

ANONYMOUS

Witness Name: **GRO-B**

Statement No: WITN1422001

Exhibits: WITN1422002

Dated 21 March 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**
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GRO-B
2. I was born in **GRO-B** who came from **GRO-B**
GRO-B We returned to England on and off between 1983 and 1986 and then remained in **GRO-B** until about 1995 when my parents divorced. I then returned to England with my mother, at the age of 13.
3. I was Infected with Hepatitis C as a result of receiving contaminated blood products
4. This statement has been prepared without the benefit of access to my full medical records.

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Section 2. How Infected

5. I suffer from Haemophilia B classed as severe with a clotting factor of less than 0.01 %. I was diagnosed when I was about 9 months old, my parents were called in to Johannesburg Hospital due to my bruising and suspicion of child abuse issues. At that time, it was a relatively new condition.
6. I received several different blood products FIX (BPL) FIX_9A (BPL), Replinine (BPL) and BeneFIX. I refer to **Exhibit WITN1422002** which is a copy of my National Haemophilia Database record which details the blood products I received throughout my life.
7. Between 1983 and 1986, I received Factor IX as and when necessary. As a small child, I lashed out and did not want the injections when my mother administered the blood products to me. At present, I am administering a clotting factor called "Idelvion" for me it has been a life changing clotting product due its half life of approximately 2 weeks.
8. I was treated at Lincoln General (now County) Hospital, Haemophilia Centr. I do not recollect the names of my consultants. The only names I can now recollect of who treated me are a Sister Brown and a Doctor Pagnall.
9. Upon returning from South Africa in the mid 1990's, my mother was given a letter from Johannesburg General Hospital to pass on to the Haemophilia Centre at Lincoln General Hospital which explained that I was Hepatitis C positive. This was the first instance when my infection was brought to light. My parents were not informed about my infection prior to this occasion.
10. To the best of my recollection, the Lincoln Haemophilia Centre, in particular Doctor Pagnall, confirmed that I had been infected through receiving contaminated blood products in England sometime between 1984 and 1986.
11. I believe neither my parents nor I were given any information in relation to the risks of infection from receiving Factor IX blood products.

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12. I recollect my mother and I were called in to Lincoln Haemophiliac Centre, to discuss the matter and the information given in relation to the infection was minimal. We were told that Hepatitis C was not as infectious as Hepatitis A or B and the doctor also attempted to explain some of the symptoms. The doctor also mentioned there were risks in having sexual partners and of having children. In the event of blood spillages, I was told to be as careful as possible.
13. I do not think we were given enough or adequate information in order to manage the infection.
14. I believe that full and adequate information should have been provided to me as soon as it was found out that I had been infected. I should have been told about my infection as soon as possible. I am a very strong-minded person and try to overcome negative news and take it as well as I can. Nevertheless, my parents and I should have been fully informed.
15. I was told at that time, there was no known cure or successful treatment which could be offered to me. Having Haemophilia B from birth, I was always given negative information about my health. Although it was difficult to digest sometimes, it became a big part of my life. The news about Hepatitis C was just another negative piece of news which I had to get on with.

Section 3. Other Infections.

16. In or about 2000 to 2001, I was called into the Lincoln Hospital to discuss whether I at risk of vCJD as a result of receiving contaminated blood products. The doctors told me that I was not exposed to any batch's infected with vCJD.

Section 4. Consent.

17. I was a child when I received the contaminated blood products in the 1980's, which means my parents would have had to consent to my treatment. I therefore have a very blurry recollection.

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18. As far as I am aware, I have not been treated without my knowledge or consent, however as a Haemophiliac, I am used to my blood being taken for tests, and not every test being explained so I may have been tested without my knowledge or consent.
19. To the best of my knowledge and as far as I am aware, I was not used for the purposes of research.

Section 5. Impact

20. Apart from severe fatigue and general tiredness I did not notice any physical effects when I was very young, and I continued to have as much fun as a young child could. At the time, I did not know about any infections.
21. In 1995/1996 my viral load became extremely high and it was considered necessary for me to commence treatment. I had Pegylated Interferon in the form of injections which failed to clear my infection. One injection was to the side of the stomach, and another was to the top of my leg. I recall that I had to take 4 injections a week. I recall experiencing flu-like symptoms as a result of this treatment. The doctors tested my viral load and confirmed it was not reducing, therefore after about 3 months it was decided I should stop the treatment.
22. In or about 2003/2004, I was treated with Pegylated Interferon and Ribavirin in the form of 4 injections taken with tablets weekly, this also failed to clear my infection. The side effects of this treatment were extremely difficult to cope with. The doctors advised me the treatment would be harsh. Ultimately, I lost 2 stone in weight which with my stature (it was a fifth of my body weight) was significant to show I was very ill and cause weakness, and tiredness. I also experienced extreme itchiness which I had to use a key to relieve; scratching and cutting my skin which was a risk in itself for a Haemophiliac.
23. Often, I could not keep my food down, resulting on one occasion in me breaking my front teeth on the toilet seat due to rushing to be sick. I was

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crying in the shower feeling depressed, I questioned absolutely everything and wondered why all this had happened to me; everything built up and I felt a burden on my shoulders. It was the worst thing in the world to me at the time. I recall, one night I was in bed and I couldn't sleep with worry, anguish, anger, wanting to end it I contemplated running and jumping out of the window. Fortunately I knew the feelings were a side effect of the treatment so instead I to drove to the hospital and checked myself in to speak to a psychiatrist as a cry for help. In the morning I spoke to my mother and a Haemophilia nurse and, seeing the state I was in, I was taken of this treatment immediately.

24. In approximately 2016, it was proposed I have a third course of treatment. Due to the side effects of the second course of treatment I had to think about this. I eventually agreed and I was treated with Harvoni and Ribavirin in the form of tablets which thankfully cleared my infection. I questioned whether I wanted to go through rigmarole of medication, having experienced the awful side-effects of my previous treatments. In comparison, this treatment was a painless, complication-free experience which cleared the virus within 12 weeks.
25. I have developed cirrhosis of the liver from the Hepatitis C infection and I have an abnormal liver function. I also still suffer with depression.
26. Whilst undergoing my treatments, I had a good rapport with the nursing staff at the Haemophilia Centre who listened to my questions and advised me appropriately.
27. I had to attend a dental specialist based in GRO-C in Lincolnshire due to my Hepatitis C infection they were also aware that I was a Haemophiliac.
28. I feel that I have been quite lucky in relation to the effects on my private, social and family life. My parents never suggested keeping my infection a secret, it was my personal choice. I have kept it to myself but if I was bleeding in public, I would ask people to move away and stay away from me. I have had to be a bit aggressive when people insisted on helping to clear up my

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blood to help me. In the long term, I think it was for the best that I kept it a secret.

29. I believe that my mother was impacted by my infection. Although I have not discussed it with her openly, I have noticed that her life has been impacted through weight gain and her emotional wellbeing. She was definitely heartbroken.

30. Financially, my mother struggled as a single parent. The most significant financial effect was that I had to quit my work for approximately a year whilst undergoing the treatment for Hepatitis C.

31. I worked as much as I could to keep money coming in. I did not want people to think I was lazy, but in reality my ill-health caused the problems.

32. I do not believe that my infection affected my education; I have some qualifications.

33. There was a huge stigma in relation to Hepatitis C which was associated with drug abuse, alcoholism and promiscuity. As a result of this, I kept my infection a secret for years as I did not need any negative stigma in my life.

34. I constantly worried about having to take my Haemophilia treatment and wondered what else I was possibly putting into my body.

Section 6. Treatment/Care/Support

35. I did not find it hard to find treatment as it was offered to me at the time. I tried all of the treatments in hope that they would work.

36. To the best of my knowledge, my mother and father were not offered any counselling or psychological support.

37. I have always been a strong character, and feel I did not require any psychological help or counselling other than I mention in paragraph 23 above.

Section 7. Financial Assistance

38. A doctor at the Haemophilia Centre advised me I should apply to The Skipton Fund for financial assistance.
39. I received the Stage 1 payment of £25,000.00 in about 2004 and the Stage 2 payment of £50,000.00 in or about 2005 or 2006.
40. I completed the application form and my doctors verified the details in relation to my health. I do not feel that I experienced any obstacles or difficulties in the application process.
41. I receive monthly payments of approximately £1,500 from the EIBSS which is about £18,000 per annum and a winter fuel allowance payment of approximately £500 every December.
42. My only observation in relation to payments from The Skipton Fund is that they are arguably too low. In Scotland for having been infected with Hepatitis C you receive a higher amount. Therefore, I question why we are treated differently. I think that financial assistance given should be higher.

Section 8. Other Issues

43. I wish that the Government would listen to what people are trying to tell them.
44. An apology is not an issue for me; however lives were put at risk, lives were lost, families have suffered the Government should deal with these issues appropriately.

Anonymity, disclosure and redaction

45. I wish to be anonymous and to give oral evidence to the Inquiry.

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Statement of Truth

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

Signed

GRO-B

Dated

25/3/19