

ANONYMOUS

Witness Name: GRO-B

Statement No: WITN2981001

Exhibits: 0

Dated: August 2022

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 1957, and I live at GRO-B GRO-B
2. My husband, GRO-B: H born on GRO-B 1956), was infected with the Hepatitis C Virus (HCV) through contaminated Factor VIII (FVIII) concentrate.
3. This Witness Statement has been prepared without the benefit of access to my husband's medical records.
4. My husband has provided his own Witness Statement to the Inquiry GRO-B. This Statement should be read in connection with my husband's Statement.

Section 2. How Affected

5. My husband [H] has severe Haemophilia A. He was infected with HCV some time between 1970 and 1980. [H] has been treated at various Haemophilia Centres over the years, but he was under the care of the Queen Elizabeth Hospital, Birmingham between 1970 and 1975 and at St James University Hospital in Leeds between 1975 and 1980. [H] wasn't told that he had been infected with HCV until he attended a routine appointment at the Edinburgh Haemophilia Centre in 1993. By then, [H] and I had married (in [GRO-B] and had had three children together (without information or advice to help us understand and manage the infection).

Section 3. Other Infections

6. I do not think that [H] was infected with anything other than HCV.

Section 4. Consent

7. [H] was tested without his knowledge and consent. The HCV diagnosis was a bolt out of the blue.

Section 5. Impact of the Infection

8. I refer to [H]'s Statement.
9. I am one of the affected persons in terms of going through the Hep C infection suffering journey with my husband, not knowing how long he was going to

survive due to Hep C infection with the risk of other possible infections and how I and my three children were going to survive without their father.

10. I was the person who provided his daily care when he was feeling so sick due to Hep C infection, the treatment for it, his last stages of liver failure, waiting on liver transplant list, the liver transplant and recovery from it.

11. The whole Hep C suffering journey has had a major impact on my wellbeing, health, and post trauma effects and could not go out to work because my husband needed so much care.

12. The whole Hep C had such a stigma attached to and I could not talk to anyone, there was/is no support system from NHS, could not talk with my family members and close friends. To date 28 years of suffering!

13. I endorse everything [H] has outlined in his own Statement in relation to the failed attempts at clearing the virus and his worsening health as his liver went into decline. When [H] finally had the liver transplant, I had a complete breakdown. He experienced dreadful post liver transplant side effects and he was on heavy medication. He didn't know what to do about me and phoned the GP who came to visit.

14. My GP was shocked at the state I was in. She told me that I was suffering with the effects of PTSD. She prescribed anti-depressants that only served to make me feel even worse. I felt like a zombie.

15. I don't know how I managed it, but I had to learn to get by little by little and pull myself out of the quagmire. Too many people relied upon me, and I had no one to rely on but myself. [H] needed me as did my three children, one of whom was still at home doing her A levels (one was at university and the eldest was doing the requisite training upon completing a five-year medical school course). I have never made a list, but I would go out with a list in my head and come back from the shop empty handed. It wasn't a small thing when you are

looking after a sick husband, trying to run a home, manage the finances and everyone else's lives (namely three children) to make sure they were all OK, have money and a roof above their heads. I did my daughter's move to and from university single handed. I looked around at what needed to be done and I knew I couldn't give up. I had to deal with it. I resigned myself to thinking 'this is as good as it is going to get'.

16. We had to keep [H]'s HCV infection a secret. Up until two years ago we hadn't told any of our friends that [H] is a haemophiliac because of its associations with HIV and HCV and the resultant stigma. Moreover, if you tell anyone that you need a liver transplant, they think you must be an alcoholic. It is a lot for a person to carry on their shoulders. I had no-one I could reach out to. No-one knew why we were suffering.

17. [H] had been in very poor health for so long but after the liver transplant I was hopeful of a little bit of light at the end of the tunnel and that we might all have a breather. You spend your time waiting for the ordeal to be over and then you get thrown another curveball. I look back now and wonder how the heck I got through it all. Within six months of the liver transplant, we learnt that the HCV had come back with a vengeance and [H] was back on the Interferon. [H]'s character changed with the Interferon. It was almost impossible to manage his mood swings. I wouldn't wish it on anyone.

18. [H]'s HCV infection took a toll on my physical health. I suffer with Discoid Lupus Erythematosus which worsened because of the stress that I was under. My rashes were out of control. My skin turned black, and my hair started to fall out. The steroids I was prescribed adversely affected my mood and made me angry. I struggled to calm myself down.

19. We had to tell our children what was going on so that they could make some sense of what was happening to [H] and me. My youngest was going through her A levels. It was very difficult for her to focus. She was in the thick

of it and, whilst we tried to hide as much of it as we could from her, she saw it all. She was scarred by it.

20. Much of what happened to us is too horrible to revisit. To cap it all, [H] and I are still in effect under Covid lockdown conditions. This is due to [H] liver transplant and on suppressants, he is identified as extremely clinically vulnerable with low immune systems. We haven't been able to see the children and grandchildren properly. Because our children are of school age, they would need to be isolated from their friends for a week before coming into direct contact with us. [H] and I feel like lepers due to HepC and now Covid. We can only see our family in our garden. It is a lonely place to be.

Section 6. Treatment/care/support

21. I refer to [H]'s Statement for details of his three attempts at clearing HCV (the third being successful), the liver transplant and the associated complications. During three lots of HCV treatments, each one lasting from 6 months to 18 months, [H] suffered from major side effects such as anaemia, eyesight, brain fog, blood through urine, diarrhoea and not being able to eat food. As a support person, I suffered from extreme levels of stress, emotional and physical. There were many weeks/months when [H] even needed help with walking to the bathroom. With all this additional strain of looking after the house, children, shopping, garden work, I have developed a weak back and at this stage the surgeon recommended to have my vertebrae fused. I decided not to proceed with the procedure and am living with a weakened back.

22. We were never offered counselling or psychological support arising from [H]'s HCV infection.

Section 7. Financial Assistance

23. I refer to H s Statement.

Anonymity

24. I wish to apply for anonymity, and I understand that this redacted Statement will be published by the Inquiry.

Statement of Truth

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

Signed..... GRO-B

Dated8th September 2022.....