

# ANONYMOUS

Witness Name: **GRO-B**

Statement No: WITN2525001

Dated: 11<sup>th</sup> June 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 am the wife of infected person **GRO-B: H** We have been married for 20 years and we have a son together who lives at home with us.

#### **2. How Affected**

1. **H** has suffered from severe Haemophilia A since birth.

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2. I cannot provide the medical history of [H]'s haemophilia but I know that he has been treated since a child. [H] was first treated at the [GRO-B] before the haemophilia centre was moved to the [GRO-B] [GRO-B]
3. From what I have been told by [H] he began treating himself at home with a whole blood product called Factor VIII at around [GRO-B] years old. He was taught how to do this at the Haemophilia Centre whilst he was under the care of [GRO-B]. I know [H] is confident it is this particular product that infected him with hepatitis C (HCV).
4. Before [H] and I had started dating, we had worked together for a number of years, so I had gradually become aware of his haemophilia but it was never something he announced or talked about. It wasn't however until around a year after we started dating that that he informed me of his HCV. I believe the reason for him keeping it from me was due to the stigma associated with the condition and therefore he feared that it may impact upon our relationship. It was the same as the way he dealt with his haemophilia – very privately; only sharing the facts of his conditions if absolutely necessary.
5. I do not know when [H] was diagnosed with HCV. However, as mentioned previously, [H] and I have been married for 20 years and he was diagnosed before this. So it was either in the 90s or 80s that he would have been diagnosed with the condition.

### 3. Other infections

1. In addition to HCV, [H] was diagnosed with hepatitis B which he told me about at the same time.

2. He was also told that he may have vCJD, also referred to as mad cow disease. He was given the all clear a couple of years after being informed that he may have the condition.
3. In GRO-B H was diagnosed with liver cancer. I will discuss this in more detail below.

#### 4. Consent

1. I am confident that if H or his parents were aware of the risks associated with using the Factor VIII product they would never have agreed to it.
2. Even though they did not inform H of the risks, he still holds the medical professionals in the highest regard. I have a different opinion, as I cannot believe the way they treated people. Haemophiliacs had complete trust in medical professionals and H's feeling towards them to this day goes someway in illustrating how much trust they had in them. That trust was broken as far as I am concerned.

#### 5. Impact

1. H had a cancer scare in GRO-B. I was very upset and worried at the time but due to his attitude towards his condition again, it was something we got over after he received the all clear. However H treated himself on a prophylactic basis and he would go for his regular checks at the hospital. It was more of an afterthought than something that I was overly concerned about in general. I suppose a lack of knowledge about HCV and H's attitude led me to believe our lives may not impacted upon at that time.

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2. [H]'s cancer scare had been triggered by the first phase of treatment for his HCV in [GRO-B]. I will never forget how ill he was throughout this time. From the moment he started to deteriorate I couldn't sleep or eat properly and I cried a lot. I was sick with worry. It was very traumatic watching [H] go through the treatment.
3. It also impacted on my work and it was very hard to look after my son, especially as I was trying to protect him from what was going on.
4. Following his treatment, it was devastating to find out that it had been unsuccessful. [H] had been so ill and he struggled with his mental health during the treatment so I worried what impact the negative result would have on him. In addition to this, I couldn't help but think that I may be widowed at some point and I would have to raise our young son alone. This was the first time that it really brought home the severity of what our family was up against.
5. After [GRO-B] [H] continued to be monitored and we went back and forth to the hospital for check ups. His liver began to take a turn for the worse in the years after the unsuccessful treatment and he was told that he had cirrhosis. Our fears then become reality in [GRO-B] when he was diagnosed with liver cancer. Put simply, it was horrific and without doubt the worst time of my life. Having to sit there when he was undergoing ten hours of surgery, not knowing if he would come out alive; there are no words to describe the emotions I went through in those twenty four hours and the weeks that followed.
6. As well as the above, [H] and I have had to live a life of secrecy. The stigma associated with his disease and how it would make him feel if it ever came out that he had HCV has been difficult to live with over the years. There is always that worry that someone may find out, which

could then impact on our relationship with that person and others if word got out, so to speak. We also worried about the impact it would have on our son if anyone found out about his father's condition and so we have had to tell him to be careful with what he says around people. In fact, we have only gone into any real detail with him as the Inquiry started to unfold. It's unfair to put that kind of pressure on him at such a young age but we have to do it for the family and his sake.

7. I feel so angry at the people responsible for doing this to [H] and our family. It has caused untold damage to ours and other peoples' lives. Everything we have been through has happened because medical professionals thought it was worth running the risk for the sake of advancing the treatment available. It should not have been their decision to make.
8. [H]'s conditions, his illnesses and treatments, particularly his liver transplant, has left me with a deep-rooted anxiety. I am afraid to think that everything will be okay, as I can't help but think about what is around the corner. I find it very stressful going to the hospital and lie awake at night thinking about the further surgery he needs to address the hernia he has as a result of the transplant.

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

1. [H] has undergone a number of treatments over the years for his HCV. The first being in [GRO-B] when he underwent the Ribavirin and Interferon treatment. In [GRO-B] [H] underwent another 3 month trial of Sofosbuvir which was also unsuccessful. It was another blow and was a very worrying time as we felt that he had exhausted all avenues.



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2. In [GRO-B] after routine tests [H] was sent for further tests which revealed that he had liver cancer. We had to wait for the news whether he was eligible for a transplant over the Christmas holidays and my thoughts run away with me. I couldn't stop worrying about whether he would be accepted onto the list. It placed a very dark cloud over that year and our Christmas.
3. On the [GRO-B] [H] was accepted onto the list and then a new period of anxiety set in. Would a suitable donor become available; when would the call come; would he require surgery?
4. Fortunately [H] was called for a transplant and he underwent a liver transplant on [GRO-B]. They operated on him at the [GRO-B] [GRO-B] in [GRO-B]. As I previously mentioned, the ten hour wait whilst they operated on him was horrendous. I stayed in [GRO-B] on the residents' wing at the [GRO-B] while he recovered and this wasn't straightforward. [H] suffered from complications. I remember him calling me from the hospital to tell me that he thought he was going to die. I felt helpless and the weeks and months following were an emotional rollercoaster. During this time, I juggled caring for [H] and looking after my son who was at home with his grandmother, visiting his dad only on weekends. It was exhausting and excruciating for all of us.
5. [H] requires further surgery on his stomach as he has a very large incisional hernia. As I have mentioned above, the nagging anxiety continues whilst still trying to carry on as normal. It

### **7. Financial Assistance**

1. [H] received the stage 1 and 2 payments from the Skipton Fund.

2. He is also in receipt of a monthly payment from the Welsh Assembly of £1,500.

**8. Other Issues**

1. I can think of no other issues that will assist the Inquiry at this time.

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## Statement of Truth

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

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

Dated... 11/6/19 .....