

ANONYMOUS

Witness Name: GRO-B

Statement No: WITN3666001

Exhibits: 0

Dated: October 2019

INFECTED BLOOD INQUIRY

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FIRST WRITTEN STATEMENT OF GRO-B

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I, GRO-B will say as follows:-

**Section 1. Introduction**

1. My name is GRO-B and I was born on GRO-B  
I live at GRO-B
2. I make this statement as an affected daughter of my father, GRO-B: F  
F who was born on GRO-B
3. My father was infected with HIV, Hepatitis C and Hepatitis B via his use of contaminated Factor VIII concentrates.
4. **This witness statement has been prepared without the benefit of access to my father's medical records.**
5. Both my mother, GRO-B and my father have provided witness statements for the Inquiry.

# ANONYMOUS

## Section 2. How Affected

6. My father has severe Haemophilia A with a zero percent clotting factor. He initially received Cryoprecipitate and then progressed to Factor VIII concentrates when they became available; receiving large quantities of the same throughout the 1970s and 1980s.
7. My father was treated at the York District Hospital ("the Hospital") under Dr Wiley.
8. He was not given any information or warning in relation to the risk of infection from Factor VIII concentrates.
9. My father was infected with HIV, Hepatitis C (Non-A Non-B [NANB] Hepatitis as it was known then) and Hepatitis B. I believe that he was infected with all three viruses in the 1980s. As far as I am aware his first positive tests for all three viruses was in 1984 and this was when he was told about his infections.
10. My father received a letter from Dr Wiley in mid 1984 advising that he had been infected with HIV. He therefore telephoned the Hospital because he was really frightened as the media was portraying AIDS in a terrible light at this time. Dr Wiley did not want to speak to him and it was a real struggle to obtain an appointment with him. He finally agreed that he would see my father, but for a maximum of only 10 minutes.
11. My mother accompanied my father to the meeting with Dr Wiley, who was very rude and dismissive and it was plainly evident that he had no time for my father, despite the enormity of the situation both he and my mother were facing. Dr Wiley asked my father what it was he wanted to know. My father replied "*it is ok to kiss or do I need to separate myself from my wife*". Dr Wiley just said "*oh yes you have got it just use extra protection with your wife, good day*". My mother and father received no information or advice to allow them to understand or manage my father's HIV.

## ANONYMOUS

12. My poor parents returned home in complete shock not knowing what to think. They were both petrified because they had only got married in the May of 1984 and they had young children, including me.
13. My mother and father attended a further meeting with Dr Wiley in 1984 when he broke the news to them that my father was infected with both NANB Hepatitis and Hepatitis B. He was very curt, matter of fact and completely dismissive in the manner in which he imparted this news.
14. It was not until the late 1980s when my father and mother travelled to the Churchill Hospital in Oxford to see Dr Rizza and Dr Matthews, that their minds were put at rest in relation to the infections. My father was finally provided with factual and practical information about his infections and he felt that he actually mattered. I believe that my mother was tested for all three viruses at this time and thankfully the results were negative.

### **Section 3. Other Infections**

15. My father received a letter advising that he had been put at risk of vCJD. I am unsure as to the date of this letter.

### **Section 4. Consent**

16. My father was tested for various viruses without his knowledge and therefore without his consent. Evidence for this is the fact that my father had not idea that he was being tested for HIV, NANB Hepatitis and Hepatitis B in 1984. Furthermore, given the above it is preposterous to think that he was only tested on these three occasions.

### **Section 5. Impact**

17. My whole world fell apart in 2013 when I was aged 33. I can't remember which month it was but I got up one morning and went to work as normal having said goodbye to my father who had been in bed that day due to his

## ANONYMOUS

depression. I then received a telephone call at work, from my mother, to tell me that my father had tried to take his own life. I told my boss that I needed to leave work immediately and headed to the Hospital. Upon arrival, I saw my father lying in a bed in the Accident & Emergency Department. I remember trying to talk to him and then a female doctor rushing in and the next thing I heard was "*medication HIV*". I said "*sorry, pardon*". I immediately turned to look at my mother who was looking at this female doctor. A male nurse who was present instantly realised what had happened and put his arm around me and ushered me into another room. I nearly vomited and was provided with a sick bowl.

18. A short while later my mother came into the room and told me that my father had been infected in the 1980s as a result of receiving contaminated blood products. I was completely shocked and the news "*knocked me for six*". I was completely astounded that they had managed to keep this secret for over 30 years. I could not understand how they could have kept such a huge secret for so long. I asked my mother who else was aware of this and she told me that my brother GRO-B knew but that my brothers, GRO-B and GRO-B did not.

GRO-B

GRO-B I said to my mother "*well mum you must have it too then*". I thought that if my father was infected then my mother would be as well. She said "*I don't*" and I replied "*You do*".

19. I was already suffering with depression and finding out about my father's infection triggered a depressive episode for me. I remember returning home and religiously looking through all of the medicines to see whether my mother was taking any HIV medication. I continually questioned my mother as I was sure that she was infected and she continued to deny that she was not. It took me a long time to accept that my mother was not in fact infected; a fact in itself which is nothing short of a miracle. It has created trust issues between my mother and I because I question what else she may have kept from me, given that she managed to keep such a big secret for over 30 years.

## ANONYMOUS

20. I don't think the manner in which I found out helped. It was a breach of patient confidentiality because my father's hospital records recorded the fact that his HIV was only to be discussed with him and/or my mother.
21. When I found out about my father's infection I was in complete shock and I felt the need to tell **GRO-B**. We were so close and I could not keep it a secret from him and I remember telephoning him at work. He was shocked; he is very private person and to this day won't discuss it.
22. Not long after I discovered that my father had HIV, I started to struggle at work and could not concentrate on my working day at all. My depression worsened as time went on and I became extremely paranoid.
23. I telephoned the Terence Higgins Trust who were a fantastic source of support. They furnished me with important facts, not scare stories, and were able to reassure me that people with HIV often lived for as long as people who weren't infected. I also spent hours trawling the internet to further my knowledge and to find out about people's experiences with HIV. When I started to read about how the Department of Health were aware of the risks of infection from the contaminated blood products I became very angry. This fuelled my desire to speak out and to ensure that justice ensued for both my father and all of the other people who have been both infected and affected by this tragedy.
24. It broke my heart to find out that my beloved father, who I adored, had been through so much having been infected in the way in which he was. I was both angered and saddened by the way in which Dr Wiley treated both my parents. I almost can't put into words how much it has affected me knowing that someone I love so much suffered so greatly through absolutely no fault of their own. My father was such a proud man who would have loved to provide for his family but the infections stole his ability to lead a normal working life and support his family.
25. I have not really disclosed my father's infections to many people mainly because my mother and father wanted such matters to remain private.



However, about two years ago my mother had an operation on her back and I got talking to one of her nurses who had worked with people with HIV and I was able to chat to her about matters.

26. My mother also told me about how the media basically "outed" my father as being infected by identifying that there were 2 or 3 infected haemophiliacs in the market town of [GRO-B] [GRO-B] was a small market town where everyone knew everyone and particularly in my father's case because his parents were [GRO-B]. Following the media's actions, my mother had an unpleasant and difficult experience at the local florists when she was asked outright whether my father had HIV.

27. As a child growing up, I remember that my father often looked quite pale and I was aware that he was not a well man. I think he probably looked quite poorly but I was used to him looking like that.

28. I also remember my mother and father having quite a lot of hospital visits. I remember that in the mid 1990s they went to the Oxford Haemophilia Centre and they seemed to be a lot happier upon their return. I am now aware that this was the first time that they were both treated like human beings. My father seemed so much more content after this visit and now I know why.

## **Section 6. Treatment/care/support**

29. My father was treated like a leper by the NHS as a result of his infections. He was given plastic plates, knives and forks to eat his meals with when he was an inpatient at the Hospital. The medical professionals who dealt with my father were fully masked and gloved. This was upsetting for my mother and father. The Hospital also insisted that she wore a mask when visiting my father which was nonsensical as my mother did not take any such precautions at home.

30. I was never offered any counselling or psychological support. I sourced this from my GP by explaining what I had found out about my father and the manner in which this news was conveyed to me.

**Section 7. Financial Assistance**

31. I think my mother and father are a little confused about the payments they received. I understand that my father received the sum of approximately £80,000 in 1984. I am unsure as to whether it was from the Government or a Trust. I believe they also received another payment sometime later. I also remember my parents telling me that they had to sign a waiver in connection with one payment but I don't know which payment this was.
32. My father now receives just over £3,000 per month from the EIBSS together with a £500 winter fuel payment.
33. I have not had any financial or practical support from any of the Trusts. I have dealt with matters alone and by speaking with my mother and also a campaigner who I met via the Haemophilia Society. This campaigner, who I won't name, has been a tremendous support to me.

**Section 8. Other Issues**

34. I want the Inquiry to properly and generously compensate those victims who are still alive, including my father. The Inquiry cannot change what happened but by providing financial security it can take away the worry of what would happen to loved ones in the event of a victim suffering a terminal bleed.
35. I also want a written account of what the Department of Health did and I want this account to be published for the whole world to see. I want people to be aware of the fact that there were people in Whitehall religiously shredding vital evidence.
36. I hope that the above actions will go some way towards stamping out the outdated and totally unjustified stigma surrounding these infections. It astounds me that in this day and age the stigma still exists.

# ANONYMOUS

## Anonymity

37. I want to apply for anonymity and I am prepared to give oral evidence to the Inquiry provided that my anonymity can be guaranteed. ✓

## Statement of Truth

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

Signed.

GRO-B

Dated.....

25 October 2019