

Witness Name: GRO-B

Statement No: WITN6893001

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Exhibit: 0

Dated: September 2021

INFECTED BLOOD INQUIRY

FIRST WRITTEN WITNESS STATEMENT OF GRO-B

I, GRO-B, will say as follows:-

Section 1. Introduction

1. My full name is GRO-B. I was born on GRO-B 1937 and I live at GRO-B with my husband, GRO-B.
2. My son, GRO-B (born on GRO-B 1965), was infected with the Hepatitis C Virus (HCV) from contaminated blood products. This witness statement has been prepared without the benefit of access to my son's full medical records.

Section 2. How Affected

3. GRO-B has severe Haemophilia A, diagnosed at five months old. He was under the care of the Southampton Haemophilia Centre at the Southampton Children's Hospital until it closed in 1974 and then for a relatively short period of time at the

GRO-B before being treated at the Southampton Haemophilia Comprehensive Care Centre at Southampton General Hospital (SGH) from in or around 1977. Dr Morag Chisholm was the Haemophilia Director at the SGH. I am a (retired) State Registered Nurse and I worked at the SGH.

4. **GRO-B** was treated with Cryoprecipitate predominantly up until he came under the care of the SGH. After that and throughout his teens **GRO-B** was given Factor VIII (FVIII) Concentrate **GRO-B** and I were given no warning as to risk of infection through FVIII concentrate. FVIII concentrate was heralded as a miracle treatment. Cryoprecipitate came in huge packs that took up a lot of space in the freezer. Up to as many as 8 packs at a time were needed for just one injection. The FVIII concentrate came in little powder filled containers. They were far more convenient and enabled us to have holidays. We agreed to it's use because of that, but there was no shortage of Cryoprecipitate at SGH.

5. In or around 1983 or 1984 I read a report in the Echo linking infected blood products to HIV/AIDS. I used to collect the FVIII treatment from the SGH and no-one there had said or even suggested that there was any problem with it. **GRO-B**, **GRO-B** and I were all unhappy for **GRO-B** to continue to use it and it was **GRO-B**'s idea to send it back. When I took it back, Dr **GRO-D** was very unhappy and argued that **GRO-B** should continue to use it. She said that the treatment was by far the lesser of two evils as **GRO-B** was unprotected without it, he would be in a lot of pain and could even die if he had a major bleed. Her argument didn't stand up as there was always the option of a blood transfusion in an emergency. **GRO-B** was used to living with pain and he managed to cope without any treatment at all for around year despite a lot of trouble with his ankle. **GRO-B** really is unbelievable. He never complains.

6. **GRO-B** was just 19 years old, when we were wrongly informed that **GRO-B** was infected with HIV. I took what was a short and blunt phone call from one of the doctors giving me the news and said that **GRO-B** would receive a confirmation letter

in the post which should arrive the next day. I had a sleepless night that night (one of the first of many) and when the letter arrived the next morning, I remember picking it up and handing it straight to [GRO-B] to open. It was truly awful. [GRO-B] had a lovely girlfriend and I worried about how he was going to tell her and what would happen if he had already passed it on to her. We believed that [GRO-B] had HIV for well over a month before Dr [GRO-D] eventually called us to say it was a mistake. I remember that period of time fell over Christmas which we just weren't in the mood to be able to celebrate. [GRO-B] was in his first year of Art College and should have been enjoying his life. Instead I wanted to watch [GRO-B] all the time as I feared he might easily be suicidal. He was under such terrible stress.

7. When Dr [GRO-D] called and said the HIV result wasn't positive after all, I asked her 'how could such a bad mistake have been made?' She made light of it and said that there had been two notice boards, one of which had something covering [GRO-B]'s name. I rang [GRO-B] at work, and he came home on his bike with a bottle of champagne. I cannot help but think how different things would have been if [GRO-B] hadn't refused to take FVIII concentrate around that time as it is highly likely he would have been infected with HIV/AIDS. Moreover, when [GRO-B] was a child, the Headmistress at his school wanted us to send [GRO-B] to the Treloars Lord Mayors College where so many boys were infected with HIV/AIDS and died as a result.
8. My younger brother of 4 years, [GRO-B], had haemophilia. We were very close. I used to give him his injections as he couldn't do it. [GRO-B] had haemophilia and was also treated at SGH. I tried my best to ensure that [GRO-B] and [GRO-B] were both given home produced/NHS FVIII concentrate as opposed to FVIII concentrate sourced from abroad. I was concerned about the shortage of NHS FVIII products at that time and put my concerns in writing to Dr [GRO-D]. He assured me that all the commercial FVIII concentrate they used was heat treated and therefore safe to use.

9. [GRO-B] transferred to the Haemophilia Centre at the Royal Free Hospital in the late 1980s. I do not know when [GRO-B] was told that he was infected with HCV, but I believe that it was very many years later. He didn't tell [GRO-B] and me for some time after that. He kept it to himself. He had his first attempt at HCV clearing treatment in 2000, the year he was married, and we knew then. [GRO-B] finally cleared HCV with his third attempt in 2016. My brother [GRO-B], also infected with HCV, died of cancer in September 2018.

Section 3. Other Infections

10. [GRO-B] was once told that he had been exposed to vCJD through someone who had donated their blood. He was one of many placed at risk.

Section 4. Consent

11. [GRO-B] was tested for infections without his or our knowledge and consent. [GRO-B] and I both think that he was used as a guinea pig, for the purposes of research. They must have known what was going on and we weren't told. The blood they used was sourced from junkies and prisoners in America.

Section 5. Impact

12. [GRO-B] doesn't complain and is very protective of us. He kept it to himself for quite some time and only told us when they started talking to him about treatment. I remember [GRO-B] was really ill when he was first given the news. He had a persistent cough, he was exhausted, he had aches and pains and had lost loads of weight. [GRO-B]'s GP referred him for an x-ray and he cycled to that hospital appointment on his bike. He looked and felt really ill. When they called his name in the waiting area, he stood up and was told rudely told by the radiologist that he wouldn't be x-rayed as 'tiredness' was not good enough reason for the referral.

We were all very upset that fatigue was the only symptom provided by the GP on the referral.

13. [GRO-B] looked terrible on the day of his wedding. The Ribavirin and Interferon treatment was a dangerous treatment that made him nauseas and gave him terrible headaches. There was many a time when he would visit us and collapse in the chair with exhaustion, being able to do nothing but rest after the journey. It was a continuous worry. He has now cleared the virus but still has liver scans. [GRO-B] is a father to a daughter and son, and they are a credit to him and our daughter in law. He has a little dog that he adores and whilst he can still ride his bike, he lets the others walk it. He really wants to walk but isn't up to it.
14. Because of the associated stigma, only [GRO-B]'s family and very close friends and relatives know that he has haemophilia. He never shares the information with a potential or prospective employer. As [GRO-B] always says 'if two people interview for a job and one has haemophilia and the other doesn't, who would they have?'
15. I often think of the other (parents and) boys we met at the SGH and got to know when they went for their routine haemophilia appointments and treatment. One boy from Fareham was a little character and would shout 'get it (the treatment) in there' when he was in pain. I wonder whether he is now and if he is OK.
16. My own younger brother, [GRO-B], suffered with haemophilia from a young age albeit he was 4 years old before my parents knew he had haemophilia. He had terrible nose bleeds. My mother kept as many odd pieces of cloth as she could, ready for every time it happened. They were always scalding in the sink to get clean for the next time.

Section 6. Treatment/Care/Support

17. We were never offered any counselling

Section 7. Financial Assistance

18. I will leave it to GRO-B to comment on the issue of financial assistance.

Anonymity, disclosure and redaction

19. I am applying for anonymity and would like this Statement redacted. I understand this Statement will be published and disclosed as part of the Inquiry.

Statement of Truth

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

Signed..... GRO-B

Dated *29/09/* 2021