#### **ANONYMOUS**

Witness Name: GRO-B
Statement No.: WITN0407001
Exhibits: WITN0407002 - 4

Dated:

18/3/19

#### **INFECTED BLOOD INQUIRY**

WRITTEN STATEME	NT OF	GRO-B	]				
provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 23 November 2018.							
, GRO-B	, will s	ay as follows: -					
Section 1. Introducti	ion						

- 1. My name is GRO-B My date of birth is GRO-B 52 and my address is known to the Inquiry. I am and have been a widow since GRO-B 1983. I had to work exceedingly hard to earn a living to support my two children and myself. Being the only breadwinner I worked to improve my GRO-B career over the years. I am now retired.
- I intend to speak about my late husband, who contracted HIV as a result of being given contaminated blood products.
- In particular, I intend to discuss the nature of his illness, how the illness affected him, the treatment received and the impact it had on him and our lives together.
- 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. My brother

## Section 2. How Affected

My husband was the love of my life. We were engaged two weeks after meeting, and married after six months in 1974.

6.	He	was	а	businessman.	GRO-B
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- 7. I was working when we first got married, but I handed my notice in prior to the birth of our son and did part time work to help with household finances. We were a team; he would have the children whilst I did a couple of days of work.
- 8. Our daughter is disabled GRO-B I was bathing our son when she was a baby, and came downstairs to find her blue in the cot. I gave her mouth-to-mouth and rushed her to hospital. Due to oxygen starvation, she is physically disabled GRO-B

  GRO-B I fought for her to be in a normal school, where she worked hard to earn a place at university. She continues to live with me.
- 9. In 1980, just before we moved to the house where I currently reside, my husband became ill. He would get hot sweats at night and he also had something wrong with his eye. He went to the optician but after examination was told the condition was medical.
- He was diagnosed with acute myeloid leukaemia in December 1980.
- 11. We were living up the road at this point, but thankfully we had signed and sealed the paperwork for our new house before he was diagnosed. If not the mortgage company would not have approved us.
- 12. Originally it was said using tablets alone would control the leukaemia. A bone marrow

transplant later became an option, once his medical care was directed by the Hammersmith Hospital under Professor Goldman and Dr Annabelle Bourne.

- 13. My husband had an enlarged spleen, so this was taken out in September 1982 in preparation for the transplant.
- 14. In November, he was admitted to Hammersmith Hospital for a bone marrow transplant. His bone marrow was killed off and a donor became his transplant, because they were a good match. Their bone marrow would spread and replace his bone marrow.
- 15. For the transplant to be successful he had to undergo irradiation to kill his immune system. During this time he was in isolation at Hammersmith Hospital. It was a completely sterile environment, with barrier nursing, and all of his food had to be microwaved.
- 16. Whilst in isolation, he was regularly given platelets through a Hickman line. Even I would hook them up for him.
- 17. He did come home occasionally when allowed over the next few months but often not for long, as he was susceptible to infection. He caught measles when he returned home, so was admitted to Harrow on the Hill Hospital for interferon to be administered.
- 18. The interferon allowed him to come home for a while, but he never got over the measles. He was constantly in and out of hospital and I was confused why he kept getting infections.
- 19. In June 1983 he had mumps and was admitted to Hammersmith Hospital. This was the beginning of the end; as his body began to shut down. He had a collapsed lung and his organs had started to fail. He then contracted pneumonia and was on life support.
- 20. In GRO-B 1983 I went up to visit my husband. I came home to receive a phone call to say he had died.

- 21. Throughout, I was lead to believe he died from 'Graft Versus Host disease', as he did not have leukaemia when he died as the transplant had been successful.
- 22. In July 1992 I received a letter from Professor Goldman at the Hammersmith Hospital, asking me to contact him. This letter is exhibited as WITN0407002 I met with him at the hospital where he explained my husband had been given blood infected with HIV. During the time since his death, I had been soldiering on in ignorance. It seems that they had gone back to look at his blood slides. I cannot recall the other information told.
- 23. He was given platelets and possibly other blood products in the course of treatment, in an attempt to boost his immunity. Through these products he was infected with HIV.
- 24. We were originally told that if he survived 6 months post-transplant it would have been successful. He did survive longer, but it was not meant to be, due to the HIV infection.
- 25. I was asked to have a HIV test. I hoped I would be clear as I had no symptoms in the preceding nine years but felt great anxiety whilst being tested and awaiting for the results.
- 26. Professor Goldman provided me with a medical report published in March 1987, and told me that one of the case studies was my husband. Exhibit WITN0407003. When he died HIV was very much in its infancy.
- 27. The report details how the blood products were infected as the donations were from a highrisk group.
- 28. Whilst we were aware of the illnesses, we were never told at the time that he was infected with HIV. Looking back it was clear he had HIV, as his immune system was shutting down.

- 29. I recall seeing articles on HIV and thought the pictures looked like my husband in his last months, but I had no evidence until I was contacted.
- It was nice to finally know it was out of my husband's control and that it was someone else's fault.
- 31. To my knowledge he did not receive blood transfusions or blood products before the leukaemia treatment. He was ill as a child with a whooping cough, but apart from that was fit and healthy.

### Section 3. Other Infections

32. I do not know whether my husband received any infections other than HIV, as a result of being given infected blood products.

### Section 4. Consent

- 33. My husband was treated with a bone marrow transplant to eradicate his body of leukaemia. We knew the risks associated with the procedure, and with the transplant there is an acceptance that you will receive a transfusion. However we knew nothing about the blood products being infected.
- 34. Whilst he was in isolation at Hammersmith Hospital, someone stated that the blood products were irradiated. I thought it was part and parcel of the sterile environment, and to ensure infections were kept to a minimum but it did not eradicate the HIV.
- 35. I am not aware of him being tested for the purposes of research.

# Section 5. Impact

36. My husband suffered unnecessarily as a result of being given infected blood products, although we did not know at the time. It was nothing he had done, but we have had to live with the consequences since.

- 37. He was very ill and the quality of his life was not very good. He had ulcers, blisters on his skin and he lost his hair. He would wear a hat because of his hair loss. He was fragile and did not look like the same man as before.
- 38. He was unable to pick up the children and cuddle them, attention which my young son wanted.
- 39. He suffered with the major childhood infections including chicken pox and measles, these impacted on his body incredibly. One of his lungs collapsed, which is a classic measles symptom.
- 40. I was told that had he lived, he would have permanent lung damage because of the measles. Therefore he could not have lived the life he wanted. Knowing this has often been a way of coping with his death.
- 41. He became very low and down. The hospital staff kept saying to me that he had to want to help himself. In hindsight he could not because he was so poorly at the time. They would often ask me to encourage him to be more positive, I felt awful after, when I realised he could not help it.
- 42. Every time he went downhill, I was only told that his immunity was low. They did not know what HIV was at the time, at least it was never mentioned.
- 43. I think at the end he knew he was dying. When I last saw him, I felt that he was waiting for me to go home before he died.
- 44. My husband's infection with HIV caused his death as his body could not fight any infections. I am sure he would have survived, as the leukaemia had been eradicated, had he not been given infected blood products.
- 45. When he died his skin was very brown and the undertakers did not even want me to see him.

- 46. Not only was he unable to work, but he also had no social life during this time. Friends and family would go in to visit him at hospital, yet I would manage this on a rota. His parents would try to interfere with the rota, but my husband specifically wanted me to manage it.
- 47. My husband was unaware he had HIV so did not face any difficulty receiving dental care.
- 48. I was notified of my husband's infection 9 years after his death. This is frightening in hindsight, as I could have also been infected. Thankfully I was clear; otherwise it would have caused further implications for my family.
- 49. When he was alive we did not face stigma, as we did not know he was infected with HIV. When Professor Goldman told me, I only informed my Mum, my brother and his wife. I decided to tell the children when they became adults.
- 50. When AIDS first hit the headlines, people were even suggesting it could be contracted through saliva. The last thing I wanted to do was open up about my husband.
- 51. I had to lie about why I was taking time off work to visit the Hammersmith Hospital for a HIV test and follow up appointments,. This was due to the stigma around HIV/AIDS and the lack of understanding in society at that time.
- 52. I have since told friends, but people's understanding of HIV and AIDS has moved on. There is not as much prejudice, and from my experience people are sympathetic and appalled.
- 53. Losing my husband at such a young age had a big impact on my children's lives and mine.
- 54. The biggest impact was my children not having a father. They were only 5 and 3 at the time of his death.

**ANONYMOUS** 

- 55. My own father also died GRO-B before my husband, whilst they were young, so there was an absence of a father figure. Apart from my brother, women brought them up. My brother was a support but he was at university initially.
- 56. The children have very few memories of their father, as they were very young when he died. This had a great impact on them growing up for a whole host of reasons.
- 57. I focused on bringing up our children in the way that we had planned, and keeping a roof over our heads. I worked hard to give them stability. Out of work, my life revolved around the children's extra-curricular activities in music and sport.
- 58. In the immediate 6 months following his father's death, my son did not learn anything at school. It was a big gap for his age. I was not aware, as he would go off to school every day. At that age children do not talk about their feelings, so no counselling was offered. He did starting reading etc. after the 6 months, but who knows what effect this had on his learning and mental wellbeing over the years.
- 59. In the September I went back to part time work, and in 1984 I went full time. This was hard as my children were only 6 and 4, but my daughter was allowed to go to school slightly earlier because of her disability. It was a financial necessity for me to have a proper job and thankfully the employment was local.
- 60. I would not have been so career driven if my husband was alive, as my income would have just been an extra boost. Due to his death I had to become the breadwinner, so I pursed further qualifications and a degree to progress up my professions ladder. I overcame many obstacles, and ended up in a senior management position.
- 61. The hardest year financially was when my

- 62. Due to the fact that I had to go back to work, and being in management, my husband's death also had a profound effect on my Mum. My Dad died in GRO-B 1983, so she helped with childcare. She would let herself in the house with her own key and be there for the children in my absence. I could have not coped without this support.
- 63. My husband was the driving force of the family business, so it went downhill to a degree after his death. His death put a strain on my relationship with my in-laws.
- 64. I tried to keep the relationship going with his parents after his death, but they would not settle his side of the estate. GRO-D

**GRO-D** 

GRO-D This placed greater financial burden on me for years, until his estate was finally settled.

- 65. My children receive birthday and Christmas cards but that is the only communication that occurs.
- 66. The only reason I could stay in the house was because it was covered by an insurance policy. Financially it was difficult.

## Section 6. Treatment/Care/Support

67. I never received counselling or support, other than from family and friends who helped with childcare so I could work fulltime. I have never felt the need to ask for counselling. It is very easy to say 'why me', but I am stronger than that.

# Section 7. Financial Assistance

- 68. My husband received no financial assistance.
- 69. It was Professor John Goldman at

Hammersmith Hospital, who explained I was entitled to compensation through the Department of Health. The sum of money had to be claimed within 10 years, but 9 years had already elapsed since my husband's death.

- 70. Professor Goldman wanted me to go out to the press as an example, and to encourage others to claim compensation. I discussed this with my mum, but she told me to think very carefully. I was worried about the children at school and my job in the teaching profession, so decided not to go to the press as there was still a stigma concerning HIV.
- 71. We received £80,500 from the Department of Health with a scheme at the time, for those infected with HIV through blood or tissue transfer. It was a set amount that someone had arrived at.
- 72. The Department of Health had a number of recommended solicitors to draw up the paperwork for the compensation. I chose the services of Mr Michael Jolly of J. Keith Park and Co. They were paid by the Department of Health.
- 73. Of the £80,500 the children received £30,000 each and I received the remainder. The sum of money left to me was not enough to bring up my children, especially having a disabled child. I could not utilise the money in their names, so I just had to get on with it.
- 74. I had to sign a deed to receive the money, which included a waiver. I had to sign an undertaking that I would not at any time bring any proceedings against the Department of Health. Exhibit WITN0407004.
- 75. The court retained the money allocated to my children until they were 18. I then had to sign a form to release the money when the children became of age, so that it could be reinvested. There was no issue accessing the money when the time came.

76. I feel that the payment was an insult, it could not ANONYMOUS compensate for the lack of a husband and father for all these years.

77. The Eileen Trust offered me support, but I did not follow this up.

### Section 8. Other Issues

78. All the individuals that received a bone marrow transplant, at the Hammersmith Hospital, around the same time as my husband, died.

### Statement of Truth

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

