ANONYMOUS

Witness Name: GRO-B
Statement No: WITN0354001
Exhibits: WITN0354002
Dated: 1st May 2019

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF GRO-B (ANONYMOUS)

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 8 February 2019.

I, GRO-B will say as follows: -

Section 1. Introduction

1. My name is GRO-B My date of birth is the GRO-B 1975 and my address is known to the Inquiry. I currently live alone and I am unemployed, unable to work due to my condition.
2. In this statement I will discuss my infection with Hepatitis B (HBV), Hepatitis C (HCV) and HIV as a result of taking Cryoprecipitate and Factor VIII to manage my haemophilia.
3. In particular, I will outline the nature of my illness, how the illness has affected me, the treatment I have received and the impact it had on my family and I.

Section 2. How Infected

4. I am a haemophiliac, with severe haemophilia A. My Factor VIII level is around 1%.

5. Haemophilia runs in the family on my mother's side. My maternal great-grandfather was a haemophiliac and my mum was a carrier. I am the only one of my siblings to have haemophilia.

6. My early memories of growing up with haemophilia are very poor; I can only remember some things and in not that much detail. However, I will outline what I can.

7. I was initially given cryoprecipitate to manage my haemophilia but I don't remember that. I only remember taking Factor VIII.

8. I remember going to the hospital fairly frequently. We would often go to Guy's Hospital in London, waiting there for a doctor who would then come and 'play God'. We would go to the hospital at any time of the day, frequently in the middle of the night, and we would be left there for hours and hours waiting for an on-call haematologist.

9. I do not believe that waiting for a haematologist was adequate; they are someone who studies blood, we needed someone who could deal with joints and so forth. It is a better set up now, you don't see doctors as much because you don't need to, they just need to figure out your Factor VIII level. Instead, now there are a lot of physios and nurses who are better at dealing with haemophilia.

10. I was diagnosed with Hepatitis B (HBV) when I was very young. They found out because my mum was ill, and they tested everyone else in the family to see if anyone else had it. They believed that I had been infected with Hepatitis B and passed it on to my mum and sister when I was teething. I exhibit a document of my mum's dated 1st June 1976, from Guy's Health District, indicating that I passed the Hepatitis B on to her as WITN0354002.

11. I started to self administer Factor VIII aged eight. I remember my dad and I just got left in a room at Guy's hospital and we were just told that we had to self-inject the Factor VIII.

12. We were not given any guidance on how to inject the Factor VIII, we were not even told that I should not inject air because it could kill me, until I was about fifteen.

13. I was never sat down and given a proper lesson on how to inject the Factor VIII, for example using an orange, until about ten years ago when I was in my thirties and I had been injecting the Factor VIII for decades.

14. I am sure that some people must have died because of lack of adequate guidance.

15. I was supposed to inject the Factor VIII every two days: Monday, Wednesday and Friday. However, it has only been the last few years or so that I've been doing it as regularly as I should. Instead, I previously often put off injecting myself and would just inject myself on demand instead. I could feel when pain was starting to set in, and that is when I would administer the Factor VIII.

16. I was first diagnosed with Hepatitis C (HCV) and HIV when I was thirteen. I was getting chest infections and I think they tested me after I told them; I hadn't thought it could be HIV.

Section 3. Other Infections

17. I do not believe that I have received any infection other than HIV, HCV and HBV as a result of being given infected blood products.

Section 4. Consent

18. I do not believe that I have been treated or tested without my knowledge or consent.

Section 5. Impact

19. My infection with HCV, HBV and HIV has impacted every part of my life.

20. I've not adequately been given a fair chance at life. Even though I started off disadvantaged with haemophilia, I have had any kind of a life taken from me because of the infected blood products that I had been given.

21. Given that I took in cryoprecipitate and then Factor 8 so regularly and over a period, so many times, there were so many opportunities for me to become infected. It could have been one bad batch or many infected doses. There is no way of knowing and given the manner in which these products were made, I and many haemophiliacs like me didn't stand a chance. I should never have been given a single infected dose but this was not a simple case of one 'slipping through the net', it was a complete disregard of where this blood came from.

22. Even when it was known that infected blood was being brought into the UK and given to Haemophiliacs and people needing blood transfusions, they still continued to do it. Why? To save money.

23. Not only has it affected my health, but it has consequently affected my ability to build relationships, have a social life and a career.

24. From 1976 until I was about eleven or twelve I frequently went to Great Ormond Street and here I met other haemophiliac children the same age as me. However, this connection with other haemophiliacs stopped as I got older and no longer went to Great Ormond Street.

25. My schooling was disrupted quite often, firstly because I was a haemophiliac and later with the addition of my HIV infection. The more it was disrupted, the more I would disrupt it as well. This is because the more you don't go in, the less you want to go in, and I didn't get on well at school. When I was a teenager I ended up getting home-schooled because I was missing so many lessons.

26. I was very scared when I was first diagnosed with HIV. I can't remember what information I was given about the effect it would have on my life, but I remember a lot of the publicity about HIV and AIDs in the 1980s and although I was young I associated that with what I had. As a result, I didn't tell anyone about my infection: I didn't tell any of my friends, or any of my peers, that way I was able to minimise the stigma but at the cost of not making friendships outside of the haemophiliac community.

27. The first symptoms of HIV that I had were bad chest infections, which happened a lot. As a result, I was put on AZT when I was about fifteen. I think AZT was the first drug for HIV; it affected me alright at first, but it was never enough to do anything long term.

28. I would also get a lot of flu and things like that, due to my poor immune system. I remember going to my sister's in Birmingham for the weekend once and I was getting ill with flu-like symptoms the whole time.

29. From about seventeen onwards I had a severe infection in my throat and mouth. It was an infection caused by the yeast Candida. There were points where I wasn't eating at all because I had lost appetite and I was unable to eat; as a result, I lost so much weight. During this time there was a few years where I was really quite ill, and this lasted until I was about twenty-two. I didn't go out a lot in this period.

30. From the age of nineteen I was on a cocktail of drugs to combat the HIV and I went into remission a bit. When I was around twenty-two I started eating more and I was able to start college again.

31. I am still on a cocktail of drugs, about a dozen different drugs that I have to take at least daily, some more than once a day. This is on top of the Factor VIII injections that I administer three times a week or so.

32. I have multiple side-effects from taking so many medicines I am generally a thin person but I have a distended stomach, which I am very self-conscious about.

33. I also have trouble sleeping, which is caused by all the meds I have to take. I usually get about three hours sleep a night.

34. I suffer from neuropathy, which is a lack of feeling in my fingers and toes, also due to the medicines I have to take.

24. At one point, in 2015, I couldn't take my medication for about six months because my body wasn't responding to it. I had to stop taking it and instead wait for new ones to come out. It took them a while to find something that would work. As a result, I had a bad infection in my right foot; I'd had a bleed and it was infected for months.

25. Other than having the antibodies, I've never knowingly experienced the symptoms of Hepatitis, However, I have been worried a lot. I believe that doctors have a lot of power and that they like to stress you out. For example, I was recently informed that my Hepatitis B was spiking, and they started talking about liver cancer. It is just something else to worry about. I believe that doctors regularly enjoy doing that. They love the power. I believe that it's the stress as well as the side effects of the meds that cause me to not sleep well.

26. I also have Haemochromatosis, which means that I have too much iron in my liver, and as a result I sometimes have to have blood taken from me. The doctors say that it is hereditary, but I don't understand how because no one in the family has had it. However, secondary Hemochromatosis can be caused by chronic liver disease, such as Hepatitis C.

27. I am quite cynical about the health service, I don't have any confidence in it and I don't trust any doctor straight away. I've had some terrible doctors. I've had some nice ones, but some really crap ones.

28. As a result of my HIV, I have never been able to work.

29. Had I only had haemophilia and nothing else I would have a good job. I have a degree in computer science and I would have liked to have pursued a career in I.T.

30. As a result of my infections I missed big chunks of my life; my education was disrupted, and there are huge gaps in my CV due to not holding down a job in adulthood being severely disrupted because of illness and constant appointments.

31. No one will employ you with big chunks missing from your CV, or knowing that you might have to take a lot of time off work for hospital appointments.

32. My infections have also prevented me from building social relationships that I should otherwise have had.

33. My infections have affected my ability to build and maintain personal relationships. I have never really had a partner relationship.

34. Consequently, this has affected my ability to have my own family.

35. I have had friends die as a result of infected blood. I had a friend, GRO-B who I was friends with through the haemophilia centre. He had HIV and he wasn't taking his medication; he had an infection in his knee that got out of control and as a result he died when he was seventeen. I had known him for about five years.

36. I lived on my own in GRO-B London when my family moved to GRO-B then I moved to GRO-B to be nearer to them. I currently live in a one-bedroom flat that is privately rented.

37. I have found the stigma that I have endured to be fairly minimal. However, this may be down to the fact that I haven't socialised as much, I was infected from a very young age and I haven't been able to work or go out as much.

38. I will not tell people about my HIV status. I don't mind as much with the Hepatitis, but I don't want anyone to know about the HIV.

39. My HIV has not only affected myself, but everyone in the family. I still depend on them to a degree in my forties. For example, at the moment I depend on them to get me to hospital appointments and drive me around because I recently had an operation on my foot.

Section 6. Treatment/Care/Support

35. I don't trust the healthcare system anymore. I mostly have a bad impression of all those that have dealt with me. This is largely due to the fact I don't believe I have been given adequate information to manage my infections because of contradictory information. I've never been confident that what I've been told was the right thing.

36. The worst doctor I have had is Terry Wong, the head gastroenterologist at St Thomas' Hospital, London. He would say stuff that would blatantly be a lie.

37. For example, he sat there and told me that I had cirrhosis 100%, then he backtracked on this about six months later. He never said he was wrong, he just said something completely different.

38. He would act as though I was taking money out of his hands; he would lecture me about the tablets I had to take to manage my infections.

39. In the end, I've never really known what my liver result was. He should be struck off as a doctor.

40. In about 2016, I saw a liver doctor at Canterbury Hospital. I can't remember his name, he was Indian but I do remember him asking me if there was a chance that I got my infections from somewhere else? I told him that there was no point in us continuing as it wasn't going to work out between us. I haven't seen a liver doctor since.

41. When I was living in London I was having a fibro scan every nine months, to assess my liver as a result of having Hepatitis. However, since moving to GRO-B I have not had a fibro scan since 2014/2015. There is only one place in GRO-B that has a fibro scan, William Harvey Hospital, and I have to travel to Ashford to get it done. I'm being referred to a another liver doctor soon, finally.

42. Since moving to GRO-B I have had to go to the 'Gate Clinic' in Canterbury, a sexual health clinic, to be seen for various things related to my infection. I absolutely detest the place. I'm sat there and everyone around me is there because they have caught STDs, and I am there through no fault of my own because I have been given bad Factor VIII. I am made to go to a sexual health clinic because I have HIV.

43. Additionally, I do not think my liver is being looked after properly here. Haemochromatosis was written in big letters at the front of my file, but I had to point that out to them. You don't expect to have to do that with healthcare professionals.

44. I have not experienced any issues with dental care since I being HIV positive. However, I don't go to the high-street dentist, and if I did it might be a different story. Instead, I go to a special-needs dentist due to my haemophilia.

Section 7. Financial Assistance

45. I receive money from the Skipton and MacFarlane Trust Funds.

46. I received the first stage payment of £20,000 from Skipton without a problem.

47. However, my liver is going to have to get worse to get the second-stage payment of £50,000. This is despite having an enhanced liver fibrosis test in 2013 that showed I had a score of 10.15, putting me into the

'severe fibrosis/cirrhosis' category. The top score is 12.00 which is full cirrhosis.

48. I get the feeling that you have to be on death's door to get the stage two payment. You think about how many people's payments Skipton is holding onto, maybe thousands of people. They're accumulating interest and worth on this money, and I believe they are doing this to make money, not out of the goodness of their own heart.

49. I receive money from the MacFarlane Trust as a result of being infected with HIV. It took years to sort out, but now I receive about £18,000 a year. It's not a bad amount but I could never be properly compensated for everything I have lost or missed out on.

50. I also get benefits from the government to assist me. I get Employment and Support Allowances, and Personal Independent Payment (PIP, formerly Disability Living Allowance). I also get help with my rent, although I don't get the full housing benefit, and help with council tax.

51. I had some trouble with PIP and the government stopped it for about three months. However, later they gave it to all haemophiliacs who had Septic Rheumatism and I started receiving it again.

Section 8. Other Issues

I would like this Inquiry to result in the people and organisations, including the government, who were responsible for bringing in contaminated blood to be held responsible. They need to find out when it was known and how long after that it was allowed to continue. I would also like those infected and the ones who have been affected to receive compensation, not to replace what they have missed out on but to help them live a little better and to manage their conditions. Apologies are empty, they don't mean anything. Anything like this should never happen again.

Statement of Truth

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

Sig GRO-B

Dated 01-05-19