

ANONYMOUS

Witness Name:

GRO-B

Statement No: WITN2575001

Exhibit: WITN2575002

Dated: 22<sup>nd</sup> June 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF

GRO-B

I provide this statement in response to a request under Rule 9 of the Inquiry rules 2006 dated 12<sup>th</sup> December 2018. I adopt the paragraph numbering in the Rule 9 request for ease of reference.

I, **GRO-B** will say as follows: -

1. Introduction

1. My name is **GRO-B** My date of birth is **GRO-B** and my address is known to the Inquiry.

2. I am in a relationship with **GRO-B** of the same address and have been in a relationship with her for **GRO-B**

3. We **GRO-B** but share a **GRO-B** together. **GRO-B**  
**GRO-B**

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4. I would confirm that I am a haemophiliac and that I have been diagnosed with severe haemophilia.

## 2. How Infected

1. I would confirm that due to the severity of my haemophilia I was frequently in and out of hospital when I was younger.
2. There was no other history of haemophilia in my family but at [GRO-B] or thereabouts I bit my tongue and it bled for [GRO-B]. As a result, I was admitted to hospital and it was found out that I was suffering with haemophilia.
3. Throughout my childhood I received a lot of treatment for my haemophilia and therefore I missed a lot of school. Having frequent hospital appointments and treatment definitely impacted on my education. I fell very far behind as I was unable to attend lessons regularly.
4. I would say I was in hospital more than I was in school during my childhood. [GRO-B] would have a tutor visit the house as [GRO-B] was off school more than me.
5. I really liked [GRO-B] and everyone would be finishing their work whilst I would only be able to finish half a job due to the number of bleeds I would have.
6. I always went to school but left when I was [GRO-B] and got a job at one of [GRO-B] in [GRO-B].
7. There were certain jobs I couldn't do. For instance I only felt comfortable working for my [GRO-B] on his [GRO-B] as this meant my hours would be flexible. He understood my condition and I would work for him when I was able to.

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8. I don't remember specific instances of when I was in hospital but those admissions would have been as a result of bleeds in my joints.

9. In those days I would have been treated at **GRO-B** then at the **GRO-B** I can confirm that I was treated by **GRO-B** **GRO-B** at both hospitals.

10. The only treatment available at that point was through admission at the hospital. Whilst at the hospital I would receive injections three times a day and wait for the bleeding to stop.

11. I was young and did not know what was in those injections nor did I or my mother ever ask any questions regarding that.

12. I cannot recall any changes to the type of treatment that I had although I began injecting at home when I was about **GRO-B**

13. My **GRO-B** who is **GRO-B** had haemophilia. I recall **GRO-B** would inject at home.

14. Initially, my mother was shown how to administer the Factor VIII to me, but when I was slightly older a haemophilia nurse showed me how to inject myself. I can remember there being two bottles containing powder which we would mix with water and we would have to inject this whenever we had bleeding in our joints. That treatment has now changed and I now have an injection every other day to prevent bleeds rather than to treat them.

15. My **GRO-B** discovered in the **GRO-B** that **GRO-B** had contracted HIV through contaminated blood products.

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16. I found out I was infected with hepatitis C I believe in the [GRO-B] and I cannot be certain of the specific date. I can recall that [GRO-B] [GRO-B] were called into the Hospital to receive this news.

17. Following [GRO-B] HIV diagnosis I was a bit concerned when I was called into the hospital in the [GRO-B]

18. We were told that I was infected with hepatitis C. [GRO-B] was infected with [GRO-B]

19. I would confirm I was given no further information regarding the infection and was basically left to get on with it.

20. One thing that I do recall is that prior to being told that I was infected with hepatitis C, one of the nurses on the haemophilia ward, [GRO-B] indicating to myself and my mother that we shouldn't have the American products

21. I would confirm I knew absolutely nothing about blood products at that point in time.

22. I often had to look after [GRO-B] The fact [GRO-B] was [GRO-B] had [GRO-B] or [GRO-B] and it was horrible watching [GRO-B] go through such a hard time.

### **3. Other infections**

1. I have not suffered with any other infections as a result of receiving contaminated blood products.

### **4. Consent**

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1. I was obviously young at the time the treatment started and therefore would not have consented to it but I assume my mother must have consented to me receiving the products.
2. The general feeling at the hospital in regards to GRO-B was that he was regarded very highly in his profession, well-respected and never questioned on the decisions he made.
3. It was simply a case of having whatever treatment was needed without I believe any discussion as to the benefits or otherwise of those treatments.
4. I didn't know I was being tested for hepatitis C, therefore when I was called into the hospital to discuss a blood test result that had tested for hepatitis C, I was quite shocked.

### 5. Impact

1. When I was diagnosed with hepatitis C, I very much blocked it out. I didn't want to accept that I had it and I had always been very private in any event about my haemophilia. As a result, I told no one about the infection.
2. I began a relationship with GRO-B and didn't tell GRO-B for a number of weeks that I was haemophiliac or that I had hepatitis C.
3. I felt very wronged when I found out I had hepatitis C. I thought I was going to die.
4. I turned to alcohol as I didn't think anything was going to help.
5. I feel as though I have struggled emotionally with what has happened. I have always kept it to myself that I have hepatitis C. Only my wife and very close family know. I did not tell my GRO-B until last year.

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6. It affected me in practical ways in that when [GRO-B] and I decided to buy a house together I had a £20,000 pay out from the Skipton Fund and put that down as the deposit. However I was unable to get a mortgage in my name because of the hepatitis C.
7. Additionally when I had to take out insurances those were more expensive because of the hepatitis C.
8. As well as the issues with the mortgage etc. I was also depressed about the fact I had contracted hepatitis C and that this was something I would have to live with. I would like to add that the treatments I had to undergo for the hepatitis C caused me to become quite depressed.
9. I would become snappy with the [GRO-B] and would have quite dark moods.
10. When I would go to the haemophilia Centre for treatment I would often see people I knew. Some of them had contracted these horrible viruses and knowing that some were dying made me worry I would be next.
11. In terms of employment I have always been able to work. Initially I worked as a [GRO-B] and then [GRO-B]. After working I always feel extremely tired and I am unsure if this attributed to my illness.
12. [GRO-B] was the clinician who looked after me once I received my hepatitis C diagnosis. I liked him very much. He was a very kind man.
13. In terms of the physical impact then I began three treatment trials. I will discuss these treatment trials in further detail in the section titled "Treatment/Care Support".
14. Around 3 years ago I had another trial. That one was not funded to [GRO-B] Health board but instead was funded by [GRO-B] Health Board and I understand the cost was some £25,000 or so.

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15. I was being treated at the [GRO-B] in [GRO-B] and that treatment was successful as it cleared my hepatitis C. I was cleared of the virus physically but I don't think I will ever be cured of the mental effects.
16. The physical impacts of the treatment were mainly that they made me very tired and lethargic.
17. In terms of my condition presently, my liver is scanned regularly. I understand I have a fatty liver with some scarring but there is not much feedback as to whether there has been any regeneration or not.
18. I have always regarded myself as being quite lucky in comparison to [GRO-B] [GRO-B] and also being fortunate that the treatment has worked but I feel as though the illness has ruined my life.
19. One of the other major impacts I should raise is that the haemophilia community was quite a close-knit community in the sense that lots of familiar faces would attend hospital appointments together. Over a period, there were probably half a dozen of us who would attend regularly at the same time for appointments and I got to know those reasonably well. One of the big affects has been seeing those numbers lessen as people have died as a result of their hepatitis C infection. The illness has felt like a death sentence hanging over my head.
20. One of those who passed away was someone from the [GRO-B] area of [GRO-B] and [GRO-B] ran a [GRO-B] there. Unfortunately [GRO-B] died as a result of the hepatitis C infection and I always felt that there was every chance I would be next.

### **6. Treatment/Care Support**

1. As a baby I would often receive Cryoprecipitate. Following this I started receiving Factor VIII. I am not sure of the exact date that I started receiving the Factor VIII I would say this was in the late 1970s/ early 1980s.

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2. In terms of my recovery since then, I am now significantly better than I was. I feel as though I have more energy and I am more positive.
3. I can confirm I was never warned of the risks of being exposed to hepatitis C.
4. From viewing my medical records I can confirm it was in 1997 when I received my first treatment for hepatitis C. I refer you to Exhibit WITN2575002, this is a copy of my medical records chronology. The chronology shows when and where I received treatment for my hepatitis, specifically referring to the treatment trials.
5. I received my second treatment in 2009 and experienced terrible side effects as a result of this second round of treatment. The second round of treatment consisted of Pegylated Interferon and Ribavirin. I refer to my medical records chronology at Exhibit WITN2575002 which shows that I began the second round of treatment in 2009. The chronology also demonstrates that in 2010 specific treatment failed to clear the hepatitis C infection.
6. I can confirm I received my first and second round of treatment for hepatitis C at the GRO-B
7. I still have moments where I become quite depressed. I have no trust in the NHS in regards to treatment I now receive for my haemophilia and previously the treatment I received for hepatitis C. The reason for that really is not in terms of the medical care they provided as such but the fact that I have always felt I was in this position having contracted hepatitis C as a result of their failings.
8. I have received a number of scans and had an MRI scan. I believe the purpose of this was to detect if I had any other liver abnormalities.
9. I experienced issues with funding, specifically in regards to treatment. I am referring to the occasion when I received my final round of treatment for the hepatitis C in 2013. The final treatment consisted of Ribavirin, Telaprevir and



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Pegasys. However, it was determined that funding was only available for this particular treatment within the [GRO-B] it was not readily available within the parameters of the [GRO-B]

10. I was then referred to [GRO-B] in [GRO-B] There I was prescribed treatment and would have to attend the hospital to see how I was getting on with the medication.

11. One thing I would say about the clinic at [GRO-B] was that those who had contracted hepatitis C from contaminated blood were placed in a clinic with patients who had contracted it through alcohol misuse and drug misuse. I believe that those who contracted the hepatitis through the infected blood should have been placed in a separate clinic.

12. It also concerns the amount of knowledge the medical staff had and the strong belief they knew much more information about the blood products than they ever passed on.

13. The overall opinion of [GRO-B] many years ago was really that he was superb and very committed to his patients. However we now know that information wasn't passed on to patients he was treating. This behaviour was allowed as he was never questioned by patients regarding treatments they were receiving.

14. In regards to dental treatment I would have to attend the hospital for this. I now have to pay private to go to the dentist and in all honesty I would say it's quite expensive.

15. In addition to receiving treatment for my haemophilia and hepatitis C. I also receive orthopaedic treatment for my joints.

### **7. Financial assistance**

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1. I confirm that I did receive a payment of £20,000 from the Skipton Fund. I also now receive and have received for the last 18 months or so £641 per month from the **GRO-B** NHS Trust.
2. I have also received money from the Caxton Fund. This consisted of a grant that helped with paying for household bills such as central heating and water.
3. I believe we received this money quite late as when me and **GRO-B** first got together, things weren't as secure as they now are financially.
4. I have struggled financially all of my life. As a result of this struggle I have taken it out on my loved ones. I think £20,000 seems like a lot of money but I did not want this contaminated blood in the first place. I think I would've become a better person had I not received this blood. I feel extremely angry, frustrated and let down.
5. I was represented by **GRO-B** in a litigation against the pharmaceutical companies. **GRO-B** received compensation from this litigation. However myself and **GRO-B** never so much received an acknowledgement from the pharmaceutical companies. This really knocked my confidence as I found out that those with hepatitis C received the minimal amount of compensation compared to those who had HIV.
6. For us to take part in the litigation I had to request my medical records, this was at a fee of £75. I recall the hospital were not very happy about this as there were about four huge boxes of records that had to be transported to the solicitor's office.

### **8. Other Issues**

1. I am glad there has finally been an Inquiry as I believe this has been a long time coming. Those affected and infected by this scandal deserve justice.

**Statement of Truth**

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

Signed. GRO-B .....

Dated... 22/6/19 .....