

Witness Name: GRO-B

Statement No: WITN2814001

Dated: April 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 1960. My address is GRO-B
GRO-B
2. I make this statement with regard to my father GRO-B: F who was infected with Human Immunodeficiency Virus (HIV) and Hepatitis C (HCV) from contaminated blood products. He was born on GRO-B 1941 and died on GRO-B 1992. My sister, GRO-B has also made a statement for the Inquiry.
3. This statement has been prepared without the benefit of access to my father's full medical records

Section 2. How Affected

4. My father was a severe haemophiliac, type A.
5. My sister has tried to trace his medical records but has been unable to recover any. I understand that she has been told by Dr GRO-B Consultant Haematologist at GRO-B Hospital that my father's medical records have been destroyed.

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6. He was hospital treated at [GRO-B] Hospital and then treated at [GRO-B] Hospital, [GRO-B] Kent, which was local to us. His consultant was Dr [GRO-B]. He also attended [GR [GRO-B] Hospital [GRO-B]. I remember we used to go with him to [GRO-B]. Dad had trouble finding his veins so he did not regularly home treat.
7. He was told by Dr [GRO-B] in 1985 that he had been infected with HIV from a bad batch of Factor VIII in 1982/1983 at [GRO-B] Hospital.
8. He died on [GRO-B] 1992 of Bronchopneumonia, Acquired Immunodeficiency and Haemophilia.

Section 3. Other Infections.

9. I am not aware of any other infections.

Section 4. Consent.

10. My father was treated and tested without any consent or knowledge of why his blood was being tested. He was constantly asked for blood tests but did not know what these were for.

Section 5. Impact

11. My father went to [GRO-B] school which was a boarding school in Kent for children with disability. This is where he met my mother. They married young but divorced in 1964. He was single after this until he met his partner [GRO-B]. I lived with my mother until I was 18 and then I moved in with dad in 1978.
12. I remember distinctly when Dad told me that he was HIV positive. We were standing in the [GRO-B] Road and he said [GRO-B] I've got something to tell you – my blood is infected and I

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have AIDS". I didn't quite understand it all at this time. We never got any support and we were not educated with regard to the condition and its meaning.

13. He also told me that he got the infection from a batch of treatment in 1982/1983. I remember that he was unwell and very poorly at that time and he said to me "that's when I got the bad batch [GRO-B]".
14. My father's quality of life was completely destroyed for the 9 years that he suffered after being infected. He received very little support for his condition. He required 24 hour care between 1987 and 1992. He suffered terribly and was unable to cope with the Haemophilia and the bleeds that he suffered on top of his AIDS.
15. I was working in a nursing home whilst living with my father and I wanted to go back to nursing at the time but I couldn't return while my father was unwell. I began to care for him full time. Since my father's death I have returned to nursing. I have brought my kids up and I have always worked.
16. I began to be his full time carer. Whilst he attempted to carry on with his life he did get depressed and very stressed at the lack of knowledge and what was happening to him.
17. His body started to deteriorate. He lost a lot of his friends because people did not want to be associated with him. He stopped going out and this changed his whole life. I saw his personality change and he got angry. He was very frustrated and felt let down. He was given some medication but it didn't do anything.
18. I gave birth to a baby boy approximately one year before Dad died. I wanted to go back to work but I couldn't as I was the only person that could care for Dad. I had to hand my baby over to my Mum to look after as I was my father's full time carer.
19. I had not appreciated that my dad would deteriorate so quickly and had not realised the enormity of the deterioration and the affect of the illness on him.
20. I tried to keep his days as normal as possible which was hard because he was getting so frustrated. The television controls would be flung at the telly regularly. He lost patience and he became aggressive. Prior to diagnosis he had been a placid person but his character

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just changed. I would sit up with him day and night and my days and nights would run into one.

21. He was in pain and would have to deal with his bleeds as well. We had to go on regular trips to the hospital; it seemed very much like a waiting game. I tried to keep his social life with his lady friend together as well so I was his taxi driver. Whilst he had lost a lot of his friends he was with his partner **GRO-B** for 25 years. They did not live together. They had a strict regime of seeing each other 3 times a week; on a Tuesday, Thursday and Saturday night. This routine stayed the same up to his death.

22. I lost my social life. This was really a result of having to look after my father and also of people realising why my father was ill. People would think of me as being dirty or diseased and didn't want to come near me.

23. In his latter days he became very ill. He was in **GRO-B** hospital quite a lot. I would be there all day and I was pretty much living at the hospital. The staff seemed to treat him ok. However he was always in a side room and never in a ward but there was no issue with the care he received whilst he was in hospital.

24. Towards the end of his life he started to cry a lot. He was in so much pain. He had terrible cold sores on his mouth and a lot of phlegm that came out of his mouth. People didn't like looking at him. This went on for quite a while. He went through so many boxes of tissues because of the phlegm. It really wasn't easy for me. He also had to have a catheter bag which really stressed him out; he wasn't happy about this. He got lots of sores on his skin especially on his bottom because he had lost so much weight and became jus skin and bone. He could not get comfortable. I just wanted to put it right for him but I knew that I couldn't. My father was 15 stone before he was infected and lost half his body weight because of it; he was like a skeleton by the end.

25. I have said that his character changed and he became aggressive. One example of this is when he was in hospital towards the end of his life. I would go to see him and he would say "what do you want" in a disparaging way. This was not my father; he used to love having my sister and I around him. Towards the end of his life I could have been anyone in the room and he started being nasty to me saying things like "what are you looking at".

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26. Dad insisted he came home to die. He made me bring him home; he didn't want to die in hospital. He came home on the Friday and died on the Sunday. We had a nurse who came in. She was lovely and she treated us so well.
27. The doctors never spoke to me whatsoever about anything to do with his infections.
28. I missed out a lot with my baby in his first year. Dad never really got to say goodbye to Mum as she was looking after my baby. They had a really good relationship even though they weren't together.
29. When Dad died I had to move home as there wasn't enough money for me to stay in Dad's house.
30. Dad died a week before my eldest son's birthday. I know that he was disappointed that he couldn't be a proper Grandad. I had a second son born in 1995 who never got to meet my father.

Section 6. Treatment/Care/Support

31. Dad had cataracts in his eyes which he needed treating desperately and he also needed work done on his teeth. No one would treat him because of the infections and I remember him being cross about this. He felt alienated a lot of times. He chewed on chewing gum so that it would act a little like fillings and it did not hurt as much when he ate.

Section 7. Financial Assistance

32. Dad was registered with the MacFarlane Trust, (his number was 1135). He received a very small amount of money before he died in 1992. I remember this as he got the payment by cheque and he put it on the mantelpiece. He said "that's not how much my life is worth". It was disgusting. He was really depressed as a result. I think this was about £10,000 and he only got the single man's payment which we thought was unfair; he was divorced but still

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had children and had got the same infection as others. I think he received a second payment though from the MacFarlane Trust but I cannot be sure.

33. Since then we registered with the Skipton Fund and received two payments, Stage 1 £20,000 in May 2015 and Stage 2 £50,000 in June 2015 which my sister and I split equally.

34. After the Penrose inquiry an additional ex gratia payment became available. However this was only available to infected men or their spouses. We contested this; it was not fair. We were told to write to our local government but were basically told to forget about it. We were unsuccessful. We felt this was discrimination but we did not pursue it further.

35. We have had no other financial help and had no help with the funeral.

Section 8. Other Issues

36. We feel passionate about getting justice for our father; he lost his life through the negligence and/or criminal actions of others and we want the truth.

37. We know that no amount of money can compensate us for our loss but we know that our father would have wished us to pursue this matter.

Anonymity, disclosure and redaction

38. I would like to apply for anonymity. I understand that this statement will be disclosed to and published by the Inquiry. I do not wish to give evidence to the Inquiry.

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Statement of Truth

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

Signed

GRO-B

GRO-B

Dated

7/5/2019