

ANONYMOUS

Witness Name: **GRO-B**

Statement No: WITN1290001

Exhibits: 0

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** and I live at **GRO-B**
GRO-B
2. My husband, **GRO-B: H**, died **GRO-B**
GRO-B after being infected with HIV and Hepatitis C from contaminated blood products **GRO-B: H** and I divorced in **GRO-B**
3. The cause of death on **GRO-B: H** death certificate was recorded as "metastatic carcinoma of the liver."
4. This witness statement has been prepared without the benefit of access to my late husband's 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 Affected

5. [GRO-B: H] was a haemophiliac. He suffered from severe Haemophilia A. As a result he regularly injected himself with Factor VIII concentrate to relieve the painful effects of knocks and bruising caused by internal bleeding into his joints. Initially he was treated with a frozen solution (known as cryoprecipitate) but eventually his treatment was provided as a powder that had to be diluted and then injected intravenously (Factor VIII concentrate).
6. Initially [GRO-B: H] was treated at [GRO-B] and was under the care of [GRO-B] a haematologist. His care subsequently transferred to [GRO-B] [GRO-B] and then [GRO-B].
7. I believe he was treated with contaminated blood products from around 1975 to around 1985/6.
8. Neither [GRO-B: H] nor I were ever given any information about the possible risks associated with treatment with blood products.
9. [GRO-B: H] Hepatitis C infection first presented itself when he was diagnosed with jaundice in 1975. They did not call it Hepatitis C then; we were just told [GRO-B: H] had jaundice.
10. I believe [GRO-B: H] was first tested for HIV in 1985. We do not know how long the virus had been in his system.
11. Initially [GRO-B: H] was told that he had tested positive for the antibodies to HIV and that this was a good sign as it proved that, although the virus was present, he had been successful in repelling the disease. This of course turned out to be false.
12. In the early days, the information we received centred around personal hygiene and the possibility of transmission via blood contamination. We were made aware of the issue around contaminated needles and that we should be vigilant if [GRO-B: H] had any external bleeding. We were strongly advised to put aside any thoughts of having a family as the effects of HIV on mothers and/or

ANONYMOUS

babies were not understood at that time. We did not feel that the information we were given was adequate in any sense. We were not given any indication as to [GRO-B: H] prognosis or the potential impact on his life expectancy. We were also not given any advice about the mental stress and stigma that we were likely to endure because of his diagnosis.

13. I believe that information could and should have been provided to us earlier through official sources. It was widely known in the haemophilia community that blood products were being sourced from America but we were reassured that there was no danger to people in the UK despite the fact that donors were not screened and blood was purchased from anyone who was willing to sell it for profit. Kenneth Clark spoke in Parliament and gave reassurance that there was no evidence that blood products from America were not safe to use. We also know that blood products were available in the UK from Cambridge but that they were not being made widely available as they were deemed too expensive.

14. The results of tests on infected blood products were not comprehensive and there appeared to be a lack of concern, even then, for the damage that could occur and the possible devastating effects on individuals and their families.

15. The information we were provided with was very basic. We were informed about the hygiene issues and about the safe disposal of needles and used Factor VIII. Warnings were given about the sharing of needles and about avoiding touching infected blood.

Section 3. Other Infections

16. I do not believe [GRO-B: H] was exposed to any other infections other than HIV and Hepatitis C.

Section 4. Consent

17. I believe [GRO-B: H] was tested without his knowledge and without his consent. He was not given any information about testing.

18. I believe it is possible that [GRO-B: H] was tested for the purposes of research but I have no proof.

Section 5. Impact of the Infection

19. The mental and physical effects of having HIV and Hepatitis C were catastrophic. [GRO-B: H] was a successful businessman who worked as a financial advisor. He was constantly worried that his clients would withdraw their business if his health status was revealed. He refused to tell anyone about his infections and he swore me to secrecy as well. [GRO-B: H] demeanour changed after his diagnosis. He was bitter and resentful. He formed relationships with business colleagues because it was necessary but our social life diminished.

20. The fact that I was unable to speak to anyone about [GRO-B: H] infection put a tremendous strain on me.

21. [GRO-B: H] also suffered from digestive problems and rosacea.

22. [GRO-B: H] HIV was treated with anti retroviral drugs. His Hepatitis C was treated with Interferon.

23. [GRO-B: H] was then diagnosed with liver cancer which resulted in his death in 2010.

24. Over time [GRO-B: H] became increasingly secretive in his dealings with both his family and his clients. His illness had far reaching effects on insurance, life policies, holidays, financial planning, mortgages etc. He was constantly on edge with friends and worried that his HIV status would be discovered and that people would shun him.

25. The impact on our family life was huge. As I was asked to keep his HIV status a secret I had to carry the burden alone which became unbearable. He never initiated conversations about his illness at home and the stress

ANONYMOUS

eventually resulted in me having a nervous breakdown in 1996. I spent 5 weeks in a psychiatric clinic where I was also finally tested for HIV and I was prescribed strong antidepressants including Doxypin and Lithium which I continued to take for years.

26. When I was finally able to return to work it was on a job share basis so my salary was affected. I had to inform my boss [GRO-B] about [GRO-B: H] infected status because of my job role dealing with children. I retired early at age 50; the stress of concealing [GRO-B: H] illness for 10 years took its toll and I was no longer able to function effectively. This had a huge impact on my pension rights and future financial security.

27. The strain of living with HIV destroyed our marriage and we eventually divorced in [GRO-B]. The regret of listening to flimsy advice not to have children has remained with me and haunts me every day as I see my friends busy with their children and grandchildren. I feel enormous sadness that I wasn't given the opportunity to have my own family.

28. The stigma of living with HIV was huge. As HIV/AIDS was then associated with the gay community anyone who was perceived to have the infection was automatically assumed to be homosexual. This is not the case now but in the 1970s/1980s when homosexuality was not accepted it was imperative that [GRO-B: H] infection was kept secret to prevent undue impact on his business dealings and social life. There was also a public perception that HIV/AIDS was a problem associated with drug addicts which again was a slur on [GRO-B: H] personal integrity and lifestyle. The mental strain was an enormous burden that we both lived with on a day to day basis.

29. Neither of us told our parents about [GRO-B: H] diagnosis so we had no support from our families. My husband's [GRO-B] also a haemophiliac, was also infected as a result of contaminated blood products and whilst their cases were similar they took different paths in dealing with their disease.

Section 6. Treatment/Care/Support

30. The treatment that [GRO-B: H] underwent took its toll on his health as well. He took a cocktail of anti retroviral drugs. He took Interferon and other unproven remedies. The effects of those treatments were unknown when [GRO-B: H] was prescribed them. It was a case of trying anything to reverse his infections. Although the doctors at [GRO-B] offered some treatments [GRO-B: H] gradually lost confidence in their ability to provide support and transferred his care to [GRO-B: H] [GRO-B] where he felt they had more specialist knowledge.
31. All the treatments were experimental. I am not aware of any other treatment or support which could have been offered apart from counselling which was never forthcoming.
32. Counselling was never made available to either of us. It wasn't until 10 years after [GRO-B: H] diagnosis when I had a breakdown that I was given counselling.
33. [GRO-B: H] medication had to be strictly administered. He frequently fell ill during treatment and struggled to maintain and grow his business. We had financial worries as a result and as these increased his physical condition deteriorated.
34. [GRO-B: H] was always referred to [GRO-B] for any dental treatment because of his infected status. He resented the fact that he needed specialist treatment and felt that he was treated as a leper which impacted on his self esteem.

Section 7. Financial Assistance

35. As set out above, my husband became increasingly secretive about our financial affairs following his diagnosis. He did not discuss any requests for financial assistance with me so I am unable to give much information in relation to this issue.

ANONYMOUS

36. I am aware that GRO-B: H received some financial assistance but I do not know which Trust/Fund he claimed from or what the process was.

37. I have never received any direct financial assistance.

Section 8. Other Issues

38. None.

Anonymity

39. I would like my witness statement to be anonymous.

40. I do not want to give oral evidence to the Inquiry.

Statement of Truth

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

Signed. GRO-B

Dated 18 | 1 | 19