

ANONYMOUS

Witness Name: GRO-B

Statement No: WITN2725001

Exhibits: 0

Dated: March 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF GRO-B

GRO-B will say as follows:-

Section 1. Introduction

1. My name is GRO-B I was born on the GRO-B and I live at GRO-B I am married and I run my own business.
2. I make this statement on behalf of my two GRO-B:B (deceased), B1 and B2
3. B1 was born on GRO-B and died on GRO-B at the aged of GRO-B as a result of AIDS.
4. B2 was born on GRO-B and died on GRO-B at the aged of GRO-B as a result of a brain haemorrhage.
5. This witness statement has been prepared without the benefit of access to my GRO-B 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.

Section 2. How Affected

6. Both [B1] and [B2] were diagnosed with Haemophilia A at birth. I am a haemophilia carrier. I decided not to have children of my own because of my haemophilia.
7. [B1] and [B2] attended [GRO-B] and they were treated with Factor VIII (FVIII) at the college as they had a Haemophilia Centre. When they were not at [GRO-B] they were treated at [GRO-B].
8. They both received Prophylactic FVIII in order to keep their bleeds under control, which they took on a daily basis.
9. My mother was the only carer for my [B] [GRO-B]. [GRO-B] My mother thought my [B] were receiving treatment for their haemophilia which would help them live a normal healthy life. She just thought it came from chemical labs. She did not know that the FVIII products were taken from other people who were already infected.
10. My mother administered FVIII to my [B] when they were young children and then when they were older, they self-administered FVIII.
11. I remember there was a big platform where the news leaked that haemophiliacs were infected through contaminated blood products and had died as a result of it. This was devastating to hear.
12. I do not believe that my [B] or my mother were provided with adequate information beforehand about the risk of being exposed to infections.
13. Both my [B] were infected with HIV as a result of being given contaminated FVIII blood products. I do not know whether they were infected with Hepatitis C (Hep C) although it is possible that they were.

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14. I do not believe they were provided with any information or adequate information to help them understand and manage the infection. They were terrified when they received their test results.

15. I believe that information should have been provided to them earlier. My [B] found about HIV in a very bad way, through the media. They were kept in the dark until it was too late.

16. I believe no information was provided to my [B] about the risks of others being infected as a result of the infections. I believe this because my [GRO-B] [GRO-B] was infected with HIV through [B2]

Section 3. Other Infections

17. I do not believe my [B] were infected with any other infections other than HIV and Hep C. However, my mother believes that [B1] was infected with other viruses.

Section 4. Consent

18. I believe that my [B] were treated and tested without their knowledge. I also believe that everything was kept quiet from the beginning. However, when talk about the infections came out in the media, I believe that is when the hospitals started acting on it.

19. I believe my [B] were treated for their Haemophilia with their consent but they did not know they were being given contaminated FVIII blood products.

20. I believe [B1] and [B2] were treated and tested without being given adequate or full information. They believed that they were being treated with synthetic clotting factor, not a product that was a spin off from other people's blood that was infected.

21. I do not know whether they were treated or tested for the purposes of research.

Section 5. Impact of the Infection

22. Both my [B] were mentally affected as a result of the infection. They were absolutely shocked and devastated when they read the newspaper stating there was a possibility that they were infected with HIV, which they had no clue about. They realised from the media that other Haemophiliacs had died as a result of the infection and they themselves had been given the death sentence. They were [GRO-B] and it was hard for them to accept it. They were so terrified about being infected and their personality changed after finding out.

23. [B1] was depressed but he wanted to fight for justice. On the other hand, [B2] carried on working and pretended like nothing happened. He wanted to deny everything. He kept his anger and depression to a minimum so he could live a normal life.

24. [B1] had a lot of complications as a result of the full blown AIDS. About 12 months before his death, he became very poorly. He was in and out of hospital. He lost his memory, had dementia and eventually got pneumonia. He was only [GRO-B] years old but looked like a very old man. His health deteriorated from that year onwards quite rapidly.

25. A few weeks prior to [B2] death I recall he went home one night, fell asleep on the sofa and woke up very disorientated. My [GRO-B] called an ambulance and he was taken to MRI and it was confirmed that he had suffered a brain haemorrhage. He was kept alive in order to have some tests done on him and eventually the life support machine was turned off. It was a sudden death.

26. My [B] were given HIV cocktail drugs for treatment. Everyone had different versions of this treatment. They were using people for tests and trialling the treatment on people as if they were guinea pigs. It was a massive testing trial to see if they could get everyone's HIV under control.

27. I do not know whether there were any treatments which ought to have been made available to my [B]

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28. The mental and physical effects of the treatments were awful. My [B] were scared and terrified that some of the cocktails drugs were affecting their bodies. [B1] was very thin and he lost a lot of weight. He was very withdrawn. The effects of the treatment continued until they were able to find the right treatment that worked for them.
29. My [B] had to tell their dentists about their HIV status which was not an easy thing to do.
30. The impact on my [B] private, family and social lives was horrendous. They were scared and the worst thing for them was that people around them who had haemophilia were dying as a result of the infection. Everyone was scared and my mother was so broken. She felt very guilty as well as my grandmother (my mother's mother) as they were haemophilia carriers and passed it on to my [B]. We all tried to stay positive to help each other. [B2] did tell some close friends and they helped him to live the best life that he could. [B1] was quite a studious person and he worked and was good in the community but with his social life he just wanted to read to escape from his thoughts. He was not as outgoing as [B2].
31. My [B] infections and death have had an awful impact on me. I remember being so shocked at the time when I heard the news. It had absolutely torn all our lives apart. We were all terrified and my [B] were living in fear. We wanted to support them but did not know what to do next. People were asking questions and we did not want to tell them that they had HIV.
32. There was a stigma attached to the HIV at the time and so we had to keep it a secret. It was like living in a big secret but we did not know much about the secret ourselves as no information was provided. We kept it private but [B1] wanted to tell everyone as he felt this was injustice. [B1] went on the local TV news but [B2] always denied having HIV saying it did not affect him, as he wanted to live his life as normally as possible. It was such a huge story which held a massive taboo in the 1980s. The media scare mongered

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everyone about AIDS and people thought AIDS only came from gay people or drug users. In the early 1980s, I went to [GRO-B] where I remember reading about HIV in the newspapers and it was awful the way it was portrayed.

33. We all just wanted to try and stay low key regarding my [B] HIV. We were still trying to get to grips with it ourselves.

34. [B1] suffered work-related as well as financial effects. He was honest with his employers and took time off whenever he felt sick. He struggled at work and tried to fight it but eventually gave up his job in the end as he could no longer cope.

35. [B2] just carried on working as it was his way of trying to live a normal life.

Section 6. Treatment/care/support

36. I am not sure whether [B2] and [B1] faced any difficulties or obstacles in obtaining treatment, care and support as a result of being infected with HIV.

37. I do not think my [B] were offered any counselling or psychological support as a result of being infected with HIV.

38. I went for private counselling in order to help with my anxiety that I was suffering as a result of what happened to my [B]. The counselling really helped me at the time.

Section 7. Financial Assistance

39. I am not sure whether [B2] or [B1] received any financial assistance.

40. My mother may have received some money in relation to [B1] but I do not know.

Section 8. Other Issues

41. My family was ripped apart as a result of this scandal. My [B] were just [GRO-B] given the most horrendous news. It has been the worst nightmare that anyone could have gone through. I feel for my [B] who lost their lives. It has not been easy at all.

Anonymity, disclosure and redaction

42. I wish to remain anonymous.

43. 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

17/3/2019