

ANONYMOUS

Witness Name: **GRO-B**

Statement No: WITN2878001

Exhibits: 0

Dated: March 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** I was born on **GRO-B** and I live at **GRO-B**
GRO-B
2. I am separated from my wife. I have been living on my own and I am retired.
3. I make this statement on behalf of my later mother, **GRO-B: M**
and late brother, **GRO-B: B**
4. My mother was born on **GRO-B** and died in **GRO-B** as a result of Hepatitis C (Hep C). The Hep C affected her liver and caused varicose veins in her gullet to burst. This caused her death as she bled to death.
5. My brother was born on **GRO-B** and died on **GRO-B** as a result of AIDS and Pneumonia. I believe he was also infected with Hep C.
6. My whole family suffered from blood disorders. My **GRO-B** and **GRO-B** were haemophiliacs. I am on the borderline of having Von Willebrand's (VW) disease. I do not require treatment unless I have a severe injury.

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7. This witness statement has been prepared without the benefit of access to my late mother's and late brother's full medical records. I have been told that both my mother and brother's medical records have been destroyed.

Section 2. How Affected

8. My mother suffered from mild Haemophilia. I do not know what Haemophilia she had as she was a very private person and kept her medical affairs to herself.
9. Once, she went to hospital for an operation and she was given Cryoprecipitate and/or AHG. However, my aunt told me that she was usually treated with Factor VIII (FVIII) when she had bleeds in her ankles, knees and had heavy menstrual cycles. She had FVIII a few times prior to this hospital admission. I believe that the FVIII concentrate she received infected her with Hep C. Over the years her health became worse, and she started to have problems with her liver.
10. My brother had severe Haemophilia A and was diagnosed from the age of **GRO-B**
GRO-B He received Cryoprecipitate but mainly received AHG which was in a frozen form. When we went on holiday, we had to take FVIII with us as it was easier to transport.
11. My mother was mainly treated at **GRO-B**
12. Initially, **B** was given FVIII at the hospital. When he was younger, **B** was treated at **GRO-B** He was then transferred to **GRO-B** when it opened its Haemophilia Centre and he was treated with FVIII.
13. I believe my mother found out in the early 1990s that she was infected with Hep C. However, my brother and I were not told about the infection until a few months prior to her death.
14. I do not know how my parents were told or what information they were provided about the infection.

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15. I believe my brother found out in the early or mid 1980s that he had HIV. In relation to the Hep C, I believe my brother found out around the same time that my mother did. I do not know how he was told about the infections or what information he was given as he dealt with his own appointments with his wife.

16. In the late 1970s and early 1980s, we knew that the blood was coming from the United States but were told that it was heat treated. I do not believe my mother and brother were provided with any information or advice beforehand about the risk of being exposed to infection/s.

17. I believe at some point my brother was told about the risk of transmitting the infection prior to his marriage. However, I do not believe that my mother was told about the risk of infecting others, until she researched it herself.

Section 3. Other Infections

18. I do not know whether my mother or my brother had any other infections, other than what has been stated above.

Section 4. Consent

19. I do not know whether my brother and mother were treated or tested without their knowledge. I believe there is a possibility that they were tested prior to their knowledge and consent.

20. I believe it is also quite possible that they were treated and tested without being given adequate or full information.

21. I also believe it is quite possible that my mother and my brother were treated for the purposes of research.

Section 5. Impact of the Infection

22. My mother suffered mental effects as a result of being infected with Hep C. She was worried sick and she knew she could not do anything about it. When

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she found out she had Hep C, she turned into a nasty person as she started to become paranoid. She would not speak to people about it including us, her own sons. She would not even speak to [B] about it even though he was infected with Hep C and HIV the same way. I believe the infection affected my mother more mentally than physically.

23. My brother handled things differently to my mother when he found out the about the infections. He did not let the infections bother him and he took it one day at a time. He just wanted to live a normal life as if nothing happened. He always used to cover things up and always wanted the best for his children and gave them everything he possibly could. I do believe deep down he was concerned about his future.

24. I do not know whether my mother or brother suffered any further medical complications as a result of the infections.

25. After my mother found out about the Hep C in the early 1990s, I noticed that her skin started to turn yellow. In the final year of her life, I believe she got cirrhosis and it got worse and caused varicose veins in her throat and her gullet burst. Following this, she died. She rapidly deteriorated in the last year.

26. My brother spent a lot of time in hospital towards the last couple of years before his death. He was being fed liquid food. It got to a point where his body started to reject everything. He had HIV for years which he was managing but it developed into AIDS which caused his death. His speech went three weeks before he died and his body was shutting down. Earlier on in the day before he died I was sitting with him. He was sitting in his chair and after having a drink, he said 'my bum hurts' this was the first time that he spoke in months. I told the nurses and they asked me to wait outside for them to put him in bed. Then the nurse told me to call [GRO-B] [B]'s wife, as he was dying. I waited with him until his wife came and told him that [GRO-B] was on her way. He kept looking at me and moaning. I could see in his eyes that he was fighting to stay alive until she arrived. I went outside to give them some space and then I was told by [GRO-B] that [B] had

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died. It upset me the way GRO-B told me, he told me in a cold and emotionless way. GRO-B B's GRO-B was broken and I was trying to console her.

27. B was kept in a freezer but when I saw his body, he looked sweaty. The funeral directors also charged double to bury him because he was infected.

28. I am not sure what treatments my mother and brother received but they were on a lot of medication.

29. I do not know if my mother or my brother faced any difficulties or obstacles in accessing treatment. I do not know if they had mental or physical effects from the treatment.

30. My mother's infected status impacted on her private, family and social life. My parents did not tell anybody about the infection and my brother and I only found out from the hospital that she had Hep C prior to her death. She was very secretive and did not get close to people.

31. B did not let his infected status affect his private, family and social life. He did not tell people he had HIV and Hep C apart from me and our parents. He did not let his social life be affected because that was his way of living.

32. My private, family and social life was impacted as a result of what happened to my mother and brother. I grew up seeing B attending hospital a lot since he was GRO-B. It became a part of my life. When B first told me about HIV, I was so shocked and I felt like my life was coming to an end. When he later told me that he was also infected with Hep C, it nearly tipped me over the edge. I lost trust in the NHS and that trust has never come back. We were worried sick about B as HIV was more of a big thing back then compared to Hep C.

33. There was definitely a stigma attached to HIV at the time. We dared not to tell people about the infection. I blamed the media for how they portrayed HIV at the time. B used to repair cars for his neighbours, even if they were short of money. However, after he was buried, somehow his infected status became public knowledge and I believe some of his neighbours wrecked his

grave. This happened approximately 5 times. The stigma was terrible at the time.

34. My father did not show his feelings when he found out that my mother and brother were infected. However, I can imagine how devastated he must have been to know that both his wife and son were going to die as a result of the infections. **GRO-B** was a wreck and had to put on a brave face for the children. She never got over **B**'s death even though it has been approximately **GRO-B** years since he died. **GRO-B**

GRO-B

B's children showed anger towards **B** prior to his death. One **GRO-B** was frightened and angry at everything that was happening and **B** honestly thought she hated him. The other **GRO-B** was only **GRO-B** years old when **B** died and did not really know her dad, which is really sad as she never really got to spend time with him. **GRO-B**

35. **B** was a **GRO-B** and he did not tell his employer about his infected status. 2 or 3 years before his death, he had to give up work as he became poorly. I believe this affected him financially.

36. I had to take time off work to be with my mother for a week in hospital before she died. I also had to take time off from work for **B** to take him to the hospital.

Section 6. Treatment/care/support

37. I do not know if my mother or brother faced any difficulties or obstacles in obtaining treatment, care and support.

38. I do not know if my mother or brother were offered any counselling or psychological support as a result of the infections. I was not offered any counselling or psychological support in consequence of what happened.

Section 7. Financial Assistance

39. I do not believe my mother received any financial assistance as a result of being infected with Hep C.

40. I believe B received financial assistance but I do not know how much he received.

41. A few years ago, I was told by the doctors at the GRO-B to claim compensation for my mother. I needed my mother's medical records for this but when I requested them, the Haemophilia Centre at the GRO-B told me there had been a fire and all the medical records had been destroyed. My claim was therefore rejected as there was no evidence and I did not receive any financial assistance.

Section 8. Other Issues

42. I am disgusted at the way my mother's wishes were not accepted when she was dying by the hospital. After everything that she went through, she stated that she did not want to be resuscitated but the doctors put her on life support (into an induced coma) and she kept trying to remove it as she did not want to go on it. We were told we had no choice, including my mother, as they were the doctors and not us. It was a week later that the doctors told us that they were going to turn her life support off as there was nothing more that they could do to save her.

43. We were mortified how the funeral directors put her in a plastic bag and buried her like that, without even dressing her. They just laid the gown over her in the coffin and said they were not going to touch her because she had Hep C. This really upset me and the family.

44. It has been approximately GRO-B years since my mother died and GRO-B years since my brother died and I have never got over it. My father gave up and he died approximately 12 months after my mother died and B died shortly after my father died. I try to carry on with life because I have to, but when I think about it, I break down. I believe someone needs to pay for what happened.

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Someone needs to be imprisoned because what they did was wrong and they have ruined people's lives forever.

45. What they did decimated my small family and the fact that they try to cover up this scandal is totally out of order.

46. I need closure and I know the government was behind this scandal. They have taken lives, which could have been prevented.

47. I have lost my confidence in the Haemophilia Centre and the NHS because of what happened to my mother and family and also because they destroyed medical records quite conveniently when I asked them for it.

Anonymity, disclosure and redaction

48. I wish to remain anonymous.

49. I wish 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

27/3/2019