

ANONYMOUS

Witness Name **GRO-B**

Statement No: WITN1228001

Exhibits: 0

Dated: June 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF **GRO-B**

GRO-B will say as follows:-

Section 1. Introduction

1. My name is **GRO-B** and I live at **GRO-B**
GRO-B I was born on **GRO-B** I have been living in **GRO-B** for **GRO-B** years
and I live with my husband **GRO-B** and my two sons, **GRO-B** and **GRO-B**
GRO-B
2. I am a **GRO-B** working in the **GRO-B** I have a **GRO-B** brother
called **GRO-B** who lives in **GRO-B** and my mother, **GRO-B** lives
alone in **GRO-B** and has submitted a witness statement for the Public Inquiry.
3. I make this statement as an affected daughter in relation to my late father,
GRO-B: F who was infected with HIV and Hepatitis C via his use
of contaminated Factor VIII concentrates.
4. My father was born on **GRO-B** and passed away aged only 48
on **GRO-B**
5. This devastated me because I was extremely close to my father.

6. This witness statement has been prepared without the benefit of access to my father's medical records.

Section 2. How Affected

7. In the 1970s my father was diagnosed with mild Haemophilia A with a clotting factor of 4.2%. He was seen by Professor Stewart at the Middlesex Hospital in or around 1976.
8. In 1981 or 1982 my father, under the care of Mr Winstock, underwent several tooth extractions at the Middlesex Hospital. People with Haemophilia bleed a lot through the mouth during a tooth extraction and the hospital therefore prepares them with Factor VIII concentrates. My father knew that he was going to be given Factor VIII concentrates prior to the procedures.
9. He was advised that all the products were being screened and although general heat treatment had not yet commenced, my father was advised that the risk of contracting any type of infection was very low. I am of the view that my father was not given sufficient information or advice in relation to the risk of receiving Factor VIII concentrates.
10. My father was infected with both HIV and Hepatitis C following these tooth extraction procedures.
11. My father's consultant confirmed that he had been infected with HIV and Non-A Non-B Hepatitis via the use of these contaminated batches of Factor VIII. Unfortunately, I do not have a record of the batch numbers.
12. My father's death certificate records his causes of death as: 1a) Liver failure, b) Cirrhosis, c) Non-A Non-B Hepatitis, 2) Haemophilia A.
13. During the 1980s my father had been working in GRO-B and when he returned, everybody was talking about AIDS, which by this time was all over

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the media. In July 1985 my father also noticed a series of hard nodules on the back of his head. He was worried that he might have been one of those who had been infected with HIV so he took himself to the Middlesex Hospital to be tested so as to reassure himself.

14. My mother has a vivid memory of when the hospital telephoned with the results; it was at 5:25 pm on a Friday and they asked my father to contact them. My mother therefore telephoned my father, who was at his office, and he contacted the hospital immediately. However, the department had closed for the weekend and it was cruel that my poor father was left waiting all weekend.
15. My mother and father went into the hospital on the Monday morning to see Dr [GRO-D]. My father went into the consultation room alone whilst my mother waited outside. My father emerged looking grey and pale and my mother knew that he had received very bad news. Dr [GRO-D] advised my father that he had been infected with HIV.
16. Due too the amount of media coverage on HIV and AIDS, my mother and father had some idea of what this infection. However, they were not given sufficient information or advice by Dr [GRO-D] to allow them to either understand or manage the infection. During the appointment, Dr [GRO-D] told my father that they could continue to live a normal life but he was told not to share the diagnosis with anyone because it would affect his social life and relationships. Dr [GRO-D] did tell my father not to share his toothbrush but apart from that my mother and father continued living their life, but of course they now harboured a terrible secret.
17. My mother was later tested for the virus but fortunately she was HIV negative.
18. I think that it was unacceptable that my parents received a telephone call so late in the day regarding the horrific and life changing news. This meant that they had to wait all weekend to have the news confirmed to them.

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19. I don't have any information about how or when my father was told about his Hepatitis C infection (Non-A Non-B Hepatitis as it was then known).

Section 3. Other Infections

20. I do not think that my father was exposed to any other infections.

Section 4. Consent

21. I do not think that my father was tested or treated without his knowledge or consent.

22. My father consented to being placed on an AZT research trial. However, it is questionable as to whether he was provided with sufficient information in order to understand exactly what he was consenting to, because the AZT damaged his lymph nodes.

Section 5. Impact

23. My father wanted his condition to be kept secret and therefore only he and my mother were aware of his HIV infection. He did not want his family or friends to see him as someone who was ill or condemned.

24. The mental effects on him must have been devastating. He was still so young. He was often sad and angry. Furthermore, the stigma around AIDS in the 1980s was even stronger than it is now so revealing his condition was quite impossible, something which I perfectly understand and respect. Had he confided in people, he would probably have been rendered an outcast; possibly even rejected by some family members and friends and work wise, I have no doubt that it would have been a disaster.

25. The physical effects were wide ranging and included lethargy, exhaustion, progressive weight and muscle loss over the years and pronounced weight loss in the six or so months prior to his passing.

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26. As a result of his infections my father was often ill and went to the doctors frequently and was a regular inpatient at hospital.
27. He suffered from a number of health ailments to include the existence of hard nodules on the back of his head, shingles, candida in his oesophagus, dry coughs, difficulty speaking, shortness of breath, enlarged lymph nodules, enlarged spleen and bacterial pneumonia.
28. My father suffered cirrhosis of the liver which caused liver failure. This was caused by his Hepatitis C (Non-A Non-B Hepatitis as it was then known) infection.
29. In some ways, my father managed to maintain his way of life for some time because he never revealed the existence of his infections to anyone. He had a good social life with many friends. I cannot offer any insight into how my mother and father dealt with his infections privately because they kept this information to themselves. GRO-B
30. However, as a family, I could sense that something was not right because there was a lot of secrecy and discussions taking place behind closed doors. I thought that my parent's marriage was in trouble and I also recall my mother telling me off when I drank from my father's glass on an occasion and also when I assisted him following a nose bleed. The general atmosphere was a bit heavy; it was not a very happy home.
31. I also remember financial difficulties as my father was a GRO-B
GRO-B and following his infections, he struggled to maintain this level of work and therefore the family finances took a nosedive. My paternal grandparents paid for our schooling fees for many years. My brother and I attended the GRO-B
32. My teenage years were, unfortunately, an unhappy time. I had a slight eating disorder for a short period of time when I was aged about 14, I was very skinny but I did not intentionally want to eat less. My parents were very concerned and talked to me about Anorexia which I had never heard of

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before. The strange thing is that looking back, I had this eating disorder over exactly the same period of time that my father was tested and discovered he had been infected with HIV (1985).

33. I also remember never having birthday parties at home during this period of time, nor wanting to invite friends over as it was not a very happy home. I tried to get out of the house as much as I could by babysitting or sleeping over at friends' houses.

34. **GRO-B**
GRO-B I am reminded every day that haemophilia, even the mild version, can kill.

35. Not a day goes by when I don't think about my father and how unfair it was that he lived such a short life. I know how much his friends miss him and how sad it was that he left my mother a young widow at the age of only 46 who has never remarried.

36. I think about my father's talent and what he could have accomplished. I imagine him growing old and I miss our great relationship. I think about all the things he's missed out on like his children's graduation, his children turning 18
GRO-B his absence at my wedding, never knowing what
GRO-B
grandchildren.

37. However, thankfully I do have some very good and soothing memories too.

38. I am going to be 48 next month, the age that my father was when he died and I can't stop thinking that this is when life ends for some people, maybe even for me. Sometimes, I imagine myself being a widow soon and trying to figure out how I could cope with that. When my son **GRO-B** in **GRO-B** this year, all I could think about was that my father died **GRO-B** before my **GRO-B** birthday and how lucky I was to be alive to see my **GRO-B**. My mother was a widow at age 46 and never wanted to remarry. She was married for 25 years and has been a widow for 30 years now.

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39. This is definitely not the life I would want for myself. I hardly ever talk about my father with my mother; it's too painful and I still feel some slight resentment for having been kept in the dark which meant that I didn't have enough time to say goodbye to my father.
40. My father's condition was kept secret in order to protect my family from suffering the stigma associated with HIV. In the public eye, HIV was the infection homosexuals and drugs users got. In fact, the worst thing about this infection was that many people saw it as a type of retribution. People were misinformed about HIV and made jokes about AIDS and AIDS sufferers. I remember that at the time we talked a lot about AIDS at home and at school too. So as a teenager at that time, having sex meant potentially contracting AIDS and dying. There was a lot of paranoia.
41. Due to the secrecy that our family had maintained over the years, when my father passed away, I told my friends that he had died of cancer. I continued with this version of events for about 20 years as I couldn't deal with explaining what had really happened and justifying the fact that he had AIDS.
42. Our family, including my brother and me, only learned that my father was in fact dying and had AIDS about a week before he passed away. I was not that surprised, contrary to my brother who was in total shock and disbelief. About two years prior to this I had discovered that something was not right whilst looking for something to wear in my parents' closet. I had found some pills hidden away in a sock draw and on the pill bottle there was a laboratory /company name which I recognised and a newspaper clipping next to it. The article talked about that company which was testing a drug for those with HIV and we had also talked about this in a biology class. I was in a panic and had asked my mother that evening about these pills but her response was that my father was a haemophiliac who was being treated only as a preventative measure but that he was not in fact infected. I chose to believe my mother, but was not totally convinced.
43. Other family members were shocked to discover that my father had AIDS and some were even angry about having been kept in the dark. There are quite a

few haemophiliacs in the family, but to my knowledge none had been infected with HIV. I later learned that some had Hepatitis C. I think that

GRO-B

GRO-B

44. My father passed away when I was aged GRO-B which was only two months before my final school exams. I was so determined to leave the house and to start my new life that I carried on as best I could and passed all of my exams. I did quite well but I could, of course, have done better had the situation been different. That same year in September I went to live in GRO-B as an GRO-B before moving to GRO-B. I did not do brilliantly in my studies because I needed to escape and forget what had happened which I did by partying a lot and at times, I took drugs. This lasted for a period of about four years and then one day I woke up and decided to move on with my life.

Section 6. Treatment/care/support

45. I do not know what other alternative treatment my father could have had. At that time, there seemed to be no treatment. I believe that he was offered a short course of Interferon in the late 1980s but that this was both expensive and unsuccessful.
46. The nurses were very nice to my father and mother; he was treated well in this regard and they tried to make him comfortable during his inpatient stays.
47. Our family did not receive any psychological support. My mother told me that at that time, the attitude was to *'get on with it as best as you can'*. I was never offered any counselling or psychological support and I think that I would have benefitted from this and that it should have been offered due to three main factors: (a) my father was very young when he passed away (b) he was HIV positive and developed AIDS in the 1980s when the stigma was at its highest (c) he already had a medical condition that was not easy to deal with every day and on top of that, some high placed people in Government, Medical

Professionals and the Pharmaceutical World decided to play Russian Roulette with patients who, in their minds, were ill anyway so taking a risk on them was a decision they took lightly.

Section 7. Financial Assistance

48. The MacFarlane Trust provided my mother and father with £2,000 in approximately 1988. They also paid for my father's funeral.

49. In 2011, my mother received a payment of £70,000 from The Skipton Fund.

50. My mother was a party to the 1991 HIV Litigation and my mother was forced to sign a waiver in this regard. She received £44,000 and £16,000 for GRO-B brother and me. This helped my mother but it did not represent the earnings of my father. My mother also never saw my father's medical records again following this litigation.

Section 8. Other Issues

51. My father did not die of natural causes, nor in an accident; he was poisoned and made to suffer by a system that chose to look the other way because of the financial aspects. This makes me very sad and angry.

52. I hope that one day the whole truth will be told and that the people involved in this scandal are held to account for their cruelly inconsiderate choices and criminal actions.

Anonymity

53. I would like to be anonymous and I do not wish 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. 01/07/2019