

# ANONYMOUS

Witness Name: GRO-B

Statement No: WITN3676001

Exhibits:

Dated: September 2019

## INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF GRO-B

I, GRO-B will say as follows:-

### Section 1. Introduction

1. My name is GRO-B I was born on GRO-B I live at GRO-B  
GRO-B with my husband GRO-B: H We have  
two children aged GRO-B and GRO-B GRO-B  
GRO-B.
2. I make this statement in relation to my husband H born on  
the H who was infected with Hepatitis C (HCV) as a result of  
receiving contaminated blood products. H has provided his own  
statement to the Inquiry (GRO-B).
3. This witness statement has been prepared without the benefit of access to my  
husband's medical records. If and in so far as I have been provided with  
limited records the relevant entries are set out in the medical chronology at  
the end of this statement.

**Section 2. How infected**

4. [H] was diagnosed with Von Willebrand disease (VWD), a blood clotting disorder sometime between 1978 and 1980 when he was sent by his local dentist to Musgrove Hospital to have two impacted wisdom teeth removed. During the procedure [H] bled profusely and after a number of tests were carried out he was diagnosed with VWD.
  
5. [H] received his first dose of Factor VIII concentrate treatment during the wisdom teeth procedure and we believe it was during that treatment he was infected with HCV. During that admission [H] was in hospital for 10 days and when he was discharged from the hospital he was extremely jaundiced.
  
6. In 2011 [H] was employed as a [GRO-B] The [GRO-B] [GRO-B] introduced a "cycle to work" scheme and [H] started cycling to work. However, it wasn't long before the cycling took a toll on [H] and he was not able to continue cycling.
  
7. [H] made an appointment with the doctor because he felt so bad and he had a number of blood tests. [H] was referred to Musgrove Park Hospital by the doctor because his liver function test results were abnormal.
  
8. [H] cannot remember whether it was his GP or the consultant at the hospital that told him he had HCV but he thinks it was the consultant. However, he has no recollection of any advice that may have been given to him. He became aware that his liver function tests showed signs of abnormalities 5 years prior to that but he had never been informed.

**Section 3. Other Infections**

9. To the best of [H]'s knowledge he has only been infected with HCV and he has not been advised of any other infections.

**Section 4. Consent**

10. I do not know if [ H ] was tested without his knowledge or consent.

**Section 5. Impact of the Infection**

11. When [ H ] was given the diagnosis he was shocked. After the shock had sunk in the upset set in. [ H ] started to find out information about the impact it would have on him and how it actually happened. He became very angry which was so uncharacteristic of [ H ]

12. I was worried about what the diagnosis meant for [ H ]'s health. I did not know if it was something that was curable. There were a lot of questions I did not have answers to and it really worried me. I then became concerned about the fact we had been told it was contagious. It occurred to me that I could have been infected unknowingly and if I had been there was also a possibility I had passed it on to the children.

13. [ H ] was sent to Bristol for a body scan and he was diagnosed with cirrhosis of the liver. A lady named [ GRO-B ] organised treatment for [ H ] and on the 2<sup>nd</sup> November 2011 he commenced treatment on Pegylated Interferon and Ribavirin. He injected the Interferon into his stomach on a weekly basis and he took the Ribavirin tablets on a daily basis.

14. The only way to describe the treatment was as gruelling. The treatment lasted for 5 months and it really took its toll on him. It was so hard watching what he had to go through and enduring so much pain.

15. [ H ] had to attend hospital every week and it was a 48 mile round trip. He also had to have lots of blood tests at the local doctor's surgery and at the hospital. This was very difficult financially because we had to pay for the journeys to the hospital and for car parking. By that time [ H ] was unable to work and I worked to support us which meant that I was unable to go to all

the appointments with him. [H] really struggled with going to the appointments on his own and he would have wanted me to go with him.

16. The treatment really affected [H] and he suffered with really bad side effects. He suffered with depression, severe mood and temper swings, severe fatigue and weight loss. It was horrible to see [H] change into a different person. He was not easy to live with because he would lose his temper so easily. Thankfully his bad temper only seemed to be directed towards me and not other members of the family.

17. After 5 months of treatment [H] said he could not take it anymore because he found it very difficult. I tried to convince him to carry on with it but his mood just got lower and lower, and by the time he finished he was at rock bottom. He felt so bad that he even said he would, 'rather have the virus' than continue with the treatment. His first treatment was not successful in clearing the HCV.

18. The doctors told him there was a new treatment that would become available but it was hugely expensive. He was told because he had cirrhosis he would be near the top of the list but there was a bracket of people above him. I was angry about that and in my opinion [H] should have been at the top of the list as it was the NHS that had given him the virus in the first place. I was very conscious that the longer he waited for the treatment, the worse his cirrhosis would be.

19. In early 2016 [H] underwent a second course of treatment which was Sofosbuvir, Daclatasvir (Harvoni) and Ribavirin. It was a 12 week treatment and the side effects were better than before. It worked and now [H] is monitored every 6 months.

20. When [H] first found out he had been infected he did not want anyone to know and that included our family and the children. Even now, [H] has only told immediate and close family. He was scared of the stigma and what

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people think because it is a dirty and contagious infection only linked to drug addicts and alcoholics. We live in a very close community and people tend to be quite nosey and like to know your business. People asked questions when [H] was off work and we just told them that [H] had a liver problem but we didn't elaborate any further than that.

21. I worry about what will happen in the future. I worry every time [H] goes for a liver scan and that he will be told that his liver has deteriorated. It has been mentioned that cirrhosis can turn into cancer and I am concerned about how they are going to keep it at bay because he is not having any treatment.

22. It also affects our travel plans and I worry about going abroad on holiday. We are at an age now where we should be having holidays abroad, but I worry about travelling out of the country. It is impossible to obtain both travel and life insurance so I feel we are trapped here.

23. It is simply unacceptable that you put your trust into the medical profession to make you better and instead they make you seriously ill. This infection was given to [H] by somebody and it shouldn't have happened. We believe that someone knew the blood was contaminated and despite knowing, it continued to be used. The consequence of the infection is that it has ruined our retirement and our future is going to be very different to what we would have had.

24. I retired early so we could spend some time together because we now think of things differently. [H] and I would have both still been working if it was not for his poor health but we are unwinding early.

25. We are selling our house because we can't manage and the garden is simply too big. We have lived in the same house for 37 years and it has been a really difficult decision for us to make. In fact it carries on being very difficult.

26. I think the children worry about their father but they don't talk about it much and I think they have the same concerns. The children try to be positive because we can't live the rest of our lives worrying constantly. I just feel so angry that he has been infected with HCV.

27. [H] was employed by the [GRO-B] During his first treatment in 2011 he was unable to work. His employers could not accommodate him working a day here and a day there. He was told that he had to work full time or not work at all. After the first treatment [H] did go back to work but there were days he felt that he was unable to do the job. In the end [GRO-B] decided to let [H] go with his on the grounds of ill health in 2016.

28. Before I retired I was working 28 hours a week as a [H] at the doctor's surgery. There were times when I was the only person bringing an income into the house. [H] was conscious of the fact that he was not bringing money into the household and we struggled with just my wage.

#### **Section 6. Treatment/care/support**

29. We have not been offered any counselling.

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

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

31. [H] receives monthly payments from the EIBSS and has been receiving these since June 2015. He had been receiving £1,500 per month but from July 2019 it increased to £2,300.

32. The financial situation worries me and especially for the long term. It is [H] that gets the payments and I'm not sure what happens with that those in the event that anything happens to [H]

**Section 8. Other Issues**

33. I get really upset because this shouldn't have happened. I think somebody should be held responsible. I am providing a statement to the Inquiry because I need everyone to know the affect this scandal has had on our entire family not just the infected person. It has affected everyone around [H] and it always will.

34. The worry I have will not go away no matter what the outcome of the Inquiry is. The damage has been done and no amount of money will put this right. We would give the money back in a heartbeat for [H]'s health. The virus may be clear but they have left [H] with cirrhosis of the liver.

**Anonymity, disclosure and redaction**

35. I would wish to apply for anonymity. I understand that my statement will be disclosed and published by the Inquiry. I do not wish to give evidence.

**Statement of Truth**

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

Signed [GRO-B] .....

[GRO-B]

Dated 27/09/2019.