

# ANONYMOUS

Witness Name: GRO-B

Statement No.: WITN2712001

Exhibits: 0

Dated: 25 September 2019

## INFECTED BLOOD INQUIRY

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FIRST WRITTEN STATEMENT OF GRO-B

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### Section 1. Introduction

1. I, GRO-B will say as follows:-
2. My date of birth is GRO-B 1965. My address is known to the Inquiry.
3. I live with my husband in GRO-B. I met my husband in 1984 and we married in 1985. I already had one son, and we had two daughters together, the first born in 1986 and the second in 1987. Our children are now grown up and have left home.
4. My husband has prepared a witness statement for the Inquiry and I make this statement in support of his statement. He has set out the details of the impact infected blood has had on our lives and my statement describes the impact from my perspective.

**Section 2. How Affected**

5. My husband has haemophilia A of mild severity. He believes he was infected with Hepatitis C (HCV) through treatment with Factor VIII in 1985.
  6. We found out about the infection in 1986 when a haemophilia health visitor came to our house and asked for a blood test, telling my husband they suspected they had given him AIDS. They tested both my husband and me. When the results came back the health visitor told us my husband had tested negative for HIV but positive for 'non A, non B' Hepatitis. My results came back negative.
  7. I do not feel we were given adequate information to help us understand or manage the infection. As my husband explains in his statement, the health visitor told us it was a benign virus and, although it would remain with him for the rest of his life, it would not cause the same damage as Hepatitis A or Hepatitis B. The only advice the health visitor gave was that my husband should not drink any alcohol, so he gave up drinking altogether. They wanted to continue testing his blood so did so every month for the next six months.
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8. We were very relieved my husband did not have AIDS and we carried on with our life.
  9. The next time a health visitor came it was a different person. When she arrived at our house she handed me a bag of condoms and told me to use them to protect myself. This was a huge shock and I was very frightened. I couldn't understand why she gave me the condoms. I thought she meant they would protect me from HIV, but we knew my husband did not have HIV and had been told the HCV was benign, so we didn't use the condoms. I didn't realise from what we were told that HCV could be passed on.

## ANONYMOUS

10. I feel I got no support through this time and didn't understand anything about HCV or the risk it presented to others.
11. I became pregnant in 1986 and when I saw the haemophilia health visitor again she was surprised and asked how this had happened. She asked me whether we had been using the condoms? I said no, we hadn't, and I asked why. She said it would protect me from my husband. Looking back, I believe the health visitor knew more than she was letting on.
12. The next time we saw a health visitor it was a different person again. I explained my concerns about what the previous health visitor had said to me. She said that the previous health visitor was being paranoid and had now been dismissed due to her having upset other patients.

### **Section 3. Other Infections**

13. My husband was told in 1997 that he had been exposed to vCJD implicated products and went on treatment strike as a result.
14. My husband also has concerns about recombinant treatment he has received since 2004 when it was introduced. After he received some of the new treatment he came home and felt very sick for a week.

### **Section 4. Consent**

15. Neither my husband nor I know whether he has been treated or tested without his knowledge or consent or for the purposes of research.

### **Section 5. Impact**

16. The treatment my husband received for HCV in 2004 was debilitating: he suffered severe side effects and was unable to work for a year. The treatment took its toll on his mental health and his personality changed.

## ANONYMOUS

He is no longer outgoing or jokey like he used to be. He is no longer as loving towards me or the children and has become very emotional, with frequent mood swings and a quick temper. The anti-depressants he has taken since the treatment in 2004 made him angry and very difficult to live with.

17. The stigma of the disease has been very difficult to bear. I didn't tell anyone about the infection when my husband was diagnosed and felt very anxious. People would come round to our house in 1986/7 and accuse us of having AIDS. One person wanted to hit me. I was pregnant at the time and said, 'I am pregnant, you can't hit me'. When I was pregnant with my second child my GP would use two pairs of gloves to take my blood.
18. I still feel anxious about the disease and its stigma. We have just moved house to have a new start and I don't want the new neighbours or anyone to know.
19. It has been necessary for me to work over the years to help support us as we cannot afford to live on my husband's benefits and payments from the Caxton Foundation alone. I was working for a GRO-B when my GRO-B and I was very nervous about the reaction from my GRO-B employer because my husband's campaign was GRO-B I then left the GRO-B and started to work for a local company. I was shaking when I went into work the day after he had been on television. I took anti-depressants to help me through it. When my employer found out I was on anti-depressants they let me go. My father was taken ill and I became his carer for the next year.

**Section 6. Treatment/Care/Support**

20. Neither my husband nor I have ever been offered counselling or psychological support in consequence of what happened.

**Section 7. Financial Assistance**

21. My husband's statement sets out in detail the financial assistance we have received from the various Trusts and Funds. When my husband's application for SCM payments was rejected on the grounds he had not been affected by HCV he suffered considerable stress and nearly committed suicide.

**Section 8. Other Issues**

22. I hope the Inquiry will achieve better treatment for our grandchildren and future generations with haemophilia.

**Statement of Truth**

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

Signed

GRO-B

Dated

25 September 2019