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Witness Name: **GRO-B**
Statement No: WITN2427001
Dated: 8th 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** My address is known to the Inquiry. I'm the wife of **GRO-B: H** I have three children; three **GRO-B** aged **GRO-B** who are all still living at home. I'm not working at the moment as I have been diagnosed with **GRO-B** I've been a carer for my husband **H** for the past 15 years.

2. How Affected

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1. I met [H] in 1985. We got to know each other and he explained that he had Haemophilia A and that it was mild. From then on I frequently attended the hospital with him. I believe [H] was given Factor VIII for his haemophilia although I'm not entirely sure. He was infected with Hepatitis C (HCV) around the early 1980's after he had tooth bleeds. We were just called in for an appointment with the doctor and told.
2. We were told that [H] had Hepatitis C by [GRO-B] in 1995, after it was found that [H] had a tumour on his liver. At the time he had just been involved in a road traffic accident. After a biopsy he was diagnosed with Non-Hodgkin's Berkitts Lymphoma which was related to his Hepatitis C as a result of this he required chemotherapy.
3. He was up and down health wise for a long time and had problems with pains. He had to attend [GRO-B] in [GRO-B] where he was seen by a number of doctors. He also saw [GRO-B] at the [GRO-B]. No advice was given as to what the infection meant for [H]. What information they did have should have been provided earlier.

3. Other infections

1. [H] also has arthritis as well as Fibromyalgia. All of a sudden he had all these pains and for a long time and we couldn't figure out where they came from. He was seen by a Neurologist and they told us that they would have to cut the nerve supply in his back on the right hand side. We also received a letter about his risk of having vCJD.

4. Consent

1. We were not given adequate knowledge about the infection and the effects it would have on [H]'s health. We didn't know anything. [H] wasn't treated for the purposes of research.

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5. Impact

1. There was a huge social stigma surrounding [H]'s diagnosis with Hepatitis C. This was because people assumed he was an alcoholic and/or a drug user because he had liver problems. It was hard to explain time and time again that this wasn't the reason. It was mentally draining for both of us.
2. The [GRO-B] were affected a lot. Our [GRO-B] didn't understand but the older two understood more. Our [GRO-B] ended up having problems at school with the stigma. She was forced to explain a lot. It's heart-breaking as the [GRO-B] were not able to do things with their daddy that other kids were doing.
3. It ended up with him not being able to work because he was in so much pain. He would also fall asleep at a drop of a hat. He lost his job [GRO-B] [GRO-B] I was lucky work-wise. I was a [GRO-B] at the time and I felt that my employers were very understanding if I needed to go to hospital appointments. It wasn't as bad as working somewhere else.

6. Treatment/Care Support

1. In [H] had one course of treatment which was provided by the Haemophilia Society. He was given Interferon and Reliferon. He was only on it for a week because it was that bad. His liver was in such a bad condition and he lost a lot of weight. He also suffered with haemorrhoids, tiredness diarrhoea and vomiting. He was then referred to the liver clinic where he was placed on the transplant list. He eventually had a liver transplant in [GRO-B] It was difficult accessing the treatment for [H]'s Hepatitis C because we had to get permission from the Government. I found this extremely frustrating.

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2. I remember that because of the fears surrounding Hepatitis C he had to be seen in the GRO-B for treatment as he couldn't be seen anywhere else. When he was receiving the second course of Hepatitis C treatment called Pegylated Interferon I couldn't look at him. This treatment made his behaviour extremely unpredictable. I was getting erratic texts from him. It was hard on me and the kids because we didn't know what kind of mood he would be in.
3. We've never been offered counselling or psychological support although he's been prescribed anti-depressants as he suffered from mental health issues.

7. Financial Assistance

1. We received money from the Skipton Fund through the Haemophilia Centre in GRO-B. We receive £1,500 a month. The first payment we received was £20,000 in 2005 and second was £25,000 in 2011. The Skipton Fund was actually quite easy to apply to as the Haemophilia Centre did all of the work for the patients. We filled in forms and all the details required and sent it back. I think we did have to sign a waiver saying that we wouldn't ask for more money or take private legal action. But the thing is, we would never ask for more money.
2. He is presently on benefits. His disability allowance is changing to Personal Independent Payments (PIP). When the assessors came to our home he felt he had to justify why he was on benefits and over-emphasise his condition.

8. Other Issues

1. I would like to know how they got away with it for so long. He had a gap in his treatment for 20 years; that's 20 years of not knowing he had been

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given infected blood products. Our lives have been destroyed by what happened to H The truth needs to come out.

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Statement of Truth

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

Signed... GRO-B

Dated... 8/3/19