Witness Name: GRO-B
Statement No:WITN1557001
ExhibitsWITN1557002:
Dated 20 March 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF GRO-B

I, GRO-B will say as follows:-

Section 1. Introduction

1. GRO-B

2. I was infected with HIV and Hepatitis C 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 from Haemophilia A classed as mild to moderate with a variable clotting factor averaging around 7%. I was diagnosed when I was about 10 years old as whilst I bruised a lot as a child it took them a while to determine that I was suffering from haemophilia.

5. I first received Factor VIII on 29 January 1979 for bleeding arising from loose milk teeth. I had training to receive home treatment but I don't recall ever having treatment at home; I would always go to Pembury Hospital for treatment where I was under the care of Dr Colin George Taylor or later GRO-B Hospital under the care of Doctor Winter .My Haemophilia Database records are exhibited at **WITN1557002.**

6. Neither I nor my parents were informed beforehand that there was any risk of being exposed to infection from receiving blood products. In 1985 my mother was told that the products were heat treated, but by this stage it was too late.

7. I first tested positive for HIV on 02 September 1985. I was called into Pembury hospital by Dr Taylor shortly after the positive test; who sat me down in a consulting room. I can't recall everything that he told me. I asked how long I had to live to which he told me most people with the virus live on average 18-24 months. I don't recall receiving any information as to the management of the condition but I do remember being told about possible routes of transmission, although I am not sure if this was at the initial meeting or later on.

8. After they told me I went home in shock and didn't go back to the haemophilia centre for another five years. HIV was all over the media at this time with the tombstone adverts on TV and it was a very frightening time. I next heard from the hospital in May 1990, and when I returned my care was taken over by a Dr Gillet; I never saw Dr Taylor again.

9. There are no entries in my medical records about being tested, my results or my appointment with Dr Taylor.

10. I was not told that I had been infected with Hepatitis C until around 1993 when I started attending the Kent Haemophilia Centre, initially in GRO-B and later at GRO-B Hospital. He mentioned the infection at a routine appointment and when he saw how shocked I looked it became clear to him that no one

had told me about the infection before. At the time this was just another thing to worry about and it was considered less of a problem than HIV.

11. I consider it completely appalling and irresponsible that I had likely been infected with Hepatitis C for a number of years without being told. I should have been informed about the infection as soon as it was diagnosed.

Section 3. Other Infections

12. I received a letter in 2004 from the hospital telling me that I may have been exposed to vCJD. I understand that there is not a reliable test for this virus and it remains a concern for me.

Section 4. Consent

13. I was told that they were going test me for HIV but I am not aware if they had already tested me before the last test.

14. I had no knowledge that they were testing me for Hepatitis C and therefore could not have consented to these tests.

15. It is possible that I was tested for the purposes of research in view of the above circumstances of being tested without Consent or knowledge.

Section 5. Impact of the Infection

16. Being told as a teenager that I only had a few years to live has had long term effects on me both socially and psychologically. I try to put it to the back of my mind and live a normal life; I just wanted to forget about it and only worry when something happened.

17. I considered the risks of passing HIV to someone I cared for, however small, to be unbearable and I made a decision to avoid sexual contact. As I later found out more about the virus, it seems to have been a sensible decision. I

have always carried this mind-set and have backed off from any relationship where I may have been getting 'too close'. There was never really a good time to tell a person that you have two conditions that could kill you both.

18. I underwent a splenectomy in 1998 as I suffered from Immune Thrombocytopenia, which is linked to HIV. Since this procedure I have had several bouts of sepsis, two of which required admission to the Intensive Care Unit. The first time I was admitted was in 2006 when I had severe sepsis and was showing signs of renal failure so I was kept in ICU for around five days.

19. The first time I was given treatment for Hepatitis C was in 2008. An error was made with the treatment as the Pegylated Interferon contraindicated one of the HIV drugs I was on and they should have changed it before hand. They therefore had to change my medication half way through the treatment and I only lasted 4-6 weeks, during which time I felt generally unwell, tired and physically sick.

20. I had my next batch of treatment with Pegylated Interferon in 2012 at King's College. I lasted on this treatment for around six months and suffered from the same side effects as before, as well as neutropenia and anaemia. At this time I also had a bought of sepsis. Whilst undergoing this treatment, I had to go to King's College in London to pick up my medication which was both difficult and expensive to do each week whilst undergoing the treatment. The treatment dropped the viral load but not as much as they wanted it to. I soldiered on but we weren't getting anywhere near the results they wanted so we decided to stop the treatment.

21. I was next treated in 2016 with a different medication, the name of which I cannot recall. I was on this treatment for three months. I felt generally unwell whilst on the treatment but definitely not as bad as when on the Interferon, which was the worst treatment I have ever had. Fortunately, this cleared the virus.

22. I've generally tolerated the side effects of the HIV medication pretty well, but the hospital were quite good at changing my medication if I started to suffer. I was particularly bad when taking Kaletra, which made me feel nauseous, tired and I suffered with diarrhoea.

23. I had a pacemaker fitted in 2016 as I suffered from heart block and atrial fibrillation. It is my understanding that these conditions have been linked with Interferon treatment. I also suffer from psoriasis which is stress related and likely a result of my treatments for Hepatitis C.

24. I have also been diagnosed with polycythaemia which requires me to undergo venesection fortnightly. Whilst this is not directly attributable to HIV or Hepatitis C, it is quite rare in someone my age. This could be an indication that my cells have aged prematurely, either due to my infections or long term treatment.

25. I have been on just about all of the available treatments for HIV and I do not believe I have suffered any real difficulties in accessing treatments.

26. It is possible I may have gone to university had I not been infected and told I had two years to live. Instead, I worked mainly in retail and worked my way up to department manager.

27. I have never able to plan long term financially as I frequently required time off work when I was ill. I currently do gardening jobs in the summer and I am a part-time carer for my father.

28. It is only my immediate family that know about my infection, but it's been incredibly worrying for them. My mother also worries about me being lonely.

29. I have not really suffered from the stigma of my infections as I have told so few people, although I remember being in hospital and overhearing a derogatory comment about AIDS as they didn't know that I suffered from HIV.

30. I worry about my future and I do feel lonely sometimes. I live at home with my parents and have no wife or children, I am not employed and I have a very small circle of friends. I feel a sense of loss to what my life could have been had I not been infected.

Section 6. Treatment/care/support

31. I was not offered any counselling when I was first diagnosed. I was offered counselling around 1993 but have resisted it as I am not really someone that likes to talk about it all.

32. I had a vicar contact me from Pembury and ask if I wanted someone to talk to, although I refused. I am not sure how he was even aware of my infection.

Section 7. Financial Assistance

33. I was party to the 1991 litigation and I was made to sign a waiver as I was told that if I didn't sign it then nobody would receive anything. At this stage I did not know about my Hepatitis C infection.

34. I think I was contacted by the MacFarlane Trust (MFT) after this. In or about 2004 I started receiving monthly payments from them they were not very much to begin with. I also received the winter fuel allowance. I have not applied for any more grants. I later received a second payment from the MFT and some top-up payments.

35. I received the £20,000 Stage One payment from the Skipton Fund.

36. It is difficult to obtain anything from EIBSS as I am unable to prove my earnings as I only do a few gardening jobs each summer. I am therefore

unable to claim top-up payments, an issue that the MFT were a lot more flexible and understanding on.

37. I was always made to feel like I had to beg for anything from the various schemes.

38. Had we received proper compensation, financial support would not be required by so many.

Section 8. Other Issues

39. I am unable to obtain life insurance which means I have never been able to get a mortgage. Travel insurance is extremely expensive and I think this is something that the Inquiry needs to consider.

40. I think we have been treated badly by politicians both here and in the US. The situation with Bill Clinton was disgusting – it was he who paid prisoners to give blood and then banned us from entering the US.

41. People need to be held accountable and people like Ken Clark should not be allowed to wriggle out of any responsibility.

Anonymity

42. I would like my statement to be anonymous and do not want to give oral evidence at the Inquiry.

Statement of Truth

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

Signed...... GRO-B

Dated 20-3-19