

ANONYMOUS

Witness Name: **GRO-B**

Statement No: WITN2465001

Dated: 12th March 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 12th 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. I live with my wife of **GRO-B** years. I have two daughters, **GRO-B**. They are both grown up. I work as a **GRO-B** locally.
2. As a result of treatment with contaminated blood I was infected with hepatitis C (HCV).

2.How Infected

1. We first found out when I was about 18 months old that I had severe haemophilia type VIII. Tests showed my blood had a 1% clotting factor. I have haemophilia because my mother is a carrier.

2. When I was younger, I went to a special school in [GRO-B] up until the age of around [GRO-B] or [GRO-B] I was then [GRO-B] until I was around [GRO-B] to [GRO-B] years old. It was too difficult for me to attend school full time when I was little as I spent half of my life in hospital. This was due to constant injuries, bumps and scrapes causing frequent bleeds. My constant need for medical attention had a direct impact on my Mum, my Dad and my Sister and our family life.

3. I was mainly treated for my haemophilia at [GRO-B] [GRO-B] and the doctor responsible for my care was [GRO-B] from [GRO-B] up until [GRO-B]

4. At age [GRO-B] I went to [GRO-B] as I needed to have 4 teeth extracted. This caused severe bleeding and I was given a whole blood product there to stop the bleeding.

5. At [GRO-B] years old I underwent hip replacement surgery at the [GRO-B] in [GRO-B] I attended [GRO-B] on a few occasions and I recall it was a [GRO-B] who did my operation.

6. I attended numerous hospitals over the years including: [GRO-B]

[GRO-B]

[GRO-B] I received blood products in most of them.

7. Over the years I was treated with lots of different types of blood products including cryoprecipitate (Kryoglobulin). At one point when I was around [GRO-B] or

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- [GRO-B] years old I went to the [GRO-B] and participated a trial for animal blood products overseen by [GRO-B]
8. I started home treatment for my haemophilia around age [GRO-B] or [GRO-B]. This meant that I did not have to attend the hospital quite so often. This meant more freedom for me so I was really happy about it. I believe I was infected with hepatitis C as a result of the Factor VIII home treatments. I saved some of this product and gave it to [GRO-B] a freelance reporter in [GRO-B] for TV programme [GRO-B] [GRO-B] which was in [GRO-B]. I am confident that these samples will be found to be infected if tested.
9. At age [GRO-B] I collapsed following a bleed in my arm and I was admitted to [GRO-B]. I was told I would be allowed home the following day from [GRO-B] but I collapsed again on my way up to the ward. Nobody knew what was wrong with me at the time. I was kept in hospital for six weeks suffering with unexplained jaundice and liver problems.
10. Over the years I became such good friends with [GRO-B] that he attended my wedding and even [GRO-B] off me.
11. I was never warned that the blood products that I was prescribed to control my haemophilia carried with them the risk of infection.
12. I was first told by [GRO-B] that I had contracted hepatitis C in the mid [GRO-B]. My medical records state that I was told in [GRO-B]. I think I was infected maybe [GRO-B] years before this and that's probably what had caused my jaundice and liver problems earlier on. I had a lot of blood tests over the course of that [GRO-B] year period for both hepatitis C and HIV.
13. I remember being convinced that I had HIV which was a huge concern to me especially when my daughters were being born. I was worried that I had passed a killer virus on to my own children unintentionally.

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14. I don't recall being given any specific advice at the time about managing the symptoms of hepatitis C. I was told about possible transmission of the virus to members of the family but I don't recall receiving any advice on how to reduce the risk of passing the virus on. It was a constant worry for me. I remember my wife got tested but thankfully her result was negative.

15. I don't feel like I was supported at all when I was told I had been infected.

3. Other Infections

1. In [GRO-B] I received a letter informing me that it was possible that I had been infected with CJD.
2. It wasn't until [GRO-B] that I received a letter confirming that there was no further risk of this.
3. I do not recall any other infections.

4. Consent

1. For the pig's blood trials in [GRO-B] I certainly didn't consent and I don't know whether or not my parents did.
2. I have been tested throughout my childhood and teenage years without knowing what the tests were for.
3. I must have been tested for Hepatitis C without my consent because I wasn't aware I had been tested for Hepatitis C at the time I was told I was infected with it.

5. Impact

1. I stopped drinking when I found out about the hepatitis C infection which was difficult at that age.

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2. I had two cousins [GRO-B] and [GRO-B]. Both were haemophiliacs and they were both treated in [GRO-B] for haemophilia. Both of them passed away when we were in our [GRO-B] and their deaths hit me very hard.
3. Back in the [GRO-B] and 90s you could not discuss conditions such as hepatitis C and HIV due to the stigma surrounding the way that they were transmitted. There were news programs and advertisements which worsened that stigma around HIV and hepatitis.
4. I lived in a [GRO-B] town where gossip travelled easily. In the early [GRO-B], one of my business competitors spread the rumour around my town that people should not [GRO-B] from me because my illness was so contagious.
5. This meant that I had to be very careful who I talked to about my condition. It also meant that I tried to bottle up my feelings about it to protect my family.
6. When I was aged [GRO-B] or [GRO-B] and I had been going off the rails, drinking a lot and unable to cope with my friends and [GRO-B] dying around me and my own uncertain future, [GRO-B] arranged for me to see a psychiatrist. This didn't really help my state of mind at the time and I struggled to cope.
7. A turning point came for me when one of my best friends, who had [GRO-B] passed away. In a way that snapped me out of my destructive phase as I felt fortunate to be alive when compared to my friend - he wasn't so lucky. From then on I have tried to make the most of life and I have tried not to let my condition affect my family life too much.
8. Hepatitis C has affected my finances. Our mortgage is in my [GRO-B] as it was very difficult for me to obtain a mortgage due to the hepatitis C. Holiday insurance is also more expensive for me compared to the price that my wife and other family members pay.

6.Treatment/Care/Support

1. Around [GRO-B] I was offered a treatment for hepatitis C called Interferon. When I took this medication I had a horrible time of it. I couldn't work, I couldn't function, my body was riddled with aches and pains and I kept breaking down. It was the worst I had ever felt. It makes me angry that I hadn't been warned about the potential side-effects of Interferon.
2. It was very frustrating that due to my low tolerance for the medication, I had to stop taking it after two weeks. I had a mortgage to pay and couldn't afford to stop working.
3. In [GRO-B] I was surprised to test negative for hepatitis C for the first time since I was infected. My level is now so low that hepatitis C is no longer showing in my bloodstream. I still need to be tested every six months for hepatitis C and the infection over the years has taken its toll. My liver is enlarged and also needs to be scanned every six months. I am in constant fear that I will test positive again for hepatitis C and that it will come back aggressively. I also worry that the damage to my liver will not be repairable and will only get worse.
4. When the new Interferon treatment came out in 2013/2014 I went to [GRO-B] [GRO-B] for testing by Dr [GRO-B] from [GRO-B] to see whether or not I qualified. I had to go to [GRO-B] as the [GRO-B] was not prepared to pay for it. I was refused because the levels of hepatitis C were too low in my bloodstream by that point.

7.Financial Assistance

1. In 2001 I received approximately £20,000 from The Skipton Fund and also from the [GRO-B] I receive approximately £1,100 every three months but I have never applied directly for financial assistance.

8. Other Issues

1. I have always felt in a way that I was experimented on as a child and as a young adult and that my life was in many ways out of my control.
2. I never wanted anyone to know about either my haemophilia or my infection with hepatitis C. If someone asked about it I would say that I had had an accident. I just wasn't comfortable telling anybody.
3. Seven of my friends from the haemophilia ward at [GRO-B] have passed away along with [GRO-B] of my [GRO-B]. I feel so sad to have lost so many people close to me but also very lucky to be alive. I feel that they were denied the opportunity to tell their stories and get answers and It is difficult to know how justice could be done now they have lost their lives.
4. My friends and I were used as guinea pigs. [GRO-B] was a close friend and it is troubling to me to think that he knew about the risk associated with the blood products he used to treat me and didn't tell me. One the one hand I feel really angry but on the other hand I am still really grateful that he helped me with my haemophilia.

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Statement of Truth

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

Signed ..

GRO-B

Dated ..

12/03/19