Witness Name: GRO-B
Statement No: WITN1286001
Exhibits: WITN1286002
Dated: 9th April 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

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2. **This witness statement has been prepared without the benefit of access to my full medical records.**

3. I was infected with HIV and Hepatitis C as a result of receiving contaminated blood.

## Section 2. How infected

4. I suffer from Haemophilia A classed as severe with a clotting factor of less than 0.1%. I was diagnosed with Haemophilia in 1972. I was at a relative's house with my parents, when a doctor came to see the relative. I had a lump on my head, and the doctor looked at it and said that I was a haemophiliac.

5. I then had my first blood test at GRO-B West GRO-B where it was confirmed I was a Haemophiliac. I was then transferred to Birmingham Children's Hospital (BCH) My doctors at the time were , Dr L M Franklin and Dr F G Hill. I am currently being treated at Queen Elizabeth Hospital (QEH)

6. Initially I was treated with Cryoprecipitate at BCH. I started being treated at BCH with Factor VIII (FVIII) products from1978, and from 1988 I was treated with Factor VIII products at QEH. I refer to **Exhibit WITN1286002** which is a copy of my records from the National Haemophilia Centre.

7. I first tested positive for HIV on 15 April 1986. Prior to this, I was tested for HIV on 4 July 1985 and the result was negative. However, it was not until about January 1986 that I was informed I was HIV positive.

8. I was told I was Hepatitis C positive in April 1994 by a Dr Wilde at QEH but I do not know when I first tested positive.

9. My mother believes that I may have been infected with HIV and Hep C in around July 1985 as I was given a lot of Factor VIII following an accident on my bicycle My mother remembers at the time that the nurse in charge was hesitant to give me so much Factor VIII but that "it had to be done".

10. My parents were not given any warning or advice beforehand, that there was risk of me being exposed to infection from Factor VIII products.

11. When I first found out I was HIV positive, I was only 14 years old. My parents were called into the hospital a week prior to me and told that I tested positive for HIV. My mother remembers the doctors referring to it as the AIDS virus and glazing over, as she had never really heard of the virus at that point. A week later I was told by the doctors. I was young and naïve and I did not take it seriously. I do not remember the whole conversation apart from the fact that I was told I had AIDS instead of HIV.

12. Neither my parents or I were given adequate information to help understand and manage the HIV or of the risks of others being infected . We were just told that AIDS had been in my treatment, but that they did not know where and when I was infected.

13. I believe we should have been given a far more information about HIV and as soon as I had tested positive. We should not have been kept in the dark about it.

14. It was not until I was about 16 and started to meet girls that I was told by the doctors about not having unprotected sex, but no one told to me about blood to blood contact. About a year after I was told I was HIV positive I was shaving and my little cousin touched the razor. My mother was horrified and had to tell my aunt that I had HIV. My cousin tested negative and was not infected, thankfully. I am a very private person and not many people know my situation but my aunt had to know. This situation would have been avoided if we had been provided with information about the risks of passing on HIV at the outset.

15. When I found out that I was Hepatitis C, positive I was 23 years old. This was the age when I had partners but I was not given any information about passing Hepatitis C through unprotected sex or at all. I believe I should have been given this vital information as soon as they knew I was Hepatitis C positive as I could have infected my partners.

16. As a result of a condom splitting m y wife became pregnant and I told the doctor my wife was expecting. All he said was congratulations instead of advising me of whether I could have passed on my infection to our baby. Thankfully after being tested, neither my sons or wife have been infected.

17. I do not know whether I had Hepatitis B and cleared it myself but my medical records show that I have Hepatitis B antibodies. I have never been told that I had Hepatitis B antibodies I only found this out recently from my medical records.

## Section 3. Other Infections

**18.** I received letters from the NHS in 2004 and 2007 about being at risk of having been infected with vCJD. However, there has been no follow up since then.

## Section 4. Consent

19. I believe that I have been treated and tested without my knowledge or consent and without adequate or full information as neither my parents or I were ever told I was being tested for HIV or Hepatitis B or C. I do not know if I have been tested or treated for the purposes of research

## Section 5. Impact of the Infection

20. It was degrading to find out as a young boy that I had HIV and then as an adult, that I had Hepatitis C. I know my parents told my Head teacher about my HIV infection but I never knew which teachers knew and which didn't .

21. I have two sons, one is 26 and the other is 27 and neither of them knows of my infections. My wife and I decided not to tell them, but they know that I have haemophilia. Now I have to hide this big scandal from my sons which is very hard for me and my wife. When anything related to this Inquiry is on TV, I have to keep my feelings and emotions hidden. I have kept it a secret since I was 14 years old which has been playing on my mind and is very stressful.

22. I suffer from colds and coughs from the infections but the mental effects are far greater on me than the physical effects.

23. When I was told about the Hepatitis C by Dr GRO-D I was told as if I only had a common cold and he made it seem as if it was nothing. Looking back at it now it was like a passing comment which was a bit of a joke. I cannot believe that he downplayed the infection so much. There was no feeling or emotion and it was said in a totally cold manner. The Hepatitis C has cause scarring of the

liver and I believe this could have been prevented had I been told about it earlier and given treatment for it.

24. I am treated with Atripler, and Efravirenz. ( Truvada ) for the HIV I take one of each tablet once a day. However, the doctors keep changing the treatment. The pharmacist told me that I was put on cheaper tablets as the company which made the better treatment pattern for the drug had expired. I take the tablets at 10:00 pm everyday and towards 12:00 I feel quite tired and as if I am going into a spiral state.

25. I was first called in and told I could receive treatment, for Hepatitis C but when I went for a blood test, I was told the treatment was too expensive, and it was not until much later that I finally was treated with Harvoni. Fortunately there were no side effects and the treatment has cleared the infection.

26. Although the HIV tablets do not have many side effects, a couple of hours after taking the medication towards end of the day I feel a bit woozy.

27. My infected status has impacted on my treatment as when I have gone into hospital for an operation, the doctors leave me until last so that they can clean the place in the end and to prevent cross infection. It is quite tiring to wait a whole day to be treated.

28. As previously stated, the doctors keep changing my HIV medication. I am going away on holiday and one of the questions the insurance company asked was whether I have changed my tablets in the last 3 months. This affected the Insurance premium and I have been charged more which was unnecessary as both treatments for HIV have the same ingredients. I believe my tablets were changed for financial reasons.

29. I do not tell people about my infections. I just tell them anything other than HIV or Hepatitis C. When people talk about their illnesses and how it has affects them, I cannot do the same thing due to the stigma associated with HIV. I am not able to discuss my feelings with anyone which s not good for me.

30. My wife and I keep a lot of secrets, especially from our sons and I do not feel comfortable hiding the truth from them. It upsets my wife to be hiding such a big thing from our sons. Prior to marrying my wife, I did not have many partners due to the HIV and my fear of passing it on. There is a constant stress on my children finding out.

31. There is definitely a stigma attached to HIV .I am never going to gamble with telling people I have HIV due to the stigma that I believe still exists . As a result of the stigma, I kept the infections private and do not tell anyone. My friends do not have a clue even about my Haemophilia. When I go out for a drink I have to quickly take my HIV tablets without anyone seeing. It is a constant pressure that I have been suffering for many years.

32. I always put my infections at the back of my mind when I was 14 years old but as I grew older it started to play on my mind more ..

33. I have suffered financial effects as a result of the infections. I cannot obtain life insurance or mortgage protection and travel insurance is very expensive. There is no long term security for me and my family.

34. My parents also suffered as a result of my infected status. They did not speak much about the infections to me due to the stigma attached to HIV . I knew that my parents were devastated but they did not want to discuss it with me. My wife knows about the infections and she has been supportive. Even when my wife and I speak about the HIV, we refer it to as 'the other infection'. We are very careful about other people finding out which is hard for us.

## Section 6. Treatment/care/support

35. I have suffered difficulties in obtaining treatment as a result of my infected status. I am always at the end of the queue and the Harvoni treatment was

delayed for months before I was put on it or even told of the treatment. The doctors like to tell people how much treatments cost rather than giving the treatment. I am a patient not an accountant and I believe they infected me so they should cure me.

36. The Macfarlane Trust (MFT) offered me counselling but I never took it. No counselling or psychological support was offered to my parents or me by the NHS.

37. I believe it was important for my parents to receive counselling but they did not. My parents went through so much especially with the adverts and the stigma attached to HIV back in the 1980's. I cannot imagine how bad they must have felt. They do not say a lot but I know what they must have gone through. My wife was saying that it must have been hard for my mother to know that she injected me with the viruses herself, in home treatment when she thought she was doing something good for me.

## Section 7. Financial Assistance

38. In early 1991, I received a lump sum of around £20,000. From the MFT but I had to sign a waiver. I used the money for a deposit towards a flat. I think I found out about the MFT through the Haemophilia Society.

39. I received a sum of about £15,000 a year from the MFT. I now receive a annual sum of £18,000 from the EIBSS and a top up payment of £479 per month from them and a further sum of £18,000 under the Special Category Mechanism.

40. I also received £3,000 a year from the Skipton Fund at one stage. I may have received a lump sum from the Skipton Fund but I cannot recollect.

41. I believe the hoops the Funds and Trusts make jump through for grants and financial assistance are ridiculous and unnecessary There is a lot of

paperwork and you always need a letter from your haemophilia unit or doctor and then you have to wait 28 days before receiving a response. If you need financial assistance urgently, these Trusts and Funds are useless.

42. For example if my car went in for a MOT in theory, to receive financial assistance, I would have to take my car to two garages to obtain the two estimates required before I could receive financial assistance.

43. I believe it should be far simpler to receive financial assistance, as the victims of this scandal have been infected wrongly. I believe I should not have to reaffirm my circumstances every 12 months as not much is going to change in terms of finances every year.

## Section 8. Other Issues

44. I understand the Inquiry has to look through every one's records and statements and it will be quite a time consuming process. However, if the Inquiry started earlier, all of this would have been resolved by now. People have been made homeless and some have died.

45. It is ridiculous to have to ask for a more financial assistance. The funds and trusts were set up for us, but we have to jump through the hoops in order to obtain financial assistance. Instead, I believe they should have given compensation to every one.

46. The Government says they did not know a lot of things relating to this scandal but I believe they did know and I would like to see some justice.

## Anonymity disclosure and redaction

47. I wish to be anonymous and I do not wish to give evidence at the Inquiry.

## Statement of Truth

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

Signed. GRO-B .......

Dated ......9-4-2019......