

# ANONYMOUS

Witness Name: GRO-B

Statement No: WITN1142001

Exhibits: 0

Dated: May 2020

## 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 infected with the Hepatitis C Virus (HCV) through contaminated blood products. He died on GRO-B aged 58.
3. This witness statement has been prepared without the benefit of access to my husband's full medical records.

### Section 2. How Affected

4. H had severe Haemophilia A. He was treated at the Lewisham Hospital Haemophilia Centre initially under the care of Dr Whitmore. He was also treated for a period of time at the Oxford Haemophilia Centre and latterly at

the Kent Haemophilia and Thrombosis Hospital at the Kent and Canterbury Hospital.

5. [H] was treated with cryoprecipitate initially before moving on to Factor VIII (FVIII) treatment. [H] was never warned of any risk in being treated with FVIII concentrate.
6. [H] struggled with poor health throughout his life. He had terrible problems with his knees due to haemophilia bleeds and, later in his life, he needed knee and hip replacements before, ultimately, losing a leg.
7. [H] told me that he had contracted hepatitis not long before we met in the early 1980s and had needed quite a lot of time off work sick. He had been very ill and his weight had plummeted to around 8 stone. That was what he told me. I do not know whether [H] was infected with Hepatitis B Virus (HBV) at that time but HCV was something that [H] seemed to know about for as long as I can personally remember. It was known then as Non A Non B (NANB) Hepatitis and it was something [H] just put up with. [H] did regain his weight for some time but in the latter years it became very difficult. He couldn't maintain his weight because his body was shutting down. He developed intestinal ischemia and infarction (and his small bowel died) resulting in [H]'s death.
8. We were never given any family related advice in order to assist us to manage [H]'s infection. I always worried about it and was tested after [H] died. [H] spoke with his consultants on many occasions about my fears surrounding the spread of infection. The message always came back that I didn't have cause for concern and that it was unlikely that I too was infected. I was never 100% happy.

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

9. [H] was not infected with anything other than Hepatitis.

#### **Section 4. Consent**

10. I do not think that [H] was tested or treated without his knowledge and consent.

#### **Section 5. Impact of the Infection**

11. I met [H] at work at [GRO-B] Hospital in the early 1980s. I was a nurse and [H] was in administration. We married in [GRO-B] and moved to [GRO-B]. We have two children. Our daughter was born in 1985 and our son was born in 1989.

12. There was a lot of fear surrounding HIV/AIDS in the mid 1980s and haemophiliacs were stigmatised. There was a lot of ill feeling towards homosexual men and those labelled as promiscuous. Haemophiliacs and homosexuals were tarred with the same brush. Abusive slogans were even daubed on the walls of homes. I remember [H] having a bad bleed and being admitted to Lewisham Hospital. The nurses there were terrified. They didn't want to go near him. We didn't speak to anyone in the community about [H]'s haemophilia. We kept his haemophilia to ourselves and said nothing about hepatitis. I do not think that we were even questioned about it by our own family members.

13. [H] and I had a terrible time after our daughter was born. We went for an appointment with Dr Whitmore and he informed us that [H] might have HIV and he needed to be tested. I was horrified. I remember crying in the car on the way home. I thought [H] was infected with HIV/AIDS. I believed that I had it and I believed our daughter would have it too. It turned out to be a false alarm. We weren't infected with HIV and I could sigh with relief. [H] did not have HIV. He 'only' had NANB Hepatitis and that didn't appear to be a big concern back then.

14. I was healthy all my life and right up until our son was born in 1989. The pregnancy tipped my health over the edge. I was diagnosed with Cystic

Fibrosis. Despite our combined health issues, we were determined that our children would have a happy upbringing. We kept our health issues hidden from them during their childhood. [H] and I provided support to the other when one of us was unwell. It was a two-way street.

15. We were most certainly financially affected. [H] missed so much work, he then had to go part time before becoming too unwell to work at all.

16. [H] and I were together for over 30 years and I lived with the stress of [H] having HCV (and severe haemophilia) on a daily basis. I find it hard to separate the two (HCV and haemophilia) in my mind. The worry of it all clouded my mind. The abdominal pain and weight loss were the main physical affects of [H] having HCV. In the last few years of his life, [H] was in and out of hospital on a constant basis. There were times when he was in hospital more than at home. The food was terrible at the hospital and I would try to build him up when he came home. It made no difference as he continued to deteriorate. [H] was in hospital three days before he died on [GRO-B] [GRO-B] 2012. [H] was in hospital so often and we had lived with him being ill for so long that we didn't expect him to die so suddenly. All his Christmas presents were around the tree. We were left reeling with shock.

17. I get very emotional thinking about what [H] and I went through and I can start crying some days even now. We had a great love between us. He was a wonderful man, always smiling and happy. He never complained and just got on with it and yet each and every day I saw a small deterioration in him. Every time he did something for me or for himself, he paid for it. He had a horrible time. I was the worrier. I worried every day of our lives. I worried about what bad news we were going to get next. I never knew how long we had left or what was going to happen next. I have blotted a lot of the detail from my mind as a coping mechanism. I have had my fill with stress and I now try to live a quiet stress free life as much as I possibly can. [H] hid his pain and suffering from the children and from me as far as he could. He put up with HCV and how sick he had become through it. [H]'s mind set was one



of dogged determination to get through whatever happened. It rubbed off on me and made me a stronger person as well.

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

18. Given the stress we were under through our respective health issues and the passage of time since [H]'s death, I do not recall whether or not [H] had treatment to try to clear HCV. I do not think he did. I have learned far more about HCV since [H]'s death through the news and coverage through the Inquiry.

19. [H] and I were never offered any psychological support. When [H] died I went and asked to be tested for everything. It was daunting for me going to a clinic for testing. It made me feel terrible.

20. [H] and I tried to protect our children from our knowing about our illnesses throughout their childhood. As adults they are impacted more. My son has been having counselling as a result of the death of his father.

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

21. We received the £20,000 payment from the Skipton Fund, labelled as a one off ex-gratia payment. I now get the EIBSS payments (but only within the last couple of years) because my income is so low and I was previously living on my savings. It was a huge relief to learn that I had qualified for the payments. I nearly didn't fill in the application form.

#### **Anonymity**

22. I wish to remain anonymous.

23. I do not want to give oral evidence to the Inquiry.

# ANONYMOUS

## Statement of Truth

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

Signed.....

GRO-B

Dated .....

20.05.2020