neither H nor I were ever offered any counselling in relation to HIV, HBV or HCV infections or in relation to me, following H s death. The Inquiry Investigator has made me aware of the assistance available from the British Red Cross to those who have been infected and affected by the contaminated blood scandal. I have been provided with the British Red Cross counselling details, and will consider whether I will use their service in the future.

133 H did not really visit the dentist until he met me. He then suffered some spontaneous dental haemorrhages, and was treated at the GRO-B dental department. They were fantastic and he received good care.

Section 7. Financial Assistance

134. We received two ex gratia payments from the Government, one for £20,000 and one for £32,000 as part of the litigation class action against the Government. We also received a weekly payment from the Macfarlane Trust of around £80 to help with any extra costs. I think this was around 1991/1992 but I am not certain about these dates.

135. We used the £32,000 payment as a large deposit on a bungalow. Because we had such a big deposit, it did not matter that we could not get life insurance. However, if we had not had this deposit it would have been very difficult for us.

136. The fact that H was only entitled to £32,000 did affect him mentally. I remember that he said, "My life is only worth £32,000".

137. I have in my possession a letter dated 19 May 1993 from the MacFarlane Trust, following a request made to them for some financial support in getting someone to clear our garden, as this was something H and I would struggle to do. The trustees rejected H s request, and they suggested that he applied to a 'helping hands' group in our neighbourhood for this assistance. This shows the lack of support they offered to those in need of their assistance and no real understanding of the way it forced HIV positive haemophiliacs to live. I think this sums up how out of touch they were with the reality of our life. I can't imagine how we'd have explained H s illness to strangers and kept it confidential. My parents came over and we cleared the garden and laid a lawn, but sadly by then H was too ill to enjoy it by then and passed away in hospital around GRO-B later. (**WITN3940018**)

138. After H died, the only contact I had from the Macfarlane Trust was a letter dated 01 December 1993 to say that they would be discontinuing any ongoing payments to me, which was about £80 a week There was no kindness or consideration shown from the Trust, despite the fact that my husband had just died; they simply said they hoped the payments in the months following H s death had helped me in resettling my financial affairs. They could have paid some support workers to help people who had suffered a loss, but there was nothing like this provided. (**WITN3940019**)

139. As H was a civil servant that had died in service, I received some funds from his workplace, which helped me. However, the building society which we had our mortgage with wanted assurances that I would be able to pay the monthly repayments alone, and this made things very difficult for me as I had to work in temporary jobs until H died. Temporary employment gave me the

ability to take time off to look after him or he needed to go to the appointments and I could accompany him without telling an employer why. When I looked back at my National Insurance contributions over the years, the only time I had a gap was during my marriage to H as I have worked all my life. Also, whilst temping, I didn't form any relationships at work with people who might have asked questions about my husband.

140. Eventually, my parents bought the bungalow from me which gave me the opportunity to move on from it. I did not want to stay there with all the memories and could not afford to keep it anyway. I packed a bag, packed up our dog GRO-B and cat GRO-B and ran away. That was my coping mechanism and it worked well for me.

141 H did apply for a few small grants through the Haemophilia Centre that I am aware of, for convalescence in a hotel after major surgery and for the deposit on a Motability car. The Haemophilia Centre would have to justify these grants on H s behalf from the Macfarlane Trust. We only claimed expenses in relation to driving H back and forth from GRO-B to Oxford on a couple of occasions, around the time he had his bowel operation as normally they'd find somewhere to sleep in the hospital. The Macfarlane Trust seemed not to be aware that time was not on our side and when H died, they still hadn't found a way to balance the inequality haemophiliacs face when trying to get a mortgage.

142. After emergency bowel surgery, I was nervous about taking H back to GRO-B in case something happened to him, and Mary suggested that H stayed in a hotel near to the hospital until he was well enough to go home. As we could not afford this, Mary applied for a grant for us in relation to this, which was successful. We never really understood the Trust's criteria and so often asked Mary to intercede on our behalf.

143. Two days after H s death, the Motability car dealership threatened to sue me if I did not drive the Motability car back from John Radcliffe Hospital in Oxford to the Mobility garage in GRO-B They were extremely rude and nasty to me, and gave no consideration to the fact that my husband had just died. I told them that by asking me to return the car they were actually breaking the law, as I was not insured to drive the car following H s death. I believe they did eventually come to pick up the car, but this was a very upsetting incident.

144. As I mentioned above, I had no idea that H s mother had applied to the Skipton Fund in 2011, until I saw the correspondence in his medical notes. I have had very little contact with H s family since his death. I have seen a letter from Dr Paul Giagrande saying to her that H had a negative RNA H/CV test in 1991, and he was not shedding the virus. Originally, I thought she had been turned down because she was applying as his mother and it should have been me applying, but I was shocked to hear about this negative RNA test as we had never been notified of it. It does peeve me as it would have meant the same for me if I had tried to apply to the fund. Even though HCV clearly contributed to his liver damage and his death, they would have denied his family any financial support.

145. Also, if I had not asked about the cut-off date, I would not be eligible to claim because they are waiting for files that could take four weeks, so I am now filling in yet another set of forms. This form asks for a bill to prove that I or whoever was cohabiting with their partners at the time of death, lived together. Luckily for me, I have the deed of probate issued but they are asking for a bill or council tax letter as proof, many people might struggle with this. You can get a professional person as a reference to say you lived with your spouse, but for that would be impossible, as they cannot be a relative and our solicitor and medical professionals have all either retired or died or both. They also want another copy of H s death certificate, too. In my application for stage 2 hepatitis infection, they've agreed again to take H s medical record as evidence, however because I didn't send in the blank doctor's section, they wouldn't process it. I phoned and yet another person in the office said that no it would be okay and

they'd sort it out. Another email same as the first and when I phoned, they said without the blank section it wouldn't be sent to the medical team. All the way through the is process although they tell you it will be 30 days it isn't because they always want more, or different information and the 30 days doesn't start until they have everything. Add to this the dire warning against t fraud and that all this information I am giving them is going to be shared and I worry, because while the Inquiry will retract my name, what assurance do I have that anything I am giving EIBSS is confidential?

146. Both in the past and present, applying for help has been difficult for partners and widows; doubly so, I think as each new piece of evidence we are asked for reopens the past and our loss again. Wives and partners lived with the potential of infection, often making light of our fears to help our partners. We, unlike many who cared for loved ones at any time, could have been infected ourselves. Nothing is made simple and while the EIBSS are much easier to apply to with their openness about criteria, you are never given something as simple as a list of essential documents to progress your claim. The website they constantly refer you to has much in common with Hampton Court maze.

147. I have also seen a letter dated 08 July 2011 sent to H s mother from the Subject Access Team at John Radcliffe Hospital, confirming they have no records for H Brenda Whyte, the Access Team supervisor, said that any information they held had already been passed onto her through Dr Giangrande. Since then, I have obtained H s medical records and cannot understand why it wasn't possible for her to do the same or why the claim was refused when H s HCV status was obviously partly along with his HIV infection, if not wholly, responsible for his death. (**WITN3940020**)

148. I have recently been in touch with the English Infected Blood Support Scheme (EIBSS). I have received another email from them which reads that they are going to use H s records with The Skipton Fund as proof of Hepatitis C infection,

which is not possible as they established the fund after his death. Each time they send me an email, it is from a different person. So far, three different people have dealt with my inquiry and application and they each have something new they need.

149. Also, if the Blood Inquiry had not informed people the cut-off date for backdating applications, I would have lost my eligibility because files from the Macfarlane Trust and Skipton Fund could take four weeks to arrive from the solicitors, so I am now filling in yet another set of forms. This form asks for a bill to prove that I or whomever, was cohabiting with their partners at the time of death, lived together. Luckily for me, I have the deed of probate issued, but they are asking for a bill or council tax letter as proof. Many people might struggle with this. You can get a professional person as a reference to say you lived with your spouse, but for me that would have been impossible, as they cannot be a relative and our solicitor and medical professionals have all either retired or died or both. All this information I am giving them is going to be shared and I worry, because while the inquiry will retract my name, what assurance do I have that anything I am giving EIBSS is confidential? I know I sound paranoid but combined with my anxiety when I feel people are talking about me and my feelings of guilt that I've had a life when H didn't, this means that nothing is as simple as filling in a few forms.

150. I know H would want me to claim anything he was entitled to on principle alone, but as I expected, doing this is having a detrimental effect on my mental health. I have had to prove we were married to get the files from the solicitors who hold The Macfarlane Trust files, prove to EIBSS that we were cohabiting at the time of his death, actually I was sleeping on a mattress on the floor by his bed in the hospital for the last three weeks of his life. Also, anyone whose partner was receiving payments from a trust at the time of their death should not have to prove they were still cohabiting.

151. I feel that if the EIBSS are going to be dealing with the infected and affected, then they should have more training and that, rather than anyone in the office dealing with these historic claims, they should assign a designated case worker as many who lived through the difficult times and stigma attached to infection feel vulnerable when having to give such personal information out.

Section 8. Other Issues

152. The group legal action that H was involved in against the Government, was brought about by the influence of the Haemophilia Society in around 1989/1990, however, I am unable to recall the exact dates. I recall H being forced to attend an appointment with a psychiatrist in Nottingham as part of this class action, to assess the impact having HIV had on his mental health. I attended this appointment with him, and they asked me some questions too.

153 H was depressed that legal aid was removed at the time of the settlement of £32,000 as he still wanted answers. Right up until the end, H wanted to know why this happened to him. He wanted to keep going so that the truth would come out as he believed that the Government was responsible for what had happened to him and others; he wanted to make sure this could never happen again. I recall the solicitor dragging us into his office to tell us that legal aid had been withdrawn H asked whether he could still continue with the case and he was told point black he could not afford to do so. He was advised to accept the settlement and had to sign a document to say that was the end of it.

154. John Major's government made the offer to settle out of court so that legal aid would be lost to the haemophiliacs and this caused severe problems and caused the class action to collapse. It ended with an ex gratia payment of £32,000 being paid to those involved in the class action.

155. I am grateful that this Inquiry has come along in my lifetime, I really am. Lots of peoples' stories might look the same but our experiences are different. To be honest, all our stories include the same terrible thing that happened, but how different people dealt with the things thrust upon them is what differentiates them. How unfortunate and how unnecessary this all was is really sad. I have tried to listen to the hearings but to be honest I was getting so depressed by it all and some of the attitudes of some witnesses has made me angry.

156. I really hope this Inquiry makes a difference, although most of the people who had a say in what happened from the top down are now dead or in their dotage. I remember very clearly that the Government said that in public interest the class action documents would be locked away for 30 years and H said that we would all be dead in 30 years and no one would be interested then. I think he was wrong, from my observations and experience none of us ever got closure. This was not a terrible accident, people made choices and decisions that devastated lives.

157. I remember clearly both H and I knew it as a fact that information had been put away for 30 years in the interests of public security and we never knew any more about that and what happened to all this information hidden away. The cynic in me believes that some faceless clerk has shredded the files 'by mistake'.

Statement of Truth

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

Signed GRO-B

Dated 25/7/2022

Table of Exhibits:

Exhibit number	Date	Description
WITN3940002	GRO-B 1993	'Death summary' of H sent to Dr GRO-B of GRO-B GRO-B produced by Dr Will McConnell of John Radcliffe Hospital, Oxford.
WITN3940003	GRO-B 1993	Death certificate of H listing his date of death as GRO-B 1993 at John Radcliffe Hospital.
WITN3940004	GRO-B 1993	Histopathology report in relation to H produced by Dr Trowell at John Radcliffe Hospital, Oxford.
WITN3940005	Undated	Letter from Dr C.R Rizza to H informing him that they have 7 results for him in relation to AIDS-related virus, and asking him to get in touch with him or Dr Matthews should he wish to know the results.
WITN3940006	16 February 1986	Letter from Dr C.R Rizza to H asking him to complete the enclosed form about whether he has been informed of his HTLV-III results. H s response which is attached confirmed he had been told the results.
WITN3940007	Undated	Photographs of H and GRO-B
WITN3940008	Undated	Photographs of H and GRO-B
WITN3940009	13 October 1993	Letter from Mary Fletcher to GRO-B with blood test results from a sample taken on GRO-B 1993. She also confirms that GRO-B was first tested for HIV on 15 October 1986.
WITN3940010	22 March 1988	Note from Oxford Haemophilia Centre's follow-up clinic saying that MF had sent a letter to GRO-B s parent's address which her mother had opened, and her parents have since shunned both of them due to the

		HIV diagnosis.
WITN3940011	25 May 1988	Letter from Mary Fletcher to GRO-B and H regarding a short survey for wives and girlfriends, to enable them to give better advice in the future.
WITN3940012	04 June 1992	Laboratory test results for H with a sample collection date of 10 May 1991. It says Anti-HCV detected but HCV RNA not detected.
WITN3940013	01 October 1992	H s clinical notes which confirm he is HIV and HCV positive.
WITN3940014	19 April 1993	H s clinical notes which confirm he has been HIV positive since 1985 and is also HCV positive.
WITN3940015	30 April 1985	Letter from Mary Fletcher to H saying that Dr Rizza asked her to get in touch with H to ask him if he would donate an extra blood sample to help with work being done on heated Factor VIII.
WITN3940016	23 October 1987	Letter from Mary Fletcher to H asking him whether he would give them a blood sample, but she does not mention what this is for. She asks whether she can come and speak to him about this.
WITN3940017	GRO-B 1993	H s clinical notes,which contain an entry by Dr Trowell at 14:00 that H had a poor prognosis and he was not for ventilation.
WITN3940018	19 May 1993	Letter from Macfarlane Trust Administrator – declining request for 'helping hands' for garden clearance to witness.
WITN3940019	01 December 1993	Letter from Macfarlane Trust Administrator informing of the termination of payments.
WITN3940020	08 July 2011	Letter from Brenda Whyte, Access Team Supervisor – Subject Access Team, John Radcliffe Hospital to Mrs GRO-B – re lack of medical notes