

ANONYMOUS

Witness Name: **GRO-B**

Statement No: WITN1225001

Exhibits:0

Dated: December 2018

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** I was born on **GRO-B** and I live at **GRO-B**
GRO-B
2. This witness statement has been prepared without the benefit of access to my full medical records. If and in so far as I have been provided with limited records the relevant entries are set out in the medical chronology at the end of this statement.

Section 2. How infected

3. I was diagnosed with severe Haemophilia A from birth.
4. I was initially treated with cryoprecipitate at the Royal London Hospital under the care of Dr Brian Colvin. I required treatment fairly regularly when I was younger because my haemophilia was so severe. Initially this was on demand treatment but I then moved on to have home treatment.

ANONYMOUS

5. On one occasion when I was about 9, I turned yellow after receiving cryoprecipitate and was taken to hospital as I was jaundiced.
6. I managed to recover naturally but it took me about a year. I had about 4 months off school and I was permanently tired in this time; I just slept all day. I wasn't really told what was happening to me. It wasn't until around 1990 that I was told by Dr Colvin that I had had Hepatitis B as a child that I realised what I had been suffering from. At the time of my illness I was just told it was jaundice.
7. I believe I was first treated with Factor VIII when I was around 11 or 12 although I cannot be sure of the date because of the passage of time. When I was moved onto Factor VIII treatment I was told it was a new treatment that was faster acting than the cryoprecipitate. I was not told of any risks and I do not believe my parents were advised of any potential risks.
8. In the early 1980s I remember starting to see adverts on the TV talking about AIDS. At that time it was portrayed as a 'gay disease' so I didn't really take any notice of it.
9. One day Dr Colvin called me in for an appointment and asked me if I had heard of the AIDS virus. He said that they had found out it could be transmitted through blood. He told me that it could have been in my blood products. I asked him if I could catch it in my injections. He said yes but there was no test for the virus and I shouldn't worry because although a lot of American haemophiliacs had caught the disease that was in America. He finished by saying that he just had to tell people about it.
10. After this, HIV (or AIDS as it was known then) started to become more heavily publicised in the news. It was initially just linked to people in Africa and gay people in America, but then there were warnings for people who had received blood transfusions and blood products. I remember seeing pictures of Africans and gay men in America dying from AIDS and then the suggestion

ANONYMOUS

being raised that anyone who had received blood products could end up like that too.

11. At that time I had review appointments with Dr Colvin every 3 months. At one of these appointments I asked Dr Colvin again about AIDS. He told me not to worry, that it wasn't in the UK and that it was not in the treatments here. He said again that there was not test for the virus.
12. From about the age of 15 I had a lot of bleeds in my elbow and it became a target joint which required a lot of injections. I remember speaking to Dr Colvin again at one of my appointments when I was about 17 and being told that I was okay at the moment but that they had to look for a marker for the virus and at that time they could not find it in my blood so I was okay.
13. The link between haemophiliacs and HIV was becoming even more apparent in the media and there were documentaries saying that haemophiliacs would only have 5-10 years to live due to HIV. This worried me as I had planned surgery on my elbow coming up and I was going to need a large quantity of blood products.
14. My father and I went to see Dr Colvin together to address this issue. We asked that I only be treated with NHS blood products that had been sourced from the UK but Dr Colvin told us there was no NHS Factor VIII in the country. My Dad told Dr Colvin he was worried about AIDS. He had just received a £20,000 redundancy payment and he offered to pay it all to Dr Colvin so I could be treated with safe NHS Factor VIII but Dr Colvin just repeated again that there was none available. He said they had to get Factor VIII from America. I have since discovered that NHS Factor VIII was available because in Scotland they refused to accept American products and had NHS Factor VIII. I believe this was the case at the time of my operation.

ANONYMOUS

15. Dr Colvin reassured us that we didn't have to worry and on my 18th birthday GRO-B I had surgery on my elbow, for which I received Factor VIII before, during and after surgery.
16. A few months after surgery I went for a follow up appointment with Dr Colvin. He started to tell me that some haemophiliacs had caught the virus. He pointed out that I had received a lot of treatment (with Factor VIII) but said that he hoped I would be okay. He then said "a lot of people who've caught the virus are quite well at the moment but could get worse later on". These cryptic conversations went on for months. I do not recall a conversation at that time where he made it clear that he believed I had contracted the virus. It was all very vague and unsettling.
17. In or about early 1985 Dr Colvin told me they now had a test for HIV. He asked me if I had had flu like symptoms or had been unwell. I told him I had not. He said that I had shown "some signs" of having come into contact with the virus. This was despite the fact I had not reported any symptoms and that, to my knowledge, he had not tested my blood.
18. Dr Colvin told me there was no treatment for the virus. He said that they believed after 5 years about 25% of 'all of you' (meaning haemophiliacs) would become ill, after 10 years 50% would become ill, and after 15 years we would all be ill.
19. I remember at one appointment saying to Dr Colvin that if I had had NHS treatment I would not have been in this position. He said that there was no NHS treatment because people were frightened to give blood. I said "even in America?" He said it was different in America because it was such a vast country and they had a surplus of blood.
20. Dr Colvin never explicitly told me that I was HIV positive. It was always explained to me in loose terms such as 'people like you that may have come into contact' and 'you may have fought it off'. There was no clear diagnosis or advice.

ANONYMOUS

21. Over the next few years he continued to tell me not to worry. He told me that people were working on treatment but it could take another 5 years. Whenever I saw a new breakthrough on the TV I went to see him but he always told me that the treatment was 5 years away and I shouldn't worry. I remember my Mum called him once as well and he told her that everyone was making a big thing about HIV and that if I stayed at home (which I was doing at that time) I would become ill.

22. I was never really given any information about the disease itself, its prognosis or the possible routes of transmission. My dad was told to stop being a blood donor due to his proximity to me but that was it. My dad had been giving blood since I was born as he wanted to give something back, so this was upsetting for him.

23. I was told about my Hepatitis C infection by Professor Lee at the Royal Free Hospital in or about 1993.

24. I don't recall being told anything about the disease itself, simply that I would be seen by doctors from the liver clinic. I was told there was no treatment for it and they just had to keep an eye on my liver. I felt that they were a lot more honest at the Royal Free and when I had questions they would answer them where possible and if they didn't know the answers they would say.

25. I believe that it was the factor received for my elbow surgery that caused my infections.

Section 3. Other Infections

26. When I went for a review one day at the Royal London Hospital I was told that I may have been exposed to vCJD. I was told there was no test for it and that everyone who had received blood products was at risk. This was later confirmed in a letter.

ANONYMOUS

Section 4. Consent

27. I believe that Dr Colvin tested me without my knowledge or consent. I was not aware that I was being tested for HIV or Hepatitis C and therefore did not consent.

Section 5. Impact of the Infection

28. After my discussions with Dr Colvin about HIV, I became extremely paranoid about my health and worried about every little thing. If I had a spot I worried that I was about to come out in lesions.

29. I also suffered from depression. I was too scared to leave the house. I was afraid I would get a horrible reaction from people. I remember thinking that I was glad that I was diagnosed after I had left school because I would have been bullied otherwise.

30. For about 5 or 6 years I refused to go out anywhere or do anything. I weighed myself everyday and constantly panicked as all I knew about the disease was what I had seen on the TV. I saw people with HIV dying on TV and thought it was going to be me next.

31. In or about 1992 I was told by Dr Colvin that there was a new drug treatment for HIV called AZT. At that time the only test available to check your progress was for your CD4 levels to be monitored. When I was put on this treatment my CD4 levels started to improve.

32. I panicked every time I had a blood test. I always phoned for the results because I worried it would be bad news but everytime I was told there had been an improvement. Fortunately I didn't get any side effects from the AZT.

33. One night I had a horrendous nightmare that I was told by Dr Colvin that I only had one year to live. It was so real and vivid and I found it so terrifying that I

ANONYMOUS

couldn't go back to the Royal London Hospital again. I transferred my care to the Royal Free Hospital.

34. When I moved to the Royal Free and was placed under the care of Professor Lee, I was put more at ease which in turn made me feel less panicked.

35. Since AZT I have been put on many different treatments for my HIV.

36. I was put on 3TC which I had to stop after a week as my mouth and lips become absolutely covered in painful ulcers.

37. After this I was put onto DDI which gave me terrible stomach pains. Under the care of Professor Margaret Johnson we discovered that DDI and AZT was a fairly effective combination.

38. In or about 1994//1995 I was moved onto Saquinavir, a protease inhibitor. This started to curl up my toenails so I had to stop taking it; however I suffered from the side effects for 7 months after stopping the treatment.

39. After this I took Kaletra for a long time which worked brilliantly with no problems, before I was moved onto Tenofovir and Ritonavir. The latter gives me a lot of stomach acid and indigestion which I take Lansoprazole to alleviate.

40. My viral count is presently undetectable and my CD4 count is up to the level of an ordinary person.

41. The treatment I have received for Hepatitis C has been significantly worse.

42. I was treated with Pegylated Interferon and Ribavirin for about 6 months. This involved injecting myself in the stomach and taking a tablet every day. I was warned by the staff at the Royal Free that it would be very tough. I had the worst fever I've ever had and I was warned that I may even start to feel suicidal. I was told that I should speak to them if I ever felt that way.

ANONYMOUS

43. The first 5 or 6 injections completely knocked me. I got very emotional and found myself crying for absolutely no reason. I had intrusive thoughts in my head and at night it felt like I was sleeping in a freezer despite being wrapped in 5 blankets because of the fever. I took paracetamol and folic acid whilst I was on the treatment.
44. These drugs absolutely ruined my life and the side effects continued for years. I am frightened about the long term affects that the Interferon may have had on me and what it has done to my brain as I still occasionally suffer from the side effects and get emotional for no apparent reason.
45. For a few months after the treatment my Hepatitis C viral load was undetectable but after a short while Dr Patch apologetically told me that my viral load was increasing. He explained that although the drugs had worked with some people I was a non-responder. I was absolutely devastated and this meant that the terrible year I had been through was all for nothing. I asked about more treatment but he said new treatments were years away. However he did tell me that there were signs of recovery in my liver following the period of decreased viral load which had been achieved by the treatment which was good news.
46. A short while after this (I believe around 2004) I began fainting out of the blue. I was told that I had internal bleeding and after some banding and a transfusion I was okay. However, a few months later the same thing happened again.
47. The doctors discovered that there was something wrong with my liver, and I had to have a stent put in my liver to keep the aorta open and stop the veins popping in my oesophagus. The surgery took 4 hours. The stent is monitored regularly.

ANONYMOUS

48. Around 2015 I received more treatment in a further attempt to clear the Hepatitis C. I was put on very expensive treatment for about 48 weeks. The funding needed to be approved by the Government before I was put on the medication but I was put forward for it by my doctors because I had cirrhosis so I did not struggle to obtain the treatment. I cannot recall the name of the treatment. Before I started the treatment I was told it had a 95% success rate. At that time I was under the care of Dr McDonald at the Royal Free.

49. After taking the drugs my viral load dropped immediately. At my 6 month review it was undetectable and after 5 tests I have now been told that I have cleared the virus.

50. I still have cirrhosis of the liver although apparently my liver is starting to improve. My liver is monitored regularly.

51. I am very selective about who I tell about my HIV infection due to the stigma surrounding the virus. My relationship with my ex-wife broke down when she realised she couldn't be with someone with HIV.

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ANONYMOUS

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GRO-B

55. I have never been able to work as a result of the combination of suffering from haemophilia, HIV and Hepatitis C. They also undoubtedly impacted my education.

Section 6. Treatment/care/support

56. I do not feel that I have had to fight for treatment. Even though the last treatment for Hepatitis C was expensive my doctors told me it would be sorted out because I met the criteria to receive it.

57. I was offered counselling at the Royal London in relation to my HIV diagnosis and was put in contact with a social worker called Nigel Harvey. This didn't last long as I felt that I wasn't really getting anywhere with him although I did find it beneficial having someone to talk to other than my parents.

Section 7. Financial Assistance

58. I was involved in the 1991 HIV litigation and received an initial payment of £20,000 followed by a top up from the MacFarlane Trust. I also received a monthly payment.

59. I was made to sign a waiver. I was told that if I signed I would receive the money within 2 weeks, but if I didn't I would receive nothing. I spoke to a

ANONYMOUS

lawyer who told me the Defendant wouldn't budge on the offer and I had no option other than to take it as I would be dead soon.

60. I have received the Stage 1 lump sum payment from the Skipton Fund.

61. I receive payments from the DLA and ESA, as well as housing benefits. With the upcoming implementation of Universal Credit I will soon be worse off in terms of the monthly payments I receive. It is frustrating for me to have to repeat the same tests and forms every time the financial schemes change as I suffer from an incurable disease.

62. I currently receive monthly payments from EIBSS who I have not encountered any problems with.

Section 8. Other Issues

63. I am not happy with the name of the England Infect Blood Support Scheme (EIBSS). My infections are something I have kept a secret for a long time and I think there could have been a more tactful name for the group.

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Anonymity, disclosure and redaction

64. I would like to be anonymous.

65. I do not want to be called to give oral evidence to the Inquiry.

ANONYMOUS

Statement of Truth

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

Signed GRO-B

Dated 6-12-18