

ANONYMOUS

Witness Name: Mr. **GRO-B**

Statement No: WITN3224001

Exhibits: 0

Dated: July 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF **GRO-B**

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

Section 1. Introduction

1. My name is **GRO-B** **GRO-B**
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GRO-B

2. I was infected with Hepatitis B, Hepatitis C and HIV as a result of receiving contaminated blood products.
3. **This witness statement has been prepared without the benefit of access to my full medical records.**

Section 2. How infected

4. I suffer with Haemophilia A classed as severe with a clotting factor of less than 1%. I was diagnosed when I was five years old. I had bitten my tongue and kept bleeding so the doctors conducted tests and diagnosed Haemophilia. I cannot recall which hospital I was diagnosed

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in, but at the time I was living in **GRO-B**, West Sussex so it was possibly Worthing or Chichester Hospital.

5. I was initially treated with Cryoprecipitate. I cannot remember if I received blood products prior to a hernia operation in or about 1968 which is the first time I received blood products.
6. I attended the Lord Mayor Treloar School (LMT) as a pupil from the age of 11 until the age of 16. I cannot recall the names of the medical professionals at LMT and when I left LMT I moved back to **GRO-B** and was treated at, Worthing Hospital and Chichester Hospital. When I was 17 I moved to Manchester and was treated at the Manchester Royal Infirmary (MRI) eventually under the care of Dr Hay. I moved to Lincoln in 2005 and I am currently under the care of Dr Myers at Lincoln County Hospital.
7. I have been receiving Factor VIII blood products since 1968. I recall brands such as Baxter and Amour but do not have any details. I now receive recombinant Factor VIII.
8. Neither my parents nor I ever received any advice or information beforehand about any risk of being exposed to infection from blood products.
9. Whilst I was at the LMT, I was informed that I was infected with Hepatitis B. I was still a minor at the time, and I do not recall my mother ever being told about this diagnosis. She certainly never told me she had. A group of pupils were told collectively that we had been tested positive. We were also told that because we were Haemophiliacs we would get over it unlike other people.
10. I was diagnosed with HIV on 25 September 1985. Unfortunately I cannot remember the name of my first Consultant at the MRI who told me of the diagnosis as I was in his care for a very short time. I was simply told that I had the infection in a very matter of fact way and was

asked for a list of all my partners. By asking for a list of partners it perhaps implied that I had HIV for a while. They tested my GRO-B and that was all we initially heard about the HIV. I did not receive any information or advice on the risks of transmission, or how to manage the infection. In my view the information provided was wholly inadequate. In addition to this, I did not know I had been at risk or that I had been tested so it came as a massive shock. Any information I knew, I sourced through the media. Full and detailed information should have been provided to me and they should have told me immediately I tested positive. Instead, my doctor who conveyed the HIV diagnosis didn't seem to be that bothered about it.

11. In 1986 I was told I had Hepatitis C. This was after my marriage and it was Dr Hay at the MRI who told this to me. All I was told was that Hepatitis C was slightly different from HIV and I would need to go on antiviral drugs for a year.

12. Again I was not given adequate information or any information about the risks of others being infected.

Section 3. Other Infections

13. I received a letter in the 2000s that there was a risk that I may have been exposed to vCJD. The letter landed on my mat out of the blue. There were no prior consultations or warnings given which seemed a very cold way to inform patients about such a terrible disease. I remember that vCJD had garnered attention in the media so to get such a scare was not appreciated.

Section 4. Consent

14. When I was at the LMT, I was still a minor, but I do not believe that my mother was ever asked for consent prior to me being tested or treated. I

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know for a fact that she would not have given consent to me being treated with infected blood had she been told the risks of infection.

15. I believe I was tested for Hepatitis B, HIV and Hepatitis C without my consent, or knowledge and without being given adequate or full information. While I was at LMT, they drew our blood on numerous occasions, but prior to being diagnosed I had not known that I had been tested for HIV or Hepatitis. Each time a new diagnosis came to light it came as a major shock.

16. I believe that I was tested and treated for the purposes of research. As an MP once said, "Haemophiliacs were cheaper than monkeys".

Section 5. Impact of the Infection

17. When I was first told about HIV, I had expected not to live very long. I was only 22 and it was just before I got married. I thought it was only a matter of time. It was shocking and utterly devastating to hear. I had barely started my life. In addition to this, I was also jaundiced, tired and fatigued, which I did not know were symptoms of Hepatitis C. I am still HIV positive, although now my viral load is undetectable. Due to the Hepatitis C, I believe I developed Gallstones which in turn caused Pancreatitis. I also suffer from Arthritis.

18. I have not received any treatment for HIV until recently. For approximately three years I have been taking a tablet called Triumeq on my virologist Dr Saing's recommendation.

19. I was put on a course of Interferon and Ribavirin to treat the Hepatitis C. I self administered the treatment for 12 months which involved one weekly injection into the stomach and a daily tablet. I started this treatment almost immediately after my diagnosis in 1986. Since then, I have been tested for Hepatitis C every now and again, but I am always tested negative.

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20. I am not a medical professional; therefore I do not know whether there are treatments that ought to have been given to me. Maybe they should have put me on treatment earlier, but I do not know exactly when I was tested or when treatment was first introduced. When I was completing my forms for financial assistance it came to my attention that, after I had been diagnosed with Hepatitis C, I should have been referred to a liver specialist, however the first time I had any contact with a liver specialist was last year.
21. During the year I was on Interferon, I became very depressed, moody and impatient. I constantly felt as though I was wound up and suffered from severe mood changes coupled with flu like symptoms; it really was not a good combination. The moodiness came almost instantly after the injection and I became very difficult and angry. From my point of view I was still okay, but other people's perspective on me changed. They saw me in a different light. My wife described that I was on a short fuse and she would have to walk on eggshells around me. It was not a pleasant time for either of us. I continued to feel tired and fatigued, and also suffered from brain fog. I was working night shifts at the time so it wasn't ideal.
22. For as long as I can remember, very few people knew about my conditions. I kept it to my close family members as I was worried about the stigma. Only two of my friends know and they have been very supportive about it. The lead up to the conversation was not nice. I was worried about their reactions and whether they'd be sympathetic.
23. By the time I was diagnosed with HIV, I had left education, although I didn't achieve any decent grades. I achieved CSE's but that was it and I found out after I had left that I was dyslexic.
24. In 2006, I had to take early retirement due to my joints. Work never knew about my infections, although they knew I had Haemophilia. Even though I was working in the NHS, the Haemophilia unit at the MRI said

that I had no duty to disclose my infections to Occupational Health as I wasn't working in operating theatres.

25. My wife was absolutely devastated to hear about my infections. We were childhood sweethearts who met at LMT and both of us wondered how long our relationship would continue. Due to both our disabilities, my wife and I had decided that we would not have children; however when we were informed about the infections, should we have wanted to change our minds, the opportunity was no longer available to us. That choice was taken from us. Meanwhile, our friends were having children and sometimes we felt as though we missed out. A couple of years after marriage, we tried to see a doctor to get a vasectomy due to the risk of transmission, but I was turned down for being too young.

Section 6. Treatment/care/support

26. If I needed dental care, I had to go to the hospital's dental clinic, but hospitals no longer do that. I now have a dentist who is fine with my condition. The only trouble I had was when I had another hernia operation in late 2018 at Lincoln County Hospital. It was just after Christmas and they knew that I had HIV and had had Hepatitis C, but that did not concern them. They panicked more at the fact that I had received a letter regarding vCJD. I found it strange as surely the issue should have been what I had already been diagnosed with.
27. After my HIV diagnosis, a counsellor was sent to my house and the arrangement was that she would come weekly. After the second week, without notice, she stopped turning up. I believe she moved on to another job, but nobody replaced her. I do not remember gaining much out of those sessions. Aside from that, no counselling or psychological support was ever made available to me in consequence of what happened.

Section 7. Financial Assistance

28. I receive monthly payments of just over £1000 from the MacFarlane Trust (MFT) I found out about the MFT through the MRI.

29. I also received a Stage 1 payment of £20,000 from the Skipton Fund and am in receipt of monthly payments, although I do not know the exact amount. Again, one of the consultant's at the MRI told me about the Skipton Fund.

30. When the EIBSS took over from the Skipton Fund, they started offering discretionary top up payments. As I had cleared the Hepatitis C, I believed that I would not be entitled. Nevertheless I decided to try for it. I had scarring on my liver and other hepatic symptoms; therefore I was entitled to the payment.

31. In total, I now receive approximately £3000 per month which comes through as two separate payments.

32. I found that the application process was difficult and made me think about things I didn't want to think about. Bringing back and reliving those memories is difficult. The process is time-consuming and tiresome and it feels like I am being audited every year. It also necessitated a doctor confirming the diagnosis therefore the Haemophilia unit had to complete part of the forms in support of my application.

33. We are made to feel like they're doing us a favour when really, all things considered; the amount they pay is not that great. I feel they should have paid more considering it was medical compensation. If we raised a private claim in the courts, we would have been paid more compensation.

Section 8. Other Issues

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34. I was involved in the 1991 HIV litigation and had to sign a waiver agreeing not to take further action against the NHS to receive any money. That didn't go anywhere and I received around £20,000 through the MFT.

35. If a private company did what the government did, they'd be charged with corporate manslaughter, but the government has gotten away with that for over forty years. It's unforgiveable! Not only have they escaped liability, they have made attempts to cover up their mistakes. Many MPs made statements that were hurtful and unhelpful to Haemophiliac patients. One suggested that decent Christian people would not get AIDS.

36. People say that the Inquiry is only at an early stage, but it doesn't feel like that to us as we have been suffering for over thirty years and due to this delay, we are having to relive the past and bring up all those awful memories.

37. We want somebody to hold their hands up, admit their faults and say that they knew all along and got it catastrophically wrong. Also to hide and destroy documentation that could possibly constitute incriminating evidence was truly awful. I understand Dr Hay was specifically known for shredding documentation at the MRI. What chance do we have with all that's been covered up?

Anonymity

38. I wish to be anonymous and I am not willing to give oral evidence at the Public Inquiry.

Statement of Truth

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

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GRO-B

Signed.....

Dated... 2/7/14