

Witness Name: **GRO-B**  
Statement No: WITN2857001  
Dated: 14<sup>th</sup> March 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** 1954 and my address is known to the Inquiry.
2. My two sons, **GRO-B: S1** and **GRO-B: S2** both suffer from haemophilia B. **S2** is a moderate haemophiliac and **S1** is also moderate. Both **S2** and **S1** developed hepatitis C (HCV) around **GRO-B**. I also have **GRO-B** other children who are not affected.

#### 2.How Infected

1. My two sons, **S1** and **S2**, are haemophiliacs and have been going back and forth to the University Hospital of Wales (UHW) from a young age. Both my sons took Factor VIII products. When **S1** was **GRO-B** years old, he fell with a toothbrush in his mouth and had to have a blood transfusion at

[GRO-B] When [S2] and [S1] were around [ ] and [GRO-B] years old respectively, I took them to UHW and their doctor, Dr [GRO-B] asked to speak with me alone. He told me that they both had developed hepatitis C (HCV).

2. I was told that the virus came out of [S2]'s body but stayed in [S1]'s. I asked how this could have happened and I was told that it was in the treatment, which could have either been Factor VIII or the blood transfusion. Dr [GRO-B] asked if I wanted him to tell my sons but my husband and I decided to tell them ourselves that they had hepatitis C (HCV). They both took it badly, but [S2] has been affected ever since, as even though the virus left his body. It is not clear whether it could come back.
3. I think the information Dr [GRO-B] gave my sons and I was adequate and he could tell them more about the hepatitis C (HCV) than I ever could. He did give some information about the risk of infection i.e. use your own toothbrush, and if my sons had a bleed, make sure there was no blood contact. [S1] had to take his girlfriend to [GRO-B] to be advised on the risk of infection. He told me about meetings I could attend at [GRO-B] to discuss what had happened with the treatment, how the infection happened, how the hepatitis C affects people and the treatment available.
4. I think the information could have been given earlier, it feels awful knowing that. It was bad enough having to deal with haemophilia. Someone is responsible and we should be compensated a lot for what we have been put through. [S1] was [GRO-B] years old when he was given a blood transfusion, and I wasn't told until he was [ ] and we were in the hospital most of the time, which means they knew a lot longer than we did. I don't really have a view on how the tests were communicated to my sons.
5. They were also tested for Acquired Immune Deficiency Syndrome (AIDS) and had to wait a few weeks for the results, which were clear. I don't really know about other results as they usually handled it on their own once they were

older. **S1** still has regular check-ups as even though his hepatitis C (HCV) has now cleared, his liver is still scarred.

### 3. Other infections

1. I don't believe my sons suffered from any other infections as a result of being given infected blood products.

### 4. Consent

1. I suppose my son's must have been tested without their consent, as I was just told out of the blue that they had hepatitis C (HCV) so the doctors knew something. Dr **GRO-B** didn't say that he thought there was a chance they had hepatitis C (HCV), so he must have already checked to know they had it.
2. I don't believe they were tested on for research purposes, but **S1** was given trial treatment for hepatitis C (HCV), which didn't work on most of the people who took it, so I think that was a test in itself.

### 5. Impact

1. Since I found out about the hepatitis C (HCV), there has just been a constant worry. For a while I didn't understand what was happening or how it could have even happened. My husband shut down completely and became ill with worry, which meant I had to try and hold things together. I have **GRO-B** other children besides **S1** and **S2**, and I was so focused on them that I felt I was neglecting my other **GRO-B** children, as I had to leave them with family to take **S1** and **S2** to the hospital. **S1** is a **GRO-B**, and even though the hepatitis C (HCV) wasn't genetic I was always worrying something would happen to his **GRO-B: D**. I am physically drained, and it's a constant worry for me that one day the hepatitis C (HCV) will come back in either of them. I'm always on guard and I can't switch off, as even though they are grown up now I still think they are going to have a bleed and I will need to take them to hospital. It's always in the back of my mind.

2. As a result of his treatment, [S1] has high blood pressure, a scarred liver and suffers from thyroid problems. [S2] also has high blood pressure and arthritis which could be linked to the hepatitis C (HCV), or it could be due to stress as he has been unstable ever since he was told he had hepatitis C (HCV). They both have depression and weakened immune systems, so if there is a cold going around, they will surely get it.
3. I am not aware of my son's facing any difficulty in accessing treatment, and I can't think of any treatment that should have been made available to them. It would be nice if I could have a social worker come to the house to see how I am doing, as if I want any support then I have to attend groups at [GRO-B] which I don't go to as I try to get on with it.
4. There hasn't really been much of an impact on me as a result of my son's treatment, I just wanted them to get back to normal. When [S1] first had his hepatitis C (HCV) treatment, he had a 3-month treatment at home, which affected him badly, and a few months later the hepatitis C (HCV) came back, so he had to wait a year before he could have it again. The hepatitis C (HCV) has now cleared up, but we don't know if it's gone completely, and this is always in the back of my mind.
5. There has been a big impact on my private and social life, both mentally and physically. When [S1] and [S2] were children, I was constantly going back and forth to the hospital, so I didn't go out much. My son's only have my husband and I to rely on, and they won't tell their friends or talk about it to anyone else. I try to cope alone, as it is very difficult for my husband. There hasn't been any impact caused by stigma, as we have kept it to ourselves.
6. My other [GRO-B] children don't get along with [S2], which is half his fault and half their fault, as [S2] can be fine one day and a completely different person the next. It would be nice if his [D] would ask how he was doing, but she doesn't really understand the impact on him. We haven't told a lot of our



family members, as they wouldn't understand, and those who do know think it's a terrible situation to be in.

7. There haven't been any educational effects and there hasn't really been any work-related effects on me personally. I have had to take days off work to go to the hospital, but besides this nothing else. There has been some financial impact, I have had to lend money in the past to my son's as neither of them are able to work, but it is not so bad now as **S2** is married and **S1** can look after himself. I wanted to travel to places when I was younger but I had to cancel these plans and I wouldn't go now because of my son's.

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

1. I am not aware of any difficulties my son's have had in accessing treatment or support. My husband and I are the ones who have always looked after them, and now if anything happens to **S1**, his wife will come to me. I think I was offered counselling at some point but I went to the support meetings in UHW instead, which I no longer go to.

#### **7.Financial Assistance**

1. I know **S1** applied for financial assistance, but I don't know who it was with as I wasn't involved at all and I have never applied on either of my son's behalf. I am not aware of any financial assistance they could be entitled to.
2. **S2** recently had his mobility allowance taken off him. He was told he was fit to work because he could walk unaided and had his car taken off him which he needs to get to hospital. He now depends on me, my husband and his wife to get anywhere. His review was declined so we have to go to court to try and get it back. My son is not fit to work as he has arthritis, stiffness and other hepatitis C (HCV) related symptoms and if he were to return to work, he would end up on sick leave.

## **8.Other Issues**

1. I have never taken part in any other litigation related to the use of infected blood products. I am not aware of any documents I may have which may be relevant to the Inquiry.

**Statement of Truth**

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

Signed: GRO-B .....

Dated: 14 3 20 19 .....