

ANONYMOUS

Witness Name: GRO-B

Statement No: WITN4015001

Exhibits: 0

Dated: January 2020

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF GRO-B

I, GRO-B will say as follows:-

Section 1. Introduction

1. My full name is GRO-B of GRO-B GRO-B, Sheffield GRO-B. I was born on the GRO-B 1953. I live with my son GRO-B. I have never worked as I am GRO-B's main carer. I have always been his main carer.
2. I write this statement in relation to my son GRO-B who was born on the GRO-B 1979. GRO-B was infected with HIV and Hepatitis C (Hep C) as a result of receiving contaminated Factor VIII Concentrate (FVIII).
3. GRO-B has also provided a witness statement to the Inquiry, GRO-B.
4. This witness statement has been prepared without the benefit of access to GRO-B's full medical records.

Section 2. How Affected

5. GRO-B was diagnosed with severe Haemophilia A at around 18 months. I was accused of child abuse; he had hurt his shoulder and we didn't know how he did it. We had noticed little bruises on him. I was told that either my husband

ANONYMOUS

or I had been hitting him. Haemophilia does not run in my family, so it was a surprise to him and all of us for GRO-B to have been diagnosed with it. The first time we took GRO-B to hospital was for his shoulder, and they just didn't know what it was. His father, my ex-husband, and I had travelled up to GRO-B for an event, and when we took his coat off he just screamed. I took him to the GRO-B I was told I wasn't allowed to touch him or be in the same room as him without a nurse.

6. He was then transferred to GRO-B When I went to see him, I was told by the doctors that he had Haemophilia. I believe this was the first time that he was treated with clotting products. His care was then transferred to the GRO-B, where he received more clotting treatment and I believe it was FVIII. This was his main treatment centre until we moved to GRO-B when his medical care was transferred to GRO-B I believe he also received FVIII at this hospital. When GRO-B was about GRO-B years old we moved to GRO-B and his medical care was transferred to GRO-B where he was also treated with FVIII.
7. We were told that we would have to take GRO-B into the hospital whenever he had a bleed and required treatment. I was told we should wait an hour between telling the hospital that we were coming and arriving so that they could get the clotting products ready. I believe that GRO-B was given FVIII in the early 1980s, but I cannot remember the doctors telling me that it was FVIII.
8. I started to treat GRO-B at home when I was going through my divorce with my husband. I believe this was when GRO-B was about GRO-B years old. His father used to home treat him prior to this, and had done so since GRO-B was about GRO-B or GRO-B years old.
9. GRO-B was infected with both HIV and Hep C as a result of using FVIII. I believe he was infected with HIV at the age of GRO-B GRO-B but I do not know exactly when he was infected with Hep C.

ANONYMOUS

10. I was given no information beforehand about the risks involved when using FVIII. I was not even given the opportunity to ask any questions or discuss the implications of FVIII with the medical professionals in charge of my son's care. I thought that FVIII was just something [GRO-B] had to have. We were given no alternative treatment options.
11. I recall being sent a letter from [GRO-B] in the mid 1980s, to make an appointment to see a doctor. My ex-husband and I went to the appointment and they took us into a private room and they just told us that [GRO-B] had tested positive for HIV. I was told I would be lucky if [GRO-B] made it to his [GRO-B] birthday. I was also told that we shouldn't discuss his HIV positive status with anyone, not even our family members.
12. At the time, I didn't really understand what it meant for [GRO-B]. It was only when the adverts started on the TV that we gained an understanding of the severity of the infection. It was at this point we wanted more information from the doctors. I still don't think that at this point we received adequate information.
13. I received a letter from Dr Lilyman at [GRO-B] stating that he wanted to see me. I cannot remember when I received this letter. They sat us down. It was at this appointment that I was told that [GRO-B] had Hep C. I was told that Hep C could cause liver cancer. I do not believe that the information we were given was adequate at the time, we didn't really understand what was going on. We never even really knew what [GRO-B] was being injected with. I would have liked to know that there was a risk with FVIII, and we would have tried to find alternative treatments, but we were given no choice.
14. It was disgusting that we were told our son would be lucky to make it to his [GRO-B] birthday, and then later told he would be lucky to make it to his [GRO-B] birthday. I would have liked to have someone tell us in the proper manner what his infections were, why they were using the products and how it happened, but we were given no adequate answers.
15. We were not given any information about the risks of [GRO-B] passing the infections to others. They said 'you do know what to do if [GRO-B] cuts himself'.

ANONYMOUS

We had no idea what they were talking about. We were told to wear gloves, and bleach anything he bled on. This was about 6 months after being told he was infected with HIV.

Section 3. Other Infections

16. In or about the early 2000s, I was told that GRO-B may have been exposed to vCJD. However Dr Lilyman told me that we would not know for sure until GRO-B had died and they had checked his brain. The way I was told was shocking.

17. I was not given any further information about vCJD.

Section 4. Consent

18. I did not know that GRO-B was being tested for HIV or Hep C. These tests were done without my knowledge and consent. All we had was a letter asking us to make the appointment to see them.

19. I believe that GRO-B was tested and treated without being given adequate information.

20. I do not know if GRO-B was tested for the purposes of research.

Section 5. Impact of the Infection

21. We were told not to tell GRO-B that he was HIV positive, and to treat him as normal. We were told not to worry him.

22. Mentally, it had a huge impact on him, he started to act out and shoplift. They robbed him of his childhood. He went off the rails when he found out. There was not a police station in GRO-B that I didn't have to bail him out of.

23. When I initially told GRO-B I don't think he understood the severity of the infection. It wasn't until he got older that he used to lash out, and cry. He was sad that he could never have children.

ANONYMOUS

24. I do not know whether he was ever treated for his infections. I don't think his treatments came until he was older, and could make the decisions for himself. I wish to rely on [GRO-B]'s witness statement in this regard.
25. When [GRO-B] was about 15, he was transferred from the Children's Hospital in [GRO-B] to the [GRO-B]. When I took him for his first appointment, they said it was time he started going to the appointments on his own. From the age of [GRO-B] [GRO-B] started going to his hospital appointments alone.
26. [GRO-B] commenced Interferon and Ribavirin treatment for Hep C in or around 2008 at the [GRO-B]. The first time he had the treatment it did not work very well. He started smashing things up in the house and went totally crazy. The medical professionals decided that [GRO-B] could no longer continue with the treatment and they immediately took him off it.
27. It was not until about 7 years later that the medical professionals revisited the Hep C and once again [GRO-B] started on a course of Interferon and Ribavirin. This time [GRO-B] managed to complete the course and he successfully cleared the Hep C in or around 2015. However, as a result of this treatment [GRO-B] came out in awful rashes, lost a lot of weight, was permanently exhausted and struggled mentally.
28. When [GRO-B] found out about being infected with HIV, he was depressed. He would sit crying, going over the same things over and over. It wasn't until [GRO-B] was in his late 20s that he truly started to accept what had happened. They robbed him of his childhood and then robbed him of his manhood.
29. [GRO-B] went off the rails when I told him about the infection. Whenever he met girls, he never took it too seriously, because he knew eventually he would have to sit down and tell them what had happened, and then they wouldn't want anything to do with him. He used to drink a lot and every time he went out I used to wait for the police to knock on my door.
30. I was very depressed about it all. I did eventually start seeing a psychiatrist. I never really opened up about [GRO-B]. I used to blame my struggles on the loss of

ANONYMOUS

other family members, such as my brother or my father. I just found it hard to open up. I used to drink quite heavily myself, just to get through it all.

31. When we left GRO-B and moved up to GRO-B we didn't tell many people about GRO-B's infected status. It did eventually get out, and the council moved us to a different road, and the school refused to take GRO-B on. He had to have home tuition for a period.
32. We did suffer from stigma as a result of GRO-B's infections. One instance comes to mind which was when I tried to get GRO-B into a junior school. I telephoned the school and told them about GRO-B's infected status. The school told me that they were full and could not offer him a space. My sister then telephoned the school on the same day (I didn't know she had done this), seeking a place for "her son of GRO-B's age" and he was immediately offered a place. When I told my sister about this, she told me that she applied and her son got a space. I then contacted the school and told them that I knew that the school was not full and explained how I knew. The school were unimpressed with my behaviour but offered me a meeting and they eventually agreed to offer GRO-B a place on the provision that I would be available to collect GRO-B immediately if there were any problems with him at the school and that I would attend all school trips which GRO-B went on.
33. I think GRO-B used to get into scrapes because he hated school so much. I used to get called up to the headmaster's office often. I accepted GRO-B wasn't an angel, but every fight couldn't have been his fault. He missed a lot of school because of his infections.
34. My mother had her own responsibilities looking after my father, who was a sickly man. I never told my mother about what we were going through, as she had enough on her plate with my father.
35. GRO-B never went to nursery, so he started school when he was 5. At first I did not tell the school of his infections because the doctors told me not to, but they were aware of his Haemophilia. I had to be on call for GRO-B in case he got in a scrape at school so that I could bring him home.

36. I used to be on edge all the time. Every time GRO-B would get a cough or a rash I would panic. I used to think 'this is it, he has AIDS'. I would constantly worry that my son was going to die.

Section 6. Treatment/care/support

37. I was never offered any form of counselling or psychological support. GRO-B was offered counselling at the age of GRO-B by the NHS, and he took them up on the offer. I think that he should have been offered support much earlier as it would have helped him.

38. I did see a psychiatrist but this was after I broke up with my husband. He could never accept that GRO-B was a Haemophiliac and when he was infected he just wanted nothing to do with him.

Section 7. Financial Assistance

39. In or about the late 1980s, I received a payment from the Macfarlane Trust, which was approximately £20,000. GRO-B's consultant at the time advised me that he did not have much time left, and we should spend it whilst he was alive to enjoy it. I therefore took our whole family to Disneyland in Florida in or about the GRO-B. There was a further £20,000 which was put into a trust for GRO-B for when he turned 18.

40. I found out about the Skipton Fund and the Macfarlane Trust through the social worker at the GRO-B. I do not remember any preconditions that were imposed, or the process of applying for the money.

41. At first we used to receive about £25 a week from the Macfarlane Trust, which would have been after GRO-B. This went up to about £300 or £400 per month.

Section 8. Other Issues

42. I want answers as to what happened. If they knew the implications of FVIII why did they use it?

Anonymity, disclosure and redaction

43. I wish to remain anonymous.

44. I do not wish to provide oral evidence to the Inquiry.

Statement of Truth

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

Signed... GRO-B

Dated 21/2/20