

Witness Name: GRO-B

Statement No: WITN1121001

Exhibits: WITN1121002-5

Dated: 5 June 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 the GRO-B. I live at GRO-B GRO-B.
2. I am currently self employed as a Stamp Dealer. I am divorced and I have two daughters GRO-B who stay with me on alternate weeks.
3. 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**

4. I have severe Haemophilia A with a 0% clotting factor. My brother GRO-B was diagnosed with haemophilia at a young age. Consequently when I was born I was tested for it.

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5. I was under the care of [GRO-B] but I was also treated at [GRO-B] from [GRO-B]. They worked in conjunction with the [GRO-B] and liaised with each other. My records from [GRO-B] appear to have been destroyed but I have some of my notes from the [GRO-B]. I was treated in [GRO-B] and [GRO-B] between [GRO-B] in [GRO-B] between [GRO-B] [GRO-B] at [GRO-B] between [GRO-B] [GRO-B] between [GRO-B] and subsequently in [GRO-B].
6. When I was 6 months old I had a massive bleed into my stomach. I was initially treated with cryoprecipitate; big yellow bags of liquid which were transfused and I needed to attend hospital for this.
7. From an early age my mother had to take my brother and me to Oxford from our home in Sussex because either one of us required treatment for bleeds. I remember this being up to four times a week; it was a 200 mile round trip.
8. From about 1977 I was given Factor VIII concentrate (FVIII) and we started on home treatment. My mother would inject both me and my brother. At this stage we did not have to have as much time off school.
9. I remember when we were younger our bleeds were bad as we were involved in fights with other kids because we were grouchy. Kids took the micky out of us for being wrapped in bandages. I also remember my father saying that he would give us 50p if we did not have a bleed for a week. This didn't happen.
10. As I got older my requirement for FVIII increased annually as my bleeds increased. Between the ages of 12 and 15 I was having over 100 bleeds a year. In 1997 I started on prophylactic Factor VIII treatment.
11. As a result of the FVIII concentrate I was infected with Hepatitis C (HCV). My medical records show that I was HCV positive by 9<sup>th</sup> June 1994 but I do not recollect being told at that time. I do not know when exactly I was tested as there are no results in my records. I attach as Exhibit WITN1121002 a copy of a letter from [GRO-B] I recall that it was sometime in the early 2000s that I was advised.

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12. Between 1977 and 1985 my brother and I shared the same batches of FVIII treatment by way of home treatment apart from two particular batches in 1983 which we did not share. My brother also contracted HCV but in addition contracted the Human Immunodeficiency Virus (HIV). I attach as Exhibit WITN1121003 a copy of the batch record showing the treatment I received.
13. Every single injection and batch number was completed by my mum and me.
14. I remember that I would bleed approximately 3 or 4 times a week and that it would be rare that I would have no bleeds at all in a week. In total I have had 252 bleeds into my left ankle and over 300 bleeds into my left elbow. Both my ankles have now been fused.
15. Around 1985-7 my brother and I received two separate letters from the hospital. The letter addressed to me stated that I was tested for HIV and that the test results came back negative. The letter addressed to my brother urged to contact the hospital, which gave it away that he was tested HIV positive.
16. As far as I am aware my parents were never told beforehand that there was a risk in using FVIII concentrate.

### Section 3. Other Infections

17. My records show that in 1992 I was Hepatitis B antibody negative and in 1993 I was Hepatitis B surface antibody positive. At that time I had a course of hepatitis B vaccinations. I attach as Exhibit WITN1121004 a copy letter from my consultant Haematologist to my GP in respect of this.
18. My medical notes and records show that there is a letter from GRO-B Hospital to my GP advising that I was at risk of vCJD. To the best of my recollection I have never been advised of this. I attach as Exhibit WITN1121005 copies of the correspondence.

**Section 4. Consent.**

19. I did not know that my blood was being tested for either HIV or HCV or any infection. I am not aware if I was treated and tested for the purpose of research. I do not know whether my mother was aware that our blood was being tested or whether she had consented to it.

**Section 5. Impact**

20. My wife and I got married in [GRO-B] My medical notes show that I had HCV in June 1994 but I cannot remember being told at that time. I think I would have remembered as that was around the time I got married. If I was told at that time then it was something that was not explained as high risk to me.

21. My medical records show that I had Interferon treatment in the late 1990s but I do not remember having this treatment at all. I believe that I might have completely blocked it out, but since my records state that I had it then it must have been the case.

22. I can only recall that I was told I had Hepatitis C after our two daughters had been born. Our first daughter was born in [GRO-B] and our second in [GRO-B] I believe the infection was discussed whilst I was receiving treatment at [GRO-B] and I remember being told bluntly that I would be dead in 10 years. I cannot remember specifically who told me; but I think it may have been either Dr [GRO-D] or Dr [GRO-D] I cannot remember ever being given any advice in respect of the infection.

23. We had had plans to have a third child but being told about the severity of HCV cost us our third child. As a result of being told that I had HCV I had a vasectomy and I made a will.

24. I remember after I was told shutting myself in the bathroom and just crying. I found it hard to share; I blanked my wife out and I blanked it all out. I showed no love and I became emotionless. I learned to hide my feelings and it has taken many years for the wall that I built around me to come down.

25. Just prior to being told of the infection we had decided to move and we moved to [GRO-B] in [GRO-B] We were able to live anywhere in the country because of



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my job and my wife and I had simply put a pin in the map and we moved to where I am living now.

26. At the time I was working as a [GRO-B] and I worked all hours leaving the house early at 4.00am and returning at 8 or 9pm. I did not want to think about the HCV. I found my work a good outlet for the aggression I felt.
27. I was offered several fibro scans which showed slight scarring to the liver. I was offered treatment and I think it was in 2006/7 when I remember that I was treated with Interferon. I remember having to inject myself into the stomach subcutaneously. The interferon bubbled up under the skin and would then go down. I remember being very grouchy, irritable and bad tempered and took paracetamol tablets all the time for the headaches I suffered. I continued to be treated by [GRO-B] and I remember going to them for my results but they told me that the treatment had been unsuccessful.
28. They gave me an option to continue the treatment but also hinted at the same time that there was another treatment in the pipeline. I opted at the time not to do it again.
29. By [GRO-B] our marriage was over and my wife moved out in [GRO-B]. We were divorced in [GRO-B] although we remain good friends. Our children live with me one week and their mother the next and the arrangement works very well.
30. I had carried on having treatment at [GRO-B] and went every 6 months for check ups. I had to have my ankles fused but they did not treat me well and I decided to leave their care.
31. In [GRO-B] I moved treatment to the [GRO-B] and attended for treatment at [GRO-B] which is part of the [GRO-B]. On 12 January 2011 I started treatment of Interferon and Ribavirin and I remember going for regular blood tests.
32. I do not think I had side affects as bad as I had had before. I had a long bikers beard at the time which I had to shave off because I lost my hair. I also remember losing a lot of weight and was told that it was a good excuse for me to eat ice cream and chocolate. I was not working at the time as I had anticipated feeling rubbish so did not work.
33. Thankfully the treatment worked this time and [GRO-B] confirmed that the HCV was undetectable. However, I always think now that I still have it but it remains dormant and I

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worry that it may be undetectable to modern equipment. However, I do have regular liver function tests every six months and they appear to be alright.

### **Section 6. Treatment/Care/Support**

34. I have not had any counselling. I cannot recall whether I have been offered counselling treatment or not.

35. I remember that before I was married (I think it was in GRO-B), I was living in GRO-B and I went to a dentist. He inspected my teeth and as soon as I told him that I was a haemophiliac he put on gloves and a facemask and told me to go somewhere else. I was horrified. This happened at the time there were a lot of advertisements on television about AIDS. After this I went to GRO-B for dental treatment.

### **Section 7. Financial Assistance**

36. I have received the Stage 1 payment of £20,000 from the Skipton Fund. I cannot remember precisely but think it was in 2006 as I paid my car loan off with it.

37. Since then I have received regular payments but they do appear to fluctuate each month. I do not take anything for granted as each month differs and I am concerned I may not get anything one month. I find it quite difficult to budget.

38. I receive a special category mechanism payment of £495 as I have a daughter under the age of 18. I also receive another amount as I am earning less than £15,000 per annum.

39. I remember all of a sudden at one time receiving a sum of money into my bank account and I cried because I was having a hard time financially and I was not expecting it.

40. Initially the payments were from the Caxton Fund but now they are from the EIBSS.

### **Anonymity, disclosure and redaction**

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

42. I do not wish to give evidence.

**Statement of Truth**

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

Signed.....  
GRO-B

GRO-B

Dated..... 5/7/19 .....