

# ANONYMOUS

Witness Name: GRO-B

Statement No: WITN4013001

Exhibits: 0

Dated: March 2020

## 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 and I was born on the GRO-B I live at GRO-B  
GRO-B with my wife, GRO-B GRO-B  
GRO-B We have three boys, GRO-B
2. I make this statement in relation to my son, GRO-B: S who was infected with Hepatitis B (HBV), Hepatitis C (HCV) and HIV as a result of contaminated blood products.
3. I am aware that S has provided a statement to the Inquiry under GRO-B My wife has also provided a statement under GRO-B The parents of S wife have also provided statements under GRO-B and GRO-B
4. This witness statement has been prepared without the benefit of access to S full medical records.

**Section 2. How Affected**

5. **S** was born on the **GRO-B**. It wasn't until he was about 6 months old that he was diagnosed with severe Haemophilia A. I remember when he was a baby, **GRO-B** and **GRO-B**. We took **S** to his GP as soon as we got a chance and I was questioned, accusingly, by the GP about the nature of the **GRO-B**. **S** was also questioned by the police and was accused of child abuse. It wasn't until the **GRO-B** when we took **S** to Birmingham Children's Hospital (BCH), that they ran any real tests on him. It was at this point we were told that **S** suffered from Haemophilia. **GRO-B**  
**GRO-B**  
**GRO-B**
6. From when **S** was diagnosed in **GRO-B** he was always treated with Factor VIII (FVIII) which was administered at the Haemophilia Unit at BCH. He required treatment as and when he suffered a bleed. After a few years, my wife and I were trained to administer **S** treatment at home and we continued to do this until **GRO-B** when **S** was old enough to treat himself. We never treated **S** prophylactically.
7. **S** was only ever treated at the Haemophilia Unit at BCH when he was a child. I believe his main treating doctor was Dr Hill. Once **S** turned 18 he was then moved to the Queen Elizabeth Hospital in Birmingham (QEH) and I believe his main doctor there was Dr Jonathan Wilde. I believe that **S** was treated with Armour Factorate throughout the 1980s. He was then moved onto BPL and Alphanate in the 1990s.
8. **GRO-B** and I were never provided with any information about FVIII or told beforehand of any risks that were involved with FVIII. We were never offered any alternative treatments and all we knew was that FVIII was being used to treat his Haemophilia.
9. **GRO-B** and I shared out the medical responsibilities in treating **S** at home and taking him to his hospital appointments.

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10. When **S** was around **GRO-B** years old **GRO-B** and I attended a routine appointment with him. We were told at this appointment that he had been infected with HIV. Around the same time, we also found out that **S** had been infected with two different types of Hepatitis known as HBV and HCV (then known as Non A Non B Hepatitis). Even though our son had been infected we were never warned of the risks and the only reason we discovered that **S** had been infected with HBV was because he had become jaundiced and he was in pain.

11. When we found out about **S** infections, we also found out that the BCH had told the **GRO-B** **GRO-B**

**GRO-B**

**GRO-B**

12. **GRO-B** and I were provided with very little information on how to manage the infections. The advice we were given was that we had to protect the rest of our family from him and if he cried or bled we would have to wear gloves, clean up after him and sterilise anything he had been around.

13. **GRO-B** and I also had to go to see our GP in order to have an injection at **GRO-B**. We were given a vaccine to protect us against HBV, but our other children were not.

14. **S** was not told about his infections until he was around **GRO-B** years old. I believe he was told at one of his routine hospital appointments by Dr Hill. I remember that the hospital were constantly changing **S** treatment for his haemophilia and it felt like every time we took him to the hospital there were new suppliers of treatment. I also recall that they always took samples of **S** blood when we went to appointments.

15. Somebody must have known something earlier. I don't believe that we were told as soon as they knew of his infections.

16. The way we were told that our son was infected was shocking and we received no information or advice on how we were supposed to progress with

our lives. The knowledge we had on HIV came much later, only when it was advertised by the media and celebrities were dying. Before this, **GRO-B** and I genuinely believed that HIV and AIDS were the same thing because nobody had ever told us anything different. At the time we didn't even know it was going to be treatable and we thought our son was going to die.

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

17. I do not believe that **S** was infected with anything other than HCV, HBV and HIV.

18. I wish to rely on **S** statement in relation to this section.

### **Section 4. Consent**

19. I do believe that **S** was tested and treated without our consent and full knowledge. We were never given full or adequate information at the time. We were kept in the dark.

20. My wife and I do believe that **S** may have been tested for the purposes of research. We had always believed that over the years his blood was just being tested for his Factor levels. We were never informed why they were doing so many blood tests all the time or what they were testing him for.

21. **S** **GRO-B**  
**GRO-B**

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

22. I remember **S** used to suffer from severe migraines – to the point where he couldn't see. It is so difficult to split the symptoms he suffered from HIV, HCV and HBV. It was only later on in his life, when he was around **GRO-B** that he started any real treatment, **GRO-B** I remember at the time **S** was treated with a series of injections and tablets, which I believe was the treatment for HCV.



23. [S] has always had a good head on his shoulders, and has always been very responsible. From a young age he treated himself the majority of the time. I remember as soon as he was old enough, the hospital didn't want anything to do with us anymore.
24. Mentally and physically when he was being treated he became very poorly. He was [GRO-B] and he couldn't do the things he wanted to do. I remember him coming home crying and upset. He became standoffish because of his infected status. I believe that the hospital told him about his infections and what the future held for him.
25. It upsets me greatly when we found about the infections. It still does to this day. It is something you never want your children to have. Growing up there were certain things we couldn't do together because of [S] condition. I am still very upset especially with what is still going on at the moment. I look at [S] now and see what he has had to deal with his entire life. I think he is a lot stronger than I am.
26. People hear a lot on the TV and through the media which influences the way they think. I think if we had told people of [S] infections they wouldn't have accepted him or us. We therefore keep his infected status to ourselves. If [S] wants to tell people then it's up to him. I don't tell my friends about it, they know he has Haemophilia but they do not know about the infections. [S] two brothers were aware of the infections as they grew up with him. They see [S] as a brother. They don't feel any differently about him.
27. In our family, it is only the four of us that know of [S] infections. Within our family there is still a definite stigma surrounding HCV and HIV. [S] has a grandmother, who is still alive, and when she found out that he was infected with HBV she refused to kiss him, or hug him because she was worried she would catch it. She would sterilise all of the cutlery and crockery after he had used them. Now he doesn't eat or drink anything when he is there. Even to this day she won't touch him. She has no idea that he is also infected with HIV and HCV.

28. When **S** was young we really struggled with booking holidays and could never really plan anything too far in advance. Everything had to be done on the spur of the moment but also planned to perfection. Every detail had to include provisions for **S** and his infections and we had to ensure that there was always a hospital or medical centre that were able to deal with his condition. We had great difficulty with planning our holiday to the USA one year because of everything that was going on with HIV and AIDS at that time.
29. **S** met **GRO-B** who is now his wife, in or around **GRO-B** when he was **GRO-B** years old. He was incredibly worried about physical contact between the two of them; even kissing was a concern to him. When they had been together for around **GRO-B** he decided it was the right time to let her know of his infections. I still remember how upset he was after he told **GRO-B** he had HIV and HCV. Thankfully, **GRO-B** and her family were completely accepting of **S** and we had a meeting with her parents to discuss everything and what his infections meant. Despite this there are always going to be things that **S** and **GRO-B** cannot do like normal couples would.

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

30. We never received any care from the hospital. Nobody wanted to see us or talk to us about it. If **S** cut himself we just had to mop it up and disinfect the area. If we accidentally stabbed ourselves with one of his needles we had to tell the hospital. We had to make sure everything was kept clean. We had no support; they didn't supply us with any thing – not even gloves. The only thing they gave us was the needles and the FVIII treatment. No one gave any adequate information or provided us with support.
31. No counselling was ever offered to **S** at the time, but we believe it would have helped had it been offered **GRO-B** and I weren't offered any form of counselling or psychological support. It may have helped had it been offered.

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

32. We had no financial support for **S** until around 1991 when we received a lump sum payment of around £20,000. I do not remember signing a waiver for

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it, and at the time we believed it was because of **S** Haemophilia. Even the hospital said to us 'all Haemophiliacs are getting it'. We had no idea it was related to his infections.

33. I do not recall if we had to fill out a form to receive the payment.

34. When **S** was around 6 years old we did receive an allowance from the Government. However we had to pay it back because **GRO-B** worked and we were not entitled to it.

## Anonymity, disclosure and redaction

35. I wish to remain anonymous.

36. I do 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

26/03/2020

**GRO-B**