Witness Name: GRO-B
Statement No: WITN1157001
Exhibits: 0
Dated: 17 April 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF GRO-B

I, GRO-B will say as follows:-

Section 1. Introduction

1. GRO-B
GRO-B

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

3. I was infected with the Hepatitis C Virus (HCV) as a result of receiving contaminated blood products.

Section 2. How Affected

4. I suffer from Haemophilia A classed as mild. I was diagnosed when I was about 7 years old as I had a cyst removed that bled for a week, and my parents were advised to book an appointment with the Haemophilia Centre.

5. I have always been treated at the Royal Victoria Infirmary Hospital ("RVI") Haemophilia Centre in Newcastle upon Tyne, initially under the care of Doctor Peter Jones and now Doctor Talks. This is where I was treated and received Factor VIII blood products from when I was diagnosed as a Haemophiliac until the present time.

6. In or about 1997 I went for my annual check up at the RVI and had what I thought at the time was the usual blood phials taken, and my usual chat with Dr Jones. However, about 3 weeks later a letter arrived at home, informing me I had tested positive for Hepatitis C and requesting I contact the RVI. This came as a huge shock as I had not been told I was being tested for Hepatitis C and there had been no mention of this at any of my previous appointments. I was not aware of any risk of being exposed to Hepatitis C.

7. I arranged to see Dr Jones as requested, and he confirmed that I had tested positive for Hepatitis C but he could or would not tell me how long I had been infected. All I was told was "not to worry as it was not life threatening and go and lead a normal life, but it could lead to liver cancer or other diseases". He went on to tell me that he only knew "one person who had died from Hepatitis C, but they were a publican". This seemed contradictory to me, as it seemed like this death was being put down to the publican having been a heavy drinker due to his occupation, so if Hepatitis C wasn't life threating how had this person died from it?

8. Neither my parents nor I were given any information or advice before being given blood products that there was a risk of being exposed to infection.

9. I was not given adequate information to understand and manage the infection and I was not given any information about the risks of others being infected.

10. I should have been given adequate information to manage the infection and about the risks of others being infected when I was first infected. I also should have been provided with the information as to how long I had been infected.

Section 3. Other Infections

11. I was told by Dr Talks at a routine appointment that I was at risk of vCJD as a result of receiving contaminated blood.

Section 4. Consent

12. I believe I have been treated, and tested without my knowledge or consent and without being given adequate or full information, as I was not told I was being tested for Hepatitis C. I am not aware if I have been tested for the purposes of research.

Section 5. Impact of the Infection

13. I had been married for 6 years at the time of being told I had tested positive for HCV. I already had one child with another on the way and I was working within the GRO-B business. When I was told about my infection, it felt like a rug had been pulled from underneath my feet. This was made worse by the fact that I had already been told I was clear of HIV. Being told I was clear of HIV made me feel on top of the world. I had a good job and a healthy family and this news was devastating.

14. Being told I had HCV threw everything up in the air. My first thoughts were 'are my GRO-B and GRO-B going to be okay?' Will GRO-B be okay? Will I live long enough to see them grow up to be adults? Will I live to see their sports days?' If I had known about this information earlier, my life may have been quite different regarding having children and being married.

15. After I had been told, it became such a psychological burden for me. It was a constant worry. I could not stop thinking about the potential consequences this situation could bring. I could not concentrate on my job or my family life. I was getting a horrendous amount of acid reflux due to the fact that I was worrying about my infection so much. This got so bad at one stage that I was actually hospitalised for 5 days because I was producing so much acid that it burnt a hole in my stomach lining and I was vomiting blood, and there was

blood in my stools. This was all because of me getting extremely anxious about my HCV. I was then put on some tablets to help with the acid reflux, that I am still on some 18 years later.

16. In more recent years, I have had some joint problems such as hip and back problems which x-rays have revealed is arthritis that could be a potential side effect from the HCV.

17. It has been a constant battle virtually everyday with stress and anxiety. Just a mention of the word 'Hepatitis' sends a shiver down my spine. You think you are okay one minute then it just takes something small to set it all off again. I suffer from horrendous mood swings, one minute I am happy as anything, the next I am snapping at GRO-B. This has put a huge amount of strain on my marriage which has in turn led me to drink excessively at times, which only aggravates my HCV even more. It is a vicious cycle.

18. Drinking excessively was the only way I felt that I could deal with this horrible situation. Overall, it put even more strain on my marriage and eventually this led to a separation between us. We went from playing happy families to dungeons and dragons. I was then living on my own and this made me feel more stressed and anxious. I could not have cared less if I lived or died by this point. Thankfully, I was able to sort out my drinking problems and GRO-B and I have remained together to this day.

19. Back in 2007 I started a course of treatment for my HCV. It consisted of taking oral medication and injections for three months. However, I had to stop this treatment as the side effects were so bad. I suffered from depression and sleep deprivation, and I had to see a counsellor to discuss my problems. I still see someone to this day.

20. My depression got much worse following these symptoms. I did not go to work, I would sit indoors all day and bust into tears in front of my wife which was highly embarrassing. I did not want to speak to anyone and I was very short tempered all the time and with no energy.

21. After my unsuccessful treatment in 2007, I had regular appointments and various scans over the next few years until about 2013 when my doctor said there was a new treatment available which only consisted of tablets. After discussing this with my wife I decided to agree to being treated. I was approaching 50 years of age, so at my next appointment I told my doctor that I wished to start the treatment. He told me it was not as straight forward as just accepting the treatment because of the immense cost involved. I found this to be extremely unfair because I had been infected with something that I had not asked for. I believed that the treatment I received when I was younger for bumps and knocks was helping me, not infecting me with a deadly virus. Being told that the treatment that may cure me was too expensive was absolutely disgusting.

22. I then spoke to my consultant's registrar and they informed me that the Government was not making funds available to them. I could not get my head around this. It was the British Government who was at fault when they infected me with HCV, and now they are saying the treatment is not available. They were the ones responsible for this catastrophic medical blunder.

23. I asked the consultant if I was able to write a cheque for the cost of the treatment then would I be able to have the treatment? She said yes and after about a year of trying I did eventually receive treatment in 2016 which was thankfully successful.

24. I am still not convinced that the treatment has entirely worked. I still get anxious about the possibility that my HCV will return. I have been able to deal with these symptoms of stress and anxiety but it has still has a massive impact on my life, even after being given the all clear.

25. About two years ago I gave up working because I did not have the energy or the spark to continue to work. I also constantly worry about people finding out because there is still a massive stigma attached to HCV. I have heard people make passing comments in the pub, when something comes on the TV about contaminated blood infections. They say comments like "they are all faggots and should be dead". I heard this first hand when a famous TV star

was diagnosed with HIV. I have also heard people say "If one of them came in here I would take their pint off them and refuse to serve them". This has made me feel dirty and disgusting even though my infection was no fault of mine.

26. If I cut myself shaving, I get rid of the towel I have used to wipe the blood because I am so scared of my family being infected.

27. Overall, my life over the past 20 years has had a lot of ups and downs but a lot more downs. I have to explain myself and bare my sole to try and tell people how my infection has affected me. All I can say is that now that my HCV has been cleared, the mental scars still remain and cannot be forgotten.

28. It has left me stressed, anxious and my nerves feel shot at times. I used to enjoy playing golf, going walking and cycling; I used to find that doing these activities helped me to take my mind off of things.

29. I used to have GRO-B, but since being infected with HCV I have not been able to get myself out of bed to do the activities I have listed above. I find it disgusting that no one wants to take responsibility for what has happened.

30. I am now on anti-depressants to help me cope with my problems. Once every two weeks I see a psychologist.

31. I didn't tell GRO-B until they were old enough to understand it all. I told them just before my second course of treatment when GRO-B and my GRO-B.

32. The stigma attached to the virus means that it is something people haven't been able to shout from the rooftops about. We have been forced into silence.

Section 6. Treatment/care/support

33. I faced financial obstacles in trying to obtain the new treatment for my HCV. I have also had a good deal of counselling to help me cope with my problems.

Section 7. Financial Assistance

34. I received the Stage One Payment from the Skipton Fund after receiving a letter from them telling me that I would be eligible.

35. I receive monthly payments from EIBSS. I was informed about the EIBSS by one of the social workers at the RVI.

36. I was initially receiving £252 per month from EIBSS but it has now increased to around £1500 per month. It was a long winded process and I found it very uncomfortable having to explain in 500 words about how the virus has affected my life.

Section 8. Other Issues

37. It should not have taken this long to try and get justice. They should have made sure we were looked after, and financially secure for the rest of our lives as soon as it happened. We should not have had to feel like we had to beg for money.

38. I want to know why it happened. I want answers.

Anonymity, disclosure and redaction

39. I confirm I wish to be 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 17/4/2019