

# ANONYMOUS

Witness Name:

GRO-B

Statement No: WITN5648001

Exhibits: 0

Dated: MARCH 2021

## INFECTED BLOOD INQUIRY

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FIRST WRITTEN STATEMENT OF

GRO-B

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I, GRO-B, will say as follows:-

### Section 1. Introduction

1. My name is GRO-B. I was born on GRO-B and I live at GRO-B.
2. My husband, GRO-B: H (born on GRO-B), was co-infected with the Human Immunodeficiency Virus (HIV) and the Hepatitis C Virus (HCV) through contaminated blood products.
3. This witness statement has been prepared without the benefit of access to H's full medical records.

### Section 2. How infected

4. H has mild/moderate Haemophilia A, diagnosed when he was 11 years old.

5. [H] was treated with Factor VIII (FVIII) concentrate at various different hospitals for tooth extractions and knocks and bleeds. He moved around because his father was in the army.
6. I met [H] in 1986 when we were aged 15. He was then under the care of the Worthing Hospital (WH) and he had not long been told that he was infected with HIV.
7. I was pregnant with our first child at aged 16 in 1987, the year [GRO-B: H] and I also married. Our son was born three months premature on [GRO-B] 1987. [H] and I were both very young. I did not fully understand and/or appreciate the gravity of what had happened to him at first. It didn't sink in. It just washed over me. We were given very little information and advice about HIV and the spread of infection. I started to appreciate how serious it was when I became pregnant.
8. [H] wasn't aware that he had been infected with HCV until around a decade later in 1996. No-one told us. We saw the information/read it in [H]'s medical notes handed to him by a nurse at the Haemophilia Centre. We were very cross and upset. A doctor subsequently told [H] 'not to worry' about it because he had 'had it for a while' whilst also telling him that it could affect his liver and that it could be sexually transmitted (to me!). We should have been aware of the issue much sooner as [H] had apparently been infected with HCV (known then as Non-A Non B Hepatitis) some time in or before 1984.

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

9. [H] received a letter from WH some time in 2004 stating that he had been given a batch of FVIII which contained blood from someone who had died from vCJD.

**Section 4. Consent**

10. [H] believes that he was treated and tested without his knowledge, consent and without being given adequate information. He believes that he was treated and tested for the purposes of research.

**Section 5. Impact of the Infection**

11. Trying to deal with HIV at the age of 15 was very hard for [H]. He didn't tell me about it at first. He was drinking a lot of alcohol to block it out and he had some anger issues. He was told that he would die young and I made allowances for that. He was very thin and emaciated and suffered with health symptoms that we now know to be HIV related. When the tombstone adverts started appearing on TV it was awful. Looking back and given the level of fear and stigma back then, I think we were very brave. I remember [H] and I going into a pub with my Nan and a woman walking out in protest at us. I didn't say anything in response to her behaviour. I wouldn't be so nice now. I have a patient easy going temperament and I didn't fully understand what lay ahead for me personally. [H] gets depressed to this day. I just plod on. The doctors took blood from me and I was tested for HIV on several occasions throughout my pregnancy.

12. As stated, my son was born three months premature. My waters broke over a nurse and I later found out that she was not allowed to work for 6 months thereafter. My baby son was not allowed in the nursery with the other babies in case he made them sick and I was not allowed to use the phone like other mothers there. I was a new mother at just 16 years old, trying to bond with a premature baby and it was horrific being stigmatised in that way. Ironically, our baby needed a blood transfusion and the hospital called [H] to ask if he would donate blood. [H] said 'Don't you read my notes'.

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13. I went on to have two more children born in 1988 and 1990 respectively.

They weren't allowed in the nursery either. I was turned out of the hospital within no more than 6 hours after both births. All three children were born at

GRO-B

in

GRO-B

14. In 1992 **H** had pneumonia and I thought he was going to die, leaving me widowed with three very young children. Luckily AZT had just been discovered and was given to him straight away. A few years later he went on to DDI and has had other treatments all with numerous of side effects. He has a shadow on one of his lungs thought to be HIV related. **H** has developed asthma and diabetes type 2.

15. **H** had Interferon treatment to clear his HCV in 2004. I had to inject him weekly as he is scared of needles. The treatment lasted approximately 10 months. The treatment affected him mentally and physically. **H** became so hard to live with. All of the children moved out (to friends and my Mum) because they didn't want to be here. Even on the occasions when a sales person phoned **H** would shout for me to get off the phone. He had a short fuse and a bad temper. I was on the verge of leaving, but I stuck it out. I knew **H**'s behaviour just wasn't like him. It was a considerable strain on us all but we got through it.

16. **H** and I suffered financial hardship. **H** has been unable to work since 1992 and I do not know how we would have managed at times, with a young family had I not been able to borrow money from my Mum. **H** has only recently cleared HCV (in April 2020) and has developed liver disease. I have never been tested for HCV and have had no advice in relation to the spread of infection (for example warnings of caution when cleaning up **H**'s blood etc).

17. There was a lot of stigma associated with HIV and HCV. People started to treat us differently when we have told them and we have even lost friends

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along the way. My philosophy is that you cannot change the world but we are lucky to have had the full support of our family.

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

18. I rely on H's Statement.

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

19. I rely on H's Statement.

### **Anonymity, disclosure and redaction**

20. I confirm that I do wish to apply for anonymity.

### **Statement of Truth**

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

Signed..... GRO-B .....

Dated.....28/04/2021.....