Witness Name: GRO-B
Statement No: WITN1365001
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Dated: January 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF GRO-B

I, GRO-B will say as follows:-

Introduction

1. My name is GRO-B My date of birth is GRO-B and GRO-B GRO-B

2. I live at GRO-B with my wife. I do not have any children of my own; however, I do have two step children. I am currently self-employed as a GRO-B

3. I was infected with HIV and the Hepatitis C Virus (HCV) as a result of receiving Factor VIII treatment for my haemophilia.

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

How infected

5. When I was 3 days old, I suffered from a swollen hip and I was rushed in to GRO-B GRO-B in Birmingham. I had some test and I was diagnosed with severe haemophilia A.

6. I was initially treated with viper venom from snakes, then fresh frozen plasma, then cryoprecipitate, and then the freeze dried Factor VIII treatment.

7. I first received Factor VIII treatment in the early 1970's at the Churchill Hospital in Oxford. I was treated with Factor VIII until I had my liver transplant in 1999.

8. I was told that my treatment would be changing to the Factor VIII and I would be able to self-administrate this at home. This was a relief since I was constantly going back and forth to the hospital when receiving cryoprecipitate. I accepted what my doctor told me and nothing further was discussed, no risks or side effects associated to the Factor VIII were communicated to me.

9. I missed a lot of school due to my hospital visits. I also changed schools a few times before being admitted to a special boarding school in Birmingham. My parents were left with no choice but to send me to a boarding school as it was easier to keep me in isolation. I believe this school was called GRO-B boarding school and they had an on site doctor who took care of me. My parents were scared that I would get bumps and cuts if I freely mixed with the other kids. As a result, I spent a lot of my time alone in my room, reading books or daydreaming. There was not much I could do about my condition, I had to put up with it and get on with my life.

10. It was very hard for my parents to deal with my haemophilia, but they did everything in their power to make sure I was in 'good hands.' At one point they even asked for my treatment to be transferred to the Nuffield Haemophiliac Centre in Oxford, they felt that I would receive better care here.

11. In 1982, my left foot was operated on as it had become deformed due to all the bleeds I had from my ankle as a child. I was advised that the procedure would involve breaking my foot, and then straightening it, so that I could walk better. This operation was not successful and had to be done again, however, the second attempt was also unsuccessful. I continued to receive Factor VIII treatment and I was discharged with a cast. After 6 months I decided to contact the Haemophilia Society to see if there was anything else that could be done for my foot. I was advised to seek a second opinion from St Thomas Hospital in London.

12. In 1984, I was seen by Dr Savage and Dr Smith at St Thomas Hospital who informed me that my foot and leg had been plastered for longer than it should have been, and I would have to have my leg amputated as I had gangrene.

13. I had numerous blood tests; however, I thought this was normal due to my leg amputation. Following the tests, Dr Savage told me that I have HIV. This conversation took place towards the end of 1984. No further information was given to me. I was merely told I had HIV which was a new condition they discovered, and that it almost certainly came from the Factor VIII treatment I had been receiving. Dr Savage advised that he did not know enough about this disease to medically advice me, and he simply said, “Some people will live and cope with the illness; whereas others will die.” I was told I needed some tests to see if I could be treated with AZT.

14. In or around 1997, I went to see Dr Savage as part of a routine check-up. I told him that I am felt bloated and had constant flu like symptom's. I had some blood tests, following which I was advised that my liver was not looking good and that I had been infected with the Hepatitis C virus (HCV).

15. I had never heard of the HCV before this, and I definitely did not know I was being tested for the HCV. I was told to give blood, but I did not question this as I had always had blood tests.

16. I was under the care of St Thomas Hospital from 1984 until 1999; however I was also under the care of Dr Wilde at the Queen Elizabeth Hospital in Birmingham during the 1990's.

17. During one of my routine appointments in or around 1997, Dr Wilde sat me down and informed me that my liver was very bad. His exact words were, "I don't think you realise just how bad your liver actually is, you also have cirrhosis." He recommended that I see Dr David Mutimer who could give me more information about my liver as this was his specialism. I went to see Dr Mutimer and he diagnosed me with end stage liver failure. I was told I had approximately 12 months to live. I was shocked as I did not realise it was that bad. Around this time I was already trying to arrange a liver transplant through Kings Hospital. I informed Dr Mutimer of this and he advised that it would be better if I had the liver transplant at the Queen Elizabeth Hospital, Birmingham instead. He wanted me to be their first co-infected haemophiliac patient to undergo a liver transplant.

18. At that time I was very confused as it was a big decision to make. I kept thinking that if I didn't go ahead with the liver transplant, I was going to die anyway, so I had nothing to lose. After some careful thought and deliberation, I decided to have the transplant.

19. Once a suitable liver was found, Mr Mayer performed the operation. Although at one point he thought I was going to die, the operation was successful. However, 6 months after the transplant, I was told that I still have the HCV and this was infecting my new liver.

Other Infections

20. I had a hernia after the liver transplant but this was subsequently repaired.

Consent

21. I believe I was tested for HIV and the HCV without my knowledge or consent.

22. I believe I was tested for research because Dr Savage was not familiar with HIV at the time. Around the time I was diagnosed, I remember having several tests and blood tests which I now believe were linked to my HIV.

Impact

23. It is difficult to explain exactly how much impact my HIV and HCV has had on me and my family life. It is a constant feeling of mixed emotions, including anger, pain, and loneliness. I have coped by blocking everything out.

24. I was in a relationship with my wife in 1981 and we got married in 1989. Around the time I was diagnosed with HIV, she was pregnant with my child and we were forced to terminate the pregnancy. We were advised by Dr Savage that the risk of the mother and child being infected was extremely high and that it is best she has an abortion.

25. Following my HIV diagnosis and after the baby was terminated, my wife was also tested for HIV. I was so scared that I may have infected her but luckily she was tested negative.

26. We were so excited to start a family, but this was taken away from us due to my HIV infection. I have never been able to get over this, neither has my wife. It was the hardest decision she has ever had to make and I have to live each day blaming myself.

27. I have never been able to plan my life, I always thought I was going to die so I tried to enjoy each day as much as I could, however, this was extremely difficult as I was constantly thinking about my wife and what would happen to her if I died.

28. No one knows about my HIV and HCV besides my close family and wife. I decided not to tell anyone else due to the stigma attached to HIV and the HCV.

29. Although, my wife was extremely supportive, there were some things I could not discuss with her due to the nature of our relationship. As there was no one else I could turn to, I felt very lonely and isolated. I still feel like that now.

30. I wouldn't wish this life on anyone. I try and be as positive as I can for my wife and family but it gets very difficult sometimes.

Treatment/care/support

31. The only treatment I was given for my HCV was a course of tablets; I took these for 6 months following my liver transplant. I cannot recall the name of this treatment but it made me feel very unwell. I was offered Interferon prior to my liver transplant which I did not take.

32. I have been given a lot of medication for my HIV including AZT. I experienced many side effects, including headaches, sickness and tiredness. The biggest side effect I experienced is lipodystrophy. This has left me feeling very self-conscious about my legs and arms.

33. I was not offered any counselling. I do not think this would have helped me.

Financial Assistance

34. I received from £15,000 from the Macfarlane Trust and £15,000 from the Skipton Fund. I also received a further £20,000 from the Skipton Fund a few years ago.

35. I did not directly apply for any financial assistance; someone from the Haemophilia Society contacted me.

36. Sometime in around the 1990's, the Government gave me £60,000. I was told that if I did not take the money, this would affect everyone who was infected

with HIV. I only signed the waiver and received the money because I felt compelled to sign.

37. I am not part of any health groups as I have learnt to keep myself to myself. Even my step children and grandchildren do not know about my infections.

Anonymity, disclosure and redaction

38. I confirm that I wish to apply for anonymity.

39. I understand a redacted statement will be published and disclosed as part of the Inquiry.

Statement of Truth

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

Signed GRO-B ....

Dated 20/1/2019