

Witness Name **GRO-B**

Statement No: WITN1278001

Exhibits: WITN1278002

Dated: 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** **GRO-B**. I live at **GRO-B** with my husband, **GRO-B: H**
2. **H** was born on the **GRO-B** We got married in 1991 and we have a daughter together. **H** has also provided a statement to the inquiry. His statement number is **GRO-B**
3. This witness statement has been prepared without the benefit of access to my husband's medical records.

Section 2. How infected

4. **H** was diagnosed with severe Haemophilia A when he was an infant. This was following an incident of prolonged swelling and bruising to upper arm

and ankle. He required urgent medical attention and he was rushed in to the Leicester Royal Infirmary (LRI). He was under the care of Dr W.J. Matheson then later Dr V Mitchell and Sister Martin.

5. [H] was initially treated with Cryoprecipitate before his treatment was changed to Factor VIII sometime in or around the 1980's. The blood products he received were mainly Cutter Factor VIII (Koate), Factor VIII (BPL) and others. This information is sourced from the UKHCDO national Haemophilia database Manchester which is exhibited at WITN1278002.
6. No information or advice was provided to him or his parents beforehand, nor was the risk of being exposed to infection from blood products discussed with them. As a result, he was infected with the Hepatitis C Virus (HCV).
7. Following his diagnosis, he was not given adequate information to help him understand and manage the infection. He believes information should have been provided to him when they first knew he was infected with the HCV and during the time when he was being tested for HIV and HCV without his knowledge. He was not told anything. It was only when he enquired about a vasectomy reversal in 1992 that he was told he have been tested positive for the HCV as a result of contaminated blood products.
8. [H] also has a younger brother [GRO-B: B] who was a Haemophiliac and died in 1996. We were shocked when [B] died as we later found out that his death was due to HIV and HCV. [B] had told no one about his infections.
9. [H] was not given adequate information to help him understand and manage the infection until 1996. It was only when [H]'s brother died we were given information verbally by Sister C Martin at LRI. We were told that [B] and [H] had been treated with the same batch of Factor VIII, but [B] had been infected with HIV and the HCV. She said they did not know why [B] had been infected with two viruses and [H] with one. At this time we were told that we must wash everything in bleach if [H] bleeds, wear gloves, keep his tooth brush and razors in a safe place.

Section 3. Other Infections

10. [H] received a letter in 2004 saying he had been exposed to vCJD.

Section 4. Consent

11. [H] was treated and tested without his knowledge, consent and without being given adequate or full information. We never had any written notification that [H] had the HCV or that he was being tested for it.

12. I do not know if he was tested for the purposes of research.

Section 5. Impact of the Infection

13. The mental and physical effects on [H] were enormous. He became tired, suffered from memory loss, sweats and became reclusive. [H] also suffered from depression and anxiety and, as a result, he became very isolated and withdrawn.

14. [H] had Interferon and Ribavirin treatment for his HCV in 2001. We were never warned of the side effects. He had to have two courses of treatment as the first one was unsuccessful. Both courses of treatment carried terrible side effects which affected both our lives.

15. The HCV treatment changed [H]'s personality. He became aggressive and would fly off the handle. It was frightening. It was like living with a different person. Things were so bad that I lost my voice because my vocal chords were pulling the wrong way caused by the stress and I had to go for speech therapy.

16. Being diagnosed with the HCV also had a massive impact on [H]'s private, family and social life. He became isolated as he would not go out because he

feared having a bleed in public. This is also why he stopped swimming and he would not even go for a hair cut. He was no longer invited to meals or on holidays with friends. Due to the way we were treated by friends and medical staff, this is why we became isolated. We were made to feel like we were dirty.

17. On one occasion, sometime in or around 1995, we were visiting [H]'s mother, when a woman came to the door and pushed her way in, demanding to know if [B] had HIV. She said if he had anything wrong with him he should not be out in a social place. We asked her to leave and afterwards [B] said it was because he had lost a lot of blood at a venue he was at the day before, and the ambulance men had to wear gloves and aprons, so she had jumped to the wrong conclusion. The following week he received a letter stating he could no longer attend the club any because people had raised concerns in relation to his Haemophiliac status and the link between HIV/AIDS. [H] was not aware that his brother had been infected with HIV and the HCV at this point.

18. When [B] died, [H] received comments like 'oh you and [B] both have got that bleeding thing and some of you lot got HIV haven't they?' We were no longer asked out for meals or to go on holidays with people we had gone with before. This was before we opened up to anyone about his infection. I cannot even imagine how our lives would have been if we had confided in all our friends and family. As a result, we had to keep it a secret because of the stigma attached to his infection.

19. [H]'s infected status has caused me to suffer from depression and become isolated myself. I suffer from depression due to living such a secret and isolated life. I have had counselling, but I could never disclose [B] or [H]'s condition because it had been such a secret.

20. The stigma associated with the HCV has caused us to be totally isolated and withdrawn. It also put a lot of strain on our personal relationship as [H]

limited the intimacy between us. It is like we have lived on the edge of society.

21. We have a daughter who was born through assisted donor insemination after finding out [H] was infected with the HCV in 1992. [H]'s infected status resulted in our daughter missing out on her childhood years as most my time and attention was spent nursing [H] struggling financially, and living with a secret which made it very difficult to mix.

22. In 1997 [H] was told he had to give up work due to having lots of bleeds in his joints. This affected us financially and we nearly lost our house. The hospital sent someone to help us put things into place and explained what benefits we could receive, but this did not solve all our financial problems. At the end, my dad had to help us financially as things could very tough.

23. Through the financial pressure put on us in 2015 we had to sell our house and move out of the area we have always lived in, as we could not afford to keep it in good repair and warm in winter.

Section 6. Treatment/care/support

24. No counselling or psychological support has ever been offered to me. Had this been available at the time, I may have benefited from it.

Section 7. Financial Assistance

25. Sister C Martin told [H] about the Skipton fund.

26. He received £20,000 in 2004 from the Skipton fund which we used to pay off some of the mortgage. Then, in 2015 he started to receive £200 a month from the Caxton Foundation.

27. We have asked for help from the Haemophilia Centre and the Skipton fund, but things were never made clear and it was never easy. We wasted a lot of

time filling in applications and we had to apply at various times. This was not helpful when you needed the financial assistance immediately.

Section 8. Other Issues

28. When an Inquiry was announced I felt a great weight lifted of my shoulders. This is still a secret in the family as only H's sister knows of what they had. I just hope we are able to get the answers and justice we all deserve.

Anonymity, disclosure and redaction

29. I confirm that I wish to apply for anonymity.

30. I understand a redacted statement will be published and disclosed as part of the Inquiry.

Statement of Truth

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

Signed. GRO-B

Dated 26.3.2019.