Witness Name: GRO-B
Statement No:WITN1103001
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. I was born on the GRO-B and I live at GRO-B I am married with a young GRO-B and I am currently employed.

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

Section 2. How Infected

3. I was misdiagnosed with mild Haemophilia A at approximately 6 weeks after birth.

4. I was treated at the Haemophilia Centre at GRO-B GRO-B until I was 18 years old. I was under the care of GRO-B in the 1980's and GRO-B in the 1990's. My care was transferred to GRO-B GRO-B when I turned 18. I was told at this hospital that I did not have Haemophilia.

5. To my knowledge I believe I was treated with Factor VIII (FVIII) on many occasions for approximately 5 years, but there were two major occasions that I was given a lot of FVIII. The first was just after I was born while undergoing an operation in GRO-B. The second was when I was being treated for a GRO-B as an inpatient in GRO-B; this was the last time I remember receiving FVIII.

6. I do not believe that my parents were told beforehand about the risk of infection from FVIII concentrates.

7. I was infected with Hepatitis C (Hep C) as a result of being given FVIII concentrates.

8. From my understanding somewhere between GRO-B said that my family needed to be tested for HIV and Hep C. We were all tested and thankfully none of my family members were HIV or Hep C positive. However, I tested positive for Hep C.

9. I do not believe I was provided with adequate information. My family and I were given little information about what Hep C was and a bleak picture was painted. I believe that information should have been provided to me earlier.

10. The information I was provided was not professional. I remember at the age of about GRO-B years old I was told that I would be dead by the age of 30. This was devastating news to be told and I had long lasting mental health implications that I still struggle with to this day. They must have been guessing that I would be dead so to relay that to an adolescent was unprofessional. We were not given specific instructions on how to manage the infection. I just felt I was left to deal with it.

11. I was given adequate information about others being infected as all of my family was tested.

Section 3. Other Infections

12. There were discussions about vCJD and other blood infections when my family were told that they needed to be tested for HIV and Hep C. I did not receive any information about vCJD personally. I do not believe that I have received any other infections as a result of the infected blood products.

Section 4. Consent

13. It is difficult to say if I was treated and tested without my knowledge because blood tests were taken from me as a normal procedure.

14. I cannot honestly say I remember any discussions about research taking place.

Section 5. Impact of the Infection

15. I cannot understate the significance of how my infected status has negatively impacted my life both mentally and physically in my personal and professional life.

16. Since I was a teenager I have coped with fatigue, anxiety, panic disorder and depression, all as a direct result of the Hep C. For the past GRO-B years I have received medication for the depression that I have suffered.

17. I had a liver biopsy in GRO-B and it showed I had scarring on my liver. I was not expecting to hear such news at the age of GRO-B

18. As a result of having Hep C for so long it is realistic to think that there will be a long lasting affect or any other medical complication in the future. Only time will tell.

19. I have had two courses of treatments to clear the Hep C. I first had Interferon treatment in GRO-B This treatment involved injecting myself 3 times a week for a year. I undertook the treatment for 11 months but it was showing no signs of success so the doctors stopped it a month early. In GRO-B I was offered a combination treatment of Interferon and Ribavirin at GRO-B This

course was for 1 year, which I completed and it successfully cleared the Hep C.

20. I faced difficulties getting the first Interferon treatment. In the early/mid GRO-B when I was first diagnosed I was told by the doctors that there was no cure for Hep C but shortly after the doctors said there was a wonder drug, which was being used in the USA. However, the NHS would not fund the treatment and they suggested that I should consider funding it privately myself. It was clear there was treatment available and it should have been offered to me.

21. The treatments had huge side effects on both occasions. I immediately lost a huge amount of weight, had flu-like symptoms, depression, anxiety, psoriasis and an over active thyroid. I was told I would lose my hair so I immediately cut my hair. I also had anger management issues, which started near the end of the treatment.

22. Being infected with Hep C had an impact on my treatment and care with other health services. A number of dentists' have refused to treat me for years. I have now found a private dentist that would treat me.

23. Being infected with Hep C had a massive impact on my private and family life. I could not develop relationships as a teenager like my peers and any relationships I did form ended when I said I had Hep C. It has not become any easier breaking the news to a partner that I had Hep C. On one occasion a partner asked to go to a sexual health clinic to discuss the infection further with a doctor. The consultant did not understand that with treatment Hep C could be cleared and he said that I had made it all up. This was a very difficult time for me. It was embarrassing for my partner to hear it. I felt the stigma that was attached to the Hep C and it was really horrible. I found it difficult to leave the house.

24. There was a massive stigma associated with Hep C. Everyone at my school knew I was infected because I was taking so much time off as a result of the treatment. Being tarnished with what was then deemed as an STD greatly

impacted my life. I was being bullied at school and having personal relationships ended at a time of emotional development.

25. Being treated with Interferon negatively impacted my GCSE's at school and subsequently my career later on in life. With everything going on, trying to get my head down in school was incredibly difficult. I started the treatment 1 week before my mock exams. The school asked if I wanted my GCSE's to be considered in a different way which I refused at the time due to my pride. I ended up with 7 C's but this was a lot lower than what was expected. This had a knock on effect as I could not go to university at the same time as my peers because I was pushed back.

26. During the second course of treatment I had to give up my job because of the treatment. My struggles with anxiety have also caused problems in my career progression. I was performing live music but I had to give it up because of the anxiety.

27. I lost salary from work and spent a huge amount of money on counselling. This had a financial impact on me.

28. The impact of this scandal was significant to me personally and to my family emotionally. Coming to terms with my infected status was hard for my parents. My parents split up and my sister left home because the pressure of it all was horrid. It greatly impacted my whole family, particularly my father, who struggled greatly with the burden of guilt and as a result became an GRO-B He died as a result of this in GRO-B aged GRO-B.

Section 6. Treatment/care/support

29. As mentioned above there was a period of time where it was positioned that I would have to pay for the treatment, privately.

30. The GRO-B was much more proactive with providing treatment in a timely fashion whereas with the GRO-B felt like they were holding it off.

31. From memory the first time I had Interferon treatment at the hospital I had a counselor but she was inexperienced and did not provide much support or advice. After this the only support I received was support that I paid for myself. I have had CBT on and off since I was 18 years old. This treatment was intensive in GRO-B and I did it alongside normal counselling.

Section 7. Financial Assistance

32. I believe I found out about the Skipton Fund from the consultant at the hospital.

33. I received an ex gratia payment of £20,000 via the Skipton Fund in 2004 or 2005.

34. I do not believe I faced any difficulties receiving this money.

35. I do not know if there were any preconditions imposed when making the application.

36. I accepted the compensation because I felt like I had no other option as I was undertaking the treatment at the time and I had to give up my job. £20,000 is not even close to making up for the impact the infection had on my family's lives.

Section 8. Other Issues

37. The Department of Health sent me a written apology in 2010. It was a random letter. I was surprised to receive such a letter.

38. I do not have any medical records in my possession. I moved to a new area and my medical records got transferred but within a couple of months the surgery burnt down and I believe my physical records were in the building. There may be electronic records but I am not sure.

39. Circa 1993, Dr Williams at BCH told me that they had lost my medical records and made a big deal stating that they had been looked for over some weeks and then came back saying they were lost.

Anonymity, disclosure and redaction

40. I confirm that I wish to apply for anonymity.

41. 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 29/4/2019