Witness Name: GRO-B
Statement No: WITN1254001
Exhibits: 0
Dated: January 2020

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF GRO-B GRO-B

I, GRO-B will say as follows:-

Section 1. Introduction

1. My name is GRO-B. My date of birth is GRO-B and I live at GRO-B GRO-B. I am married with two children.

2. 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

3. I was diagnosed at birth with moderate Haemophilia A. My elder brother, GRO-B: B was also a Haemophiliac. Haemophilia does not run in our family, and there was no knowledge of the condition prior to my brother. It is my belief that I was tested because my elder brother was a Haemophiliac.

4. I received Factor VIII Concentrate (FVIII) at the

Manchester Royal Infirmary (MRI) and I believe I was treated there from birth until 1989. Unfortunately I do not know the name of the products that I was treated with.

5. As I suffer from moderate haemophilia, I only received treatment when I had an injury. As a child I had a lot of problems with my teeth. There was no particular big incident that I needed treatment for, but I do remember being treated on multiple occasions. I do not remember the names of the treating doctors as I was often treated by different doctors.

6. Prior to being treated with FVIII I was treated with cryoprecipitate and possibly blood transfusions, but this would have been very early on.

7. I believe I was treated with infected blood products between 1970 and 1984. The MRI confirmed this when they completed their section of the Skipton Fund application for Stage 1 payment.

8. I do not recall being given any advice beforehand about the risk of being exposed to infection prior to using the blood products.

9. As a result of being given FVIII blood products, I was infected with Hepatitis C (Hep C).

10. In or about the mid 1990s I was called by the MRI to be tested for Hep C. It was confirmed that I tested positive for it. I don't recall that much, if any, advice was provided at the time of the test result. I sought out my own information about the infection from other sources and through my own research. My wife was tested on more than one occasion and she always tested negative.

11. I do not recall being given any adequate information or advice to help me understand and manage the infection. I wouldn't have died had I not been treated with FVIII so had I known the risks, I would never have agreed to the FVIII treatments. In the early 2000s I went to GRO-B in

GRO-B to get some advice on the infection, which was very helpful. Prior to this, I had to do everything off my own back.

12. When my wife and I had decided to have children, the doctors ensured to test my wife. As stated above, she tested negative for Hep C.

13. If the doctors didn't know that I had Hep C, they must have known early that it was very likely I had been infected with an infection; especially because I read in an article the infection rates at the MRI were incredibly high (80-90% of Haemophiliacs infected with Hep C and about 45% of Haemophiliacs infected with HIV).

14. I knew before I was told of the infection that it was highly likely I had been infected. It would have made little difference how they told me, as it had still happened. It would have been easier had they given me more information on the risks of passing on the infection. It was a massive worry for my wife and I and we read a lot of conflicting advice. I do not know what the level of knowledge the doctors had surrounding the infection, but everything my wife and I found out was by our own volition. It was a worrying time when we were trying to start a family.

Section 3. Other Infections

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

Section 4. Consent

16. I do not believe I was ever treated or tested without my consent. I remember being called by the MRI to be tested for HIV when the media started covering HIV/AIDS.

17. If they had known about the risk of infection as a result of FVIII treatment they should have fully advised us of the risks, or not treated us with it at

all.

18. To my knowledge, I was not treated for the purposes of research.

Section 5. Impact of the Infection

19. My wife and I were worried about having children and the risk of Hep C transmission via sexual intercourse. We did have two children and fortunately the infection was not transmitted to any of my family members.

20. It was a worrying and stressful time for me living with Hep C for 30 years. Similarly it was a worrying time for my wife, particularly with two young children to look after. I had to undergo regular blood LFT tests and liver ultrasound scans to monitor the disease progression, which again was worrying.

21. I was incredibly lucky as I did not noticeably suffer physically whilst being infected with Hep C. The main problem was dealing with the mental stress of carrying such an illness, and working out how to manage it through life.

22. I do not believe I had any further medical complications from the infection at that point. Currently my liver seems to be okay and I have now cleared the virus, following treatment but who knows what the future holds.

23. In or about the mid 2000s I was treated with Interferon and Ribavirin. I had to inject myself three times a week for four months. The physical effects were those of a severe dose of flu and violent shivering for hours after each injection. I was also constantly fatigued. I also suffered from psychological effects including anxiety and depression, which were likely caused by the Ribavirin. I carried on working during this period

but I was clearly under-par throughout. Unfortunately the treatment was not successful in clearing the virus and it was discontinued after 4 months. I was very disappointed, worried and depressed with the outcome because of all the pain I suffered whilst I was on the treatment.

24. The Ribavirin was very unpleasant; I remember being very unwell and thankfully I had a very understanding employer. To find out that I went through all of this, and it didn't work was incredibly difficult to come to terms with. I took a few days sick leave whilst on the treatment. I tried not to take much time off work during the period.

25. In or about 2016/2017 I was treated with a second course of treatment with Harvoni and Ribavirin. This was a six month course of tablets. I had no physical effects from this treatment that I recall but I had increased anxiety which I believe were worse than when I was treated with Interferon/Ribavirin combination. As a result I retired early from work. This treatment was successful with results in 2017 and 2018 showing that the virus had been cleared.

26. The Harvoni combination treatment was far easier to deal with than the Interferon combination treatment. It however played with my mind and it accelerated my anxiety. I was considering retiring at the time, and it just drove me to commit to it. I retired probably a year earlier then I would have done. I was struggling to make decisions at the time, and I felt anxious about my work, it just made me feel like I had enough.

27. I feel like I am definitely more anxious than I was prior to having any of the above treatments.

28. Shortly after taking the Interferon, I suffered from Coeliac disease and it is my belief that this was as a result of the Interferon treatment, as I did not have any symptoms prior to the treatment.

29. I did not get the above treatment through the NHS because I moved to GRO-B and therefore

received the treatment in GRO-B. They have treated me very well here. All my treatment was free from the GRO-B medical services.

30. I didn't have any problems in accessing the treatment and as a result I feel privileged. I find it outrageous that any haemophiliac who has been infected has had to either fight to get treatment or has been refused such treatment.

31. My wife had to carry the burden of knowing I was infected and deal with the possibility of being infected too. Outside of this, we didn't really tell anyone about the infection. Most people don't know that I am a haemophiliac and I kept that to myself as I didn't want anyone to put two and two together. It has not really affected my social life, I was only affected physically and mentally when I was on treatment/s and following the treatments as stated above.

32. The financial effects were related to difficulties in obtaining life insurance and the consequences of this for obtaining a mortgage. I managed to navigate through this but it did restrict my options. I did manage to get life insurance, (but only for a very small amount), and worked out a mortgage but it made my life far more stressful.

33. I was always nervous about changes in employment because of the medical exams and/or disclosures required by the employers. I was employed throughout but I felt that my options were limited because of my infection. It meant that I never really felt I could consider moving on, or go into a new job. I was always a bit tentative, not wanting to raise the issues.

34. As stated above, my brother was a haemophilic and I believe he had moderate/severe Haemophilia A. B died in B aged B He was also treated with FVIII and I believe he required more treatment more often. As a result of being treated with FVIII B was infected with Hep C. However, he had a number of health issues, to

include diabetes, which were exacerbated by the infection. I believe he suffered from the infection more severely than I did. I don't believe he was ever treated for Hep C and I believe he was still infected when he died.

Section 6. Treatment/care/support

35. I have received some help from the NHS, but the help that I received in GRO-B has been really good in relation to providing me with treatment.

36. Counselling was never offered to me and I never sought it out. I'm not sure whether it would have helped but I believe it should have been offered when I was going through treatment.

Section 7. Financial Assistance

37. As stated above, I received a Stage 1 payment in the sum of £20,000 from the Skipton Fund and more recently an annual payment of £4,500 pa from the Skipton Fund and then later received from the EIBSS. The annual payments were increased to £18,500 last year.

38. I think I heard about Skipton Fund from the Haemophilia Society News Letters and National Press.

39. The process of applying for the Skipton Fund was okay and straight forward. I did not have difficulties getting the money, but I was helped by the MRI.

40. I do not believe there were any pre-conditions surrounding the Skipton Fund application and I was not made to sign any waivers.

41. I don't believe that those infected should have had to rely on charitable trusts like the Skipton Fund. The UK Government should have moved quickly to

provide proper compensation as Governments in most other countries have done (e.g Ireland and France). It appears that only the threat of imminent legal action has forced the Government to convene this Inquiry.

Anonymity, disclosure and redaction

42. I wish to remain anonymous.

43. I do not wish to provide oral evidence to the Inquiry.

Statement of Truth

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

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

Dated 26/01/20