

# ANONYMOUS

Witness Name: **GRO-B**

Statement No: WITN2520001

Dated: 20<sup>th</sup> February 2019

## INFECTED BLOOD INQUIRY

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### FIRST WRITTEN STATEMENT OF **GRO-B**

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I provide this statement in response to a request under Rule 9 of the Inquiry rules 2006 dated 12<sup>th</sup> December 2019. 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 live at my current address with my wife and I have done so since **GRO-B** We **GRO-B** together. **GRO-B** live away from home.

#### 2. How Infected

1. I was born with severe Haemophilia A, which I was diagnosed with when I was around **GRO-B**

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2. I recall that I was initially treated at the [GRO-B] for my haemophilia. I was treated with Cryoprecipitate which was sent from the [GRO-B] and then administered at the [GRO-B] whenever I had a bleed. I would usually spend all day receiving treatment.
3. In the early [GRO-B] I was transferred to the care of the Haemophilia Centre located at the [GRO-B] also known as the [GRO-B]. I was initially under the care of [GRO-B]. [GRO-B] I was then placed under the care of a couple of stand-ins for [GRO-B] eventually taking over my care. I remain under the care of the Haemophilia Centre at [GRO-B].
4. At around [GRO-B] years old I was introduced to a new product to treat my haemophilia. The treatment was a whole blood product called Factor 8. I believe use of this product in the late [GRO-B] to be the reason I am HIV, Hepatitis C (HCV) and Hepatitis B positive.
5. After being introduced to the Factor 8 product I was taught by the medical professionals at [GRO-B] how to treat myself with it at home. At no point were me or my parents told of the risks associated with the Factor 8 product. I was simply told that it was a more effective treatment and that it would make life easier. The irony isn't lost on me.
6. I remember when the news started to break that haemophiliacs had contracted AIDS, HIV and so on. I was really worried but at the time I was at [GRO-B] and I was being treated at the haemophilia centre there, so I thought it may not have got me. Unfortunately I wasn't one of the lucky ones.
7. I was told of my HIV by [GRO-B]. At the time, he didn't tell me of the risks associated with the illness. It was very matter of fact and it wasn't until the early [GRO-B] that I was informed of the risks as my wife and I

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wanted children. I said to him that I wanted children, and I remember him saying to me something along the lines of "what's the matter with you, do you really want to infect your children?" I must admit, I was very shocked by his manner towards me in that conversation. Fortunately, **GRO-B** was a little more empathetic to our situation and he discussed the best way for my wife to conceive, which she eventually did.

8. Even when I was eventually advised of the risks, it wasn't particularly informative. I was told that it was a relatively new illness and that I should use my own towel when washing. It's quite shocking to think that's all I was told when I know now the risks associated with my condition.

### 3. Other infections

1. I was diagnosed with Burkitt's lymphoma which I was cleared of following treatment.
2. I have also been diagnosed with pancreatitis and believe this could be related to the HIV or HCV.
3. In addition to the aforementioned illnesses, I was also told that I could be infected with vCJD, also referred to as 'mad cow disease'. It was explained to me that the symptoms would arise in around 10 years after being exposed. I have not had any symptoms so I assume I am in the clear. I remember thinking at the time: that's another one to add to the list.

### 4. Consent

1. I was never informed of the risks associated with using Factor 8. If I was I would never have taken it, and had my parents been informed of the risks, they would never have agreed to it either. If any of us were told of the risks, I would have continued to use the Cryoprecipitate product. It was a pain in the

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backside and it was very time consuming, but those risks are microscopic in comparison. Put simply, I was told it would make me better and not worse.

2. In my view, they were aware of the risks associated with the product but chose not to tell me or other haemophiliacs of the risks as it would have impeded the development of the treatment. I think they probably gambled, thinking that it wouldn't affect that many people, and by the time they realised how bad it was it was, it was too late.

### 5. Impact

1. My illness has had a significant impact on my life. It's difficult to know where to start. I feel fortunate in that it hasn't really had a massive impact on my physical health but around three years ago it began to really start taking its toll on my mental health. So much so that I visited my doctor about it who then prescribed me with anti-depressants; and I still take them.
2. There are a number of reasons why it has had such an impact on my mental health. Having to live a life of secrecy because of the stigma associated with the illness is without a doubt a contributing factor. I haven't told anyone other than my immediate family. I didn't even tell my children until they were adults, and it wasn't through choice that I told them.
3. My gallstones flared up a couple of years ago and when the paramedics turned up they asked me for my medical history. My daughters were standing there and I had to give them the information; it was an awful way for them to find out. The truth is, had that situation not occurred, they still wouldn't know to this day. They seem to be dealing with it well, but my youngest keeps herself to herself and so it is difficult to gauge how she's feeling. My oldest gets upset from time to time but that's expected, I suppose.
4. I really worry about it getting out and the consequences if this happened. My friends don't know and I fear that if they ever did find out then they would no



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longer want to associate with me. Although the stigma is not as bad as it used to be, it is certainly still there, and it always will be. The fear of them finding out causes me serious paranoia at times. If anyone ever mentions something that is remotely related to my condition, I find myself worrying that they may know and that they're somehow testing me to see if I react.

5. My wife has had to put up with so much too. She has had to watch me go to appointment after appointment, worrying whether I may have bad news to tell her. Of course, the stigma has also meant that she too has lived a life of secrecy and so what I go through she goes through so that we can protect our family. My depression is difficult for her to deal with at times and my mood has inevitably impacted on my sex drive.
6. As mentioned, GRO-B told my wife and I a number of years ago that we would be mad to try for children. That was an awful time for us as we really wanted children. Fortunately GRO-B was more helpful, but I know that that was a tough time for my wife and it's something else she had to go through.
7. Travelling abroad is always a bit of a pain as I have to get my medical documentation together and make sure that I can be treated in the event that something happens. If my friends were to travel to Las Vegas for instance, which is somewhere I would one day like the opportunity to visit, I couldn't help but worry that I wouldn't be allowed in the country or I would be asked questions at the airport and then everyone would find out. It's a nightmare.
8. My family and I have gone through so much because of the recklessness of the medical professionals responsible for my care. It is has been difficult to put into words the impact it has had on my life.

### 6. Treatment/Care Support

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1. As mentioned, I treat my haemophilia at home and I am currently trialling a new blood product for the haemophilia centre.
2. The treatment I have received for the HIV has been in the form of tablets which I take on a daily basis. I am under the care of the kidney specialist at the moment as the medication I am taking for my HIV may impact upon my kidney; however the medication has not done so, yet.
3. I transferred to the Infectious Disease Centre around GRO-B years ago for treatment of my HIV. Before that it was treated at the Haemophilia Centre.
4. I underwent the Ribavirin and Interferon treatment a few years ago for my HCV, but unfortunately the treatment was unsuccessful.
5. As I mentioned, I was diagnosed with Burkitt's lymphoma in GRO-B. It was an incredibly difficult time and the timing of the diagnosis couldn't have been worse with it coming only GRO-B before GRO-B. Fortunately, I had 6 months of intensive chemotherapy that eventually cured me of the cancer.
6. I must admit that although I have never been told directly that it was brought on due to my condition, the more time that has passed, the more I believe that it is in some way connected to my HIV and HCV.

### 7. Financial Assistance

1. I have received a payment of £20,000 from the Skipton Fund.
2. I am also in receipt of a monthly payment of £1,800 from the GRO-B.

### 8. Other Issues

1. To my knowledge, there are no other issues that I can think of that will assist the inquiry.

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**Statement of Truth**

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

Signed..

GRO-B

Dated... 20th February 2019.