

ANONYMOUS

Witness Name: **GRO-B**

Statement No.: WITN3124001

Exhibits: WITN3124002 – WITN3124008

Dated: February 2020 *27-2-20*

Infected Blood Inquiry

WRITTEN STATEMENT OF **GRO-B**

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

Section 1: Introduction

1. My date of birth is **GRO-B** 1938. My address is **GRO-B**
GRO-B I am married to **GRO-B** who
has also provided a statement to the Inquiry **GRO-B**, and together
we had two sons named **GRO-B:S** and **GRO-B**
2. I am providing this statement in relation to our son **S** who died at the
age of 23 years as a result of contaminated blood products that he was
given as treatment for haemophilia.

Section 2: How Affected

3. My eldest son, **S** was born on **GRO-B** 1973. He was
diagnosed with haemophilia when he was three months old. My wife's
brother, **GRO-B:B** had severe haemophilia A, so when **S** began
getting bruises, my wife recognised the signs. At that time, we were not
aware that haemophilia was a hereditary condition.

ANONYMOUS

4. Initially [S] was treated for his haemophilia at King's College Hospital in London ("King's") and was under the care of Dr [GRO-D]. We were told to treat King's like our normal doctor, so we would attend there instead of taking [S] to the GP if he was unwell.
5. When he was young he was treated with Cryoprecipitate; which he did not like because it was given intravenously. He then began being treated with Factor VIII. The records that I have recovered from the National Haemophilia Database (the "NHD records") indicate that he began treatment with Factor VIII from at least 1977; the NHD records do not go back any further than this (WITN3124002).
6. When he first began treatment with Factor VIII, he was still being treated in hospital. However, I was then taught to treat [S] at home with Factor VIII. I was given training and advice to administer the treatment. It was nerve wracking doing it at first but I got the hang of it. He could be treated more quickly when he had bleed; it was instant. It was awful if he had a bleed as a result of biting his tongue. I remember being at work and being paged to come home and treat him. I also injected my brother-in-law with his Factor VIII on occasion.
7. We were never told of any risks associated with Factor VIII; it was wonderful for years and there was no talk of anything "dodgy" associated with it at that time. We did not know that blood was being taken from prisoners to create the products.
8. The first time we heard of any potential problems was when there was a story on the news in about 1983 that linked HIV with blood products given to haemophiliacs. I remember my wife calling me to come and watch the story. We were in shock at what was being reported.
9. We were told that [S] had HIV when he was 12 years old. By this time, we knew that my wife's brother had also been diagnosed with HIV. Dr

ANONYMOUS

[GRO-D] called and asked me to come down to the hospital. When I was there he said so casually "[S] got it you know"; he was referring to HIV.

10. I do not recall being told about the risks of transmission or being told to take any precautions when injecting [S] with Factor VIII.
11. The NHD records state that the date he first tested positive for HIV was 15 September 1986, but this must be incorrect as [S] was diagnosed before we moved to [GRO-B] earlier in 1986. A document titled "*UK HDOC Working Party AIDS Surveillance and HIV Clinical Death Report Form*" which was completed by Dr [GRO-B] following [S] death indicates that [S] first tested positive in October 1984 (WITN3124003).
12. When we moved to [GRO-B] [S] was treated at [GRO-B] Hospital and was under the care of Dr [GRO-B]

Section 3: Other infections

13. As discussed further below, in 2011 we were informed that [S] had contracted Hepatitis C and we were entitled to apply to the Skipton Fund.
14. The NHD records indicate that he tested positive for Hepatitis C in 1993 as part of a "look back" exercise (WITN34124004), however this was never mentioned when he was alive.
15. We received a letter enclosing his liver function test results date 20 May 2011 (WITN3124005) in connection with our application to the Skipton Fund, which also enclosed evidence that he was not infected with Hepatitis B.

Section 4: Consent

16. I was not made aware that [S] was being tested for HIV or Hepatitis C. The first time I was aware that [S] was tested was when Dr [GRO-D] told me the result in the casual manner described above.
17. I cannot recall if [S] was under surveillance once he had been diagnosed with HIV, as suggested in the medical records referred to in paragraph 11.

Section 5: Impact

18. We did not initially tell [S] about his diagnosis with HIV. He was very intelligent and was offered a choice of three scholarships to three public schools; the scholarships were considerable. He started secondary school at a public school in [GRO-B]. He came out of secondary school one day and said that someone asked if he had HIV, because he had haemophilia. After that he did not want to go back to school and was home schooled for just over a year. This was at the same time as when [S] learned about his HIV infection.
19. We decided to move to [GRO-B] in 1986 as there was a good grammar school in the area, [GRO-B]. I took [S] to see the head master and he sat an exam to get in. He was a real bright spark and would do just enough to get by. He was around 13 when he started attending [GRO-B] and he was happy there. The school knew that he had both haemophilia and HIV. We had to tell them as he could not play contact sports. He had good spells and bad spells with his bleeds and started treating himself later in his teens.
20. I recall [S] was put on AZT soon after he was diagnosed, which often left him feeling below par. However, a document within [S] Records titled "*Surveillance of Paediatric HIV Infection & AIDS Follow-up*" indicates that he was first treated with a drug called Pentamidine (WITN3124006).

ANONYMOUS

A subsequent form titled Form AIDS/3 Follow-up, UK Haemophilia Centre Directors Survey of Patients with AIDS or AIDS related illness dated 3 October 1992, indicates that he began treatment with AZT on 18 December 1991.

21. He was a sociable teenager and loved a drink and being out with his pals. At the time of his 18th birthday he was managing okay. None of his friends knew he had HIV and my wife and I did not tell our friends either. We told our parents and they could not believe it, especially [GRO-B] parents due to her brother also having HIV.
22. One of [S] friends, [GRO-B] may have told people in the village that [S] had HIV, but he often told stories so I am not sure anyone believed him. However, [GRO-B] always looked out for [S]
23. He went to [GRO-B] College and then attended [GRO-B] College where he obtained a HND in Business Studies. After he finished college he began working in [GRO-B] He had to take some time off for bleeds but they were not informed that he had HIV. If there had been any danger to anyone we would have told them but there was not.
24. After he had been working at [GRO-B] for around six months, his health began to deteriorate. He was given sleeping tablets and treatment for candida in his mouth. He was in and out of hospital and an ambulance had to come for him on one occasion when he had trouble breathing. The NHD records indicate that he was diagnosed with AIDS on 15 July 1996.
25. He died in the Intensive Care Unit in [GRO-B] Hospital on [GRO-B] [GRO-B] 1996. He was 23 years old. He was having trouble breathing and was on life support. I was told that if they brought him back to life he would be dead within six months. I had a discussion with Dr [GRO-B] and we decided to turn off his life support. This is still something I find extremely difficult to talk about. Dr [GRO-B] said to me "*I became a patient to cure people not to kill*".

26. Dr **GRO-B** said he would try and keep the cause of death to haemophilia as we live in a small village and if it got out that **S** had HIV it would have been very difficult for us. We told people he died of pneumonia. A woman at his funeral said that it was unusual to die of pneumonia but I just said that there were complications.
27. The undertaker knew he had HIV. The bishop conducting the funeral kept asking what he died of. We said he died of pneumonia but he kept pushing it and asking if there was anything else; we did not tell him anything further.
28. When **S** died, **GRO-B** was at university studying French and German. He was shattered by the loss of **S**. He was due to spend **GRO-B** **GRO-B** as part of his studies. He wanted to defer this for a year but was told he would have to start at the beginning of the course again, so he carried on with his plans.
29. Whilst my wife deals with her grief by staying busy and joining various clubs and activities, I prefer to be on my own. The loss of my young son is something I will struggle to deal with all my life.

Section 6: Treatment/Care/Support

30. I was offered counselling following **S** diagnosis with HIV. I attended one session but I did not find this helpful; I felt worse after it and decided not to go back.

Section 7: Financial Assistance

- S**
31. **S** was entitled to a Disability Living Allowance but instead of taking payment he opted to have a car. We had to tell people it was a gift from my mother, as we did not want people to know why he got this.

32. [S] received an ex gratia payment from the Government when he was a teenager in connection with his infection with HIV. We had to pay £1,000 in order for [S] to obtain the ex gratia payment, but I cannot remember why this was. When he died, the Macfarlane Trust sent £1,000. I tried to return this and they said that we should use it for his burial. Perhaps the hospital had told the Macfarlane Trust that he had died.
33. In 2011, my wife and I received a letter from [GRO-B] Hospital stating that they believe that there may be funds available in connection with [S]. I contacted the hospital in response to this letter and Dr [GRO-B] [GRO-B] wrote to me on 17 March 2011 confirming that [S] was infected with Hepatitis C (WITN3124007) and enclosing a letter from the UKHCDO (WITN3124008). The letter that was enclosed states that the rules surrounding entitlement to the Skipton Fund had changed. It states that those who are registering for the Skipton Fund on behalf of the estate of a person who died before 29 August 2003 must do so by 31 March 2011, which did not leave much time for me to do so.
34. I then filled in the forms and got the relevant information from [GRO-B] Hospital. It was a bit awkward trying to get this information from the hospital. I did this mainly for [GRO-B] as this was long after [S] died. We received an initial payment of £20,000 and a further payment of £50,000.

Section 8: Other Issues

35. There was a point when John Major had said that people who had been infected should apply for lottery funding; this was unacceptable in my view. I feel for families where the breadwinner had passed away and the family were left in difficult financial situations through no fault of their own. For all intents and purposes, people were murdered as a result of being given infected blood.

Statement of Truth

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

Signed **GRO-B**

Dated 27-2-20