

ANONYMOUS

Witness Name: **GRO-B**

Statement No.: WITN3296001

Exhibits: WITN3296002

Dated:

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF **GRO-B**

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 22 July 2019.

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

Section 1. Introduction

1. My name is **GRO-B** My date of birth is **GRO-B** 1958 and my address is known to the Inquiry. I am retired on medical grounds. I intend to speak about my brother. In particular, I will speak about the nature of his illness, how the illness affected him, the treatment received and the impact it had on his and our family's life.
2. Also present at the time of this statement is my sister. She will assist with details that I cannot remember regarding our brother's illness.
3. I have elected to give evidence as an anonymous witness in order to protect the identity of my siblings.

Section 2. How Affected

4. My brother was the eldest of my parents' six children. He was one of three boys. He was born on GRO-B 1951. For the sake of clarity, I will refer to him in this statement as "B".
5. B was diagnosed with severe haemophilia A in approximately 1955 when he was around four years old. Prior to the diagnosis, my mother thought that he was a "delicate child". He was difficult to settle and bruised very easily.
6. He was finally diagnosed with haemophilia when he caught his knee in a kitchen chair and his leg swelled to the extent that he was stuck. My father ended up sawing through a part of the chair to free him. While doing so, he nicked B very slightly with the saw. Naturally, the toddler would not stop bleeding.
7. My parents took him to the hospital Whips Cross Hospital and the doctors then told them that B suffered from haemophilia A.
8. My parents were very surprised because neither of them had heard of haemophilia, and neither of them had a family history of it. My parents' last son, my other brother, is also a haemophiliac.
9. B was referred to the Royal Free Hospital which housed the haemophilia centre nearest to our house in GRO-B
10. He began treatment with cryoprecipitate in the early 1960s, under the care of the Royal Free Hospital's haemophilia centre. He absolutely hated it. My mother had to fight with him to get him to go to the hospital for his regular injections for treatment for internal bleeding after knocks.

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11. We were in regular communication with the Royal Free Hospital as a result of my brothers' haemophilia. The Royal Free set up a landline for us in our home because of the need to get the emergency services if required. This was because our nearest public phone was at GRO-B GRO-B and we lived a little walk away from it.
12. In the 1970s, B began treatment with Factor VIII. He was taught at the Royal Free Hospital's haemophilia centre to administer the Factor VIII himself.
13. We believe that he contracted HIV as a result of contaminated Factor VIII product.
14. I do not believe that B was told that he had contracted HIV / AIDS. I know that he was told by a social worker in the haemophilia department at the Royal Free Hospital, Mrs Miller, that he had "an infection of some type that could not be cured". This was in about 1985 or 1986. He was about thirty-four at the time.
15. He was at the hospital because of a severe chest infection which turned out to be pneumonia. He also had a shoulder bleed at the time. He would have gone into hospital on about 23 December so would have been told around the 24th that blood test results showed he was HIV positive.
16. I remember B telling my mother that if he had a nosebleed, he had to deal with it himself. This information must have come from Mrs Miller. He knew that nobody should come into contact with his blood, but he did not know that the reason for this was HIV / AIDS. He did not know much about HIV and certainly nothing about AIDS at the time. Neither did we. It was a very different time in terms of awareness.
17. A few weeks before GRO-B in 1987, B was very breathless. My mother kept nagging him to get his chest checked out by a doctor. He was admitted to the Royal Free Hospital on GRO-B

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18. I took my mother to visit B throughout the GRO-B holiday. My father was too ill to visit his son. My father had emphysema after years as a roofer, from which he eventually died.
19. At the time that we were visiting B in hospital, we lived in GRO-B I remember answering the phone at around 11.30pm on GRO-B 1987. It was a call from a staff member of the Royal Free Hospital. I was told that B was "in a bad way" and that we should come to the hospital to see him.
20. I remember waking my mother and telling her to get ready. I then got dressed in a hurry. I was waiting for my mother when the phone rang again. It was the nurse from the Royal Free Hospital and she told me that it was too late and that B had gone.
21. At the time, I did not know how to tell my Mum and Dad. I went to tell my sister (who is with me today), who said that I had no option but to tell my parents.
22. My brother who lived across the road (and whom is also a haemophiliac) came over to the house. He and I went to pick up B's few possessions at the hospital the next morning.
23. I remember feeling very numb. My other brother, on the contrary, was very angry. That was not helped by the fact that some of B's possessions had been stolen before we came to collect them.
24. I remember going home before being told that we needed to meet with a registrar. I recall her as an official-looking woman. She was fairly elderly with dame glasses and a gold chain.
25. She signed the paperwork, including B's death certificate, and said to us that "it would be a good idea for you and your family not to talk about this disease named AIDS".

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26. That was the first time that we found out that our brother in fact had AIDS. We were in total shock. It was a complete surprise.
27. Annexed to this statement as **WITN3296002** is B's death certificate. It records the cause of his death as "1(a) Pneumonia; 1(b) HIV Infection; 1(c) Haemophilia".
28. She recommended that we tell people that B had a heart attack. This is what we did.
29. The hospital asked to do a post-mortem on B's body. My mother flatly refused. She was adamant that she wanted to see the body in order to say goodbye to her son, and she felt that her son had been through enough. She could not have been clearer in her refusal.
30. When I took my mother to see the body, the funeral director said that he had been given the body in a sealed bag and instructions not to open it under any circumstances.
31. My mother was predictably upset. It was her view that they had done a post-mortem and did not want her to find out.
32. We held B's funeral at the GRO-B When the undertakers unloaded the coffin, it was not the plain teak coffin that my mother and I had chosen a few days before. Instead the coffin was covered in purple silk with a big gold cross embroidered on it.
33. My father asked the funeral director "is that my son?". It was traumatic for all of us. The funeral director had to confirm that it was.
34. I should also mention that after B's death, the Royal Free Hospital called us and arranged a meeting with Mrs Miller.

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35. My Mum and I went to meet with her. At the meeting, she offered us an exemption from paying vehicle tax. When I asked why, she said because of my other brother's medical appointments. It felt to me that they were trying to butter us up, presumably because they had done the post-mortem without permission.

36. I was insulted. First, I said that my brother was a married man and that he is independent. Offering me an exemption from paying vehicle tax on my brother's behalf seems ludicrous. I said "no thank you; I will pay my own taxes".

37. Secondly, I demanded to know why a post-mortem was done against my mother's express wishes. Mrs Miller kept skirting around the issue. The same went for my questions about the purple coffin that we did not ask for. It was all very strange.

Section 3. Other Infections

38. I do not have reason to believe that B received any infection or infections other than HIV as a result of being given infected blood products.

39. That said, I cannot say with certainty that he did not have hepatitis C.

Section 4. Consent

40. I do not have reason to believe that B was treated without his consent.

Section 5. Impact

41. As B did not know that he was HIV positive, there was no real stigma or impact specifically attributable to HIV/ AIDS status. He also could not work as a result of his disability so his HIV infection had no additional impact on his earning capacity.

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42. That said, I do remember visiting B where he was in a separate ward. While I was there, he knocked over his urine bottle. I asked the nurse on duty whether she could clean it up. She refused and made me do the cleaning. She then told me to dispose of the paper towel in the chemical waste bag.
43. I felt that B was being treated like a leper. I was angry at the lack of care shown to him.
44. More generally, the fact that my parents had two haemophiliac children had a big impact on our family life. It required many trips to hospital at great cost and inconvenience. My father worked incredibly hard to support us all. B's knees were eventually fused straight in order to reduce bleeds. This prevented him from being mobile and he could not work.
45. Specifically, the impact of B's illness and eventual death from HIV / AIDS was incredibly difficult for my parents to deal with.
46. My father was a very tough man – what we would call, I suppose, a real “man's man”. The only time I saw him cry was when I told him that his son had died.
47. He kept saying that it was not right for a parent to bury a child. He never really recovered from it. He died two years after B died. GRO-C
- GRO-C It was almost as if his son's death finished him off.
48. From the outside, my mother coped fairly well. I think she struggled internally, though. She was very angry and she did not understand. Even the most educated of people did not understand a lot about HIV in those days. So for my mother, a simple woman, it was very difficult to deal with losing a child with so little understanding of why it had happened.
49. I feel that doing this statement is something that I would like to do for my mother. She has passed away but I feel that I should do this for her.

50. We as the siblings were scared to tell anybody about the fact that our brother had been infected with HIV/ AIDS. This was a significant fear with which we all lived, and to a certain extent, still live with.

51. I vividly remember my sister mentioning to my manager (whom we knew socially) that our brother had been infected with HIV. My manager called me into her office and told me very sternly but very kindly that I was not to mention the words HIV or AIDS to anyone at work for fear that I would lose my job.

52. She said that nobody would want to touch me or be in the same room as me. She also told me to tell my sister not to tell anybody.

Section 6. Treatment/Care/Support

53. As B did not know that he was infected with HIV, he did not receive any treatment or support for it.

54. None of my family members received any counselling. I think that the benefits of counselling may have been immense.

Section 7. Financial Assistance

55. My mother received a £20 000 pay-out from the Macfarlane Trust.

56. I do not think that she submitted the application herself. I think Mrs Miller must have done it on my Mum's behalf.

57. I am not aware of any waiver that my mother was requested to sign in order to receive the money.

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58. My Mum was told by someone from the McFarlane Trust to keep quiet about the fact that she had received the money. I think the idea was that if she disclosed that she received the money, she would have to disclose why she received the money.

59. Aside from the once-off payment, my mother did not receive any other money.

Section 8. Other Issues

60. Our family lived in fear of what would happen if anybody found out that B was infected with HIV / AIDS. We were always told that people would form negative judgments about us and therefore were very careful never to mention "AIDS". Even our close friends did not know and many still do not know.

61. I am so grateful that some light is finally being shed on this after a long time of secrecy.

62. It is really important to me that I make this statement on behalf of my Mum. This ordeal really took a toll on her. She battled through it and I feel that this is something that she would want me to do.

Statement of Truth

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

Signed GRO-B

Dated 20 / 01 / 2019