

ANONYMOUS

Witness Name **GRO-B**

Statement No: WITN1205001

Exhibits: WITN1205002- 5

Dated: February 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** of **GRO-B**
GRO-B I was born on **GRO-B** and I am retired. I have been married to **GRO-B** for 38 years and we have two children **GRO-B** who was born in **GRO-B** and **GRO-B** who was born in **GRO-B**
2. This statement has been prepared without the benefit of access to my full medical records.

Section 2. How Infected

3. I have mild Haemophilia A with a clotting factor of 9% and I received Factor VIII from 1978. **Exhibit WITN1205002** is an extract from the National Haemophilia Database which records when and where I was treated with blood products. However, this document fails to record the fact that I was given Factor VIII in 1984 at St Thomas's and Guy's Hospital.

4. My consultant was Dr Savidge and my treating hospitals were St Thomas's and Guy's and King's College.
5. I believe that I was infected with Hepatitis C on 27.10.1986 when I was given Factor VIII during a hip operation. **Exhibit WITN1205003** is an extract from my medical records confirming that I was given Factor VIII. This is also evidenced in **Exhibit WITN1205002**.
6. I was given absolutely no information in relation to the risks of receiving Factor VIII.
7. I was told that I had been infected with Hepatitis C in or around the summer of 1993. I recall attending a routine appointment with Dr Savidge when he told me that I had been infected with Hepatitis C. He advised me that there was nothing to worry about and actually said "*half the country is infected*". He totally played down my diagnosis. He gave me no information to allow me to manage or understand my infection. No advice was given in relation to the risks of transmission.
8. **Exhibit WITN1205004** is a letter dated 29.01.1992 from Dr B J Hunt, Consultant in Haematology to Dr **GRO-B** General Practitioner which states "*Just to let you know that we have been recently screening all our Haemophilia patients for Hepatitis C. This patient has antibodies to Hepatitis C and occasionally has abnormal liver function tests. This would suggest that he may have mild chronic Hepatitis C and we will be watching his liver function tests in the future. We may be able to offer him some treatment if his liver function deteriorates in the next few months*".

Section 3. Other Infections

9. It was not until 2013 that I received a letter, in connection with a colonoscopy, which confirmed that I had not been exposed to vCJD.

Section 4. Consent

10. **Exhibit WITN1205005** consists of 3 extracts from my medical records which evidence the fact that I was tested for Hepatitis B (05.12.1991), Hepatitis C (05.12.1991) and HIV (06.01.1987 and 27.10.1986) without my knowledge and therefore without my consent.
11. My medical records also confirm that I was tested for HIV on 22.07.1987, 03.12.1987, 04.08.1988 and 17.03.1989. All of these tests were carried out without my consent and therefore without my knowledge.

Section 5. Impact

12. I first became very poorly towards the end of October 1986 having suffered an allergic reaction to the Factor VIII. This is documented in **Exhibit WITN1205003**.
13. Following my infection with Hepatitis C I suffered from chronic fatigue, increased joint pains, nausea, a lack of appetite, weight fluctuations, night sweats, memory loss, depression, anxiety attacks, mood swings and poor concentration.
14. I underwent a **GRO-B** liver biopsy in January **GRO-B** which was a very painful procedure and I was left with a tear in the liver and in constant pain following this. It was meant to be a less evasive procedure than a normal biopsy but it was awful.
15. Following the biopsy I commenced the Interferon monotherapy treatment in **GRO-B**. I had to stop this treatment after only 12 weeks because I vomited within 30 minutes of the first injection and the side effects were horrific. My fatigue and depression reached new depths and I felt like I had a severe bout of flu for the entire 12 weeks that I was on the treatment. I had constant diarrhoea, severe anxiety attacks and terrible insomnia. In fact my depression

was so bad that I hoped that I would die by being hit by a car. Following this unsuccessful treatment, I had to wait a year until the next attempt.

16. In GRO-B I underwent the Interferon and Ribavirin treatment which I had to come off at only 15 weeks due to the same reaction that I had to the first treatment. If anything, my symptoms were even worse than last time. The treatment was so severe that my wife and I had to sign a document confirming that we would not try for a baby in the year following the conclusion of the treatment.
17. Following this unsuccessful second attempt at clearing the virus, I then had to wait for another 4 years before I was started on the Pegylated Interferon and Ribavirin treatment. This treatment had to be stopped after only 8 weeks due to me experiencing very serious side effects. This treatment was the most horrific. By this point, I had absolutely no appetite and the doctors prescribed me nutritional drinks.
18. At this stage of my life, I was completely stuck. I did not know what to do and I thought that I would have to live with Hepatitis C for the rest of my life. I lived in limbo for another GRO-B years until I commenced the Harvoni and Ribavirin Treatment in November GRO-B
19. During this treatment, my wife had to take my blood pressure every day and I was a frequent visitor, every two weeks, to the Haemophilia Centre so that my bloods and progress could be monitored. I also suffered from extreme headaches whilst on this treatment, but I managed to withstand the full course of this treatment and finally cleared the virus, upon conclusion of the treatment, in February 2016.
20. My wife has been my rock throughout and has provided me with unwavering support in every way imaginable. My family also understand and were supportive. However, I avoided telling people outside of my family due to the stigma attached to Hepatitis C.

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21. Hepatitis C affected how we were as a family. My children gradually became aware of my infection, assisted by the way the media is today. Had I known about the risk of transmission and I would have ensured that my toothbrush was kept in an entirely separate area.
22. Due to a combination of Hepatitis C and the problems with my hip I have been unable to work. I therefore received incapacity benefits and it was a struggle financially with two young children to bring up. We were always down to our last pennies and we had debts on loans and credit cards. In fact we had to use the Stage 1 Payment from the Skipton Fund to assist with some debt clearance.
23. Despite the fact that I have now cleared the virus, I live every day with constant reminders of my infection with untold damage having already been done. I now have Thrombocytopenia, Hepatosplenomegaly, Splenic Haemanangioma and a cirrhotic liver. I also have an enlarged spleen. I am currently reviewed every 6 months and our lives revolve around hospital visits. I also suffered from bowel cancer and I have a low immune system which means that I am prone to infections and bad colds.

Section 6. Treatment/Care/Support

24. As far as I can recall I have not suffered any obstacles in relation to accessing medical or dental care.

Section 7. Financial Assistance

25. It took 19 years before I received any payment from the Government and it took 25 years to obtain a monthly payment, once they had finally accepted my evidence of cirrhosis.
26. In 2005, I received the Stage 1 Payment of £20,000 from the Skipton Fund.

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27. I believe that I found out about the Trust through The Haemophilia Society bulletin or via the internet.

28. In 2011, I received the Stage 2 payment of £50,000 although this was only after a long battle with the Skipton Fund. A radiologist had stated that the fibroscan results were "*indicative of cirrhosis*" but this was not accepted by the Skipton Fund because the radiologist had failed to confirm that it was definitely cirrhosis. They also argued that because the fibroscan was 6 years old that it could not be used as evidence. I therefore had to request an ultrasound scan. I was disappointed by the Trust and I felt that they were very difficult and "*played on words*".

29. We also applied for grants for a washing machine, fridge freezer, sofa and a reclining armchair in approximately 2012. The application procedure was a nightmare because we had to jump through so many administrative and financial hoops. By the time we provided quotes to the trust and the vouchers arrived, the prices had gone up in the shops which meant that we had to restart the process again from scratch. There was also a limited choice of provider; we received mainly Argos vouchers.

30. Overall, I would say that the Trust was not fit for purpose.

Section 8. Other Issues

31. I have been on Facebook and looked at the Tainted Blood support group. I find this helpful as the people on there are in very similar circumstances to me and we have a shared history.

Conclusion

32. I want accountability and for people to own up to their serious wrongdoing. The truth has been hidden for far too long. Other countries have dealt with matters and we are trailing far behind. I cannot move on and I eagerly await the outcome of this Inquiry.

Anonymity, disclosure and redaction

33. I wish to retain my anonymity and I do not want to give oral evidence to the Inquiry.

Statement of Truth

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

Signed.....

GRO-B

Dated.....

21/02/2019