Witness Name: GRO-B
Statement No: WITN1666001
Exhibits: 0
Dated: April 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.

2. In 2017, my mother became ill with cancer. In order to care for her, I took voluntary redundancy from my role as a GRO-B at the GRO-B. Since she passed away, I have not returned to work.

3. I was infected with Hepatitis B and C as a result of receiving contaminated blood products. I have since cleared the viruses; however there is still an adverse impact on my health today.

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

Section 2. How infected

5. I suffer from Haemophilia A classed as mild with a clotting factor of 30%. I was diagnosed in 1978 as I had some teeth removed and started bleeding heavily. I was referred to Leeds Teaching Hospital St James in Leeds under the care of Doctor Swinburne where I was treated with Tranexamic Acid and tests were carried out which confirmed I was a Haemophiliac.

6. In 1980 I needed further dental extractions and I was treated at GRO-B Royal Infirmary where I was given Factor VIII Concentrate. I cannot recollect the name of the doctor who treated me.

7. As far as I am aware I only received Factor VIII Concentrate once in 1980, though I do not recall how many doses I was given. Since then, I have received Tranexamic Acid and DDAVP.

8. In 1996 I went to GRO-B University in GRO-B. Whilst there I felt unwell and lethargic so, in 1998, I went to a local doctor who referred me to the GRO-B GRO-B Hospital in GRO-B for a blood test. I attended for the results and was told by the doctor that the "good news" was that I did not have HIV, but the bad news was that I had been infected with Hepatitis B and Hepatitis C. I was informed that this was a serious chronic infection and that this could be one of the reasons for my lethargy. I was given literature about Hepatitis C and its effects.

9. When I received Factor VIII I was only nine and my parents have since passed away. As far as I am aware, my parents were not given any information beforehand about there being any risk of being exposed to infection from blood products.

10. The doctor told me that there may be treatment available at a later date, but that there was nothing they could do at the moment. They also gave me sexual health advice, such as to wear protection. I do not remember if we discussed the risk of transmission via other methods.

11. I consider the information I received to be inadequate and that it should have been provided to me earlier, bearing in mind that I had been infected twenty years prior. I believe that any damage would have been done by 1998. Had I not been for a blood test, nobody would ever have told me. When they did tell me, there was no investigation into how long I had been infected even though there was a high chance I could have infected others as well by then.

12. When I went for the blood test, I was only told they were testing me for HIV. I only found that out I had been tested for Hepatitis C when I received my results. The way those results were relayed to me was matter of fact with the emphasis very much on me being HIV negative. The doctor delivering the diagnosis seemed to be in a good mood because he was disclosing I did not have HIV. Of course, it was a relief not to have HIV, but at the end of the day, Hepatitis C was still a serious life changing illness.

13. In 2004, I underwent Interferon and Ribavirin treatment. I suffered throughout the treatment, but somehow I managed to pull through. Since then I cleared the virus, however I have suffered from joint problems for a number of years.

Section 3. Other Infections

14. In around 2004, I received a letter from the NHS out of the blue saying I was at risk of vCJD. I had seen adverts on the TV about it, so it came as a massive shock.

15. I remember when being told that I had Hepatitis B and C, that I may also have been exposed to Hepatitis A. I didn't know the difference between Hepatitis A, B and C, but I cleared Hepatitis A naturally and had antibodies for Hepatitis B which has cleared. I have also received booster vaccinations for Hepatitis B.

Section 4. Consent

16. I consented to being tested for HIV, but I did not consent to being, tested for Hepatitis C. To the best of my knowledge, I do not remember discussing Hepatitis C prior to the tests. If I had been told I would have researched into what it was. When I was diagnosed it came as a complete shock and I knew nothing about the virus.

17. I do not believe I have been tested for the purposes of research.

Section 5. Impact of the Infection

18. Generally the mental anguish of knowing that I have been infected with Hepatitis C as a result of receiving contaminated Factor VIII was enormous. The initial shock of finding out that I was positive through no fault of my own was devastating. I was obviously extremely anxious at the time as I was not aware of what being infected with Hepatitis C meant. I had never heard of it and all I was given to assist me were some leaflets. I was told that the hospital would follow up in the future. To be told that it was chronic and may not be cured made me extremely anxious. I did not know what would happen in the future to my health. I had read the literature and felt concerned about the possible impact on my liver and that it could potentially result in my death. I was still very young.

19. It was annoying because ever year since 1980, I had suffered headaches, aches and pains, and lethargy for which I had repeatedly gone to doctors, yet no one identified the virus. I know when my symptoms started as I recorded them from 1982 onwards. During those years, I was in a state of extreme tiredness and listlessness which, was not a nice way to have to live my teenage years. Even while at university, which was when I was first diagnosed, I struggled to cope with mild depression.

20. Following University, in the early 2000s, I returned to GRO-B and continued seeing consultants who monitored my Hepatitis C status. I was offered

treatment following a liver biopsy which showed signs of borderline scarring. Because I am a Haemophiliac, the biopsy had to be performed by the jugular vein in my neck.

21. The treatment was for a period of six months and involved self administering injections of Interferon and taking Ribavirin tablets. This was a gruelling treatment which made me feel very unwell especially in the first couple of days following the Interferon injections each week. I had to write off any socialising completely during that period of time.

22. For six months in 2004, I endured the clearance treatment. It is not pleasant injecting yourself. I experienced severe flu like symptoms alongside depression, tiredness and mood swings. I worked full time and would take the injection on Friday evening. For the next two days I would feel extremely ill and by Monday I had to go back to work, even though I was not feeling great. By Thursday I would have recovered, but then it was time to take the injection again. I became extremely angry and short-tempered as a result; I also started losing my concentration and lacked ambition. After 26 weeks of treatment, I was given the all clear, although when I was tested 6 months later I was told there was still a possibility of the Hepatitis C returning. After being tested again 12 months later, they informed me that I had definitely cleared it. I have annual appointments now to check my condition.

23. I feel as though I was made to wait until the Hepatitis C was progressing until I was allowed treatment. The choice of going on treatment was entirely mine, and I endured it in hopes of clearing the virus.

24. I do not know if there were treatments that ought to have been available. I know the newer treatment has less impact on the body, but in 2004, I was under the impression that the combination therapy of Interferon and Ribavirin was the only treatment.

25. I am registered with a National Health Service specialist dentist who deals only with Haemophilia patients. If I need any dental care, I contact that specialist. I have to tell clinicians and dentists that I had Hepatitis C.

26. In the past I have had a lot of problems with my teeth. Since the treatment, I feel as though they are decaying a lot quicker than they should and I require constant fillings. My teeth have also become much more brittle. Overall, I have more dental issues now than I used to.

27. From the day I was diagnosed, until treatment, in 2004 for five years I remained celibate. For me the possibility of passing on the virus to a partner was a serious concern. In fact, my infected status caused the break up of my then year long relationship, immediately after my diagnosis. It is very difficult for a young guy to tell a partner, "By the way, I have Hepatitis C so we have to take precautions during sex." It put me in a constant emotional turmoil. How could I say that to them? When was a good time to say that? Will they stop liking me? The media certainly did not help with the stigma and unfortunately, the gay community were at the forefront of the social stigma.

28. Because of the stigma associated with these blood borne diseases, I couldn't discuss my infection with my friends, especially in 1990s when there were so many concerns about sexually transmitted diseases such as HIV. I have a Catholic family background so my parents did not want to tell anyone about my infections as that would associate me with HIV so my extended family did not know. People would have assumed that I had been infected by sleeping around. It was stressful to keep this a secret as I had nobody to talk to about it. Only some of my friends were aware, however the wider community did not know. That way, I avoided the stigma.

29. When my parents were alive, and I told them about my Hepatitis C status, much like myself, they did not know anything about it. I briefly told them what it was after which they were concerned about my health. It was chronic and incurable, and they knew that. I was their only child and all they had. It was devastating for them, and that, in turn, impacted on me.

30. Since my symptoms of headaches and lethargy began at the young age of eleven, I believe I underachieved at school. I believe these symptoms were as a result of the Hepatitis C infection. Because of my health, I had to constantly go back and forth to the Hospital missing a lot of schooling. I attempted to go on to the sixth form and ended up failing two out of three A levels. As a result I had to go to college to repeat those A Levels which I then managed to pass. I believe failing my A levels the first time was due being unable to concentrate and the fatigue caused by the Hepatitis C. I was unable to retain information easily or to focus on my studies I had to have a lot of sleep during the daytime. By the time I went to University, I was 26. I studied Public Policy at the University of GRO-B and obtained a 2.1. After my diagnosis, I suffered a lot of anguish and anxiety as not only was it a hard hitting truth that I had a chronic disease, but I was also away from my family.

31. During the treatment, in 2004 I had discussions about opportunities for advancement at work. However because the treatment caused me to lose concentration, and generally made me extremely tired and unwell, I began to lack ambition and had to turn down offers of promotion. I worked for a large company with several branches as a GRO-B and promotion would have required me to go to the Head Office in a different city, but because my treatment was ongoing, and I was suffering from the above symptoms I needed to be close to the hospital and I felt I could not take on any more responsibility. Obviously, this meant I had turn down the opportunity to gain higher wages and more job security. I missed out on several offers of promotions, when I was young and fresh out of university, the ideal time to be progressing with your career

Section 6. Treatment/care/support

32. As far as I can recollect I was not offered any counselling or psychological support in consequence of being infected.

Section 7. Financial Assistance

33. In 2004 I received a Stage 1 payment of £20,000 from the Skipton Fund I do not recall how I was informed about them. As far as I am aware, I was not contacted about it by their representative and I may have sought the information myself.

34. I had to get my application form signed off by my consultant at the hospital who had to confirm my diagnosis. I go to my local Haemophilia Centre annually and often when I schedule my appointment, it does not always involve the consultant and they are not always easy to get a hold of.

35. I am currently receiving monthly payments from the EIBSS of £333 per month and because I am not presently working, I also receive a top up payment of £479 per month.

36. The process for applying the monthly payments is complicated, annoying and tiresome as you have to reapply every year knowing full well that they already possess the required information. Why should we have to do this? They should compensate us with no strings attached as we are the victims in this scandal. I feel that we seem to be begging for the little assistance they offer. If there are changes in your personal circumstances, then the policy should dictate that you notify someone rather than repeating the application process every year. It is far too bureaucratic.

37. Having spoken to acquaintances of mine, I know that the procedure to obtain a one off grant is even more difficult, although I have never applied myself. There is no information as to what is or is not be eligible for a grant.

38. One of the things, I have heard from others is that there is a lot of bureaucracy and attitude from representatives at the Trust/ Fund. There is a lot of proof needed before a claim can be approved. I have never spoken to the representatives at either institution, but I do get the impression that they

are not empathetic. They hold money but want to spend as little as possible, and they get away with that.

39. The amount given to us is unreasonable. I feel that as a minimum, it should match the amount of a living wage. Irrespective of how they are helping now, people have suffered for decades battling this disease. Personally, Hepatitis C took up thirty years of my life and has scarred me and left me with various problems today, so at the very least, I would expect them to pay us a minimum living wage.

40. I feel that these trusts were set up because it was the easiest option they could have taken to try and shut people up. They should have had a proper compensation scheme like they had in Ireland and liability should have been admitted.

Section 8. Other Issues

41. In my particular case, in 1978 the hospital treated me for my Haemophilia with a safe product successfully, and two years later, instead of using the successful safe treatment, they chose instead to treat me with Factor VIII Concentrate, which I believe the Authorities knew was infected and came from an untrustworthy source. Given that I responded well to the 1978 treatment because I was only a mild Haemophiliac, it is arguable that there was no need for me to be treated with Factor VIII treatment in the first place. My bleeding would have stopped in a couple of days had they done nothing, and that would have been better as I would not have been infected with Hepatitis C. It was not an emergency situation and was not a matter of life or death which might have necessitated them treating me with Factor VIII. The doctors simply used a treatment they knew or should have known there were issues with because it was a quick fix. Because of that one single dose, I have suffered for 40 years.

42. I would definitely welcome any disclosure of information that was kept form the Haemophiliac population by leading consultants about the dangers of

using Factor VIII blood products. Pharmaceutical companies certainly knew of the dangers. In 1977 David Owen said that it was imperative that the UK have their own supply of blood products, and this was ignored by the Government and indeed by successive Governments because of the need to save money.

43. Over the years I have followed the news on the infected blood scandal with great interest, especially in last 10 years. I wrote to MPs on numerous occasions to ask for investigations into the scandal, but all requests were brushed under the carpet and avoided. Successive Governments have done the bare minimum to shut those affected up, and in their desperate position the infected people have been unable to do anything. The Government should own up to their responsibilities. Ex Prime Minister David Cameron apologised for what happened, but still didn't do anything about it, and current Prime Minister Teresa May only did something as she was forced to by political pressure. They did things due to the pressure, but not because it was right to do so.

Anonymity

44. I would like to remain anonymous and do not wish to give oral evidence.

Statement of Truth

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

Signed... **GRO-B** ....

Dated........14.05.2019........