

ANONYMOUS

Witness Name: GRO-B

Statement No: WITN4711001

Exhibits: 0

Dated: October 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 I was born on GRO-B and I live at GRO-B
GRO-B with my wife GRO-B
2. My son, GRO-B: S (born on GRO-B), is co-infected with the Human Immunodeficiency Virus (HIV), the Hepatitis B Virus (HBV) and the Hepatitis C Virus (HCV) through contaminated blood products.
3. This witness statement has been prepared without the benefit of access to my son's full medical records.

Section 2. How Affected

4. S was diagnosed with severe Haemophilia A from when he was around 8 months old. He was treated at the Birmingham Children's Hospital (BCH).

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5. [S] was treated with Cryoprecipitate for quite a considerable period of time. We journeyed to and from the hospital for treatment on a regular basis, sometimes weekly. Sometimes [S] needed treatment for the same bleed on two consecutive days. Rather than stay overnight (an option offered by the hospital) [S] preferred to come home with us and return there the next day. He simply didn't like being left at the hospital on his own but the treatment itself was never an issue. We were not aware of any adverse reaction to it. If so, I am sure, at the least, they would have kept [S] in. It didn't cause any infections or any inhibitor issues. Cryoprecipitate did 'the job'. It was a reliable form of treatment.
6. [S] was initially under the care of Dr Jillian Mann and she referred [S] for the home treatment programme. Sister Butcher taught us how to administer Cryoprecipitate to [S] at home. He started having home treatment in December 1974. We stored it in our freezer. Shortly thereafter, we were able to have our first foreign holiday in Spain taking the Cryoprecipitate with us in a hand held freezer box.
7. [S] went on to Factor VIII (FVIII) concentrate as a treatment in 1977. I think he was by then under the care of Dr Frank Hill who we started to see when [S] was an adolescent and he continued to see as an adult. He was also seen by Dr Franklin at BCH. We were told that FVIII was a revolutionary treatment, easier to use and more effective. It was true to say that it was more concentrate and we didn't need to keep it in the freezer but that was all. It wasn't a necessity for [S] to use FVIII concentrate. He would not have bled to death without it. There was no warning of risk of infection through using FVIII. If there had been any suggestion of risk, I would have jumped on it and all over it.
8. In or about 1981 [S] fell ill for a short period of time after he had injected himself with FVIII concentrate. He subsequently tested positive for HBV surface and core antibodies. In early 1984 [S] became extremely ill with

Glandular Fever likely to have been triggered by something (as confirmed by [S]s GP at the time).

9. [S] was an independent adult and went to his hospital appointments without us around the time and after his marriage in August 1984 (although I sometimes took him there with his wife). Some time during the mid 1980s (I recall we were working together) [S] repeated to me the manner in which he was told that he was infected with HIV. He was told 'By the way you have been exposed to HIV'. I do not believe that he was given any information or advice about how to understand or manage the infection.
10. No-one ever sat me and [GRO-B] down to explain to us what had happened to [S] our only child. No-one has ever come to us to tell us that they are very sorry for what has happened. I do recall mention of a counselling referral through a social worker from the Queen Elizabeth Hospital, Birmingham on one occasion. We wanted counselling but nothing came of it and the social worker moved on.
11. Many years later (in the 1990s) [S] learned that he was also infected with HCV. He then became very depressed and withdrawn and has suffered with depression since.
12. The only doctor at the QEH who [S] respected and listened to was Dr Jonathan Wilde. If it hadn't been for Dr Wilde [S] would not be alive today.

Section 3. Other Infections

13. [S] was also informed that he had been exposed to vCJD through FVIII concentrate.

Section 4. Consent

14. I rely on [S]s Statement in relation to the issue of consent.

Section 5. Impact of the Infection

15. **GRO-B** and I have never spoken about the impact on us but it has in effect ruined our lives.
16. The fear and stigma associated with HIV/AIDS at that time was so overwhelming and misleading, particularly for haemophiliacs and their families. The television campaign and coverage depicted the infection as being a gay plague. There is no way that a parent of an infected haemophiliac could tell anyone. **S** did not want us to tell anyone. If we had told anyone and explained to them how it had happened to **S** we would not have been believed. We lived a lie. We had secret lives. **GRO-B**'s own brothers do not know to this day. We haven't got any close friends and no-one to visit us apart from **S** and his partner through all of this.
17. Given that **S** was by then in his twenties, we had no direct contact with other parents. The haemophiliac community is like a family. You meet other parents through the hospital visits for their children. **S** lost his very close friend with haemophilia **GRO-B: F** to HIV. I can still remember but cannot bear to listen to a record that was playing when we heard the news of **F**'s death. We entered a state of grief at the news, dreading the thought that we too could lose our only son in the same way.
18. **GRO-B** lost her hearing over 30 years ago through a stress induced virus. She has also developed asthma, triggered by stress. **GRO-B** has had to stop answering the telephone because of anxiety issues. She associates it with **S**'s health and bad news 9 times out of the 10 times she has answered it.
19. We trusted the doctors who treated **S**. We would not hesitate in taking **S** to the hospital if there was something wrong. We were not particularly wealthy. We spent every penny to get him to and from hospital because he was our life. The fact we were not told of the risk **S** was exposed to with his FVIII treatment is despicable. The thought that we, his parents, might

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have put the infection into his veins through his home treatment is an unbearable one. We are angry that no-one had the decency to warn us.

20. We cannot see why, with the information now available, those responsible shouldn't be the subject of criminal proceedings and be committed to prison. We are lucky to still have S when so many have lost their lives. This has ruined all our lives and those responsible need to take responsibility for what has happened.

Section 6. Treatment/care/support

21. I refer to S's Statement in relation to the issue of treatment

Section 7. Financial Assistance

22. I refer to S's Statement in relation to the issue of financial assistance.

Anonymity

23. I would like to apply for anonymity.

Statement of Truth

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

GRO-B

Signed.....

Dated 19.10.2020