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Witness Name: **GRO-B**

Statement No: WITN1071001

Exhibits: WITN1071002

Dated: December 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** I was born on the **GRO-B** I live at **GRO-B**
GRO-B with my wife. We have two children,
who are now **GRO-B** and **GRO-B** years old.
2. 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

3. When I was born, I was diagnosed with severe Haemophilia B (also known as Christmas disease). My **GRO-B** and my **GRO-B** are also Haemophiliacs, and my **GRO-B** and **GRO-B** are **GRO-B**
4. I rely on clotting agent to control my bleeds, in particular Factor IX (FIX) clotting agent. I cannot recall when my treatment with blood products began

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or which products/batches I received. However, my National Haemophilia Database records which is exhibited at **WITN1071002** states that I first received FIX in 1978.

5. I received FIX as and when I had a bleed. In or about the late 1980s, my bleeds became more intense and I was put on prophylactic treatment, which I took twice a week to try and control the bleeds.
6. I was treated at the Haemophilia Centre at **GRO-B** Hospital, **GRO-B** I also received treatment at a hospital in **GRO-B** and in **GRO-B** **GRO-B**
7. In or about the late 1980s, I was told by the doctor that I had been exposed to an infected batch of FIX. They wanted to test me to see if I was infected. I agreed to be tested and as soon as the blood tests were carried out, I was told that "unfortunately, you have been one of the unfortunate people that has been infected with Hepatitis C (Hep C)". The Haematology Department arranged for me to meet with the Hepatology Department. This was arranged as a joint visit, to help me to understand what this meant and whether there were any treatments and how it would affect my haemophilia. I had around 4 or 5 joint visits in total. I believe the information that they was provided was all that they knew.
8. I was told not to drink alcohol or smoke and to keep my weight down. I was also told that they would monitor my blood levels and do a small biopsy to check the condition of my liver.
9. I was not told that I could sexually transmit Hep C, this was something that I found out for myself after the AIDS scare in the late 1980s. At this time, I started looking for information about Hep C and found it difficult. I there followed similar guidelines in relation to HIV about protecting myself and others around me. My sons were born in 1990 and 1994, so conceiving them was a big risk. Thankfully, my sons and my wife were not infected.

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10. The Haemophilia Centre that I attended gave me as much information as they could, but I did not feel that the Hepatology Clinic provided me with any additional information. I felt as though they were glossing over whatever they could because they did not know any more themselves.
11. I do not believe that I was given adequate information to understand or manage the infection, but I do not see how they could have provided me with more information, as they did not understand it themselves. However, when the information was available I consider that I should have been provided with it much earlier.
12. Prior to being informed that I had been exposed to an infected batch of blood products, I was not aware of the risk involved from the blood products.

Section 3. Other Infections

13. On the GRO-B I received a letter from the hospital stating that it was possible that I was exposed to vCJD. My GP was informed and I was told that I could speak to them if I wanted further information, but there was nothing that they could do. I have not heard anything since.

Section 4. Consent

14. When I was tested for Hep C, the Haemophilia Centre had previously asked for my permission to carry out the tests and I was aware that they were testing me for infections. As such, these tests were done with my consent and knowledge. However, I do not believe that adequate information was provided about the tests, but I believe they did not have enough information themselves. I do not know if I was tested for Hep C prior to when I gave my initial consent.
15. I believe I was treated and tested for the purposes of research.

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Section 5. Impact of the Infection

16. Being infected with Hep C, had a significant impact on my physical health. In particular, I was bringing up yellow bile, feeling very fatigued and my joints felt worse than they usually did with the Haemophilia. I spoke to the doctors about this and they told me that my body was working twice as hard to fight the virus on top of the symptoms that I was suffering from my Haemophilia.
17. In addition to this, I was also affected mentally. I felt very angry all the time and was filled with a lot of rage. At other times I felt as though I could just sit and cry my heart out. This was a very emotionally and draining time in my life, and I was filled mixed emotions.
18. When I initially found out that I had Hep C, I felt a bit shell-shocked and questioned 'why me?, what have I done wrong?'. My wife and I had only just got married and bought a house to try and start a family. I questioned whether I would still be here this time next year. I put myself in a turmoil worrying about my infection and worrying about my family. I am now able to manage this turmoil, but when I was younger I was on edge all the time constantly thinking about the infection. It was an emotional rollercoaster for me. I would not wish this upon anyone.
19. In 1996, I had a liver biopsy, which was quite an invasive procedure because of my haemophilia. I spent around 4 or 5 days in hospital, and I was told that I had cirrhosis but it was at the bottom end of the scale. I was offered a course of Interferon and Ribavirin, which they said had about a 70% success rate. I felt the success rate was very poor considering I had seen the side effects that people had experienced when they were taking this treatment. I was very reluctant to be put through this aggressive treatment, knowing that there was a 30% chance that it did not work. I therefore declined it on the basis that the cirrhosis was at the bottom end of the scale. The hospital continued to monitor me and I attended regular appointments. They kept offering me the same treatment every time I went.

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20. In 2014, I was aware of the Epclusa treatment. However, it was in a study trial and I recall someone who had the same Genotype 3 as me was on the trial. I asked the doctors if I could go on the trial and the doctors told me it was for something else and they could only offer what was available at the time. I had to wait patiently for another three years before Epclusa became available to me. It was an anxious three year wait for me because I was scared the Hep C would get worse. Finally, I was contacted in January 2017 and I was told that I could begin the treatment.
21. In March 2017, I started the Epclusa treatment and it was a 3 month course. I completed the course. However, it was not guaranteed that it completely cleared the virus, but I was told that the treatment had put my liver function levels down to normal.
22. During the course of the treatment, I suffered from nausea and fatigue, I also felt that my moods changed and I became very argumentative. I was working at the same time and felt spaced out all the time and I found this difficult, but I managed to keep going.
23. I do not know if any other treatments were available for me during this time other than the Epclusa, but if they were then the hospital kept it very quiet and kept this information to themselves.
24. I was told that I was producing too much iron because of the Hep C. I had medication for it to bring my iron levels down. I have recently had an appointment in this regard and I was told that my iron levels have gone up again.
25. Being infected with Hep C, had a significant impact on my private, family and social life. In particular, it tested my relationship with my wife and left me very traumatised. When my family wanted to go anywhere, I had to look at the options and see if I was able to go with them.

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26. When people look at my medical notes they realise there is only so much they can do to help me, due to my exposure to the infected blood products. I have seen warning signs on my medical notes stating 'contaminated' or 'infected', which is very upsetting to see.
27. The stigma associated with my infection has not really been an issue for me, as I have been very private about my status and not been very open with anyone. I am able to handle this by keeping it very close to my family. I worked for thirty-four years and did not tell any of my colleagues that I had Hep C.
28. I believe my Hep C infection also had a financial impact on myself and my family. At the time of my treatment, I was trying to work towards a promotion. I was unable to handle this pressure and it was not offered to me. This really affected me, as I wanted to support my family financially. I was eventually able to progress to a supervisor position, but I was unable to progress to a managerial position. After all of this, I have had to retire due to ill-health.

Section 6. Treatment/care/support

29. I did not receive any support from Hepatology department regarding my infection. No psychological support or counselling was offered to me. If it had been offered then I might have considered it, but I did not have this choice.
30. However, the staff at the Haemophilia Centre were more than willing to help and make themselves available to talk to me. They also went out of their way to organise a joint appointment with the Hepatology Department to ensure they understood my infection.

Section 7. Financial Assistance

31. In 2004, I received a £20,000 Stage 1 payment from the Skipton Fund. I found out about this through the media and through my friends that are also Haemophiliacs. The application process was quite straightforward and I only had to provide a small amount of information, the rest of the application was

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completed by the hospital. To accept this payment, I had to agree that I would not challenge them in the future.

32. I have not applied for a Stage 2 payment from the Skipton Fund as I have not developed severe cirrhosis.

33. I have also received grants from the Caxton Fund, for things such as replacement carpets, new windows and a new fence. Applying for these grants felt like I was being made to jump through hoops and I was not initially accepted for all of them. For instance, when my windows were damaged I had to challenge their decision twice, before they finally accepted my application and provided me with the money to have the new windows.

34. The process of applying for grants with the Caxton Fund was difficult, as they always insisted for their approval first. There was one instance when my roof leaked and the house insurance would not cover it. This occurred over the weekend and I was unable to contact Caxton and had to pay for the repair myself. I then called them on Monday morning and I was told that because this was not agreed prior to the repair, they would not pay for it and I had to pay for it myself.

35. In March 2018 I started receiving approximately £1,500 a month from the EIBSS. I do not believe I would have been able to survive if it was not for the EIBSS.

36. I have struggled to get insurance or be able to work as a result of my infection, but when you try to explain this to the trusts and funds they just say "what do you expect us to do?". I have been given an infection that was no fault of my own, yet I feel unsupported by those that are responsible.

Section 8. Other Issues

37. I have had great difficulty getting travel insurance. Prior to my infection with Hep C, I did not encounter any issues when obtaining insurance. However, after I was infected with Hep C the price of insurance increased by several

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thousand pounds. The difficulty and expense of obtaining insurance is astonishing. I eventually came across a company called Insure & Go, who are reasonable and only marginally increased the price.

Anonymity, disclosure and redaction

38. 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

Dated

28-12-2018