

ANONYMOUS

Witness Name: **GRO-B**

Statement No: WITN1569001

Exhibits: 0

Dated: January 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**. My date of birth is **GRO-B** and I live at **GRO-B** **GRO-B** with my wife.
2. This witness statement has been prepared without the benefit of access to my full medical records. I am having difficulties obtaining my medical records. I have tried to contact the Manchester Royal Infirmary (MRI) for my medical records, but I have not yet received a response.

Section 2. How infected

3. I was diagnosed with severe Von Willebrand's disease, type 3 when I was born. I was tested because both my parents had mild Factor VIII (FVIII) deficiency. As my Von Willebrand's disease was so severe the hospital classed me as a haemophilic.

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4. The blood products that I have received over the years include: Whole Blood, Plasma, Cryoprecipitate, Dried Factor VIII Fraction, Type 8Y, and Factor VIII (FVIII). I currently take Voncento FVIII. I required treatment frequently.
5. I have received FVIII at 3 different hospitals. The main hospital that I received FVIII was MRI and I was under the care of **GRO-B**. I moved to Leeds for a brief period of 2 or 3 years and I also received FVIII at Leeds Hospital (LH). I was under the care of **GRO-B**. I also attended **GRO-B** and was given FVIII by **GRO-B**.
6. I believe I was first given FVIII at the MRI in or about the early 1970s. I was using FVIII treatment until the doctors changed my treatment to Voncento in or about 2015. No information or advice was given to me beforehand about the use of or risks associated with blood products.
7. I believe I was infected with Hepatitis C (Hep C) from contaminated FVIII blood products between the late 1970s and or the early/mid 1980s.
8. In or about 1994, I received a telephone call from the hospital whilst I was at work. I was told that the doctor urgently needed to see me. I left work to attend the hospital. When I saw the doctor and he told me that I had Hep C. This was the first that I was told that I had Hep C. I did not know what Hep C was. I was not provided with any information about how I was infected. I was very worried when I was told.
9. I received very little information from the doctors to help me understand and manage the infection. I do not consider the information that I received was adequate.
10. I believe information about the infection should have been provided to me earlier. I am absolutely certain that the doctors had some knowledge that I was infected, but they did not tell me.

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11. I was not aware that I was being tested for Hep C. When I had blood tests I was always told that the tests were carried out to monitor my blood levels for my haemophilia. I was never told that I would be tested for Hep C.
12. When the doctors told me that I had Hep C I was not told that it could be infectious. In or about the late 1994 or early 1995 I was told by the doctor at my second or third routine appointment that I could infect someone with Hep C through blood only. It was in or about 1999 or 2000 at another routine appointment that I was told that Hep C could be sexually transmitted. I had a child with an ex-wife and I was very frightened when I was told that it was infectious and could be transmitted sexually. I was extremely worried that I could have infected my then wife and child.

Section 3. Other Infections

13. In or about 2005, I believe I received a letter about vCJD. I recall attending the hospital to question whether I needed to do anything, but I was told by the doctor that I had nothing to worry about. In or about 2009, I received another letter stating that they had found a trace of vCJD in a haemophiliac who had died. At this point I was very worried and frustrated, but the doctors were not able to provide me with any further information.

Section 4. Consent

14. I believe I was tested without my knowledge. I recall watching something on the television in the early 1980s on the BBC Horizon stating that hemophiliacs were at risks of HIV, so I demanded to be tested. When I asked for the HIV test I was made to feel like a nuisance. However, I believe that I was tested for HIV before I asked to be tested, but I am unable to confirm this without my medical records.
15. I believe I was tested and treated without my knowledge and consent because when I was told that I had Hep C I was not told that I was being tested for it.

16. I also believe I have been tested for the purposes of research.

Section 5. Impact of the Infection

17. Since I was diagnosed with Hep C it has completely changed my life. I took it very seriously; I did not know how I had been infected, or how it would affect me.

18. I have had difficulties with mobility as a result of the Von Willebrand's disease, but I believe the infection has caused further difficulties. I suffered from nausea, panic attacks and depression because of the Hep C.

19. In 1995 or 1996 I was told that treatment was available for Hep C. I was given Interferon at LH. I do not believe I was provided with adequate information in relation to the side-effects of the treatment. I had the treatment for approximately 3 or 4 months, but I had to stop as I developed shingles. The doctors at LH told me that I had low white blood cell count and that was the reason I developed shingles.

20. The treatment made me very tired and agitated. I suffered from flu like symptoms, most days. It also affected my appetite which resulted in weight loss. I was also left with neurological burns to my ribs and back because of the treatment.

21. The Interferon treatment also impacted my mental health. I suffered from deep depression. As a result, I had to take additional medication such as anti-depressants. I continue to take anti-depressants, and I believe I will have to take them for the rest of my life. I tried to get counselling from the doctors, but it proved to be difficult. I was not offered any counselling initially and it took a few years until I it was offered to me.

22. I was working before I started the treatment. However, once I started the treatment I had to take a lot of time off from work. This affected me financially.

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23. The first treatment was unsuccessful. I was therefore offered another course of treatment, Interferon and Ribavirin in the late 1990s.
24. When I started the second course of treatment I had to give up work because I could not cope. I felt suicidal, but I wanted to clear the infection so I continued with it. Words cannot express how low I felt, it was awful. I had completed 11 months out of 12 and suddenly everything got worse for me, mentally and physically. I had regular blood tests, whilst I was having the treatment and I informed the doctors that I had severe headaches and was feeling very sick all the time. At one of my routine appointments I asked for medication to ease my headaches but I was told that they did not have any. I later collapsed in the hospital and was rushed to have a scan. The results showed that I had a brain haemorrhage. I was in hospital for approximately 10 days. I was explicitly told that the brain haemorrhage had occurred because I had a low white blood cell count as a result of the treatment.
25. As a result of the brain haemorrhage I had to take stronger anti-depressants. I now suffer from acute obsessive-compulsive disorder (OCD), epilepsy and anxiety. I still find it difficult to live a normal day-to-day life.
26. The second course of treatment cleared the Hep C. However, I wish I never had the treatment in the first place. I have nothing left in my life. I cannot explain what a mess I am in. I am always scared, anxious and worried. I felt like a guinea pig.
27. I felt that I was treated differently because of the infection. I was told that I was unable to collect my medication over the counter at my local hospital because the treatment was 'radiated'. I had to drive to LH to collect the treatment and I felt very frustrated and angry.
28. The infection has also impacted upon my dental care. I cannot have treatment at a local dentist. For all my dental treatment, I have to attend MRI, which can be a nuisance.

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29. The Hep C has had a huge impact on my private, family and social life. I had a wife at the time and I believe that the relationship broke down because I was infected with Hep C. I had to explain to my ex wife and son that I had Hep C which was not a nice conversation. For approximately 5 or 6 years I could not get into a new relationship because I did not want to tell anyone that I had Hep C.

30. I believe I lost my house and my job because of the Hep C and I am now left with anxiety. I am not the same person as I used to be. The OCD is so extreme it has affected my relationships and my day-to-day living. I had to wear latex gloves when I had a cut on my hand because I was so paranoid that I would infect someone. I still wear latex gloves when I cut myself, despite being cleared of Hep C. I believe I will be like this for the rest of my life. I tried to be private about the infection, but people still passed on information and found out that I was infected with Hep C.

31. Being diagnosed with Hep C has not impacted my education but I believe it has impacted my son's education. As previously stated both the treatments were horrible and affected everybody in the house.

32. The infection has affected my work. As previously stated I had to give up work because of the second treatment. I believe that if I had not had the treatment I would still be in work and I would have had a nice detached house. I have nothing now.

33. I am currently on benefits as I was unable to work because of the second treatment. As a result I lost my house and now I live in a rented bungalow.

Section 6. Treatment/care/support

34. I have faced difficulties accessing treatment and support. I believe that the doctors have lied to me and I have lost all faith in hospitals. MRI will not let

me talk to GRO-B since the Inquiry has started.

35. When I was first diagnosed, I was not offered any counselling. I was told that everyone was responsible for their own health. After my brain hemorrhage the GP then arranged for me to have counselling. Initially I had the counselling through the NHS and then Caxton paid £1,000 towards it. I am now having more treatment through the NHS once a week.

Section 7. Financial Assistance

36. In or about 2003, I received a lump sum payment of £20,000 from The Skipton Fund. I received £1,000 every three months from EIBSS but I was told that I will now receive £4,500 every three months.

37. I also applied for alterations to the house from the Caxton Fund. This was relatively straight forward.

38. The process of applying for the lump sum payment from The Skipton Fund was not straight forward. My doctors had to intervene and prove the mental and physical effects of the Hep C. The process has been degrading as I feel like a failure.

39. Since the Trust has become EIBSS it has become very confusing and complex.

Section 8. Other Issues

40. Being diagnosed with Hep C has completely changed my life. It is truly devastating having everything taken away from you. I have no security, no job, and I feel like a total failure.

Anonymity, disclosure and redaction

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

42. I do not wish to give oral evidence at the Inquiry.

Statement of Truth

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

Signed.....
[Redacted Signature Box].....

Dated 17/11/19.