

ANONYMOUS

Witness Name **GRO-B**

Statement No: WITN1641001

Exhibits: WITN1641002-7

Dated: January 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF **GRO-B**

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

Section 1. Introduction

1. My name is **GRO-B** DOB **GRO-B** and I live at **GRO-B**
GRO-B.
2. My husband, **GRO-B:H** DOB **GRO-B** died on **GRO-B** at the age of **GRO-B** after being infected with HIV, Hepatitis B and Hepatitis C through contaminated blood products.
3. I was also infected with HIV as a result of my husband's infection.
4. This witness statement has been prepared without the benefit of access to my full medical records. If and in so far as I have been provided with limited records the relevant entries are set out in the medical chronology at the end of this statement.

Section 2. How infected

5. [H] and I met in [GRO-B] and we married on [GRO-B]. As I didn't know [H] when he became infected, the information regarding his infection is based on what I was told by [H] and his mother.
6. [H] lived in [GRO-B] as a child and was not diagnosed as a haemophiliac until he returned to the UK as a teenager, where he was diagnosed at [GRO-B]. His mum knew that he bruised quite easily but it wasn't until his sister had children that they became aware of [H]'s haemophilia. [H]'s mum did ask about it in [GRO-B] but the doctors there had never heard of Christmas disease.
7. When [H] was diagnosed he was told his haemophilia was very mild. He rarely needed any treatment.
8. When [H] got older he was treated at the [GRO-B]
[GRO-B].
9. [H] was in a car crash in [GRO-B] which caused him to spend six months in [GRO-B]. Prior to that he ran regularly and was very fit. He received Factor IX whilst in hospital. However, one day he was accidentally given Factor VIII which was meant for another patient and I was later told that, in all likelihood, it was with this batch that [H] was infected with HIV, Hepatitis B and Hepatitis C.
10. [H]'s mum visited him the day after he had received the Factor VIII. The doctor told her that the products they had used had come from America, and his mum said that she didn't trust that stuff. The doctor laughed it off as a joke.
11. The next day that she went to visit him he had been moved to an isolation ward and was completely yellow. It was then that [H] was diagnosed with Hepatitis B.

12. There is now shown to me marked **WITN1641002** a copy of the records I was provided with from the National Haemophilia Database (NHD). This includes a sheet that specifically deals with the events of **GRO-B** when **H** was given Alpha FVIII (Profilate), Batch number **GRO-B** instead of Factor IX. The Factor VIII was meant for a patient called **GRO-B**
13. **H** was tested for HIV antibodies on **GRO-B** (clearly straight after the hospital realised the mistake in treatment). The result was negative. It appears from the NHD records that the blood sample taken on that date was stored and then re-tested as more sensitive tests became available. On 16 October 1990 the sample was re checked by **GRO-B** and reported to be "just negative" ie. borderline.
14. **H** went to the hospital shortly after for a routine appointment, where he was told 'oh by the way, you're HTLV3 positive'. **H** asked if this was something to do with Hepatitis; the doctor told him, "no, you have the AIDS virus."
15. He was told nothing about his prognosis as apparently they didn't know much about it; he might get ill or he might not. They said it might be different for him because he was a haemophiliac. He was told to just go home, forget about it and don't tell anyone about it.
16. It must have been absolutely terrible for **H** to be there alone and have to drive back from the hospital on his own after he was told such big news.
17. He relied on what they told him and was convinced that he was going to be fine. It was a few months after this that the adverts came out on TV with the tombstones and the media campaign surrounding AIDS began.
18. According to **H**'s medical records he was first recorded as HIV positive on 4 February 1985.
19. **H** was only told that he had been treated with the wrong product shortly before he died. We had a HIV counsellor called **GRO-B** who came

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to the house and said she had something to tell us. She told us that **H** had received the wrong treatment. The treatment was actually for a **GRO-B** **GRO-B** but they had been mixed up which is why **H** received his batch. I have since obtained a letter to prove this. This is now shown to me marked **WITN1641003**.

20 **H** had been ill for so long he just said he couldn't change anything about it, he was still going to die and he didn't have the energy to do anything about it. We were told that not as many people with Factor IX deficiency had been infected and it was therefore most likely the Factor VIII that he was treated with that caused the infection.

21 **H** and I met when he returned to work after his car accident. We worked in a **GRO-B**. He told me about his car accident shortly after we met, but I can't recall if he told me about his haemophilia at this stage.

22. I already had two children from a previous relationship when I met **H**

23 **H** and I soon became friends and we quickly grew close and started going out. He told me about his haemophilia and that some haemophiliacs had contracted the AIDS virus. At this stage I should have asked if he had contracted the virus, but for some reason I never did.

24. Shortly after this **H** told me that he had been infected with AIDS. He took me to the hospital with him one time when he was having his blood taken, at which stage he had not been offered any treatment.

25. We moved in together and everything was going well, but we both just didn't think that he wasn't going to get ill. He looked so healthy and we didn't know anybody who had died as a result of the infection.

26. When we decided that we were going to get married, I told my mum and dad about **H**'s infection and they were still fine about our relationship.

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27. On [H]'s side of the family, only his mum's family knew about the infection because they had other family members who had haemophilia and therefore understood what he was going through.
28. [H] tested positive for Hepatitis C antibodies in 1993.
29. I was tested for HIV after the recommendation from a counsellor who came to the house. I had to wait weeks for the results but fortunately they came back negative.
30. It was not until after [H] died that it was suggested I was re-tested for HIV. At that time I was being visited by [GRO-B] a counsellor attached to the Haemophilia Centre.
31. About four months after [H]'s death she suggested that I have another test. She took my blood whilst I was at home, and said that she would give me a call the next day.
32. I was working part time at a florist and I went to work and told my friend about the conversation.
33. When I got home from work the following day I still hadn't had a call, so I left [GRO-B] a message. As time went on and on and I just knew that something wasn't right.
34. [GRO-B] got somebody to ring me to tell me that she was coming to see me. As soon as they said that I knew that I was positive. I waited all afternoon for her to visit. My youngest son had just come home from school. I knew from her face that I was positive and I felt like I was going to collapse. When my son went upstairs I asked if the test was positive, she said that it was.
35. She left the house after that and I have never felt so frightened. I was shaking and I thought it would never stop. I then had to pull myself together, act normal and make the boys' tea.

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36. That evening I rang [H]'s brother and asked him to come over, as I just needed to tell somebody. He said he would take me to the hospital the next day and I don't know what I would have done without him.
37. I had to call work and tell them that I wouldn't be coming in, so they knew what had happened straight away because I had told my friend and colleague that I was being tested.
38. When I went to the hospital they said they would do another test, and I tried to convince myself that maybe this one would be negative.
39. I went back again a week later and was told that I was definitely positive. They were also shocked at my CD4 count which was already down to about 350.
40. [GRO-B] was very blunt about it all and told me that there was no treatment. She said my life was limited so I needed to get it into my head that I would die young. She said "deny yourself nothing and do what you want to do. If you want to go away with the children then do it." I thought at the time that this was a horrible thing to say, but now I understand why she said it.
41. Looking at my CD4 count and what had happened with [H], I thought I might have another 4 years left to live. My youngest son was 13 at the time, and I just wanted to make sure I would be there to see him through his teenage years.

Section 3. Other Infections

42. The NHD records suggest that [H] suffered from jaundice as a result of Hepatitis in 1977 which was when he was first given Factor IX concentrate.
43. There is also a clinic note (exhibited at **WITN1641004**) dated 13 November 1991 that states "*HIV +84 (also NANB + HBV in past.*" and a clinic note dated

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12 November 1991 which states "Hep B and Hep A non B – 1973 – recent episodes of jaundice".

44. There are also results from July 1979 which state he was Austria antibody positive and Hepatitis B core antibody positive. These are shown to me marked **WITN1641005**.

Section 4. Consent

45. I do not believe that [H] was consented for the tests that were carried out for HTLV III or Hepatitis.

46. I believe he was tested for the purposes of research once the hospital realised their mistake in treatment.

Section 5. Impact of the Infection

47. [H] started getting ill in 1988, a year before [GRO-B]. He felt like he had flu continuously. He would go to the hospital where they told him that everything was fine, but [H] had to give up work as he just felt too ill.

48. Everyday that I got home from work [H] would be exhausted and in bed. When we asked the hospital again they said it was probably just depression.

49. [H] went to the hospital with his brother where the doctors told him that he was just paranoid and that any breathing difficulties were probably just stress related.

50. One day when I got home from work, [H]'s parents were there and [H] really didn't look well, so I decided to call an ambulance. When he arrived at the hospital, they were shocked at the state of him and said if he had stayed home for a couple more days he would have been dead. He had PCP pneumonia and we were told he had full blown AIDS. This was in or about April 1989.

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51. He was treated with AZT from May 1989. He was also treated with Pentamidine which was a prophylaxis for pneumocystis
52. At this stage he was still just being seen by the haematologists and was not receiving care from the Infectious Disease department. His main consultant there was Dr [GRO-D] who was absolutely terrible. He made [H]'s brother so angry as he continued to disregard all of [H]'s complaints.
53. As [H]'s health deteriorated, my GP suggested I have someone look after the children so I could be in hospital with [H]. We thought he was going to die every day for about a week, but he gradually made a recovery. This is when we both first realised the severity of the disease, so we quickly booked a date to get married.
54. By the time we got married in [GRO-B] he looked fighting fit.
55. [H] was diagnosed with *Cryptosporidiosis* in August 1989. He suffered from oral thrush, mouth and tongue ulcers and diarrhoea. He was also diagnosed with depression from early 1989.
56. He was seen in the HIV joint clinic from 1992. In March 1992 Dr Lucas said he was amazed [H] was still alive given he had had such an awful time over the past few years. There is now shown to me marked **WITN1641006** a copy of his letter.
57. [H] would have loved to have children, and I would have loved to have children with [H], but we were unable to. We were never advised not to have children or about the possibility of transmission, but we decided against having children nevertheless.
58. The boys knew about [H]'s infections as the link between HIV and haemophilia had been all over the news. One day they asked if he had AIDS and I confirmed he did but told them that they could not tell anyone. The fear and stigma surrounding HIV/AIDS was rife at that time.

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59. One evening we were in the pub and someone said that [H] should not be drinking from the same glasses as everyone else. Things were often said behind his back (because people knew he had haemophilia and he looked so ill). [H] often said he would rather people actually just asked him what was wrong with him.
60. He became quite paranoid which wasn't like him. He thought everyone was laughing at him all the time; even the children. My youngest son had a book called "Computers for Dummies" and [H] got very offended thinking that the book had been bought as an insult to him.
61. We found out about [H]'s Hepatitis C in or about 1993. However, it didn't really bother him too much as he was already so ill with HIV.
62. Towards the end we were told that [H] would start forgetting things and would need full time care. He was told that he wouldn't be able to drive anymore and I think this upset him more than anything else because he didn't want to lose his independence. After that clinic appointment, when we got into the car to leave the hospital [H] said "I'm not going yet, we still have a lot to do." He also told me that I shouldn't give up my job at the florist because he knew I really enjoyed it.
63. [H] was put back on AZT because the doctors said it would protect his brain.
64. A few days later he started to feel better but he felt that he needed to start telling his family about the prognosis he had been given.
65. The week before [H] died he was very forgetful and I could tell that something wasn't quite right. Looking back now I realise that he had dementia type symptoms but, at the time, I didn't realise that was what it was. By then his weight had plummeted and he looked like a completely different person.

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66. One night after [H] went upstairs after his tea when I heard a loud bang. [H] had collapsed on the bathroom floor. I managed to get him into bed and although he just about knew who I was, he was not fully with it.

67. I called the GP as I suspected [H] had had a stroke; he couldn't move his arm and when the ambulance arrived he was fitting. He was taken to [GRO-B] where I, his mother and siblings gathered around his bed. I was told that he had had a bleed on the brain. I visited him every day.

68. On the Saturday evening I left the hospital so I could get the children their dinner. I received a call at about 9.30 pm to day that [H] had passed away peacefully. I was glad that he went that way; without any more fits or treatment.

69. Calling [H]'s mother to tell her that he son had passed away was one of the most difficult things I have ever had to do.

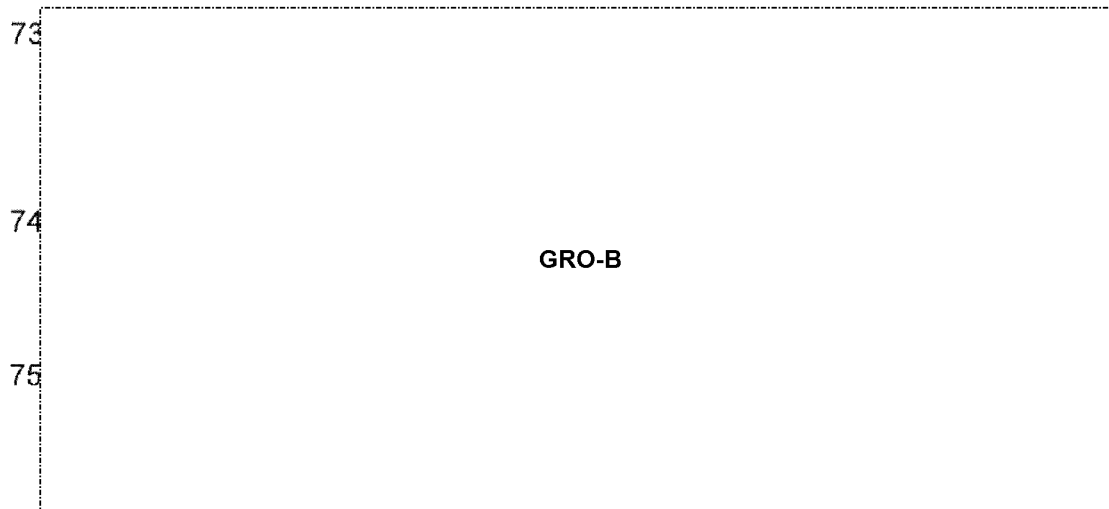
70. Years before [H] told me that he didn't want AIDS listed on his death certificate. I told the hospital this and they made sure it was not listed as the cause of death. When I later showed the death certificate to [GRO-B] she confirmed that although AIDS was not listed as the cause of death the causes that were listed allude to HIV/AIDS.

71. When I went to the funeral directors I was asked what [H] died from. I was honest and told them he had AIDS; they were grateful for my honesty and said they wouldn't embalm him because of his infection. [H] wanted a closed casket anyway because he didn't want us to see him after death.

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76. It has never been the right time to tell my family and I can't bear to cause them any more pain. My children went through such a lot when my husband was ill and subsequently died, so I just want to shield them from my illness for as long as possible.

77. This secret is always in the back of my mind and it definitely has an impact on my mental health.

78. I got quite bad lipodystrophy from the early HIV medication that I started in 1999. I was put on treatment because I started to suffer from skin infections on my face. At the time **GRO-B** told me that people were living longer than anyone thought they would and that I really should try treatment. The lipodystrophy still bothers me even though I have lived with it for years.

79. I also have peripheral neuropathy which is quite painful. I have tried various medications for this but I found the side effects affected my daily life too much.

80. My CD4 count is now normal. I currently work in a garden centre three days a week.

81. The thing I find hardest to deal with is the stigma of being HIV positive. On one occasion I bumped into someone I knew in the waiting room at the

hospital and I was thrown into a blind panic that somehow they would find out about my HIV status.

82. I don't have a lot of friends because of what has happened to me and the fact that I cannot share my story. I am not the same person that I was before all this happened.

83. I remarried in [GRO-B]. My second husband knew [H] and therefore knew about his infection. I told him straight away that I was also HIV positive, but he was completely fine with it and extremely supportive. I told him that I probably only had a few years but he said he was sure they would find better medication or a cure before then.

Section 6. Treatment/care/support

84. I remember one counsellor coming to the house was very young. I was reluctant to have counsellors in the house as I didn't want to bring the hospital home with us.

85. She was looking at our wedding photos and suggested that I should be tested for HIV.

86. She said 'even if you are positive, they'll find a cure long before you get ill'. We always thought that things would never be as bad as they were.

87. I didn't go to a dentist for years because I was terrified of them saying they wouldn't touch me. The first dentist I approached said they only treated haemophiliacs, not the wives of haemophiliacs. Fortunately, I managed to find a dentist who would treat me in the end.

88. The children were never offered any counselling following [H]'s death.

Section 7. Financial Assistance

89. [H] was a part of the 1991 litigation and was made to sign a waiver to say he would take no further action.

90. I received a one off payment from the Skipton Fund a few years ago. I was told by the hospital that I may be eligible for this.

91. I didn't have a lot of dealings with the MacFarlane Trust. [H] asked for money for double glazing on one occasion but I cannot recall the details.

92.

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93. I now receive monthly payments from the EIBSS.

Section 8. Other Issues

94. At first I don't really think that I believed all of the stories of cover-ups, nor did [H]. You just don't think that people are set out to hurt you. [H] would say "it's just one of those things". It wasn't until we saw a TV programme which looked into the American pharmaceutical companies that it all really dawned on us that there was a lot more to it.

95. There are incorrect entries in [H]'s medical records. For example, in 1991, there is reference to him suffering from Haemophilia A. This is incorrect and could have led to further errors in his treatment.

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96. I need the truth. Did our government know sooner than they said? Was it an issue of cost as it was too expensive to throw away? Why were we not made aware that the blood was being taken from prisoners.

97. I want to make sure that [H] is never forgotten. There is now shown to me marked **WITN1641007** pictures of [H] He was an individual; one of thousands affected by this Scandal and each individual should not be forgotten.

Anonymity

98. I want my statement to be anonymous.

99. I do not want to provide oral evidence to the Inquiry.

Statement of Truth

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

Signed.....

Dated

...government knew sooner than they said? Was it an issue of cost as it was too expensive to throw away? Why were we not made aware that the blood was being taken from prisoners.

97. I want to make sure that [REDACTED] H is never forgotten. There is now shown to me marked WITN1641007 a picture of [REDACTED] H. He was an individual; one of thousands affected by this Scandal and each individual should not be forgotten.

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Statement of Truth

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

Signed:

GRO-B

Dated

26/2/19.

MEDICAL SUMMARY

(This summary is not intended to be exhaustive but sets out key points in the records relevant to the Statement)

- 29.08.77 Injury to R shoulder whilst playing squash. 2 bottles factor IX conc
- 05.10.77 Jaundiced 2 ½ weeks after above
- 06.10.77 Letter to GP from PV. *We would of course like to follow Mr H very closely after this episode of jaundice. The incubation period of serum hepatitis is usually much longer than 2 weeks but obviously this is something that must be checked. We have in fact had no problems with jaundice following F IX injections.*"
- 04.02.85 HTLV-3 antibody ELISA +.
- 18.04.85 HTLV-3 antibody ELISA +. Given result 28.06.85.
- 03.07.85 Letter from Dr Wensley to GP. "...recently given the result of his anti-HTLV3 antibody test which is positive. This has been confirmed. I explained this could be transmitted by blood or sexual contact and also gave him some literature to read about this infection. We believe there is not more than a 1-2% chance of patients who are positive of going on to develop clinical AIDS..."
- 05.07.85 Direct ELISA for anti HTLV3 negative
- 14.05.86 HTVL III Ab Positive
- 08.10.87 Letter from Dr Wensley to GP. His finance was with him.....I believe it was reassuring to her to learn that the chance of a progression in his HIV infection are quite small.
- 04.10.88 Letter from Dr Wensley to GP. This patient with mild Haemophilia B has had a recent head cold and was complaining of night sweats. There were no abnormal findings on (*illegible*) but I note that he has a slightly reduced platelet count. His T4 helper lymphocyte cells are absolutely in the middle of the normal range and I have strongly reassured him that he does not have AIDS or its prodrom at this stage. I will recheck his platelet count on one or two occasions because an

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immune thrombocytopenia syndrome associated with early HIV infection must be ruled out.

- Aug 1989 Cryptosporidium
- 27.05.90 Letter from M Kumar to T Warnes (gastroenterologist) which mentions deterioration in liver function.
- 22.06.90 Letter from D Gleeson to Dr Kumar *"He says he has had several episodes of hepatitis in the past, some associated with jaundice in 1984 he had Hepatitis B and had probable non A non B hepatitis in 1989. He said he was jaundiced for three weeks."*
- 03.07.90 Letter to GP from A D Higham *"Reviewing his previous biochemistry he has had disordered transaminases since February 1988 and may well have had chronic hepatitis since his first episode of jaundice in 1983".*
- 30.07.90 Letter from D Longson to GP *"Fortunately he is not CMV positive."*
- 08.02.93 Hepatitis A virus Antibody – IgG (ELISA) Positive
- 06.10.93 Hepatitis B surface Antibody (ELISA) Positive
- 13.10.93 HIV P24 antigen (ELISA) Negative
- 24.10.95 Letter from Dr Denning to GP. [H]'s MR scan confirms that he has substantial cerebral atrophy, almost certainly related primarily to HIV. His wife, [GRO-B] came with him today and we discussed the implications of this in terms of additional home support as she works every morning in the flower shop....We are entering the terminal phases of his illness...