

ANONYMOUS

Witness Name: GRO-B

Statement No: WITN0505001

Exhibit: WITN0505002 - 09

Dated: 7 November 2021

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF GRO-B

I, GRO-B (DOB GRO-B of GRO-B will say as follows:

Section 1: Introduction

1. I make this statement for the purposes of delivering the details of my personal story to the Infected Blood Inquiry.

Section 2: How Infected

2. I am a person with mild Haemophilia with a Factor VIII assay of 17.5%.
3. I was 10 years old when I attended Bradford Royal Infirmary Hospital (BRI) following the extraction of two of my teeth by a local dentist. The dentist encountered difficulties controlling my bleeding which resulted in having the wounds stitched up.
4. I was then transferred to BRI for the purposes of carrying out blood tests and coagulation therapy. I came under the care of Professor Parapia, Consultant Haematologist.
5. During my stay at BRI, I received multiple amounts of Factor VIII daily.
6. Throughout 1981-1985 Factor VIII was administered for minor scratches and falls suffered during the course of my childhood. I suffered a serious sprain to

my leg/ankle around this time also. The medical staff were of the opinion that I had fractured my leg and therefore as a result, my leg was put into a cast.

Exhibit WITN0505002

7. I cannot recall ever being trialled on cryoprecipitate. I do recall being treated with DDAVP which worked very well for me. **Exhibit WITN0505003**
8. In or around 1993, I was diagnosed with HIV. I understand now that this was significantly later than the "normal dates" for HIV diagnosis. My dad was present with me when the doctor explained that I had been infected. I cannot find this meeting recorded in my notes however as I was in my early 20's I found it extremely hard to understand what I was being told. I do recall thinking that what we were being told was significant as my father broke down emotionally.
9. From review of medical records, it is recorded that results of a HTLV III test carried out in 1985 were returned positive and furthermore it can be seen that a decision was made not to tell my family. **Exhibit WITN0505004**
10. There is correspondence from Professor Parapia, Consultant Haematologist to my GP from the late 80's to 90's confirming my HIV status yet my family and I were left in the dark, unaware of the risks involved. **Exhibit WITN0505005**
11. Why did I not receive this HIV diagnosis until I had reached the age of 22? What was the rationale for such a significant delay in terms of said diagnosis?
12. Prior to my HIV diagnosis and whilst a teenager, I was aware of its impact. I simply thought you got HIV, then Aids and then you die. I understood that the prognosis was not good due to the stigma attached to it at the time.

Section 3: Other Infections

13. N/A

Section 4: Consent

14. There was no discussion about the potential risks of any treatment that I received, I only recall discussions relating to the side effects, namely flu like symptoms, vomiting and diarrhoea.

Section 5: Impact

15. My school years were an enjoyable time for me. I applied myself to my studies, I was focused and refused to go off the rails due to my diagnosis. The school was aware that I had mild haemophilia. Sport was unfortunately not part of the day-to-day activities that I could partake in however I enjoyed swimming whenever I could.
16. As I always had a keen interest in cars, I went on to complete a City & Guilds course in motor mechanics and welding when I finished school.
17. Prior to my HIV diagnosis and whilst a teenager, I was aware of its impact.
18. The stigma surrounding HIV at the time was frightening. The fear of people knowing and the thought of being disowned was too heavy to bear. So much so that the only people who were aware of my infection, outside of my doctors were my parents. I was involved in many physical relationships throughout my years and would always take precautions. Due to the stigma, I did not disclose to any partner that I had HIV.
19. Leading a double life came as second nature to me and I used my lung infection to cover up my HIV treatment.
20. Despite my ill health I continued to work. Over the years, I had various employers, and each were notified of my Haemophilia. No issues arose from this. However, due to health reasons I took retirement in 2015.
21. My life would have been so different had I never been infected. Most of my romantic relationships broke down, some due to the fact I did not want to have children, nor could I explain the reasons behind this. Alternative options to conceive was never discussed nor did I receive counselling.

22. As my future spans ahead of me, I am more concerned with my heart condition as the long-term diagnosis for my HIV is quite good and is being managed quite well. The HIV load is undetectable with little to low risk of transmission. My CD4 count is around 400/500. I receive LFT's once per year. Therefore, my outlook on life at present is positive.

23. Due to the lump sum payments I received from Skipton, I was able to buy my own home and my current partner has since moved in to the house. Whilst it was relatively easy to reveal I had been infected with Hep C, as the treatment cleared it, she remains unaware of my HIV status.

Section 6: Treatment/Care/Support

24. In respect of my HIV treatment, I was trialled on AZT which I could not tolerate. Similarly to previous treatments received, there was no discussion about the potential risks only discussions relating to the side effects, namely flu like symptoms, vomiting and diarrhoea. **Exhibit WITN0505006**

25. Due to my intolerance of AZT, I commenced triple anti-retroviral therapy.

26. In 2004 a liver biopsy was carried out and I was diagnosed with Hepatitis C. I was further advised that the potential of sclerosis was quite high however, surprisingly I was informed that I did not have to worry about it as the HIV was a bigger issue. **Exhibit WITN0505007**

27. I was advised that I would have been infected at the same time as HIV. It can be seen from my notes that from 1990, I was being tested for Hepatitis C. **Exhibit WITN0505008**

28. Was it appropriate to inform me that Hepatitis C was not really a big issue as I had already contracted HIV, although I potentially could develop liver cirrhosis?

29. 2007 was the year I cleared my Hepatitis C infection following combination therapy with Interferon and Ribavirin. A 40% success rate was explained but I

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remained hopeful. It was explained to me that my blood would always show that I have antibodies to Hepatitis C. **Exhibit WITN0505009**

30. There were no side effects from the HIV treatment, albeit I lost weight under my rib cage. During this treatment I suffered a serious heart attack in 2016. My treating doctor, Dr Wilson, Infectious Disease Consultant changed my HIV medication following this attack. There were no issues that I can recall until I commenced my heart medication.

Section 7: Financial Assistance

31. Financial assistance was provided by the McFarlane Trust wherein I received regular payments. Through the Skipton Fund, I received two payments, £50,000 for Hep C stage 1 and £20,000/ £30,000 in or around 2004.

Section 8: Other Issues

32. What I would like to see happening with this Inquiry is for an explanation, an apology and for someone to be held accountable. The contaminated Factor VIII that I received has ruined my life and has caused me nothing but pain, illness, upset and guilt.

33. Should I have ever received a Factor VIII concentrate, in the context of the extraction of a tooth or teeth?

34. Why was I never trialed on cryoprecipitate?

35. The biggest impact all of this has had on my life to date is keeping it a secret.

Statement of Truth

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

Signed

GRO-B

Dated

17-11-21