Witness Name GRO-B

Statement No.: WITN3130001

Exhibits: None

Dated: March 2020

GRO-B

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF GRO-B

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1. I, GRO-B will say as follows:-

Section 1: Introduction

2. My name is GRO-B My date of birth is GRO-B 1964. I reside at GRO-B I am currently working at the University of East Anglia providing services for GRO-B I have a partner, GRO-B and we have known each other since GRO-B

3. I went to the University in GRO-B in 1984 and I studied GRO-B I completed a post graduate teaching certificate in Cardiff between 1991 and GRO-B I have been teaching on and off since then. Although my degree is in GRO-B I have taught academic English throughout my career.

Section 2: How Affected

4. I have haemophilia A which is severe. I was diagnosed as a baby, when I was around a year old. There is no history of haemophilia in my family; this was a spontaneous case. I had leg swelling and so my parents took me to the doctor. The doctor thought it could be haemophilia and they were correct.

5. I was treated in GRO-B in GRO-B GRO-B as a child up to approximately age 11. Then in 1975 I went to the Treloar School and College for Disabled Young People ("Treloars"), which was a boarding school where I also received haemophilia treatment. Unfortunately, the schools in GRO-B would not accept me because I had haemophilia.

6. I was at Treloars from 1975 to 1983. For the first year I had to go to the hospital in the local town for treatment, but thereafter I received treatment at Treloars. There were doctors at Treloars you could go to if you had a bleed. They were experts in haemophilia, very knowledgeable and well-known in their field. In particular, I recall Dr Wassef, who I saw from around 1978, and Dr Aronstam. There were other doctors too but these are the two I remember best.

My experience of treatment with blood products

7. At 11 years old, in 1975, I began treatment with Factor VIII from the United States of America ("US"). The brand was called Hemofil. Prior to that, when I had a bleed, I received Cryoprecipitate. Factor VIII seemed a big improvement from Cryoprecipitate, which was frozen. This meant you could not use it straight away, it had to thaw first. In addition, it meant you could not have home treatment. With Factor VIII you could have treatment in 10 minutes.

8. At around 15 years old, I began to treat myself at home. The specialist haemophilia nurses at Treloars taught me how to mix the treatment and inject it myself. During the school holidays, I would get treatment from GRO-B and inject it at home.

9. I do not believe my parents were informed of any risks of Factor VIII and I do not recall being told about any. I do not think the risks were well known at the beginning, apart from perhaps by the manufacturer in the US. The risks only became apparent in 1977, when other boys at Treloars started to become unwell with Hepatitis. I was fortunate, as I only had some mild symptoms. At the time we

were aware of Hepatitis A and B, but not non-A non-B Hepatitis, or Hepatitis C as it later became known.

10. From around 1977 or 1978 some of the boys at Treloars became very sick and did not return to school after the holidays. I do not recall seeing the boys but we knew they were off sick with Hepatitis B; we must have been told by the nurses. The boys would recover at home and then come back to Treloars. Nobody died, as far as I can recall, they were just very ill with Hepatitis B for a time and then recovered.

11. Around 1978 or 1979 I asked one of the doctors at Treloars why the boys were getting sick. It was a female doctor but I do not remember her name. She told me we received treatment from the US and that blood donors there were not "donors"; they were paid for their blood. She explained this meant that drug addicts gave blood to buy more drugs and the drug addicts may have carried diseases. Before that I was unaware the blood products could be contaminated.

12. I received Hemofil throughout my time at Treloars. I recall they tried to bring in British Factor VIII but there was not much available. I remember the British Factor VIII originated in Hertfordshire and was called "BPL", but it was not mass produced. I believe I did receive some BPL but it would have been after we became aware of the contamination of blood products. This would have been around 1983, just before I left Treloars. The product I was given depended on what was available at the time of my bleed.

13. In 1983, I remember I first became aware of AIDS as it was on the television, before that I had never heard of it. Between 1981 and 1983, I went to the sixth form college in the local town for A levels, but I still boarded at Treloars. I recall people at college were talking about a programme they had seen on the television about AIDS and they mentioned haemophiliacs. This was the first time I had heard the connection being made between AIDS and haemophilia.

14. A short time afterwards in 1983, the doctors at Treloars spoke with all of us about AIDS. They told us *"don't worry, only two people in the United Kingdom with haemophilia have AIDS. Thousands have haemophilia, don't worry"*. I believe it was Dr Aronstam that told us and I was reassured by that. I was led to believe it was low risk but every time I had treatment I was still worried it was going to affect me. Unfortunately, it turned out to be high risk not low risk. They thought it was low risk because only two people with haemophilia had developed full AIDS in the United Kingdom, at that time.

15. At the time there was no test available for HIV, and so it was possible to have HIV for a while without knowing. I did not keep in touch with anybody from Treloars, but I heard afterwards that a lot of boys at Treloars contracted HIV.

16. Between 1985 and 2001, I received various different Factor VIII products. Between 1991 and 1993 I received treatment in Cardiff. In 1993 I left the United Kingdom and only returned in the summers, so I was receiving treatment abroad. In Greece, Portugal and Turkey, I received mainly German or Spanish Factor VIII. I was in Italy from 2000 to 2001 and then I came back to the United Kingdom.

17. I continued to receive Factor VIII until the synthetic Factor VIII, Recombinant, became available. I first tried Recombinant in Italy in 2001 when I had a bleed there. The product was used in Italy before the United Kingdom.

18. When I returned to the United Kingdom in 2001, I received Factor VIII because Recombinant was only available for children. I rang the blood bank at Norfolk and Norwich University Hospital ("NNUH"), which is part of Norfolk and Norwich University Hospitals NHS Foundation Trust, and asked about this. The blood bank got quite angry with me for asking about the type of treatment I would receive. He acted as though I was a tabloid journalist, as there had been some stories in the media about the new treatment for children around this time. I was

annoyed by this because I felt I had a right to ask about my treatment options. However, after that their attitude moderated. Recombinant became available to me at NNUH in early 2002.

Testing for HIV

19. I was tested for HIV in May 1985. At the time doctors were testing all haemophiliacs. They told me they were going to test for HIV. As a haemophiliac, I frequently had blood tests anyway. In 1985 I was a student at GRO-B University, and so I was under the care of Dr Peter Jones at the Royal Victoria Infirmary ("RVI") (part of the Newcastle upon Tyne Hospitals NHS Foundation Trust). Dr Jones was a well-known expert in haemophilia.

20. Whilst the nurse was taking the blood to complete the test she told me I would probably be HIV positive, but that *"it might be a good thing"*. This may have been because they had just discovered the test for HIV and so may have thought if you were HIV positive you would be immune from AIDS. I do not know why she thought this would be a good thing but that is what she said.

21. I was a little worried but I suppose I had known that this was a possibility following my time at Treloars, and it had been at the back of my mind for around a year. The nurse seemed to be quite relaxed about it. For a short time after the tests I was not concerned about the results but then after several weeks, I still had not received the results. I became very anxious about it. In the end I could not wait any longer and I wanted to know. By this time, it was July 1985 and I was back in GRO-B I went tc GRO-B and saw a nurse I knew. I asked her if they had received the results of my HIV test. She did not know but she went to check my medical records. She told me the test was negative, which was a big relief.

22. I asked the nurse why I had not been contacted to confirm the test was negative. The nurse said that only the patients whose test results were positive had been told. After finding out the results I felt much better. By the end of 1985, treatment

became safer too, because even the US blood products were checked and screened, and then heat treated to kill any infections.

Diagnosis with Hepatitis C

23. When the test became available, I was asked during a routine appointment to be tested for Hepatitis C. At the time I was in Cardiff, so this would have been between 1991 and 1993. I received treatment at the University Hospital of Wales (part of the Cardiff and Vale University Health Board). They told me they would take some blood and test it for Hepatitis C. I did not wait long for the test results and the test was positive for Hepatitis C.

24. I was told that I had probably had it for years but they had not been able to identify the virus with a test until now. They checked and continued to monitor my liver function to assess the effect of the virus on my liver. I was fortunate that it did not have a big impact on my liver function but the results were slightly impaired. I do not recall being told about the risk of transmission to others. I do not remember them telling me much about the virus at all. I was concerned it would turn into an awful, serious illness but I do not remember specifically being told about the outcome I should expect.

Section 3: Other Infections

25. I do not recall being told that I could contract other infections or diseases as a result of the Hepatitis C virus.

26. I think I did also contract Hepatitis B at one stage. I felt unwell in the late 1970's with bad stomach problems. Around 15 years ago I also found out that I have immunity to Hepatitis B now. I do not recall being tested for Hepatitis B at Treloars. They did undertake various tests, but they were generally routine tests. I have not contracted any other infections.

Section 4: Consent

27. I knew I was receiving Factor VIII products to treat my haemophilia from 1975 but neither I nor my parents were made aware of the risks of receiving this. I was aware I was being tested for HIV in 1985, and for Hepatitis C between 1991 and 1993.

Section 5: Impact

Impact on Family Life

28. As set out above, I do not believe that my parents were told about the risks of treatment with Factor VIII. In 1982 or 1983, when I was inwardly concerned about having contracted an infection from contaminated blood products, I did not tell them about it. Equally they did not say anything to me, I think out of fear. Nobody wanted to talk about it as it caused so much anxiety. I do not think they were aware I was tested for HIV, but I told them later when I had contracted Hepatitis C.

29. Until 1995 I was on my own, but then I met my partner, GRO-B in GRO-B I told GRO-B about my diagnosis of Hepatitis C, which she had heard of. I told her what I knew about transmission, which was that, with care, there was a low risk of transmission. She must have been a little concerned, I suppose, but I do not recall this being a particular issue.

Impact on Employment

30. I taught English abroad from 1993 to 2001, which I thought was a great way to see the world.

31. After my diagnosis with Hepatitis C, I was concerned about my work opportunities. I was diagnosed during my teacher training in Cardiff. Following my training I was applying to schools and I was asked to declare any health issues. I was worried that if schools knew I had Hepatitis C, that they would not

want to employ me. My haemophilia also meant travel was limited to those countries with good medical care. Generally, I found that care was good in European countries; Turkey was a bit more difficult.

32. In Greece in particular, my boss was very aware of my health circumstances. It was a small school and my health issues worried her too much. She did not want to employ me again after the first year as it was making her too anxious. She did not specify whether it was the haemophilia or Hepatitis C which concerned her, but she was concerned about me working with the students. The issue was not spelled out to me, which made it a bit awkward.

33. In GRO-B I asked if they would employ me for another year, but they did not want me to stay. I was not sure why they decided this. I was in GRO-B between 1996 and 1999; they were very kind to me. They helped me a lot with treatment. They knew I had Hepatitis C and they still wanted me to continue working with them. I had different experiences in different countries.

34. I applied for a job in GRO-B in 2000 and they specifically said that they would not employ anybody with a diagnosis of Hepatitis C. I did not see this condition of employment until after I had applied and was waiting for an interview. I, perhaps, foolishly told them about the diagnosis and I did not get the job, although they did try to imply that it was not due to the Hepatitis C.

35. Prior to this incident, no other employer had ever asked me specifically about Hepatitis C before. At times, I would have to ask my employer to help me to obtain treatment in a foreign country. I would have to give them a letter from the hospital which said I had contracted Hepatitis C. My employers would know I had Hepatitis C after this, which was a little awkward, but they would always help me to obtain treatment, for example by telling me the best place to go.

36. I had good jobs abroad, but I did struggle to get treatment so I moved back to the United Kingdom in 2001.

37. Travel insurance was more expensive for haemophiliacs and I had limited options. A diagnosis of Hepatitis C also made it more expensive. Nowadays it seems easier to get travel insurance with my medical history.

Stigma

38. There is a stigma surrounding Hepatitis C. I once told a friend in Cardiff about my diagnosis and he did not want to know about it; it made me feel like I should not talk about it. I did not want people to think I was a risk, or for people to avoid me. From them on I kept it to myself. I would say 20 years ago I experienced a lot of awkwardness around my diagnosis, but now it seems better.

Treatment for Hepatitis C

39. In the mid 1990's I was being treated in GRO-B at the GRO-B again. I recall being told more information about Hepatitis C at this stage. A doctor at GRO-B old me it could become very serious and he recommended treatment to clear the virus in around 1995 or 1996. The treatment available at that time would have been Interferon. At the time I was working and I was told the treatment would take 12 months. I was also told it would make me quite ill, so it seemed I would be unable to work during the treatment. I was also often abroad during this time. I was getting teaching jobs relatively easily at the time, which I felt very good about. I thought I would lose my work because the treatment was too long. I did not want to jeopardise my work opportunities and I did not feel too unwell at that time, so I decided I would not have treatment then.

40. The doctor at GRO-B also discussed a liver biopsy with me, which would determine what was happening with my liver. My liver function continued to be monitored and it was generally okay. Sometimes it was impaired but it was not bad. Therefore, a liver biopsy seemed a drastic option, particularly as it would be a difficult procedure for me, because of my haemophilia.

41. I also had regular six monthly blood tests to monitor my haemophilia during this time, with fairly regular appointments in the United Kingdom. I tried to ignore the virus, as I wanted to get on with my teaching; I tried not to pay too much attention to it.

42. I cannot recall when I was next offered treatment, but I was aware of the combination treatment of Interferon and Ribavirin, which still took six months to complete. Before I decided to have treatment I still felt okay and my blood tests were still okay. I was fortunate that Hepatitis C did not affect me that much.

43. In 2006 I decided to accept treatment with Interferon and Ribavirin from NNUH to clear the virus. I was told it might make me feel ill but there was a good chance of success. I had my first treatment in hospital and then I cycled home. I felt very unwell by the time I got home, as though I had bad flu. I felt terrible which was a bit of a shock. It would have been better to have started the treatment in the evening so that I could have slept through the worst of the effects.

44. I had to inject the Interferon weekly using a pen in my stomach and afterwards I took paracetamol to ease the side effects. I took Ribavirin tablets a few times a day. The treatment lasted six months and I felt quite rough. My hair fell out a lot and I felt strangely emotional. I would start crying at small things, so I did feel a psychological change with the treatment. I also felt generally unwell and tired.

45. At the end of the six months I found out I had cleared the virus. After the treatment the physical and psychological symptoms did go away.

Section 6: Treatment / Care / Support

46. The care I received at Treloars between 1975 and 1983, at the time, seemed very good. The doctors and nurses were knowledgeable and I felt I was in good hands. I also received good treatment at GRO-B and at RVI. This contrasts with the treatment I currently receive now at NNUH.

47. NNUH do not have that same level of knowledge and expertise, as they are not a specialist centre. They seem a little more reticent, although Dr Lyall, under whose treatment I am currently, is easier to talk to. I sometimes travel to Cambridge to the Haemophilia Centre at Addenbrooke's Hospital, part of the Cambridge University Hospitals NHS Foundation Trust, where they are haemophilia experts.

48. Having Hepatitis C has made dentists a little wary of me; they react to me but I cannot say I have been refused dental care. My dentist knows I had Hepatitis C, received treatment and now the virus has been cleared.

Psychological support

49. I was never offered psychological support or counselling in relation to my diagnosis or treatment. I think it would have been useful, especially during the time of the HIV test and then the HCV test.

Section 7: Financial Assistance

50. I received an ex gratia payment of £20,000 from the Skipton Fund in 2004. I understand all haemophiliacs infected by blood products received this. I am not sure how I found out about the Skipton Fund. I was not in regular contact with The Haemophilia Society so perhaps I was just sent a letter about it. I must have completed an application, but I do not recall anything about the process or whether a doctor assisted me with this.

51. In 2016 I received a further letter from the England Infected Blood Support Scheme ("EIBSS") regarding annual payments. They contacted me directly. I do not recall there being an application process for this but I did provide EIBSS with my bank details. I have received payments of £4,500 a year, in July, since 2016, but this has just increased to £18,000. I was sent a letter setting out the bands

and the amount of my increased payment. I believe this is as a result of the announcement before this Inquiry.

52. EIBSS contacted me directly, however, looking at their website I would have believed I was not eligible for the payments. When I saw this, I was alarmed and worried they would seek return of the money. The EIBSS website appears to contradict their letters; the messages are confusing, which may put people off applying.

Statement of Truth

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

Signed GRO-B ……

Dated……12/4/20……