

ANONYMOUS

Witness Name: **GRO-B**

Statement No: WITN4014001

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** with my husband **GRO-B** I am retired. 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 husband 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** **S** was diagnosed with severe Haemophilia A when he was about **GRO-B** months old. Please refer to my husband's statement for further information in relation to this.
6. **S** was always treated with Factor VIII (FVIII) from when he was diagnosed in **GRO-B** **S** received FVIII treatment at the Birmingham Children's Hospital (BCH) and only had it as and when he had a bleed. My husband and I were later trained to administer treatment to **S** ourselves at home. From about **GRO-B** **S** was old enough to treat himself. **S** always received treatment from BCH until he was 18 when his care was transferred to the Queen Elizabeth Hospital, Birmingham (QEH) and he care was under Dr Jonathan Wilde.
7. **GRO-B** and I were never told beforehand about risks involved in using FVIII products. We were only ever told of what FVIII was doing to treat **S** haemophilia.
8. We found out that **S** was infected with HIV when he was about **GRO-B** years old (mid 1980s). This was around the same time that we discovered that **S** had also been infected with HBV and HCV (then known as Non A, Non B Hepatitis). My husband and I were never warned of the risks of coinfections. I recall taking **S** to the hospital because he was jaundiced and in pain. Even his tears were yellow.
9. We were not really provided with any information on how to manage the infections. We were told 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.
10. **GRO-B** and I were told to go to see our GP in order to have an injection at **GRO-B** **GRO-B** and I were given it, but not our other children. I believe the injection was to vaccinate us from getting HBV.

11. I believe that information should have been provided earlier. Someone must have known something.

12. The way that **GRO-B** and I were told of **S** infections was all wrong. We should have been notified of how to move forward with it all, and deal with everything that was likely to happen. It was only later when HIV came out on the TV, and people were dying that we truly got any information about it. At that time we thought HIV and AIDS were the same thing. We thought our son was going to die. It was a loaded gun and we had no idea what was going to happen or how long we would have **S** around for. We were so worried he was going to be called into the hospital and we were going to be told he only had 6 months left to live. Now the infection is treatable.

13. Please refer to my husband's statement for further information in relation to this section.

Section 3. Other Infections

14. I do not believe that **S** was infected with any other infections other than HBV, HCV and HIV.

Section 4. Consent

15. I believe that **S** was treated and tested without our knowledge and consent. I do not believe we were given full or adequate information at the time.

16. **GRO-B** and I believe that **S** might have been tested for the purposes of research. We always believed over the years that his blood was just being tested for his Factor levels.

17. **S** **GRO-B**

Section 5. Impact of the Infection

18. I believe that being infected did mentally affect **S** when he was young. I don't think he had understood the severity of it. We didn't want him to know much about it because he was so young but he did become quite withdrawn.

19. It was in the mid 1990s that **S** was told by his doctor of his infections. It was earth shattering news for a teenage boy to be hearing. He became very withdrawn, and started to question whether he should carry on with his life.

20. I am not sure if he had physical symptoms as a result of the infections. I know **S** used to suffer with severe migraines to the point where he couldn't see but I do not know whether this was because of his Haemophilia or the infections or even the treatment he had.

21. As stated above, **S** suffered from jaundice when he was around **GRO-B** years old. He had been at school and was taken ill. The next day, before school he was very upset and he had turned yellow. Even his tears were yellow.

22. **S** **GRO-B**
GRO-B
GRO-B When **S**
 was around **GRO-B** or **GRO-B** he had a second course of treatment which was for about 3 months and again the treatment was unsuccessful. I believe that **S** has since cleared the HCV through new treatment that he has had in recent years. Please refer to **S** statement in relation to this.

23. The side effects surrounding the HCV treatment were severe **S** suffered from constant flu-like symptoms, nausea and fatigue.

24. I am not aware of any side effects surrounding **S** HIV medication as he started this after he turned 18. I believe the HIV infection is now almost undetectable.

25. In our family, only four of us are aware of [S] infections. Our family still holds a stigma towards it. Please refer to my husband's statement in relation to this.
26. We have always kept [S] infections to ourselves and we would never tell anybody of his situation unless he was comfortable with it. If people don't ask us then we don't say anything.
27. [S] never really had friends. We never wanted him to be around other children when he was very young in case he got hurt. People only knew about his Haemophilia and not that he was infected. The stigma was huge at the time and I believe it would have had a massive impact on [S] and all of us if anyone found out.
28. When I found out [S] was infected I was incredibly upset. I thought '*what did I do to deserve this?*' We had no choice but to knuckle down and carry on. [S] was upset and crying all the time and I had to be strong for him. I could have cried over [S] all the time but I had to stay strong.
29. [S] met his now wife in [GRO-B]. He was incredibly worried about physical contact between them. He told his wife about the infections and she was incredibly upset. A meeting was organised with his wife's parents to speak to them about [S] condition. They accepted [S] completely into their family but there were still a lot of things they couldn't do that normal couples could.

Section 6. Treatment/care/support

30. [GRO-B] and I were offered no care or support from BCH. It felt like nobody wanted to talk to us at all about [S] infections and they didn't supply us with anything to clean up after [S].
31. Counselling and psychological support was never made available to us. I believe it would have definitely helped [S] had it been offered to him. Its possible that counselling could have helped us had it been made available to us.

Section 7. Financial Assistance

32. At the time of [S] infections we were offered no financial support. When [S] was about [GRO-B] years old we did claim an allowance from the government through benefits but we had to pay it back because I was working about 3 hours a day.

33. I believe we received a lump sum payment of around £20,000 in 1991 [GRO-B] and I were notified of it through the hospital but we just assumed it was because of [S] Haemophilia. We just thought we were entitled to it, and had no idea it was to do with his HIV. I cannot recall if we had to fill out a form to receive the money and I have no recollection of ever signing a waiver.

34. We did not receive any other financial support whilst [S] was in our care.

Anonymity, disclosure and redaction

35. I wish to remain anonymous.

36. 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

26 / 03 / 2020

[GRO-B]