

ANONYMOUS

Witness Name: **GRO-B**

Statement No: WITN1345001

Exhibits: WITN1345002

Dated: November 2018

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**
GRO-B I was born on **GRO-B** I live alone.
2. I have **GRO-B** sisters and **GRO-B** My siblings do not have haemophilia. I had an **GRO-B** who died from **GRO-B**
GRO-B My parents are not haemophiliacs.
3. I was diagnosed as a haemophiliac at the age of **GRO-B** in **GRO-B** after I had excessive bleeding from a cut on my tongue. I have severe haemophilia (Factor VIII less than 1%). I have had **GRO-B** episodes of intracranial haemorrhage, first at **GRO-B** of age and again at **GRO-B** of age. Each episode started with intense headache followed by loss of consciousness and

hospitalisation for approximately 10 days. As a child I have had occasional bleeds in my fingers and frequent bleeds in my left elbow and left knee. I was under the care of [GRO-B] in [GRO-B]

4. 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

5. I came to the [GRO-B] in or around [GRO-B] I was under the care of Luton & Dunstable Hospital (LDH) and The Royal Free Hospital (RFH), London. In the early part of 1977, I attended LDH for mild bleeds. I was given Cryoprecipitate to treat my bleeds. The doctors told me that I responded well to Cryoprecipitate.
6. In or around 1979, I attended LDH as I had a bleed (my medical records are missing for this period). I am unable to remember where the bleed was. I was administered Factor VIII (FVIII) treatment. This was the first time I was administered FVIII. My medical records (letter from [GRO-B] [GRO-B] dated 3 June 1982) confirm that this was the first time I was exposed to FVIII.
7. In or around June 1980 I was approximately [GRO-B] I started to feel pain in my stomach and was physically sick. I therefore attended LDH and I was given FVIII. I was later admitted to RFH that evening as the pain in my stomach worsened. I was again given FVIII at RFH. The following day, I had further signs of haemorrhage and required a blood transfusion. I was in hospital for approximately 29 days (from memory) and according to my medical records, dated 28 July 1980, I was administered with FVIII twice daily in order to keep my FVIII level constantly over 50%. My medical records also state that the total FVIII that was administered during my admission was approximately [GRO-B] When I was discharged from the hospital, I was given more FVIII to administer at home.

8. My medical records from mid 1980 to mid 1982 are missing. My treatment record, which is exhibited at "WITN1350002" shows that I was given FVIII from 1980 through to 1987.
9. With further reference to paragraph 6 of my witness statement, in the letter dated 3 June 1982, which confirms that I was first exposed to FVIII in or about March 1979, it also states and I did not develop hepatitis. I had no knowledge that I was being tested for hepatitis and nobody discussed this with me. I first became aware that I was tested for hepatitis when I reviewed my medical records.
10. My medical records, dated 12 October 1984 confirm that I had tested positive for Hepatitis B (Hep B). I cannot remember having a discussion with the doctors about Hep B in or around that time. I cannot remember I had any conversations that I was tested for Hep B or that the results tested positive. After reviewing my medical records, there is a letter from [GRO-B] to Dr [GRO-B] dated 9 April 1998 which states 'he lost his antibody to Hep B'. This is all I know about Hep B.
11. In or about 1986 I was formally spoken to about the possibility of being infected with HIV. I was told that if I was infected it would have been through the FVIII that I received over the years. From that conversation I was convinced that I was infected with HIV. However, there were no blood tests to confirm my suspicions until 1987 when [GRO-B] at LDH asked me if I would be willing to take a test, which I did. I was told I was HIV positive in or around 1987. My blood test results are missing for this period.
12. No information or leaflets were provided to me when I was told that I was HIV positive; it was just a conversation that I had with the doctor.
13. I was shocked to find out that I was HIV positive. I was still confused as to what had happened. I had a further discussion with Dr Yong who spoke the same language as me at RFH. At this time my English was still not good. We

discussed what HIV was and what AIDS was. I found it difficult to process this at the time.

14. I recall telling the doctor that I did not want to involve my parents. I did speak to my older sister about my situation, as I was living with her at the time. I told the doctor that I had no sexual contacts and this news had influenced how I would feel in the future. I remember being told it was something that was not curable. The doctors seemed to be more concerned about telling me how not to infect other people. It was discussed that I could become really ill if I had a slight cold or flu as a result of being infected with HIV. When I did get a cold or flu I was really worried as I thought I was going to die. It was always constantly in my mind that even something this minor could lead to death.
15. I was given more information over the years once more knowledge about HIV had become available (as medicine advanced).
16. I knew nothing about the test for hepatitis in 1986. In my medical records hepatitis was mentioned in the 1980s but I had no knowledge of this. It was not until or about 1994 that I was told through a discussion with my doctor that I had Hepatitis C (Hep C). At this time, I do not recall a conversation about Hep B. I was shocked to hear that I had Hep C as well as HIV. I cannot recall any conversations about the symptoms or possible side effects that Hep C could have, but I assume that there was - as I was under the liver clinic. I do not remember being formally tested for Hep C, I was just informed by the doctor that I had Hep C. There was a discussion about possible medication, but nothing more was said in relation to this. Prior to finding out that I was Hep C positive, every few months I would have blood tests. I thought the blood tests were for my haemophilia. I believe that they tested me for Hep C when I thought I was having routine blood tests for my haemophilia and I was not told about it. My blood tests results are missing for this period.
17. Between May and August of 1995, I started Interferon treatment for Hep C, but this relapsed. I was later treated with Interferon and Ribavirin which I

stopped in September 1997 as it did not work.

18. I believe I was infected with HIV, Hep B and Hep C as a result of being given infected blood products – FVIII.

19. I do believe the information about HIV, Hep B and Hep C should have been provided earlier if it was available.

20. I consider consent should have been obtained when testing for HIV, Hep B and Hep C and they should have provided us with some information as to why we were we are being tested for HIV, Hep B and Hep C.

Section 3. Other Infections

21. I was told by the doctor in the consultation room that there was a possibility of me being affected by vCJD. I cannot remember when this conversation took place. I am unsure if they did tests. The conversation about vCJD was very brief. I did not receive any further information about this.

Section 4. Consent

22. I believe that I have been tested for HIV, Hep B and Hep C without my knowledge or consent. I do not recall any conversations with the doctors about being infected with Hep B.

23. As stated in paragraph 6 of my witness statement, I was aware I was going to be given FVIII. However, I was not told at the time about the risks involved with infected blood products.

24. I did not consent to any blood tests for HIV, Hep B and Hep C. I had no knowledge of this. I was not told that the blood tests that I had over the years were going to be used to test for HIV, Hep B and Hep C. I believed that the blood tests were a standard procedure as part of my haemophilia.

Section 5. Impact

25. I believe I am one of the lucky ones. I am still keeping quite well. I am now clear from Hep C this year after taking oral medication called Epclusa.
26. Being infected with HIV and Hep C has affected me mentally. After I was told that I had HIV, the information I had was very patchy. In my mind I believed I was going to die any day. The doctors had told me there was no cure. The same year I found out I was infected with HIV, I went back to GRO-B for a few months as I struggled to cope with the news. I felt that I needed to get away from the UK hospitals.
27. Mentally, I was affected drastically by not being able to have a girlfriend or a wife and being in a physical relationship. This was going through my mind every single day and it still plays on my mind. It was and it still is upsetting not being able to have a family as I love children. The thought of being infected was playing havoc in my mind as I kept thinking that I could die any day. I had one female friend and we would go out together as friends only. We never had a physical or sexual relationship, but I feel it could have gone further had I not been HIV positive. Because of the HIV I was scared to have a sexual relationship with anyone. I felt ashamed to tell anyone.
28. Eventually, she found out through a medical professional that there was a possibility that I could be infected with HIV. I had to admit that I was infected with HIV and Hep C. She did keep seeing me but only as a friend. There was no way we could go any further due to the lack of physical relationship. I was scared of infecting her and concerned about not being able to start a family and have children.
29. Having HIV and Hep C did also affect me physically. There was a period at the time I was infected that I was losing weight. My sleep was affected but this varied day to day. I am unable to confirm whether the symptoms were as a result of HIV or Hep C.

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30. My first treatment for HIV was in the late 1990s when I was given AZT. They told me that it was a drug to help keep the blood count stable and immune system healthy. That was all the information I was given at the time. I felt I had no choice except to go along with it as there was only one type of treatment available at the time for HIV. I was told there were possible side effects. In the early stages I was affected really badly; I was unable to sleep, I had continuous sweating, I had to go to the toilet a lot and I constantly had bad dreams every night – this was really significant to me. The major thing was the tiredness and my weight, it would fluctuate whilst I was on the medication.
31. My main problems were the side affects of the treatment that I had from the Hep C. As stated in paragraph 17 of my witness statement, between May and August of 1995, I started Interferon treatment for Hep C. The side effects were awful. I always had a bad flu. I was not able to do anything and I was constantly tired and always felt weak. It affected my appetite and I lost weight. I just remember the treatment as being horrible. I was later treated with Interferon and Ribavirin which stopped in September 1997 as it did not work.
32. The next treatment, Epclusa for Hep C that became available was in or around 2017. The treatment was for approximately 3 months and I hardly had any side effects. The treatment worked and I was given the all clear in the early part of 2018.
33. I was told during the treatment for HIV that the drugs would affect my bone density. I now take medication to make my bone density stable.
34. I feel my whole personality has changed since finding out about HIV and Hep C. Being haemophilia was bad enough but after finding out I was HIV and Hep C positive, I felt I was not able to meet new people and make new friends. I should have been meeting friends and meeting girls but I have convinced myself not to bother as I will be single all my life. It is more difficult now as I

am getting older and older, I know I am not going to meet a partner at this stage in my life.

35. I used to keep myself indoors a lot and avoid social settings. I am a little bit more active now within the church and have Christian friends. I feel my social life is not the same. To date, I do not find meeting new friends easy. I only have 2 friends who know my status as being HIV and Hep C positive. They are the same two friends who know my full situation outside my family. I met them before I found out about HIV and Hep C. My two friends are very faithful, trustworthy and understanding. I only spoke to my sister initially about my HIV and Hep C when I found out. The rest of my family found out much later. My parents, at the time did not really want to talk about it and did not really mention it after I told them.
36. My next door neighbour is a postman and I constantly worry if my post is delivered mistakenly to another person on my street. I worry that my neighbours will mistakenly open my letters from the hospital and find out about my medical condition. I worry about what people would say and how they would react if they find out about my situation. In an ideal world I would want to move somewhere where it is just me by myself.
37. I try to avoid going to the dentist. I only go to the dentist in the hospital. I had attended the Dental Hospital in London where I was having some wisdom teeth out. I have since been discharged and I was told by the dentist at the hospital to attend a local dentist, but to-date, I have not done so. I do not feel brave enough to tell my dentist about my condition. I am scared to go to the dentist because you have to tell them about your medical history. I do not like talking about my situation and feel that I have to explain myself. In a hospital setting they have your medical records already and you do not need to disclose anything further.
38. I have also tried to avoid the GP. I may have been a few times in the past 20 years. My first point of call would always be the hospital as I do not have to disclose anything. I have not got the guts to talk about my situation.

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39. I did not have any direct stigma because nobody knew about my status. At the time I believed that if anyone found out about my status I would have to move house. I was very scared of people finding out.

40. When I was admitted to the hospital in the 1980s I was in college doing an Art **GRO-B** I had to leave the course as I was in hospital for approximately one month. I did reapply the next year and eventually completed the course.

41. With my condition I felt it was always easier to work for my family rather than work for someone else. My father owned a **GRO-B** and I worked in his shop, working for family is more flexible, as if I was unwell I did not have to go in.

42. When my father **GRO-B** worked as a driver for a few years, part-time. My employers were flexible and if I was unwell, I was able to take time off.

Section 6. Treatment/Care/Support

43. I did not face any difficulties in obtaining treatment for HIV and Hep C. I currently take Truvada, Raltegravir, Alendronic Acid and Colecalciferol.

44. I cannot remember if I was offered any counselling. However, my medical records (letter from **GRO-B** dated 20 November 1987) state the following ".....he would benefit from more expert counselling and in particular he agrees that it would probably benefit him to take part in group meetings with others in the same situation as himself". I did not attend any one on one counselling sessions or group meetings. However, I was able to talk to the social worker, **GRO-B** anytime and she was very supportive.

Section 7. Financial Assistance

45. I have received two payments from Macfarlane Trust. The first payment was in the sum of £20,000 in 1990 and the second payment was in the sum of £23,500 in 1991.

46. I also received three lump sum payments from Skipton. The first was in the sum of £20,000, which received on the 12/08/2004 for stage 1 payment. The second lump sum payment was in the sum of £25,000 for stage 2, which I received on the 26/06/2005 and the third was a top-up lump sum payment in the sum of £25,000.00 received on the 20/04/2011.

47. I also received and continue to receive payments from the Macfarlane Trust and Skipton Fund (now EIBSS). I started receiving payments in the 1990s. I was receiving two payments, one from Skipton and one from Macfarlane. I now believe I receive the payments from EIBSS. This amounts to £3000. On top of this I also receive a top-up payment in the sum of £479 a month because I am not working.

48. I believe I was sent a letter in relation to the above payments. They wrote to me and said that I was eligible for this funding. In order to apply I had to fill in forms and send them back. I found the forms to be straightforward.

49. The monthly top-up payment that I receive is reviewed every year. I have to fill in an application every year.

50. I also received a one off payment from the US Litigation in the sum of £25,000.

Section 8. Other Issues

51. Being single and not having had a family of my own has impacted me a lot. I have had no relationships since finding out I was infected. I do not have the guts to explain this to anyone I meet. I have given up.

Anonymity, disclosure and redaction

52. I confirm that I do wish to apply for anonymity.

Statement of Truth

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

Signed.....

GRO-B

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Dated

16-11-2018

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Medical Summary

(This summary is not intended to be exhaustive but sets out key points in the records relevant to the statement)

Virology Results

12.10.1984 Tested positive for HBs AB Positive. – **Patient had no knowledge of this blood tests**

All other blood test results missing

Significant Entries/Absent Entries

13.05.1977 Letter to Dr [GRO-B] – mild bleeds, responded well to cryoprecipitate.

Year 1978 **Medical records missing**

Year 1979 **Medical records missing**

28.07.1980 Letter to [GRO-B] – administered FVIII (approximately [GRO-B]) and blood transfusion. Given FVIII to treat himself until 01.08.1980.

Year 1981 **Medical records missing**

03.06.1982 Letter to [GRO-B] 'according to our records his first exposure to FVIII was in March 1979 and he did not develop Hepatitis, however, I see that he was jaundice at the time of this admission to the Royal Free with retroperitoneal bleed in July 1980.

Year 1986 **Medical records missing**

11.11.1987 Letter to [GRO-B] – letter discussing HIV (*Please refer to paragraph 13 of my witness statement*).

20.11.1987 Letter to [GRO-B] – discussion about patient benefitting from counselling. – **Patient cannot recall being offered such treatment**

24.11.1987 Letter to [GRO-B] – discussion about HIV with patient and doctor.

11.04.1989 Letter to [GRO-B] confirm 'he has been HIV positive since between August 1980 and June 1981'.

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Patient was not informed that he could be infected with HIV until 1986 and blood tests results proved he was HIV positive in or about 1987. (please refer to paragraph 10 of my witness statement).

Year 1990 **Medical records missing**

Year 1992 **Medical records missing**

Year 1993 **Medical records missing**

21.06.1994 Letter to GRO-B - discussion between doctors.
Medical letter confirms he is also Hep C seropositive. **Blood test results missing.**

Year 1995 **Medical records missing**

Year 1996 **Medical records missing**

Year 1997 **Medical records missing**