

ANONYMOUS

Witness Name: GRO-B

Statement No: WITN 1679001

Exhibits: 0

Dated: January 2019

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. My date of birth is GRO-B 1951. I am married and live with my husband at GRO-B. GRO-B I have 2 sons.
2. Haemophilia runs in the family on my mother's side. I am currently a carer for my 91 year old mother. I have one sister.
3. I make this statement as the sister of GRO-B. B who was infected with HIV from contaminated blood. He was born on B 1958 and died of AIDS on B 1988. He was aged 29 at the date of death.
4. This witness statement has been prepared without the benefit of access to my brother's full medical records.

Section 2. How Affected

Great Ormond Street, London

5. [B] was diagnosed from birth with severe Haemophilia A. In the 1960's, he was regularly having blood transfusions at Great Ormond Street Hospital in London. I remember seeing the blood stands next to his bed. At this hospital, he was under the care of Dr Katherine Dormandy.
6. [B] was very fragile and a gentle knock would trigger a bleed. He wore padded trousers to reduce the risk of injury but this offered little protection. On many occasions, he had to be rushed to hospital in an ambulance for immediate treatment. Most of the bleeds were from his joints.
7. [B] had several transfusions at Treloar Boarding School in Hampshire but I do not have the dates when these were carried out.

Royal Free Hospital, London

8. At the age 11 or 12 [B] was transferred to The Royal Free Hospital in London. I believe Dr Katherine Dormandy saw haemophiliac patients at this hospital too. I do know the hospital was trying different treatment methods during the time [B] was being treated at this hospital. At some stage, the doctors stopped the transfusions and started using Factor VIII (FVIII) products. These were given to him intravenously whenever he had spontaneous bleeds.
9. I do not know if any information was given to [B] about the FVIII products. I have tried to obtain this information from my mother but to no avail. She has refused to speak with me about [B] because she has tried to erase her son from her memory after he died. I have not seen his medical records and I have therefore prepared this statement from my own knowledge.

ANONOMOUS

10. I believe [B] was not advised that FVIII products could lead to an infection. At the time he was a teenager and, if anything, the doctors were likely to have explained any change of treatment to my mother [B] had his whole life ahead of him and there is no reason why he would have consented to being treated with products that were a risk to his health.
11. When [B] was in his early 20's, the doctors advised him that they could fix his left knee straight and, if he agreed, after the operation he would no longer have bleeds from that leg. He consented to this because the pains of the bleeding were so bad. The operation was successful and I believe the bleeds ceased from the left knee as the doctors advised. I believe he was given large amounts of FVIII before and after the operation.
12. In the 1980's [B] was diagnosed with HIV. My mother told me he had been infected but was told by the doctors that HIV does not always develop into AIDS perhaps to cover up their error. However, in 1987, the doctors confirmed that [B] had AIDS. He was 27 years old at the time. The doctors did not tell us what caused the infection. I believe he was infected by contaminated blood used to treat him when he was at Royal Free Hospital in London.
13. The only advice that the doctors gave was to avoid touching [B] blood. At that time, AIDS was widely reported in the media and generally frowned upon because it was associated with drug users and homosexuals.
14. The hospital did not give our family any further advice as to how we should go about our daily lives. I believe the doctors thought that, as [B] was treating himself, we were not in any danger.
15. My mother did take [B] to the hospital on appointments and she would have told me if the doctors had given her any advice or information about the virus. The fact that she did not suggests, the doctors had not told her anything. I remember being very frightened for my children because I was afraid they would pick up the infection. At the time they were 2 years and 5 years old.

16. I believe Dr Katherine Dormandy did warn the hospitals of the dangers associated with Factor VIII and what was happening but her warnings were ignored.

Section 3. Other Infections

17. I do not know whether contracted any other infection.

18. I do not know whether the doctors told that he was being treated or tested for AIDS or for any other infections.

Section 4. Consent

19. I do not know what advice was given to about the FVIII products. I know would have placed utmost faith in the hospital to treat him with products that were safe to use on him.

20. I do not believe he received adequate or full information about the risks associated with receiving Factor VIII and was not therefore in a position to make an informed decision. He would not have agreed to being treated if he knew that the blood was contaminated.

21. was given chemotherapy with his knowledge and consent.

22. I do not know whether he was being used for research purposes.

Section 5. Impact

Impact on

23. I could see that the HIV infection was constantly on mind because he knew of other people who had died of AIDS. Needless to say, it was very stressful time for him and for the rest of us. I believe he was hoping the HIV

ANONOMOUS

did not develop any further. He was living by himself in a flat. He did not live very far away and we would still see him quite a lot.

24. At the time was studying full time for a degree in English Literature. He wanted to learn even though he knew he had HIV and that is what was keeping him going. eventually had to give up studying because he was too ill to continue. He had a girlfriend during this period and she was very supportive.

25. It was my mother who noticed a change in medical condition. We were constantly in contact with him and when I saw him I could not immediately detect any physical or mental changes in him. I think this must have been before he had been diagnosed with AIDS.

26. When was told he had AIDS, he wanted to be left on his own. He generally kept a lot of his emotions to himself but from time to time he expressed his anger at the fact he had contracted the virus. He had chemotherapy for six months but this was unsuccessful. I do not know whether he was given any other treatment. I do not believe he faced any difficulties or obstacles in accessing any treatment. The chemotherapy completely drained him of energy. He would not let his friends come to see him because he did not want them to see him in a poor state.

27. According to the death certificate, died of Carcinomatosis and Lymphoma ileum.

Impact on my mother

28. Over the years, I have tried to speak with my mother about but with no success. Since he died, she has never been the same. She has refused to speak with me or with anyone else about her loss.

29. My mother was understandably devastated when her son died. She nursed and protected him for 29 years. Towards the end, he spent some time in the

Royal Free Hospital but was sent home in his final days so we could more time with him. After 2 weeks at home, [B] died. He was overseen by my sister who is a trained nurse.

30. In 2013, my mother went into depression and had a nervous breakdown. The loss of her son took its toll. She loved him dearly and felt she had let him down. She is 91 years old and has been blocking painful memories of [B] illness ever since he died.

Impact on me

31. Although I knew [B] was going to die, I too was devastated to see him losing his fight to live. For many years, the family have not been able to talk about [B]. He was my friend as well as well as my brother and I still find it difficult to speak about him without getting emotional.

32. My two sons were very young when [B] health was deteriorating and as with any mother I was worried that they may catch the virus. When I look back, I feel guilty of putting the safety of my sons before [B]. However, at the time I felt I was doing the right thing. He was very close to my boys.

33. What the hospital did to [B] was criminal. They cut short an innocent person's life and I find the whole situation very unfair. The hospitals knew that [B] and other haemophiliac sufferers were being treated with contaminated blood products but they continued to do so. There are so many families whose lives have been destroyed and I am sure that all those families want to know exactly what happened.

Stigma of HIV

34. The stigma associated with AIDS in 1987 was so bad that I told close family members that [B] died of cancer. I did not want to be disappointed by other people's reactions when they found out that he died of AIDS.

35. [B] ill health did not affect his education because he was diagnosed after he left full time education. He decided to go back to college and was told he had AIDS after he passed his degree. He was never able to pursue the career he wanted.

36. Counselling was never offered to me or my sister but I am unsure of whether it was ever offered to my parents.

Section 6. Treatment/Care/Support

37. [B] did not know that money was available to him and did not receive any money. I believe he was one of the earlier Haemophiliacs to die so he was not offered any financial support.

38. My mother received money after he died. There were two payments from the Macfarlane Trust which totalled £40,000. The first payment of £20,000 was made about 2 years after [B] had died and the second payment of £20,000 was made about 1991.

39. I do not know my mother found out that she was eligible for financial support. I believe The Macfarlane Trust contacted her and told her she could claim. My mother did not make her own enquiries.

40. I do not know anything about the process as I was not involved in it. In terms of the difficulties faced, my mother was asked to sign a disclaimer form that if she received the money, she would not make any further claims. She signed it as she wanted it all to come to an end. However, no money could ever replace a person's life and the suffering that [B] and his whole family endured.

Section 8. Other Issues

41. We did not get involved in any campaigning at the time, as my mother in such a terrible state that we would avoid doing anything to make her suffer even more.

Anonymity, disclosure and redaction

42. I would like to apply for anonymity. I do not want my name and home address to be published for the general public. I understand my un-redacted statement will be disclosed to the Inquiry.

43. I do wish to be called to give oral evidence.

Statement of Truth

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

Signed

GRO-B

GRO-B

Dated

January 2019