

ANONYMOUS

Witness Name: GRO-B

Statement No: WITN1753001

Exhibits: 0

Dated: October 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 1983 and I live at GRO-B with my husband GRO-B and our GRO-B year old son.
2. I make this statement in relation to my late father, GRO-B:F (my father) who was born on the GRO-B 1956. He had severe Haemophilia A and was treated with contaminated blood products; as a result he died on GRO-B GRO-B 1992 at the age of 36.
3. I am aware that my Nan, GRO-B (my father's mother) and my sister, GRO-B have also provided statements to the Inquiry.
4. This witness statement has been prepared without the benefit of access to my father's full medical records.

Section 2. How Affected

5. My father had Haemophilia type A classed as severe. He was diagnosed at a very young age, I believe it was when he was around 4 or 5 when he had his first bleed. It was not picked up on when he was born because my Nan was not aware that she was a carrier of Haemophilia.
6. My father was treated at St. Thomas' Hospital (St. Thomas') in London with blood products from the time he was diagnosed until he died. He was treated with Cryoprecipitate until Factor VIII concentrate became available. I believe at the time his treatment was more reactive, rather than proactive.
7. I do not believe my father was given any information or advice in relation to the risks that using blood products might present.
8. My father was infected with Human Immunodeficiency Virus (HIV) and Hepatitis C (HCV) as a result of being treated with contaminated blood products.
9. My father was diagnosed with HIV in GRO-B It was only a couple of years after I was born. I believe my father found out he had been infected with HIV during a routine appointment at St. Thomas'. He had home treatment and attended St Thomas' for routine appointments. I understand it was a complete bombshell to him. He was told he had HIV as a comment rather than as a diagnosis.
10. On my father's death certificate it states my father's HIV had progressed to full blown AIDS. However he was never told of this progression.

11. We only discovered his HCV diagnosis after my father died. My sister obtained our father's records from the UKNHDO National Haemophilic Centre and the records showed he had been infected with HCV as well as HIV.

12. I am not aware of any information given to my father in relation to the risks of transmitting HIV. My Nan told me that he was just given a leaflet on how to deal with living with HIV.

Section 3. Other Infections

13. As I was so young at the time, I am not sure whether he was infected with anything other than HIV and HCV.

Section 4. Consent

14. I do not think my father was ever told about what tests were being done when blood samples were taken at the hospital appointments he attended. Whenever my father went for check ups he would have blood taken, but I believe he was under the impression it was just in relation to his Haemophilia. I do not think he knew that it could ever be for anything else.

Section 5. Impact of the Infection

15. I was only 2 years old when my father was diagnosed and 9 years old when he died. He was pretty much ill for my entire life. I think, being so young, I was protected from a lot of what was going on.

16. I believe mentally, there was a huge effect on my father. From my father's perspective his life changed after he was diagnosed with HIV. My parents' marriage broke down and my mum left the family home leaving my father to care

for two young children. Whilst I cannot say whether my parents divorce was as a result of my father's HIV infection it was likely to be a massive factor.

17. I believe my father was very bitter about what happened. None of it was his fault.

I think knowing that he had two young daughters he would never see grow up weighed heavily on him. My father was also quite a quiet private person, and when people found out what was going on, there was a definite backlash and he would not want people to know of his infection.

18. Physically, I did not see any major changes in my father until I was around 8 or 9 years old when I was at junior school. Prior to this whilst he had a leg injury from an earlier accident which I know affected him a lot, he would still attend our sports days and we would go on holidays, I had a normal childhood.

19. When I was 8 or 9 I noticed a change in my father. He spent more time in hospital and he missed out on sports days and other school events. I think especially during the year he died I became very aware of how poorly my father was. We did not do as much as he was ill. I recall him missing my dancing lessons. My Nan stepped up, and looked after us. She had become more and more involved in our lives as my father deteriorated and moved in to live with us.

20. In the last year of my father's life I was very aware of how poorly he was, he had no immune system. He would have a cold or a chest infection and the infection became pneumonia. He was very unwell in the last year of his life.

21. My father passed away on the GRO-B 1992. I remember he was in hospital a lot during the month leading up to GRO-B and he was told he did not have very long to live. He came home for our last GRO-B together. In the morning I remember my sister and I were told to go upstairs. Our father was on the sofa downstairs where he passed away.

ANONYMOUS

22. I am not sure if my father received any treatment for HIV.
23. I am not aware of any difficulties my father faced in obtaining any treatment. However, I know that he found it increasingly difficult to get to St. Thomas' for his treatment. My father was a single dad to two young daughters; it was more of a location and logistics barrier than anything else.
24. I am unsure of the mental and physical effects of my father's treatments; however, I know that he was on a lot of medication. He was always very tired and poorly, I am not sure whether this was down to his medication or his illness. My father eventually got to the point where he just could not keep up with two young daughters running around.
25. I am unsure as to how my father's infections impacted upon any other operations or dental procedures my father might have had or needed.
26. My father worked until he became infected, and then the decision was made that my mum would work and that he would stay home and look after me and my sister. He had been able to work when he had Haemophilia.
27. When I was only 4 or 5 years old my mother left the family home. I recall I had only just started school, I remember coming home in my school uniform to find she was gone.
28. We were living next door to my Nan at the time. She became very involved in our lives after my mother left. As my father was so poorly and regularly had to go up to London for treatment towards the end of his life. My Nan had to step in and became a guardian.
29. When my father passed away, my Nan became our full time guardian under the terms of my father's will and she came to live with my sister and I permanently.

ANONYMOUS

30. It was incredibly tough when my father passed away. I remember being at school, all of my friends would always have both their parents there and we did not have either of our parents. I think I was slightly embarrassed that others had their young parents attending school events and we had our Nan supporting us. It sounds bad now, but I was very young at the time.
31. My sister and I did not hear from our mother for a long time after she left. It was not until I was a teenager that we started to rebuild our relationship.
32. There was a generation barrier with my Nan which became increasingly evident when my sister and I became teenagers. I think my Nan did not really know how to deal with it all, us growing up and having our first boyfriends etc. I think even when I became engaged and was having my first child the barrier was still there.
33. My Nan and Grandad had separated many years before my father became ill. My Grandad lived in GRO-B with his new wife. When my father became ill and passed away, we spent more a lot more time with him and new wife. I think this was probably to give my Nan a break to be honest.
34. My sister and I never lived with our mother. Eventually she did come back into our lives, but I would describe the relationship we had with her to be more like an aunt than a mother. My Nan had already filled the position of mother and father. Even at my wedding, my mother attended as a guest rather than having the traditional role of Mother of the Bride.
35. It was not until my mother became poorly that my sister and I forgave her for leaving home. I just thought life is too short to hold onto anger and resentment.
36. My mother passed away in 2014, due to cirrhosis of the liver. Medically, they said it was not as a result of alcohol abuse; however I have my own views on this.

37. I do not believe many people knew that my father was infected with HIV because my father was a very private man. However, I do recall my Nan telling me stories about some people being very rude to my father because they had found out about his infection. It is difficult when you hear stories about how people have reacted.

38. When I was a teenager I found out and understood a bit more. I was almost embarrassed to tell people about what my father died of. I used to tell people it was pneumonia.

39. I think I was quite lucky because we were so young at the time, and therefore quite protected from it all. I do not think I would have been able to handle it all had people been rude to me about my father.

40. I do not know if its because I am older now or because I do not give a damn what people think, but I much more open with it all now. It is more about perception. I tell it as it is.

41. My education was not affected. After my father received financial assistance from the MacFarlane Trust my sister and I attended a private school. I had a good education.

42. I am now employed full time at an insurance company and there has been no impact on my working life at all.

Section 6. Treatment/care/support

43. I do not believe my father was ever offered or received any care or support. It all fell on my Nan, she did everything.

44. I do not believe he was ever offered any counselling or psychiatric assistance.

45. When my father passed away my sister and I saw a counsellor for about a year. This was bereavement counselling, rather than anything to do with his infections. I do not know who arranged this, I have a feeling it might have been done through the Haemophilia Society.

46. I cannot remember if I found it helpful. I was very young and I do not think I even knew it was counselling at the time.

Section 7. Financial Assistance

47. My father only received a lump sum of about £80/85,000 from the MacFarlane Trust.

48. We received a payment from Skipton Fund last year of £20,000. This was after my sister found out that my father had also been infected with Hepatitis C. It was split between my sister, myself and my Nan.

49. We have never received any other payments or grants that I know of.

Section 8. Other Issues

50. The whole thing is really sad. It could have all been avoided but as a result a massive chunk of my life is missing.

51. It is good this scandal is being looked into and I hope someone is held to be accountable.

ANONYMOUS

52. I count myself lucky to have had my sister and my Nan. I am lucky to have such a good support group in comparison to some people who were affected. We could have had it even worse.

53. In some ways I feel lucky that I was so young when it happened, I was protected a lot from what was going on at the time.

Anonymity, disclosure and redaction

54. I confirm that I do wish to apply for anonymity.

55. I do wish to be called to give oral evidence if I can assist the Inquiry.

Statement of Truth

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

Signed.....

GRO-B

GRO-B

Dated:

23/06/2020
2019