

ANONYMOUS

Witness Name: **GRO-B**  
Statement No: WITN3169001  
Dated: 18<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 14<sup>th</sup> May 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 have been married to my husband, **GRO-B:H** for **GRO-B** years, but we have been together for **GRO-B** years. We have a **GRO-B** year-old daughter called **GRO-B** who is currently in college. My husband was born with mild haemophilia, but it wasn't until he was 8 or 9 years old that it was discovered after injuring his leg.

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3. My husband became infected with hepatitis C (HCV) after receiving a blood transfusion around [GRO-B] at [GRO-B]. He had all of his tests carried out at [GRO-B].

### 2.How Infected

1. My husband received a blood transfusion, likely with Factor VIII products, when he was injured in [GRO-B] around [GRO-B] due to bleeds following a car accident. He was [GRO-B] at the time. We only found out about my husband's condition 25 years ago, around 1994, when we were living in [GRO-B] [GRO-B] as he was beginning to suffer from symptoms such as sleeping a lot.
2. We were given very little information at the time. We had decided we wanted children and we were told by the doctors that there was a risk, but that it was unlikely anything very serious would happen as a result. I was tested at the time but any risk to me was played down.
3. I don't remember being given much information about the risk of infection to myself or others and, if anything, [GRO-B] acted as if any chance of infection was unlikely. At the time it seemed like no one had any actual information about the infection and no one knew how the hepatitis C would progress in the long term. We understood that cancer was a possibility but had no sense of how likely that was to happen.
4. I don't remember anyone sitting down with me and telling me about the risk of infection to myself. I don't know if [H] was given any additional information. If he did cut himself he would make sure to clean up but this was done out of anxiety rather than any advice he had been given by his doctors.
5. Looking back, it sounds like [GRO-B] had more information than they were passing on to us. If they had been upfront about the infection then we would have had a better idea of the risks associated with it. It was like we were kept in a 'wait and see' scenario. It makes me feel sad as I don't know if

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we would have done things differently. I don't have a particular view about how H tests were communicated to him as I wasn't there at the time. I did have to go to the GP to be checked for hepatitis C but that was it.

### 3.Other infections

1. As far as I am aware, my husband did not suffer from any other infections.

### 4.Consent

1. I don't believe that my husband was tested without his knowledge or consent. I assume that they must have tested him for HIV, but I am uncertain.

### 5.Impact

1. The effects of my husband's illness have been life changing. My husband couldn't be a part of everyday life and to us it has become normal until we spend time with other people, then we realise how abnormal our life is.
2. I've been responsible for earning most of the money for my family as my husband is too sick to work. It has been hard to stay close to my husband as he is so overwhelmed with his illness. I have been depressed at times as my husband didn't feel able to go out socially and we only really have one couple over for dinner now and again. My husband finds it hard to engage with other people when he's tired and wants to know that he can go to bed when he needs to. It is hard to get him involved in family things due to him being so tired and he no longer comes on family holidays.
3. I have found having financial responsibility tough. I have suffered from a number of auto immune problems and I have had operations for hernias which could have been partially caused by the stress of everything. I haven't been able to take the best care of myself. I do think I suffer from some Post Traumatic Stress Disorder (PTSD) after everything my husband has gone through.

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4. We moved to a new house in [GRO-B] as my husband was too cold in our old, Victorian property. The bungalow we moved to was in a community of mostly retired people. I felt too young to be in this community and was really relieved when we were able to move back to the Victorian house. While we were at the bungalow in [GRO-B] [H] mother lived near in a specialist home for people with [GRO-B]. She moved to be near us as he had planned and hoped to support her but, with his illness, I ended up supporting her for three years. With [H] being unwell and her needs it was very stressful.
5. In [GRO-B] my husband had his first hepatitis C treatment at [GRO-B] [GRO-B]. He received Interferon and Ribavirin during this year of treatment. He was very unwell through the treatment period and suffered from chest infections and rashes for most of it. My daughter was only [GRO-B] years old at the time and my husband couldn't handle noise so we had to go out and drive around for most of the day on those days. Unfortunately, at the end of the treatment, the hepatitis C didn't clear so he had to deal with both his hepatitis C symptoms and the side effects of the treatment. I don't think he ever recovered fully from this treatment.
6. In [GRO-B] he had the triple therapy treatment but this time at the [GRO-B] Hospital and he was really unwell. He slept all the time and his diet was restricted because he couldn't tolerate several different foods. He withdrew from us which was hard to see. He was just focused on getting through the treatment for that whole year. He went to [GRO-B] for the treatment because, in [GRO-B] they had only just started offering the treatment in [GRO-B] [GRO-B]. There was quite a long delay and [GRO-B] advised my husband that he had the option to go elsewhere for treatment as he was so far down the waiting list and it might be months before he would be able to start. My husband is not better even after clearing hepatitis C in [GRO-B] as he still has days where he is exhausted. There is no significant difference. He was so optimistic about how he would feel after clearing hepatitis C and it was hard to see (and share) the disappointment when he realised there was no significant change to how he was before the last year of treatment.

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7. As far as I am aware, there hasn't been any impact on my husband's medical or dental treatment. However, he can't have painkilling injections at the dentist. He's waiting at the moment for his wisdom teeth to be removed and I wonder if the delay is due to the additional requirements he has.
8. There has been a huge impact on my social and private life. My husband suffers from being extremely cold so he has to sleep with a hot water bottle, two duvets and electric blanket at night. This was unbearable for me, especially as I was too warm with menopausal changes, so we had to sleep in separate rooms and we still do. We don't have much of a social life besides a few friends. I remember on Christmas Eve, which I believe was GRO-B just after my husband got the all clear, he was feeling that his legs were very cold, and recognising this experience, he became convinced that the hepatitis C had returned which ruined the entire evening.
9. There hasn't been much stigma with my husband's illness as, being a very private person and afraid of how people would look at him, he didn't want anyone to know during the early days of him being diagnosed and through the first year of treatment. This had a big impact on me as it meant I couldn't get help from others I could have spoken to. I used to donate blood regularly and I had to stop because of my husband's illness. I feel stigmatised as they will never move from their position that my blood is unacceptable despite the fact I wasn't infected. At the time we had just found out about the hepatitis C, so it did make me think about what the hospital wasn't telling us as we had been told there wasn't much risk but I was no longer allowed to ever donate blood.
10. Our daughter GRO-B had her whole childhood impacted by H illness. She doesn't feel like she has a father who wants to spend time with her. As a result, it has affected her ability to connect with men. It makes me feel sad as she used to be close with her father when she was very little and he was a good Dad before he became so unwell..

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11. I used to work as a [GRO-B] but I had to change to work in [GRO-B] as I couldn't handle dealing with mental health issues both at work and at home. I had to reduce my hours to three days a week and once I had to go away to work for a week and my mum had to bring [GRO-B] who was a baby at the time, for part of the week as [H] couldn't look after her alone for more than a couple of days. My dad became ill and Mum could no longer help which was very difficult. I am now self-employed as a [GRO-B]. Most work I do is at home and I have been developing curricula for schools for the last nine years. This work is financially insecure and I have been anxious about money especially with [GRO-B] going away to college.

12. I have suffered financial effects as [H] doesn't work and he won't receive a pension. We are not well off and I would have liked to have more security for the future. I have accepted that I won't be able to stop working for at least another ten years. We have just recently received the enhanced support payments from the NHS which has made a big difference to us but it's interesting how much feeling responsible for our finances is now a habit and something I still feel anxious about.

### 6. Treatment/Care Support

1. I am not aware of any difficulties my husband faced in obtaining treatment besides [GRO-B] not being able to offer the triple therapy treatment quickly when my husband needed it. In the past, he had to wait for hours in casualty where he would re-bleed which would have lengthened the episode significantly and, when he was finally seen, he would be told that his treatment for haemophilia was expensive. He has Factor VIII in the fridge now and easy prompt access to the Haemophilia Support Nurse.
2. My husband didn't get to talk to anyone when he was ill even though he was very depressed for long periods. As I worked in [GRO-B] he tried to explain his thoughts to me. I understand he was offered counselling but he refused as he said he could talk with me. I think he has now accepted the

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offer for counselling. He hasn't received adequate care and it was like the hospital just told us to go and muddle on to see what happens.

### 7.Financial Assistance

1. My husband received a one-off payment a few years ago. I can't remember who it was from as my husband will know more about it in his statement. We recently started to receive support payments from GRO-B and about a month ago we started receiving a higher rate.
2. I am not aware of any other financial assistance which may be available.

### 8.Other Issues

1. I haven't taken part in any other litigation regarding infected blood products. If there are any documents which may be relevant to the Inquiry then my husband will have passed them on.

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**Statement of Truth**

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

Signed

GRO-B

Dated

18/5/19