Witness Name: GRO-B
Statement No: WITN1784001
Exhibits:0
Dated: March 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 I was born on GRO-B and live at GRO-B GRO-B

2. I am GRO-B and have GRO-B I live with my GRO-B and my wife. I am not currently working as I am disabled.

3. I have a GRO-B My GRO-B is a GRO-B

4. 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

5. I was diagnosed with severe Haemophilia A when I was about GRO-B old.

6. I believe I started receiving Factor VIII concentrate (FVIII) in the GRO-B

7. The hospital administered FVIII to me for a while until my mother was taught how to do it. I required FVIII (prophylaxis) every other day in order to keep the bleeds under control. I now self-administer FVIII as and when I have a bleed.

8. I was mainly treated at the GRO-B in GRO-B Sometimes I was seen at GRO-B At both hospitals I was given FVIII. However, I believe I was infected at GRO-B When I was younger my mother was in charge of my care so unfortunately I do not remember much.

9. I was infected with Hepatitis C (Hep C) and I believe it was in or about GRO-B (at which time it was known as Non A Non B). However, I was not told about the infection until the GRO-B

10. In or about the GRO-B I attended a routine appointment and a consultant called GRO-B told me that I had tested positive for Hep C. He told that I had been given an infected batch of FVIII blood products in the GRO-B which was infected with Hep C. I could not believe that my mother and I were not told for almost GRO-B that I was given contaminated FVIII concentrate. The doctor told me not to worry it and that it was "just like having lumps on the liver". He said it was not done maliciously or on purpose. He also told me that I tested negative for HIV. I was in shock and did not know what to think. I was fairly young when I was told. My mother and I did not know that I was tested for Hep C or HIV. I thought all the routine blood tests that I had were in relation to my Haemophilia.

11. I was GRO-B years old at the time and my mother dealt with my hospital appointments. Until this day she does not know what actually happened to me and why I was given infected FVIII blood products. I believe that my mother should have been told that I was infected with Hep C there and then in the GRO-B instead of waiting until the GRO-B when the damage had already been done to my liver.

12. I believe that my parents were not provided with any information about the Hep C. I do not believe that my parents were given any information or advice beforehand about the risk of being exposed to any infections. We were told that FVIII was a life saving treatment. My parents trusted the doctors at the time and believed the advice that was given.

13. I do not believe that adequate information was provided to my parents to help us understand and manage the infection. As previously stated, we were initially told not to worry about it.

14. I was not told about the risks of others being infected until I was about GRO-B years old, when I had a routine doctor's appointment. I had to ask the doctor to give me information about the Hep C as he was not forthcoming about it and I wanted to know what I was dealing with.

Section 3. Other Infections

15. I do not know if I was infected with anything else other than Hep C.

16. I received a letter from the hospital a few years ago stating there was a possibility that I could have been exposed to vCJD. I asked the doctors about this and they downplayed it and told me not to worry about it. I believe it was wrong that the doctors downplayed it and pretended like nothing happened. I believe that they should have stopped giving me FVIII as soon as they were aware that the product was infected. I did not get any follow-up consultation regarding vCJD.

Section 4. Consent

17. I believe I was treated and tested without my knowledge. I had no clue that I was tested for Hep C and HIV until I was told of my test results in the GRO-B GRO-B

18. I do not remember providing my consent to be tested for HIV and Hep C and I do not believe my parents provided their consent either.

19. My parents and I knew that I was being treated with FVIII for my Haemophilia but I believe we were not provided with adequate or full information it.

20. I believe that people were given contaminated FVIII blood products in order to be tested for the purposes of research. I read that Chimpanzees were becoming very expensive and humans were cheaper, and so were used as PUPs (previously untreated patients).

Section 5. Impact of the Infection

21. I have suffered mentally throughout my life as a result of being infected with Hep C. I have always tried to keep my mental pain inside and tried to fight it off. I have been deteriorating from the very first day that I was infected as a child and then to be told by a doctor that my liver was also deteriorating made everything worse. I never knew what was going to happen to me and when it would happen which made me very panicky. I always felt up and down and cannot seem to live a normal life. As a result, I also suffer from depression and anxiety.

22. I also suffered physically as a result of the infection. My face became very thin and my stomach swelled up. I was always itchy and in constant pain. My sleep was also disturbed. Even though I have been told that the infection is not in my body anymore, the damage was still done to my liver as I had the infection for almost GRO-B years. Just doing something small makes me very tired. I also have fatigue and discomfort in my back and I also suffer from severe arthritis. I feel very poorly due to living with a silent killer for over GRO-B years. I believe that all the above symptoms are as a result of the infection.

23. When I was about GRO-B years old, I was offered Interferon treatment. I was told that I had to inject it into my legs. I started the treatment and had to stop it soon after as I could not endure the pain as a Haemophiliac, as I would bleed. My legs swelled up like balloons. I was then told to inject it into my arms which also swelled up like balloons so I stopped the treatment all together.

24. In or about GRO-B I was offered a 4 week course of Harvoni treatment. This treatment cleared the Hep C. However, I still feel quite ill, as if the infection is still inside me. From my research, I found out that you cannot get rid of Hep C, it is just dormant. The doctors never told me that you cannot completely clear the Hep C. Every time I get a stomach ache, I feel like the Hep C has come back. The infection always plays on my mind and I think to myself all the time that I may have to go through it all again.

25. I faced some difficulties in accessing Harvoni treatment at the beginning. I asked the doctors if I could start the treatment with Harvoni when it initially came out and I was told that it was too expensive to be given to me. It was not until about 2/3 years later that the NHS agreed to pay for the treatment. I believe that the treatment should have been given to me as soon as it became available.

26. I recall there was another treatment available at the same time, but I was not offered it as the doctor told me that it was making people very sick. I cannot remember the name of the treatment.

27. I suffered mental and physical effects as a result of the Interferon treatment that I initially received. I was unable to get out of bed and walk because my legs were so swollen from the injections. I was bedbound and it was really getting me down. I also lost my appetite. I did not want to take the Interferon but the doctors were pushing me to take it. I think the treatment did more damage than the infection itself. I was devastated at the time when I realised that the treatment was not working for me. I thought I was going to die young so I tried to live my life as if everyday was my last.

28. The Harvoni treatment made me feel tired but the effects were not as bad as the Interferon treatment. I felt like my stomach was shrinking, which was a good thing. I still feel itchy sometimes and I believe the treatment affected my immune system.

29. My dental care has been impacted as a result of the infection. I was stigmatised by the dentists when they found out that I had Hep C. They

looked at me as if I was dirty. The last dentist I saw, asked me how long I have been using drugs. I was so shocked that people still related Hep C to drug users and had little knowledge about the Contaminated Blood Scandal. I recall another incident when a nurse at the hospital asked me the same thing, 'how long had I been a drug user'. As a result, I now wait until my teeth become really bad before I go to the hospital for dental treatment.

30. As a result of the infection, my private, family and social life was impacted on. I told my wife everything that I knew about the infection and she accepted it which was why we got married. She has always been there for me, but there was a time when we separated due to all the stress whilst I was campaigning. It got in the way of our life as a married couple. It was too much and we went our separate ways for a short period. We are now back together.

31. I was scared to leave anything behind such as a small cotton bud with my blood on it. It was a constant worry for me at the time and it still is even though I have been cleared of Hep C. I had to change the way I lived and always weary. I felt like a leper in my own house and as a result I have never really had a social life. I have never had a big circle of friends, just a few friends who have been there for me.

32. As a result of the Hep C, my mother was devastated as she thought she could have done more. She blames herself even now for what happened to me. My father thinks he should have done more as he did not come to as many hospital appointments as he wanted to. All my parents wanted was what was best for me.

33. When my children were younger, they knew that I was sick but we did not tell them the cause of the illness as we did not want to worry them. We told them about the Hep C and how I was infected when they were much older and they were very shocked.

34. There was and is definitely a stigma attached to Hep C. There has only ever been one doctor that has kept his voice down when speaking to me. The others just talk out loud about the infection as if I am nothing and do not give

me any privacy regarding it. At the time, the media portrayed the infection as something you got as a result of the lifestyle that you lead. The media also portrayed it as if Haemophiliacs were going to die as a result of the infection. I therefore kept my Haemophilia private. Even now, I believe people do not understand what Haemophilia is and I have to educate them.

35. I have suffered educational effects as a result of the Hep C. I studied business studies and wanted to pursue a career in it, but could not continue the course as I became sick because of the infection. I was unable to do my exams as all I could think about was the infection and how it would affect me, I just could not concentrate. I just said to myself that I would live each day as if it was my last.

36. I also suffered work related and financial effects as a result of the Hep C. If I had not been infected with Hep C, I could have had an education and a good job.

Section 6. Treatment/care/support

37. I attended appointments approximately 6 months to a year to monitor the Hep C, but I do not think it was good enough. I believe I should be offered monthly appointments or at least 3 monthly appointments as the Hep C could come back any day. I believe the doctors could have done a better job in providing me with care and support. I felt that I was left to deal with it all on my own.

38. I was offered counselling about 3 years ago which I took. It helped me to take quite a lot of things off my chest. It also helped me to realise that I should not blame myself for what happened as it was not my fault. I believe my life would have been different now had counselling been offered a lot earlier, when I was told that I tested positive for it.

Section 7. Financial Assistance

39. In the GRO-B I received a Stage 1 lump sum payment of £20,000 from the Skipton Fund. The process was quite long winded. I found out about the

Fund through friends and Facebook. It would have been nice if I was told by the hospital and financial assistance was available.

40. I have also received grants from the Caxton Foundation. I have received funds for mattresses. I did not get the full amount that I requested from the Foundation, it was knocked down a little bit, which was disappointing.

41. I currently receive £1,500 a month from the EIBSS as a Special Category Mechanism. I started to receive this sum from GRO-B The process of applying was quite complicated. They wanted to know everything about my financial situation and were digging for more and more information even though I provided them with everything that I had. I believe the EIBSS were trying to find a way to make people ineligible for payments.

42. I was also receiving an extra £250 top up payment but since my daughter started working, I did not reapply for the top up as we would have been refused. I believe this amount was to assist with children who were still dependent.

43. I believe that the Funds and Trusts set up are unfit for their purpose. I believe infected people should assist with the Funds and Trusts as they know exactly what other infected people are going through.

44. I believe the people who run the Trusts and Funds have no medical knowledge. It is common knowledge that Hep C causes pain in your back and so you need special mattresses, but the staff at the Trust and Fund do not understand this.

45. I was infected the same way as everyone else. Although I only had Hep C whereas others had other infections, I do not understand why I should receive less financial assistance than them.

Section 8. Other Issues

46. Through this Inquiry, I want justice for everyone, not just Haemophiliacs but also those who had been infected through blood transfusions. I have waited 30 years for someone to take responsibility.

47. I want them to put their hands up and look after the people they caused problems for.

Anonymity, disclosure and redaction

48. I wish to remain anonymous.

49. I 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 21/3/19