

ANONYMOUS

Witness Name: GRO-B

Statement No: WITN1144001

Exhibits: WITN1144002-3

Dated: December 2018

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 I was born on GRO-B and I live at GRO-B with my second wife.
2. My son, GRO-B: S, died on GRO-B when he was just GRO-B years old, after being infected with Hepatitis B, Hepatitis C and HIV from treatment with contaminated blood products.
3.

GRO-B
4. This witness statement has been prepared without the benefit of access to my late son's 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.

5. However, I understand from [GRO-B] a specialist haemophilia nurse at [GRO-B] that there are records of [S] treatment because she told me that she didn't destroy them even though she had been asked to.

Section 2. How infected

6. [S] was born on [GRO-B] and was diagnosed with severe haemophilia A from birth.
7. Initially [S] was treated at [GRO-B] and the [GRO-B] [GRO-B]. His care was transferred to [GRO-B] hospital in or about [GRO-B] when we moved to [GRO-B]. He was originally treated at the [GRO-B] [GRO-B]. His main doctor there was [GRO-B] [GRO-B].
8. [S] frequently suffered from major bleeding, particularly into his knee joints, which meant he required constant treatment and hospital visits including in patient treatment. His in patient treatment was at [GRO-B] or [GRO-B] which was an extension of [GRO-B] at that time.
9. Initially [S] was treated with Cryoprecipitate which was kept in frozen sachets and was administered at the Haemophilia Centre by medical staff once thawed. However, when [S] was about [GRO-B] years old we were taught how to administer the treatment at home and with my help [S] became very proficient in injecting himself.
10. The frequency of his bleeds was virtually daily and the pain of having his joints swelling was very distressing for a youngster growing up, sometimes requiring one or even two injections daily.
11. [S] first had Factor VIII as soon as it became available. I believe this was in or around 1981. Cryoprecipitate was bulky and awkward to store and

ANONYMOUS

administer, so it was a blessing when Factor VIII was made available. Factor VIII could be stored in a normal fridge and we were allowed to keep some at his schools in case he had a bleed whilst at school. The schools were very helpful. It also gave us added freedom and allowed us to go on holiday abroad because Factor VIII could be kept in the fridges on the airplane and in the hotel.

12. Not much information was given to us about Factor VIII other than we were told it was going to make life much easier. We did not receive any information regarding any potential risks.
13. After a short while on this treatment, we were made aware that there wasn't enough Factor VIII concentrate produced in the UK and that some had to be imported.
14. [S] uncle, [GRO-B] was also a haemophiliac receiving treatment from [GRO-B]. He was called into the hospital and was informed that there was a problem with the Factor VIII as some of the batches contained the virus HTLV-3, which later became known as HIV.
15. I do not recall a specific moment that [S] was explicitly told that he had HIV; however it was almost as if it was assumed that he did because of the vast amounts of Factor VIII treatment that he had received.
16. We were told very little about the virus by the doctors. Everything we learnt about HIV came from other people we knew who were also infected with the virus. The only thing that we were really told by the doctors was that we should take every precaution in our home by keeping everything of [S] separate. We were told we should wash our clothes and bedding separately and have different cutlery for [S]. My wife and I refused to do this as we didn't want to alienate him.
17. Later, after we found out more about the contaminated Factor VIII, we were told not to worry and that everything would be alright because they were now heat treating the Factor VIII. This was too little, too late for [S].

18. I believe that we only became aware that [S] had also been infected with Hepatitis C after his death when I was put in contact with the Skipton Fund. [GRO-B] from the Haematology Department at [GRO-B] completed the medical part of the form. He had known [S] for 8 years. The form confirms that [S] tested positive for Hepatitis C antibodies. A copy of the form is now shown to me as WITN1144002.

Section 3. Other Infections

19. I do not know whether [S] was exposed to any other infections.

Section 4. Consent

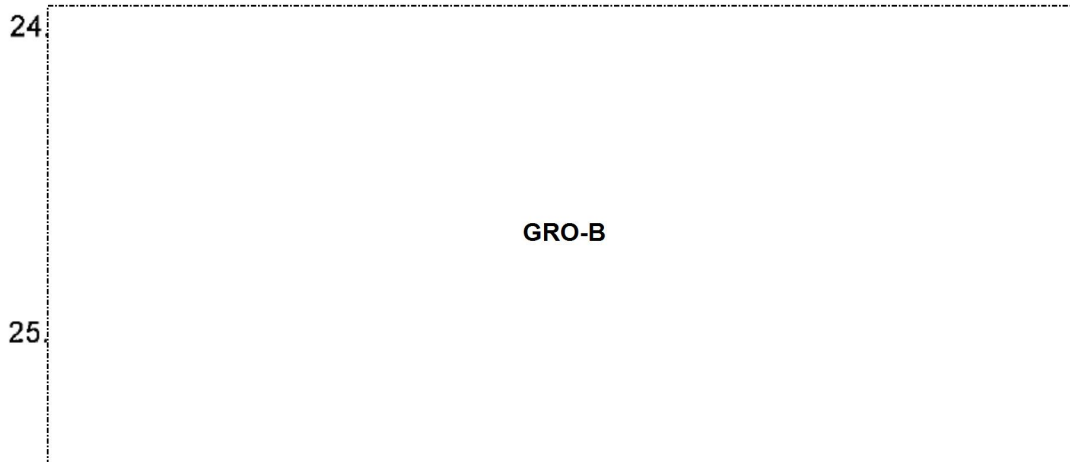
20. I do not recall if I consented to [S] being tested for HIV but if I had been asked I would have consented.

Section 5. Impact of the Infection

21. [S] knew that he had the virus but he never talked about it. He was too scared to disclose the fact that he was infected to anyone due to the stigma surrounding the virus. We couldn't even tell a lot of our family about [S] disease which must have been a huge psychological burden on him.

22. He was so scared of people finding out that when he became of adult age he even moved his GP away from the family GP so that there was no chance of people finding out. To this day, none of mine or my wife's family knows that [S] had HIV.

23. As time progressed and the popular world gained knowledge of HIV and AIDS it became stressful for [S] and my wife and I because of the fear, stigma and stress that came from the news and headlines. It was very upsetting and stressful for our growing son.



26. [S] health was okay to start with and when he left school he had a successful career as a mortgage consultant. However, as he became older the HIV virus started to take a greater hold and he became seriously unwell when he reached his 20s.

27. He lost a considerable amount of weight, became very disorientated and could not work or have a normal life. [S] was very unsteady on his feet, couldn't walk without holding on to something and fell over a lot.

28. Whenever [S] was taken into hospital he was always put in the isolation ward. My wife and I had to put on gloves, masks and robes just to visit him; again this must have had a big psychological effect on [S]. It was also very distressing for us. Even the hospital regarded a person with HIV as dangerous because they didn't really understand the infection in those days. It was only after Princess Diana started her charity work in relation to HIV/AIDS that public perception started to change.

29. [S] received treatment in hospital and underwent various procedures to address his deteriorating health. [S] became convinced that he had a brain tumour and, after demanding a scan, the doctors confirmed there was in fact something on his brain.

30. The doctors decided to do a biopsy on the mass. Shortly after this [S] suffered a major bleed in his brain. He fell into an unconscious state and died

GRO-B His cause of death was recorded as 'l(a) intracranial haemorrhage (b) Haemophilia A'. There is now shown to me marked WITN1144003 a copy of his death certificate.

31. It was absolutely devastating to lose our son at such a young age. No parent should ever have to outlive their child.

Section 6. Treatment/care/support

32. I am not aware that S was offered any counselling.

33. We had a lot of contact with the Haemophilia Society and received information from them. Also, after S was diagnosed as HIV positive we were registered with the MacFarlane Trust and received communications from them.

Section 7. Financial Assistance

34. I believe that S received a lump sum payment through the MacFarlane Trust. They offered us some moral support after S death but we didn't really want it.

35. I received the Skipton Stage One payment but was deemed ineligible for the Stage Two payment.

Section 8. Other Issues

36. GRO-B has a lot more information than I do about GRO-B's treatment particularly regarding diagnosis and infection dates which will be similar to S. He will also be providing a statement to the Inquiry. GRO-B

ANONYMOUS

37. Ultimately, someone needs to be held accountable for this atrocity and the fact that contaminated blood products continued to be given to haemophiliacs long after it was known the products were unsafe. The prescribing of contaminated Factor VIII concentrate should have ceased immediately. It may not have helped GRO-B but at least others may have benefited.

Anonymity

38. I would like my witness statement to be anonymous.

39. 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

27/12/2018.