Witness Name: GRO-B
Statement No: WITN1736001
Exhibits: WITN1736002
Dated: February 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 I am GRO-B years old. I live with my partner of sixteen years, at GRO-B GRO-B

2. I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006. GRO-B GRO-B

3. This witness statement has been prepared with 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 exhibited to this statement.

Section 2. How Infected

4. When I was around one year old, I fell and my mouth wouldn't stop bleeding. My parents rushed me to the hospital, however, the doctor was unable to stop the bleeding. I had further tests and I was diagnosed with severe Haemophilia

A. GRO-B
GRO-B

5. I was placed under the care of Dr Evans at the Pendlebury Children's Hospital, where I was treated until I was thirteen or fourteen years old. Whenever I had a bleed, I was treated with Cryoprecipitate. However, in or around 1977/8, when I was five or six years old, I began treatment with Factor VIII. I do not believe my parents were informed of the decision to change my treatment.

6. As a child, having Haemophilia basically meant that I was wrapped in cotton wool, because the consequences of playing with other children would lead to bleeds that would require treatment. I enjoyed playing football, but I had to give this up due to the risk of bleeds.

7. In 1985, when I was about thirteen or fourteen years old, I moved to Manchester Royal Infirmary for treatment with the adult hospital. GRO-B GRO-B GRO-B GRO-B When I moved to the new hospital, a nurse called me into the room and told me I had HIV. Nothing else was discussed and no further information was provided, she just told me very flippantly. I did not have a parent with me, my mum was later advised in a letter on 31st May 1985. I have exhibited this letter as WITN1736002. The letter also highlights that GRO-B I had been exposed to the AIDS virus linked to the contaminated Factor VIII.

8. At this point, I did not know what HIV was and I do not think I realised the extent of it until I saw the tombstone advert on the television. I was not provided with any information to help me to manage or understand my infection, and I had not been advised on the risks of transmission and the importance of practicing safe sex.

9. In or around 1993, I attended a routine clinic appointment and they were talking about my liver. I asked what this meant and they told me that I had been infected with the Hepatitis C Virus (HCV). This was the first time I had

been informed of this, and I had only found out by accident. At some point, I was also diagnosed with Hepatitis B. I had not heard of the HCV before, so I wasn't sure if it was serious or not. My doctor did not give me any further information on this either.

Section 3. Other Infections

10. I believe I may have been exposed to CJD.

Section 4. Consent

11. I was unaware that I was being tested for any infections; as such I consider that I was tested without my knowledge or consent. I used to have routine appointments, where I would be required to have blood taken. I did not know that this was for the purpose of testing for infections.

12. I believe I was tested for the purposes of research, because other people have similar stories to mine, the doctors were just watching to see what happened to us.

Section 5. Impact

13. When I was diagnosed with both HIV and the HCV, I was not offered any support and I did not understand the seriousness of my infections. Once I knew what HIV was, I started planning my funeral and I was very depressed. I did not come out of my bedroom and I refused to speak to anyone. When I met other people who were infected, I discovered that they were told they had five years to live. So I was planning that I would be dead by the time I was 21 years old. I was very young at the time of my diagnosis, so you can imagine how hard this was for me.

14. When I received some money from the government, I used it to go away a lot, as I felt like I could escape and be whoever I wanted to be. When I came home, I would go back into my room and be very depressed again. I did not

want to speak to my parents about it because I did not want to upset them, as I know that they would blame themselves believing that they had given me GRO-B the infections. At the same time, my parents did not want to talk to myself GRO-B about our infections because they were concerned about upsetting us.

15. My relationship with my parents was really strange and it was a very bizarre few years, because we did not really talk about anything linked to HIV. We were like ships in the night, we would say "hello" and "good morning", then I would eat my food and go straight back to my room.

16. Eventually, I spoke to my tutor at college, who helped me through this difficult time. I felt very depressed and suicidal, because I had seen the adverts on the television. My tutor helped me to get my head around everything. If it was not for her support, I do not think I would be here today.

17. Other than talking to my tutor, I spent years not talking about my infections. Whenever the family talk about it now it is always in code and we do not specifically refer to the infections. We were advised by the hospital to keep my HIV status a secret, so this is what we have done and I do not know what other family members know. In the last ten to fifteen years, I have become quite open about talking about my infection, and I have told some very close friends.

18. I have never told any of my colleagues about my infection. When I worked in GRO-B as a carer, I did not even tell anyone about my Haemophilia, because I was concerned they might make a connection between this and HIV and the HCV

19. Living with HIV and the HCV has become better, because I have become used to it. I never really acknowledged it and just tried to get used to it. A friend invited me to go on a workshop which helped me to get over my own stigma. Now all of my friends know, apart from five friends that I have not told, as I met them when I was in my phase of not acknowledging it whatsoever, and I am concerned they will ask why I did not tell them back then.

20. My infection has also impacted my previous relationships; in particular one of my previous partners who I accidentally infected after we had been together for five years. I felt terrible about this and still do, I believe it is one of the worst things that has ever happened as a result of me being infected. My former partner blamed me for infecting him and our relationship ended quite negatively. At this point in my life I had begun opening up to people, but when he became infected, I went back to how I was before. I completely shut down and did not go out or talk to anyone. I was filled with a feeling of disgust and the experience was horrific. It took me about four to five years before I attempted another relationship.

21. With regards to the physical impact my infections have had on me, these are attributable to my treatment rather than the infections themselves.

22. I was given antiretroviral medications for my HIV in or around 2000. These caused me to suffer from terrible stomach problems, including sickness and diarrhea. I also suffered from facial lipodystrophy which impacted me both physical and mentally.

23. Sometime in or around 2001/02, I had a 6-month course of Interferon and Ribavirin as treatment for my HCV. I suffered from terrible side effects with this treatment. I felt very suicidal and depressed. I could not eat anything, I lost around six stone and my hair fell out. I went to the clinic about this and the doctor put me on a tablet to bring my appetite back. Unfortunately, this tablet only made me more suicidal and the doctor acknowledged that this was a side effect listed for that medication.

24. Although the treatment was successful, the side effects lasted for the full duration of the 6-month course, and then for four years afterwards I still felt like my head was all over the place. My memory has never been the same since the treatment and I often forget things.

25. Prior to this treatment, I ended a relationship because I was not sure how it would affect me. My friendships and family relationships were also affected, because everyone was worried about me and I became very aggressive,

which is not in my nature. I also suffered from really bad insomnia, so I would only get around two hours of sleep every few days. My mum and a friend would often come and sit with me, because they knew I would not be sleeping. I know that during this time I became quite aggressive and rude towards my mother and blamed her for my infections. We have a positive relationship now, but for quite a while after my treatment I was ashamed of the things I had said to her.

26. As a result of my infections, I have suffered an educational and financial impact. I always wanted to be a nursery nurse and to look after children as a career. I was unable to do this, so I did a course to look after adults with learning difficulties. I found the course challenging because I was struggling with my physical and mental health, however my tutor was very supportive and would call me if I did not come in. With her help I passed the course and found a job in GRO-B and thoroughly enjoyed working. Unfortunately, my health got worse so I had to leave this job and move back up north. I would love to return to this career now, but I do not think my body would be able to cope. This was quite a well paid job, but ever since I had to give up work I have been back on benefits.

Section 6. Treatment/Care/Support

27. When I moved from GRO-B to GRO-B the hospital in GRO-B refused to give me my HIV medication because I had not lived in the area long enough. As a result of this, my doctor in GRO-B was required to post a two-month supply to me, which he said he should not have done. I eventually managed to get treatment in GRO-B but this experience was very stressful.

28. Since my brother and I have been diagnosed, no counselling or psychological support has been offered to my parents.

29. I have not been offered any counselling or psychological support. I believe had these been made available to me I would have benefited from it. About 2

years ago, I attended my GP and said that I thought I needed to see a counsellor. I was referred for six sessions of counselling, which were not enough. I do not believe they really helped. I have learnt to cope by just blocking it out, or just boxing it up and putting it at the back of my mind. When I had the counselling sessions I did not feel able to talk about it because I was so used to blocking it out. I believe it would have been more beneficial had I seen a counsellor when I was first diagnosed.

Section 7. Financial Assistance

30. In the early 1990s, I received an ex gratia payment of £20,000. In order to receive this, I had to sign a waiver to say that we could not go back to the government to get more money. I do not know what the process of receiving this payment was, as I was only fifteen or sixteen years old so my father sorted it out. I recall signing the waiver, but I felt forced to do so because we were told that if we did not no one else would get any money.

31. Since the early 1990s, I have also received a monthly payment from the MacFarlane Trust. This used to be around £600-700, but has now increased to £1,500.

32. I have applied for grants when I have required additional support, for instance when my washing machine and fridge broke. I also received a grant when I suffered from severe night sweats and had to wash my bedding every day. The process of applying for these grants was terrible; it was like going with a begging bowl. The whole process would take a few weeks and I had to jump through loads of hoops just to get a small amount of financial assistance. Eventually, I felt it was not worth getting myself so worked up just to get knocked back.

Section 8. Other Issues

33. As a result of my infections, I have been unable to get life insurance. If I had life insurance, then when I pass away it would have paid for my funeral and it

would have provided help for my sisters' children. In addition to this, when I was working I did not sign into the pension scheme because I did not think there was any point. I also struggled to get travel insurance, but when I was younger and wanted to go away a lot, I had to lie about my health in order to get insured.

Anonymity, disclosure and redaction

34. I wish to apply for anonymity. I understand this statement will be published and disclosed as part of the Inquiry.

35. I do not wish to give oral evidence if necessary.

Statement of Truth

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

Signed GRO-B

Dated 27/2/19