

ANONYMOUS

Witness Name: **GRO-B**

Statement No.: WITN3113001

Exhibits: WITN3113002

Dated: 14 October 2019

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF **GRO-B**

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

Section 1: Introduction

2. My name is **GRO-B** My date of birth is **GRO-B** 1977 and my address is

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3. I am 42 years old and I have been married for six years. I have two young children, one aged four and one aged 19 months old. I am a business analyst by profession, having attended university at Teesside University.

4. I grew up in **GRO-B** and my father lived in the local area all of his life. He had two brothers and a sister. One of his brothers also had haemophilia, and died a few years before my father. My grandmother on my father's side was a carrier of the haemophilia gene. I do not suffer from haemophilia and as men do not carry the gene, I cannot pass this on to my children. I had one brother, but he died when he was three days old.

5. I make this statement about the impact of my father's HIV and Hepatitis C infection, which were contracted through contaminated blood products. I make

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this statement from my recollection of events, as I have not yet received my father's medical records.

Section 2: How affected

6. My father, GRO-B had severe haemophilia A. I do not know the first time he was treated with Factor VIII, but I remember growing up with the sound of him rolling the bottles containing Factor VIII between his hands to warm it up. I cannot recall the names of all the drugs my father took, but do know he was on prophylaxis Factor VIII treatment and he took Dapsone every Wednesday to prevent pneumonia.
7. My father was a fishmonger, as was his father before him. He owned his own shop, but had to give up his work due to ill health. He sold his business, or the lease of the shop, which was the family's livelihood, in 1989. I recall that he got £40,000 from the sale, but interests rates went down and in the long term, it was difficult to manage financially.
8. My father was married to my mother during my childhood. When I was 13 years old, the relationship broke down and my mother left my father in 1990. They divorced shortly afterwards.

Diagnosis with HIV

9. When I was approximately seven or eight years old, I saw a news article on the television about contaminated blood and how haemophiliacs had been infected with HIV. I knew my father had haemophilia and I recall asking my parents if my father had HIV. They said that he did not and he was fine.
10. I knew at a young age not to go near the sharps box my father kept for his haemophilia treatment, but I did not really understand the full reasons why. I also recall a rule in the house to stay away from my father's towels and shaving sponge, but again I did not know why. I do not know if my parents received any

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information about transmission of HIV. I recall being in a health food shop when I was young, and think my parents were looking for a homeopathic treatment to help prevent transmission.

11. On one occasion, before I was aware of his diagnosis, I accidentally closed the car boot on my father's head and he started to bleed. He shouted at me to get inside the house, and I realise now that this was to get me away from his blood.
12. I found out about my father's HIV diagnosis when I was around 13 or 14 years old, which was after my mother had left the family home. This would have been around 1990-1991. I remember my father coming into my bedroom and asking if I knew what was wrong with him, before telling me he had HIV. I cannot remember my exact reaction, but I do not think it was negative. On reflection, I believe it would have been easier to tell me when I was younger as it would not have made a difference to me at a young age. In any event it did not make a difference to me when I was told, but my father would not have had to go through the distress of telling me, had I known about his infection from a young age.
13. I do not know when my father found out that he was HIV positive or when he was infected. I have always believed it was after I was born in 1977. I do not know if my father's HIV developed into AIDS.
14. I did not know much about HIV before my father told me about his infection. My knowledge of it was from the school yard. I once asked my father why he continued to take Factor VIII, as it was the cause of his HIV infection. He said he needed the treatment, and he already had the infection anyway.
15. I was not allowed to talk about my father's HIV, and it was not really discussed in the house or between family. I remember a particular science class where my teacher had talked about haemophilia. I had mentioned that my father had

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haemophilia and the teacher wanted him to come into class to talk about it. I asked my father if he would, but he said he could not do it.

16. My uncle also had haemophilia and had been infected with HIV and Hepatitis C. He died three to five years before my father, and his condition was a lot worse. I remember he suffered from heavy nosebleeds and had been given cocaine to stop the bleeding. I was told his death was as a result of liver failure. I am angry about this, as it was not the root cause of his death; it was a lie. The root cause of his death was HIV and Hepatitis C, which was as a result of receiving contaminated blood products.
17. After I was told about my father's diagnosis, I recall his health was generally well. However, I recall him picking me up from university one evening in November 1996 as I was ill, and he went out to a social event. Shortly after that, in November 1996, his health deteriorated quite rapidly. He previously had colds, but recovered well. Over the Christmas period in 1996, my father developed shingles. I took him to Newcastle Royal Victoria Infirmary ("RVI"). My father became very confused, almost delirious due to the medication the RVI gave him. I almost found his condition funny at first, as I had no major cause for concern at that stage. I left him at the RVI that evening, and when I returned the next day, the serious nature of his condition hit me. He had been asking to speak to his mother, but could not remember her phone number to write it down. He was really struggling; he was in agony with the shingles and a headache.
18. My father came home just before Christmas day. He took his usual painkillers, Dihydrocodeine, to try to get through Christmas, but these made the shingles worse. I took him back to the RVI on Christmas day. He had a cold, bronchitis and pneumonia. My father was in hospital for several weeks. He was optimistic that he would beat the pneumonia. However, I was aware that the RVI had placed him in the room where my uncle had died. I knew this was a bad sign.

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19. I received a phone call from my aunt who was at the RVI with my father. My aunt suggested that I ask my friend to stay over at home with me but she did not tell me that they feared the worst. The next morning my uncle knocked on the door with our next door neighbour, and they told me my father had died. He died on GRO-B 1997 when I was 19 years old.
20. The cause of his death was recorded as pneumocystis pneumonia [WITN3113002]. I am angry that this was recorded on his death certificate, and that there was no reference to HIV or contaminated blood products. At the time, the doctors suggested they were protecting me by not recording HIV, when I think they were protecting themselves. They said if they put this specific type of pneumonia, no one would ask any questions. I do not know why they said this.
21. I recalled after my father's death that the RVI had not given my father the Dapsone that he usually took every Wednesday. I spoke to my aunty about this, and understand that the RVI would have been aware of what medication he needed. However, it always bothered me and I wonder whether this was one of the reasons he died.

Section 3: Other infections

Hepatitis C

22. My father was also infected with Hepatitis C. Again, I do not know when he was infected or when he found out about his infection. I think this was less important to him than having contracted HIV, although I still do not remember any conversations about Hepatitis C. I think he thought it was less significant because medical professionals had put the cause of his Hepatitis C as resulting from "impurities in the medication".
23. I do not know if my father took medication for Hepatitis C. I found out about his diagnosis as my uncle also had Hepatitis C. I cannot recall when I was told about

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his Hepatitis C diagnosis, but I was told something along the lines of "*your father has it as well, but not as bad.*"

Section 4: Consent

24. As I do not know when my father was tested for Hepatitis C or HIV, nor when he was infected, I do not know whether he consented to the tests. I do not know when my father was tested for HIV and told, but I would like confirmation of this and, if the dates are far apart, I would like to know the reasons for this.
25. I do not know whether he was aware of any risks associated with his haemophilia treatment and whether he consented to this.

Section 5: Impact

Psychological and physical impact

26. I did not see a prolonged deterioration in my father's health, but it did feel like forever at the time. When looking back through photographs, it is clear that he had lost weight.
27. I do not know the full psychological impact of my father's infections, as conversation about his diagnoses with HIV and Hepatitis C was limited. I do know that he had courage and strength just to live his life.
28. I once discovered that watching my father inject himself made me feel physically sick, despite having seen him inject himself on a regular basis. This made me angry and scared, as I could not watch him do something which was so important to him.
29. With hindsight, it is clear that I would have benefitted from counselling at the time of my father's death, as I had no one to talk to about the situation. My relationship

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with my mother broke down after she left. I remember trying to speak to my aunty on the day my father died, but she was not interested and it was difficult for her to talk about it because of my uncle's death.

Impact on private, social and family life

30. My father did not have a childhood. He was placed in a hospital in GRO-B for his own protection, due to his haemophilia. This was miles from home.
31. Towards the end of my mother and father's relationship in 1990, they were not happy together and I recall a lot of tension in the house. My mother was having an affair and I think the stress of the relationship had a severe impact on my father's health. The RVI had said he needed to do something about it to improve his health. I did not know how bad my father's illness was, as he kept it hidden from me. It is clear now that he was going through a lot of distress, and he appeared as if he had a weight lifted off his shoulders after my mother left.
32. I do not know whether my father's haemophilia, HIV and/or Hepatitis C diagnoses had a part to play in the breakdown of their marriage.
33. We rarely went on a holiday as a family as my father could not obtain travel insurance at all. I recall trips to Jersey, Tenerife, Bournemouth and Florida. I am almost certain that my father made these trips without travel insurance. When travelling, my father had a letter from the RVI to explain that he was carrying Factor VIII, and the associated equipment. Nevertheless, I recall that when we arrived at Boston airport, my father was pulled to one side by security and taken out of sight to explain why he was carrying Factor VIII and the associated sharps equipment.
34. In relation to my own marriage, I initially did not tell my wife about my father's diagnoses with HIV and Hepatitis C. We met at school and started dating when I was 13 or 14 years old. It did put some strain on our relationship, as she wanted

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to move in together after I had finished university, but I would not leave my father alone at home. She could not understand the reasons why at the time, but she understood when I fully explained the situation to her after my father's death. I do not remember when I told her or anyone else I have told about my father's infections, but anyone I have told I trust explicitly. For example, it was only last year that my closest cousin found out.

35. We were a close family, but since my uncle, father and subsequently my grandmother's death, we have drifted apart. My aunty found my uncle's death difficult, and dealt with it in her own way. She did not open up to anyone, and could not help me after my father's death.

Stigma

36. There was not a lot of information on HIV or Hepatitis C in the 1970's and 1980's. My father's perception of it was influenced from information he had picked up from the press.
37. There was a lot of stigma back in the 1980's relating to both HIV and Hepatitis C. In those days, it was often mentioned that HIV was borne from primates and that homosexuals were the predominant carriers. The stigma worried my father and that was why he did not discuss it and I was not allowed to mention it.
38. It is likely that my father's business would have suffered if anyone found out about his HIV and Hepatitis C infection. He felt very strongly about not talking about it, and no one outside of the close family knew.

Impact on education and finances

39. Due to being in hospital most of his childhood, due to his haemophilia, I do not think my father had much of an education. When he was old enough, he joined the family business as a fishmonger. As I have mentioned above, he had to sell the business due to ill health, which impacted the household income.

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40. I worked throughout college, at the ages of 16 to 18 years old, to contribute to the household, as my father was unable to work and money in the house was very limited. When I was a child, I never went without and looking back now, I think my grandmother must have paid for a lot of things.
41. Caring for my father did impact my studies, and I had to re-sit my first year of college. Initially, I was unable to go away to university as I needed to live at home to look after my father and contribute to the household. I worked full time at a local garden centre and then a DIY store, working seven days a week alongside going to college. This may have contributed to needing to re-sit my first year of college. I went to university to fulfil a promise to my aunty, and graduated in 2000 after completing a four-year degree. Attending university was a massive step for me.
42. After my father died, I gave up my job in the DIY store, which was a mistake, as money became tight. I had to fight with the student loan company to qualify as an "independent student", as my father had died and I was estranged from my mother. Being classified as an independent student meant I was eligible for a higher loan and grant.
43. I was 19 years old when my father died, but I still felt like a child. Fortunately, there was no mortgage on the house and I was the sole beneficiary in my father's will. After a year, during which time the solicitors were dealing with my father's estate, the house was transferred into my name. I could not afford house insurance, and just managed to cope financially.

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Section 6: Treatment, Care and Support

44. My father was treated at the RVI by Dr Peter Jones and Dr Peter Hamilton. I do not recall my father having any complaints about the treatment he received and I do not think he would have made a complaint.
45. I do not know whether my father received adequate treatment or faced any obstacles, as I was young. I do not recall my father ever visiting his GP. I do recall that we were once on holiday in the United Kingdom, in the south, and my father required treatment. He went to the local hospital, but they did not know how to treat him and he had to travel further to the nearest haemophilia centre for treatment.
46. My father had difficulties in obtaining dental treatment, and I think this was because of his HIV diagnosis. It was all too easy for dentists to just say that they did not have the facilities to stop any bleeding. Instead, my father went to the RVI for dental work.
47. A chiropodist used to visit my father at our house. I never saw him wear gloves or wash his hands. I do not know if he was aware of my father's infections.
48. I think my father was offered psychological support, but he did not accept it. I was not offered any counselling at the time of being made aware of my father's diagnosis or his death, but I have recently sought some out. On the NHS, I was only entitled to six hours of free counselling. Even when my counsellor was able to extend this to eight hours, it was not enough to talk through the impact that my father's illness had on me and my family. If I would like further counselling sessions, I have been told that I will have to pay for these.

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Section 7: Financial Assistance

49. My father received some payments from the Macfarlane Trust and he also received Personal Independence Payments (“PIP”). My father was refused Disability Living Allowance payments on at least one occasion. I remember he had to wait for a period of time to appeal. Eventually he was awarded payments at a ‘higher’ rate. These enabled us to keep our “head above water”.
50. After my father died in 1997, the Macfarlane Trust agreed to give me £100 a month for 12 months. This was not a lot of money to live on and I struggled financially, despite having worked full time during college. I reached out to the Macfarlane Trust a number of times for assistance, but they were unwilling to give me any further help.
51. In around 2013, I applied for compensation from the Skipton Fund. I found out about this in the HQ magazine, published by The Haemophilia Society. As part of the application process, I had to ask the RVI to provide my father’s medical records to the Skipton Fund. I was never told about, nor given access to, the records that were provided to the Skipton Fund. I received £70,000 from the Skipton Fund in total; £20,000 for Stage 1 and £50,000 for Stage 2. It seemed that there were certain parameters to be met to qualify for the payments, and my father met these parameters. I found the process easy to go through, although I did discover that had my parents remained married and had my mother been my father’s main carer, she would have received £10,000 more than I received. I do not think this is a fair distinction to be drawn and I should have been entitled to the additional £10,000.

Section 8: Other Issues

52. I have considered what I would like the outcome of the Inquiry to be. I would like better support services to be established for those who have been infected or affected by the infected blood products. I believe that we should be entitled to

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more than the six hours of counselling available on the NHS. Talking about my father's situation has helped me and I wish I had the opportunity to do so earlier.

53. I would like to know what really happened. The mentality and language that the media used in those days when referring to HIV in particular was upsetting. It seems that there was a cover up, with my father being part of a "social experiment".

Statement of Truth

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

Signed . GRO-B

Dated... 14/10/2009