

# ANONYMOUS

Witness Name **GRO-B**

Statement No: WITN3401001

Exhibits: 0

Dated: July 2019

## 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 the **GRO-B** My address is **GRO-B**  
**GRO-B**
2. I am married and I have retired from work.
3. I am an affected person and I write this statement in relation to both my sons **GRO-B: S1** date of birth **GRO-B** **GRO-B** and **GRO-B: S2** date of birth **GRO-B** **GRO-B** who have also produced a statement for the Inquiry. Both **S1** and **S2** received contaminated blood and were infected as a result.
4. This witness statement has been prepared without the benefit of access to both my sons' full 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 Affected**

5. My sons **S2** and **S1** both have severe Haemophilia A, with 0% clotting factors. **S1** is the eldest and he was diagnosed with Haemophilia at a young age. **S2** was tested for Haemophilia at birth.
6. Both of my sons were under the care of **GRO-B** and **GRO-B** **GRO-B** at the **GRO-B** **GRO-B**. They were also treated at **GRO-B** in **GRO-B**.
7. Both my sons were initially treated with Cryoprecipitate (Cryo). In or about the mid 1970s when Factor VIII concentrate (FVIII) became available, my sons were treated with it.
8. No information was provided to me in relation to the risks involved in using FVIII. If I was told that there were risks, I would have asked for alternative treatment. At the time we trusted our British blood donor system.
9. My son **S2** was infected with Hepatitis C (Hep C) as a result of being given FVIII and my son **S1** was infected with HIV and Hep C as a result of being given FVIII.
10. Once I found out that **S1** was 'antibody positive', I contacted the hospital and spoke to **GRO-B** who said that **S1** was adult enough to take responsibility for his own health and future'.
11. We all sat down and spoke about the results to **S1**. We told him that he would have to be extra careful about his used needles and syringes and especially if he cut himself at work, he had to start thinking about other people.
12. As stated above, **S2** was infected with Hep C. From **S2** medical records he was tested in **GRO-B**. However, I do not know when he was told he had Hep C. Further details about how **S2** found out about the infection, will be in his witness statement.

13. I wish to rely on both of my sons' statement for the rest of this section as they were at the age to deal with their own medical care.

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

14. At some point in the early 2000s we became aware that other potentially dangerous viruses had been transmitted through plasma derived factor concentrates. These viruses were variant Creutzfeld-Jacob Disease (vCJD), parvovirus B19 and Hepatitis A (Hep A). At the time we read that 80 of the 85 people infected by vCJD had died and 7 had been blood donors. It is not possible to test for vCJD until you have passed away so we have no way of knowing if either of the boys have been exposed to it.

15. I am not sure if either S1 or S2 received any other infection as a result of FVIII. I do remember S2 mentioning something in relation to either Hep A or B, but I can't remember the full conversation. In relation to this, I would like to rely on their statements for clarification.

### **Section 4. Consent**

16. I knew that both of my sons were having blood tests. I'm not sure if they knew what they were being tested for at that time. We trusted everything the doctors said at the time and didn't really question them.

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

17. My sons have given their own accounts in regards to how the infections affected them mentally and physically. I would therefore like to rely on their statements in this regard.
18. In relation to further medical complications or conditions that have resulted from the infections, one particular incident stands out to me. I remember a period in which S1 health had worsened due to the Hep C and HIV. He got coughs, colds and pharyngitis that dogged him for weeks. He then got a few blister-like spots on his trunk which he thought were bites of some sort. I had a notion that it could be shingles but thought it was impossible, as he was

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so young. The doctor however confirmed that it was indeed shingles. I saw the fear in his eyes. I vividly remember him asking '*is this it, mum?*' effectively asking me if this was going to be the death of him. I tried to make light of it despite having the same thoughts. Luckily S1 quickly got over it like he did most of his ailments.

19. I know that my sons did face some difficulties in accessing forms of treatment. I would like to rely on their statements in this regard as their accounts will be more detailed than my own.

20. I didn't know much about the treatments that both my sons received at the time as they were at the age where they dealt with their own medical care. After they left home and got married they didn't tell me much that was going on so I'm not sure.

21. When I was told my children had these infections I thought it was a death sentence. No mother should feel like her children could die before her but that was how I felt at the time.

22. Mentally, I packed my suitcase several times. If it wasn't for my faith in God I am sure I would have 'thrown it all overboard'. The strain of what happened to my children almost ruined my marriage. I was very explosive and hated the person it was turning me into. I later realised my reactions were quite normal and probably necessary.

23. I was horrified at the feelings that arose in me when I touched S1 laundry or crockery, I felt as if they were contaminated. Although these feelings disappeared in a day or two, I knew that if I, the person who loved him most, could feel like this then others were bound to feel the same, if not worse.

24. We faced quite a lot of stigma, or fear of being stigmatised due to the fact that S2 and S1 had received contaminated blood. We actually made a pact that we wouldn't tell a soul of their infections other than the doctors and dentists that were involved. We didn't realise at the time what the implications of this silence would be and the burden we would carry as a result.



25. I remember the nickname for AIDS at the time was 'the gay plague' ensuring all those infected would be labelled 'homosexual'. People were not educated on the matter. We read stories of sackings, beatings and poisoned pen letters directed not only at men but at young innocent victims too. I had also heard a report that dustmen were refusing to collect rubbish from the parents of a victim who wasn't even living at home. I was always aware that one stray word reaching the wrong ears could destroy both my sons' lives.
26. There was a frightening report from the US where 3 haemophiliac boys had been banned from school because they were HIV antibody positive. Barbers would refuse to cut their hair and people wouldn't even stand near them. They turned to their Baptist Church for comfort but the minister told the congregation and barred the doors to the whole family. I worried that the same could happen to my boys in GRO-B It just reinforced the idea that this was something that I couldn't tell anyone.
27. On one occasion I was standing talking to someone in town and our local gay referee walked by. The person I was talking too said "yuk, he's got AIDS" I replied that he didn't have AIDS and that he was only carrying the HIV virus. This particular man had to resign as a referee and received threatening letters and even faeces through the door.
28. Occasionally someone would ask me if my boys had AIDS or if I was worried about them getting it. People were aware that my sons were haemophiliacs and there was a lot of information in the news about haemophiliacs, contaminated blood and infections. It got a bit relentless. I would just fob people off by telling them that FVIII was heat treated and hoping they wouldn't ask me anything else.
29. I worked for a few months in a rest home but all I could think about was what they would say and feel if they knew the HIV was in my family. The girls often mentioned HIV when on their coffee breaks and spoke only with disgust and fear in their voices.

30. I remember an occasion talking to **S2** and **S1** about HIV/AIDS. It was very rare for them to open up, especially **S1**. But on this occasion it all came tumbling out. **S1** told me he was very aware of his friends' views on AIDS and that the strain of pretending he was okay was weighing heavily on him. He feared being rejected and in this conversation he dropped the bombshell that if people ever discovered he had HIV and shunned him, he would take his own life. This statement weighed heavily on me and afterwards he didn't talk about his infections for a matter of months. I can't describe how painful it was to hear words like this come from one of your children.
31. All of the incidents I read about, witnessed or experienced only highlighted the fact this was something we, as a family, had to keep to ourselves.
32. We didn't talk about the infections or the contaminated blood products. We each had our own thoughts and kept them pretty much to ourselves. I spoke to God about it.
33. My husband was very supportive but I didn't tell any other family members, it was very hard keeping it a secret. My parents died without ever finding out about the infections. My boys didn't want to be treated differently and didn't want to face the possible reaction the news would bring.
34. In regards to my son **S1** my parents kept hinting they wanted grandchildren. They didn't know this upset **S1** and **GRO-B** as at the time it seemed impossible. I believe this led to them visiting my parents less as time progressed.
35. I told my brother a few years ago about what had happened to **S1** and **S2**. He was hurt that I hadn't told him earlier but I said it wasn't my secret to share.

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

36. On one occasion a 'counselling' nurse did come down from **GRO-B** to talk to **S1** and **S2** but they both felt that it was too late for words. They didn't

want to take the day off work and probably didn't want to have to talk about it anyway.

37. I am aware that S1 didn't feel he was getting any help, support or information when he was attending GRO-B which is why he transferred to GRO-B S2 also had similar issues and transferred to GRO-B. He got a lot more support once he transferred.

38. I want to rely on sons' statements in regards to any further difficulties they faced in obtaining, treatment, care and support.

39. There was no support for me or my husband we had to rely on each other. I believe that psychological help may have been beneficial but I will never know. What happened to my children did affect me, maybe having someone to talk to would have helped. My husband didn't really want to talk about it.

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

40. For a long time Haemophiliacs were in the news because of their fight for compensation. Joe Public and the Haemophilia centre wrote a lot of letters and articles in the press calling for the government to admit liability and help those that had been affected. The Department of Health gave £10 million that would be administered by a Trust to haemophiliacs who had received contaminated blood as they saw fit.

41. We never understood how the amounts each person received were worked out but I know S1 began to receive monthly payments. I believe the payments were for him to purchase 'high protein foods' to keep him healthy. S1 also received a winter allowance payment. Maybe the Trust only shared out interest they made from the £10 million I am not sure. Married men with families got a larger sum, young unmarried men/boys.

42. I know my children also had problems obtaining things such as mortgages as they needed large deposits to get life insurance due to their infections.

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43. I would like to rely on **S2** and **S1** statements in relation to any further information in relation to financial assistance.

44. I didn't receive any financial assistance. I didn't know anything was available I was never told about it.

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

45. I wish to remain anonymous.

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

### **Statement of Truth**

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

Signed.....

**GRO-B**

Dated

16/7/19