

# ANONYMOUS

Witness Name: **GRO-B**

Statement No: WITN2387001

Dated: 28<sup>th</sup> May 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 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 live with my wife **GRO-B** to whom I have been married for **GRO-B** years. We have one **GRO-B** together who also lives at home with us.

#### **2. How Infected**

1. I was born with severe Haemophilia A meaning my blood has a 0% clotting factor.

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2. I recall receiving my first treatment for my haemophilia when I was around [GRO-B] years old and this came in the form of fresh frozen plasma; also known as Cryoprecipitate.
3. I believe I was [GRO-B] or [GRO-B] years old when I first started to use pooled blood products. The particular whole blood product I was prescribed with to treat my haemophilia was the Factor VIII product.
4. I believe my use of this product to be the reason for me contracting hepatitis C. Over the years I have administered blood products at home on a prophylactic basis. This included blood products imported from America. I was shown how to do this at the Haemophilia Centre at the [GRO-B] in [GRO-B] and given the number of times I did this over the years it is difficult to pinpoint when or what batch infected me.
5. Initially, I attended the [GRO-B] for my treatment. However, in the [GRO-B] I moved, along with the other haemophiliacs in [GRO-B] to the Haemophilia Centre located at the [GRO-B] also referred to as the [GRO-B].
6. At [GRO-B] I was under the care of [GRO-B] until he [GRO-B] in the [GRO-B]. Following his [GRO-B] I was placed under the care of [GRO-B] [GRO-B] I do not recall if [GRO-B] was immediately after [GRO-B] but he did eventually take over my care.
7. I must admit that I held the medical professionals at the Haemophilia Centre in the highest regard, and I still do – although my wife may have something to say about that! The service in my view was exceptional.
8. When I was younger I visited the Haemophilia Centre every couple of weeks for treatment or a check up. However, when the whole blood product was introduced I visited less frequently as I treated myself from home.
9. I remember the Factor VIII product was considered revolutionary at the time as it treated the prophylactic flare-ups more effectively. At no point

did those responsible for my care sit me down and tell me that the blood products I was using would put me at risk in anyway. I was told it would make me better and that the product was superior to the one I had been using before.

10. The first time these risks came to my attention was in the early [GRO-B] probably around [GRO-B]. More specifically, it was the HIV/AIDS crisis and the media attention around the issue that informed me of the potential risks associated with blood products. I believe it to be around this time that I was first tested for HIV. However, I wasn't told I was HIV negative until a couple of years later.
11. I can't be sure if I was tested for hepatitis C (HCV) at the same time but I recall being told that I was HCV positive a couple of years after the HIV negative diagnosis. Additionally, I cannot recall who informed me of my HCV positive diagnosis; however, I do remember discussing this with [GRO-B] and [GRO-B] at the [GRO-B] on an ongoing basis.
12. As I can't recall the exact time of being told of my HCV diagnosis, I cannot say with certainty if the risks associated with the virus were relayed to me at the time of being informed of my diagnosis. As mentioned, it came to my attention in the early [GRO-B] that there as a problem with blood contamination therefore I was always cautious with blood spillage and so on.

### **3. Other infections**

1. In addition to HCV, I have also been diagnosed with hepatitis B.
2. Furthermore, in [GRO-B] I was diagnosed with liver cancer. I will go into this in more detail below.
3. At one point there was some concern as to whether or not I had contracted vCJD, also known as mad cow disease. Fortunately I was

informed I had not contracted this because I had not received UK pooled blood products after 1990.

#### 4. Consent

1. At no point prior to me being prescribed with blood products to treat my haemophilia was I told that there were risks associated with them. Had I been told of the risks I would have never agreed to the treatment and neither would have my parents.
2. As far as I am aware the medical professionals knew of the risks associated with blood products and so I find the entire question of consent to be quite bizarre. I may have consented to the treatment but in no way was that consent informed at the point of first infection in GRO-B
3. In my view, the lack of information provided was intentional in order to further the development of the treatment. The reason for this view is that at no point did they think "let's stop", we know there are risks and people are being infected. The best analogy I can provide is that it was like closing the gates after the horse had bolted. The safeguards they put in place were after the event, so to speak.
4. It was the responsibility of the medical professionals to keep people like me safe. I appreciate that some of the learning happens whilst people are being treated but as I have said, they continued to treat people with contaminated products after being made aware of the risks. It was completely irresponsible.

#### 5. Impact

1. Put simply, I do not speak about my haemophilia let alone the HCV. The stigma associated with HCV, HIV and AIDS and the association

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those viruses have with haemophiliacs makes it difficult to discuss. I am concerned that if anyone were to find out about my condition they would think I am some sort of freak.

2. My early education was dominated by the effect of my haemophilia. I missed a great deal of early school. My parents had to have an interview by the Head of my secondary school who made it clear that he was very reluctant that I was accepted into the school. This did happen but with conditions. I could not participate in sport/games/metal work/woodwork and was not allowed to participate in playtime breaks. I also had to be picked and brought back in the lunchtime. This made me really 'different' in a comprehensive school of 1200 pupils!
3. Things did get better as I went through school but explaining why I could walk one day and not the next, or have my arm in a sling on Monday and it be okay on Friday was challenging. Even at this stage of my life I had a real issue talking about my condition. The seriousness of the possible impact of hepatitis C was not known to me. This might have been a positive at the time.
4. I seem to recall that my first test for HIV took place when I was in form six. At the time the whole pending global impact of AIDS had not yet begun. Despite missing so much of my education, I made it to college. This was the time when the issue blew up. I was a haemophiliac, therefore I must have AIDS. The need to keep the nature of my condition a secret was crippling. The stress and emotional strain was extreme. How could I possibly contemplate a relationship with a female and disclose my haemophilia? On many occasions my concentration was shot and my studies were affected. Even If I was in mortal pain with bleeding episodes I had to maintain a 'normal' persona and outward appearance. I must have had the most 'sprained' ankles, knees and elbows in the world!



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5. This continued when I left college and entered the world of work. However by this time I had the additional burden of understanding, and living with the affects and consequences of hepatitis C. Even today I cannot bring myself to discuss my condition with colleagues despite being in a very [GRO-B] in the organisation that I work. This also applied to the events that ran into my liver transplant over three years ago. Being diagnosed with liver cancer was harrowing. Not being able to openly discuss what was happening to me with colleagues for fear it would expose my hepatitis C was crucifying from an emotional perspective and badly affected my mental health. It brought my early years experiences back, only in triplicate! It must have been extremely odd for most of my staff and work friends when I disappeared one day only to find out that I'd had a liver transplant!!
6. I remember in the [GRO-B] when the AIDS epidemic was in the news. I was an [GRO-B] year old boy at the time and all of a sudden I felt like the world wanted to quarantine me. In light of people's prejudices, I decided to keep my condition a secret as I feel I would have been ostracised from society had I not done this. I have no doubt some people would have treated me like a leper, and some may still hold onto theses prejudices despite the volume of information we have today.
7. As a result of this I have also told our [GRO-B] not to elaborate on my condition if anyone ever asks him as I fear he may be treated differently.
8. Although I have never had any difficulties in being treated for my illness, it has resulted in me having to undergo treatment that has been horrendous. For instance, the course of Interferon and Ribavirin I underwent was simply awful.
9. My mental health suffered significantly during this time and I lost an incredible amount of weight. In addition, I contracted an infection in my testicles. Had I known how bad the side effects were going to be I

would never have agreed to the treatment. To add to the suffering, the course of treatment did not cure my HCV.

10. Of course my illness and the subsequent turn of events that ensued have caused not only myself significant distress but it has also impacted on my wife. She has gone through all of this with me and during my liver transplant she had to contemplate thoughts such as whether she would have to raise our [GRO-B] alone. There were times when neither of us thought I would come out of this alive. I remember being on the phone to my wife and telling her that I think I am going to die. It was horrendous for her; and my [GRO-B] for that matter.
11. For a long time I have had this illness hanging over me and my suffering has been brought on through no fault of my own. It is difficult to swallow.

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

1. I have undergone a number of trials for my illness throughout the [GRO-B] and the late [GRO-B]. This involved several trials for new clotting products. This was after the cause of infection was understood. I also took a clinical trial for HCV in about [GRO-B]. Unfortunately none of these trials succeeded in eradicating the virus.
2. In [GRO-B] I was offered the Interferon and Ribavirin treatment. The treatment was for 6 months and included injections and tablets. I can not emphasise enough how horrendous it was; I was incredibly ill throughout this period and it was all for nothing.
3. At the same time I had a cancer scare. I had a scan that showed signs of liver cancer. However, after a month of waiting I was given the all clear. Waiting for the results was very traumatic. Following this I was referred to the care of a liver specialist at [GRO-B].

4. The same liver tests were conducted again in GRO-B and the results revealed that my liver was significantly damaged. A year later I was going back and forth for check-ups and I was then referred to the GRO-B in GRO-B I was placed under the care of GRO-B and prescribed a 3 month trial of Sofosbuvir.
5. This also failed and I was again offered a course of Ribavirin and Interferon. I rejected this and decided to wait for other treatments that I was told were imminent.
6. However, in GRO-B following routine blood test at the GRO-B they discovered markers in my blood that were indicative of cancer. After a series of tests such as MRIs, ultrasounds and blood tests: it was confirmed that I had cancer. I was immediately referred to the liver specialist at the GRO-B and then to GRO-B in GRO-B in order to be assessed for a liver transplant.
7. The assessment was pretty rigorous. In addition, the tests were conducted just before GRO-B and then I had to wait over the GRO-B GRO-B for the results. As you can imagine, that wasn't the best GRO-B
8. It was an incredibly stressful time as the majority of these types of cases do not end well and I was fully aware of that. There is only one chance with a transplant as any spreading of the cancer was considered a waste of a liver so they would refuse to operate if this transpired.
9. It was a dark time for me and it had a profound impact on my mental health. This was exacerbated by the fact that I had to lead my day-to-day life, such as attending work and managing my haemophilia, while wondering whether I would still be alive in 6 months. Put simply, I had to go about my life with a death sentence hanging over me whilst putting on a brave face.
10. Matters were made worse by the fact that they took longer than usual to inform me of whether I had been accepted for a transplant. I began



thinking that the cancer had spread and bad news was imminent. However, on [GRO-B] I was accepted for a transplant and on [GRO-B] I was called for a transplant.

11. The operation took place at the [GRO-B] and the procedure was [GRO-B] hours long. I spent [GRO-B] days in a critical care and an additional [GRO-B] weeks at the hospital to recover. Unfortunately it wasn't plain sailing from thereon in as I had kidney complication that required dialysis. I also developed a nasty infection and I can honestly say that, at the time, I thought I was going to die; I told my wife the same on the phone.
12. Further to this, [GRO-B] days after the appointment I had an endoscopy so that stents could be fitted to my liver. These were taken out after [GRO-B] months.
13. I will also require further surgery in due course as my stomach is herniated as I have no muscle in part of my stomach.

## **7. Financial Assistance**

1. I have received the stage 1 and 2 Skipton Fund payments.
2. I am also in receipt of monthly a payment of £1,500 from the [GRO-B]  
[GRO-B]

## **8. Other Issues**

1. To my knowledge, there are no other issues that I can think that may assist the Inquiry at this stage.

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**Statement of Truth**

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

Signed... GRO-B .....

Dated..... 28.5.19.....