Witness Name: GRO-B
Statement No: WITN1539001
Exhibits: 0
Dated: May 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. I live at GRO-B. I work part-time at my friend's sports company.

2. **This witness statement has been prepared without the benefit of access to my 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 suffer from mild Haemophilia A.

4. I received Cryoprecipitate alongside Factor VIII from birth. However, in 1986 I developed an allergy to Cryoprecipitate and I stopped it and I only received

Factor VIII concentrate. I continued with Factor VIII concentrate in order to manage my Haemophilia until I started the DDAVPP home treatment. I still receive Factor VIII for serious bleeds.

5. As a child I was treated at Peterborough District Hospital by Dr Fairham and Dr Jones.

6. I had to attend the Haemophilia Centre at Addenbrooke's Hospital on a regular basis because Peterborough District Hospital did not have a Haemophilia Centre. I recall that I was treated by Dr Chalmers, Dr Seaman and Dr Baglin.

7. I was infected with Hepatitis C (HCV) as a result of being given contaminated blood products however I am not sure when I was infected and it could have been over a long period of time.

8. As far as I am aware my parents were never given any information about the risks associated with these products.

9. My mother first became concerned having seen the news articles about haemophiliacs who received blood products being infected and she requested that I have a HCV and HIV test. My mother asked the doctor but he refused to do a test and essentially brushed her concerns under the carpet. We were discouraged from asking any questions and even when we did they were not answered properly and we were not told the truth.

10. My mother thinks I was around 14 years old when a doctor (who was covering one of my appointments from a different hospital) told me that I should be tested for various infections as some haemophiliacs had been given contaminated blood. I was tested and I think I received the results at Peterborough Hospital. I was not provided with any information about how to manage the infection and the way my infected status was communicated to me was horrendous. I should have been given a lot more substantive information about the infection.

11. My mother asked if the HCV infection could harm me and the doctors hesitated and said "*yes, maybe*". I did not feel ill at that time so I just switched off from it and I didn't really think about it.

12. The risks associated with HCV and how to ensure that I did not infect anyone else should have been explained to me and my parents. We were not given any information we just had to deal with it ourselves.

Section 3. Other Infections

13. I do not believe I received any other infections.

Section 4. Consent

14. We had to push to be tested for HCV, so I do not think I was tested without my knowledge or consent. However, I do not know if they tested me before this point and did not inform me of the tests or the results.

15. I regularly had blood tests and I never received clear test results back. I find it strange that the HCV was not detected during any of these tests. The doctors were very shady and I really believe I was tested for research purposes. I also believe that someone knew earlier and we were deliberately not told.

Section 5. Impact of the Infection

16. The mental effects of the HCV for me were enormous. It took me a long time to take my infected status on board and to start with I just blanked it out. When the doctors told me not to drink alcohol when I was approximately 18 years old I found it really hard. I really struggled to accept the seriousness of the condition. My behaviour was too wild and I thought it would not make a difference anyway so I carried on doing what I was doing.

17. One of the biggest things that I remember was that we had to be so secretive all the time. I was not allowed to tell my family what was happening. Luckily we were a close family and I remember having a 'no drinking for a year' party. I remember we had to lie to everyone and we told them that I was not able to drink because of the Haemophilia treatment as it would affect my liver. I really remember how difficult it was not being able to tell my friends what I was going through.

18. In terms of the physical effects I think it is quite difficult to quantify. I am 40 years old now and I do not know if the way that I am feeling is a result of the HCV or as result of my age.

19. When I was first diagnosed with HCV, the doctors did not discuss any treatment options with me. I do not think I faced any difficulties accessing the treatment when it became available. I used to attend Addenbrooke's Hospital every 6 months and they would talk to me about the treatment options available to me but I kept putting it off because I heard about the awful side effects. I did not want to have treatment that was going to make me ill. I had to have a liver biopsy every year to keep an eye on my condition. In my mind I was going to think about the treatment until my liver showed signs of getting worse.

20. As a result of the HCV I had to have liver biopsies and it was very scary. I was worried when I was preparing for it and I was anxious when I was on the ward. The first liver biopsy I had caused me a lot of pain.

21. I did start the treatment in 2012 and I was well up until that point. I was on Ribavirin and Interferon for over a year. The build up to the treatment was horrendous and it zapped me out a little but compared to some people's experiences it was not too bad. I did not suffer from sickness like other people did. I noticed I was a lot more tired but I still tried to keep as active as I could.

22. Luckily when I was on the treatment I was able to work full time. However, when I had to go into hospital for the treatment it was very hard to explain to

my colleagues why I was so ill. I did not tell anyone at work about my HCV status other than my boss because it was not something I wanted to share with anyone.

23. With regards to dental care, I went to the dentist a couple of years ago and when I was completing the forms I had to disclose my HCV diagnosis. It was horrible having to put it on the form because there is still such a stigma attached to it.

24. I did not tell my ex wife about the HCV until we were in a serious relationship and I felt bad about keeping it a secret. We had been together for 5 or 6 years before we got married and in the back of my mind I always knew we could not have children because I did not want to risk infecting her. It was a very strange and hard time in my life. My wife and I were told we could not try for a child until 3 years after the treatment had finished and this caused so many problems in our relationship. In the end it was all too much for our marriage and we split up in 2010 before I even had the treatment. I am now in a new relationship and it also took me a long time before I told her.

25. Being infected with HCV has prevented me from having children. If I was not infected I would have probably had children. I try to not dwell on my infected status but when I think about it life probably would have been very different.

26. I do feel in many ways that I am lucky because I have a small family and we have all stuck together. The whole situation has had a massive impact on my parents as well.

27. The stigma has had a big impact on me because people automatically assumed people caught it through sex or drugs. My close family did not know and it should not have been like that. When you are dealing with something so awful you should be able to have your friends and family support you. I did not even tell my own brother because I did not want him to worry about me.

28. It is hard to know the extent that I suffered at school because I am not a natural brain box. I did not feel ill and I tried not to let it affect me too much. However it affected me in junior school when it became public knowledge and it was reported on the news because children were not allowed to play with me. I tried to be happy and carry on but it wasn't always easy.

29. The HCV and the subsequent treatment has of course affected my career. When I had the treatment it physically took its toll on me at work. I was in the same job for a long time so it was hard to make the decision to leave. It was only when I finished the treatment I realised I did not want to go back to the same job. I thought I wasn't doing the job justice so I looked for another job which would be more suitable.

30. The HCV has also had major financial implications for me. I still earn money but I work fewer hours due to my health and I rely on my partner to support me a lot more than I would have.

Section 6. Treatment/care/support

31. Addenbrooke's Hospital offered me counselling at the time of the treatment but I did not feel like I needed it.

Section 7. Financial Assistance

32. In 2005 I received £20,000 for the stage 1 payment from the Skipton Fund.

33. I currently receive the EIBISS payment which is £1,500 a month. This was approved last year in around March or April. Before this I received around £300 a month.

34. It was hard work getting the payments approved. It was only because my partner forced me to apply that I bothered. I thought it was not worth it. I had

heard lots of stories about people who were made to jump through hoops only to be turned down.

Section 8. Other Issues

35. I have requested my medical records from the hospital but I am still waiting to receive them.

36. I would like to see the Inquiry establish the truth about what really happened and why it was allowed to happen. I think it is important to understand why everything was hushed by the doctors and what they were really doing with their patients.

Anonymity, disclosure and redaction

37. I am seeking anonymity and would like my statement redacted before publication. However I understand this statement will be published and disclosed as part of the Inquiry. I do not want to give oral evidence to the Inquiry

Statement of Truth

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

Signed. GRO-B ………………

Dated……17/6/19…………………………