

# ANONYMOUS

Witness Name: GRO-B

Statement No: WITN1295001

Exhibits: 0

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 of GRO-B GRO-B GRO-B My date of birth is the GRO-B I am married and I have three children. I work full time as a GRO-B
2. I am an affected person in relation to my late father, GRO-B: F F (D.O.B GRO-B GRO-B GRO-B) who was infected with Human Immunodeficiency Virus (HIV) after receiving contaminated blood products.
3. This witness statement has been prepared without the benefit of access to my late father's full medical records. If and in so far as I have been provided with limited records the relevant entries are set out in the medical chronology at the end of this statement.

### Section 2. How infected

4. My father had Haemophilia type A and it was classed as severe. There were also other members of his family that had been diagnosed with Haemophilia

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before he was born and my grandparents were aware of the possibility he might be born with it. He was diagnosed at birth after being born with a lot of bruises. Haemophilia had a big impact on my father's joints. He also developed a club foot in early childhood and was quite badly disabled as a result.

5. I believe my father received normal blood transfusions in the 1940's in order to treat his Haemophilia. As new medication progressed he received new types of treatments. I do recall that I would accompany my father as a child when he went into hospital to receive his treatment. I believe that it was called Cryoprecipitate (CRYO).
6. My father was treated at Edinburgh Royal Infirmary and his consultant was Christopher Ludlum.
7. My father started to receive Factor VIII treatment when it became available. He was on home treatment as soon as it was accessible and would use Factor VIII on demand. I remember he would inject himself a couple of times a week once he was on the home treatment.
8. I was not told whether my father ever received any information as to the risk of receiving Factor VIII blood products. However I suspect he would have thought that there wasn't really a choice as he needed the treatment and would have died without it.
9. My father was infected with HIV as a result of receiving infected blood products.
10. I am not entirely sure when my father was first infected with HIV. I think it was a couple of years before he was actually diagnosed. I found out he had been infected when I was about 13 years old and it must have been in approximately 1989. I recall that I had to repeatedly get my own blood tests taken and I didn't know why at the time. I know it wasn't to test if I was a carrier of the Haemophilia gene, we were already aware of this. Somehow I managed to

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work it out and realised that I was being tested to check whether I had also been infected with HIV through my father.

11. My father was made aware that his infection had come through contaminated blood products. Other than this I am not sure what information he was provided after diagnosis.
12. My father was offered Azidothymidine (AZT) as treatment but refused it. I am not sure if my father was offered or accepted any other type of treatment.
13. I am not aware of my father being given any information as to what HIV would mean in regards to his health. I do not know if he was told about how it would impact him or how the virus was transmitted. I believe they were given information at some point as they used appropriate contraception. It was around this time that I began having regular blood tests. My parents may not have known why they were testing me which makes me think the doctors didn't provide them with much information. The only information I know is that was my father was infected with HIV through the blood products that he was taking and that's all I was really told.
14. I recall by 1992 my father started to get ill and was losing a lot of weight. By 1993 my father was in a bad way and was tested for leukaemia. I remember hoping he did have leukaemia because it's a condition that is treatable. My father started to get a lot of spontaneous bleeding as a result of his infection. He was taken into hospital in early 1994 where it was discovered that his antibodies were attacking his blood platelets and the doctors were finding it difficult to stop the bleeding.
15. My father's health deteriorated quickly and he passed away on the GRO-B  
GRO-B in relation to illnesses brought on by HIV.
16. When my father passed away I remember something that happened that never felt quite right to me. Shortly after my father passed away, Dr Ludlum took my mother to one side and explained that he wasn't going to put HIV as

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the cause of death on my father's death certificate. Dr Ludlum said that in his opinion my father would not have wanted it listed as the cause of his death.

17. Instead the death certificate stated that my father died of something else, I think it states he had brain haemorrhage. I suspect that the cause of death was deliberately changed as a way to cover up the infected blood.

### **Section 3. Other Infections**

18. I am not aware of my father receiving any other infections through contaminated blood products.

### **Section 4. Consent**

19. I think it is likely that my father was tested without his knowledge or consent. I think he was diagnosed quite a while after his doctors had come to the realisation that he had been infected with HIV. This means they either tested him without him knowing or they lied to him about his results at a previous appointment.

20. I also suspect that I was tested without my knowledge after my father was diagnosed with HIV. I was never told why they were testing me or what they were looking for. My parents may not have been aware of the reason for my blood tests, in which case it would seem likely they were trying to figure out which family members had possibly been infected with HIV as a result of my father's infection.

### **Section 5. Impact of the Infection**

21. My father did not necessarily view his HIV infection as a death sentence. He was rather traditional and he was of the opinion that contracting HIV was indicative of behaviour. He thought that even though he had contracted HIV it wouldn't lead to his death. In my father's mind he hadn't participated in any activity that he associated with HIV such as being promiscuous, taking drugs

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or being a homosexual. I really do believe this was his way of rationalising what had happened to him. My father actually tested negative for HIV at one point which possibly reaffirmed his belief and I seem to recall that the doctors were very dismissive about his negative test.

22. My father suffered from weight loss and became more unwell as time went on. He became visibly thin and had pain and difficulty in relation to his movement.

23. I wouldn't say my father was depressed, he coped very well considering the circumstances. He smoked a lot to help him deal with the stress and the pain and he would also drink alcohol regularly. He never drank to excess, but he would drink at the end of the day as part of his routine. As he was often suffering bleeds he would be too sore to walk into a shop to get alcohol and I would usually collect his beers for him even though I was so young. The shop keeper was aware of the circumstances. Some of the locals in the area were aware that my father was very unwell and allowed me get his alcohol.

24. Around the time my father was infected with HIV there were very negative media campaigns on the TV. I remember in particular the public information advert with tombstones. It made you feel like HIV was a horrible secret that you had to keep. We felt like we would be ostracised if we told people what had happened to my father. I was sworn to secrecy and I was only allowed to talk to members of my family about it.

25. My father receiving infected blood products has had a huge effect on me and my life. I often imagine there's an alternate universe in which my father didn't die and things are very different. I cannot quantify the impact it has all had on my life. My father was such a great man, very interesting and clever. Although he didn't receive much of an education he educated himself and was someone I could talk to for hours. I remember how devastated I was towards the end of my father's life when I realised he was not going to get better. He couldn't attend my wedding and wasn't alive to see me have my own children.

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It makes me so terribly sad that my children missed out on spending time with their grandfather.

26. I am a carrier of the Haemophilia gene and this has not been a smooth journey. I had to make the difficult decision of terminating a pregnancy. I feel that my father could have helped me during that difficult time in my life. He could have helped me as a person that had suffered from Haemophilia his entire life and could have explained things to me. Also he could have helped me as my father and I know that he would have been so supportive and given me the love that only a parent can give.

27. I feel that it is so unfair that my father died so young from receiving treatment which was supposed to help him and not kill him. My father could have had a long life with all the treatment that is now available to Haemophiliacs.

28. My father's illness had a huge impact on my school life. During the time that I was at school the news was constantly showing stories about Haemophiliacs being infected with Hepatitis and HIV. No one actually questioned me about it, however I felt that everybody had made the assumption that my father had been infected because they knew he was a Haemophiliac. I felt the stigma of the infection because the other kids wouldn't share things with me. I really didn't have a great time in school. It is quite strange really because at a recent school reunion I explained to some of my old classmates that my father had been infected with HIV positive and they seemed to accept they had treated me quite badly.

29. I decided to leave university after my first term for personal reasons. I wouldn't say that my father's illness affected my experience at university although I would say that my father's infection had an impact on my working life. When I was 20 years old I ended up working in a job that required me to take GRO-B exams. Due to my father's illness and subsequent death I had to postpone these tests. I managed to do well in my working career despite what happened to my father.



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30. There were financial effects on the family due to my father's infection. He was a GRO-B but he had to take early retirement due to his illnesses. I believe he was retired by the time I was in secondary school. He was very rarely off sick when he was working and he never took any days off unless he couldn't physically move. He worked very hard. My mother also worked. Before I was born my mother worked as a nurse and that is actually where my mother and father met. My father was a patient of hers. Later in life my mother was a cleaner and did other similar jobs until she found work at a bank. My mother worked hard and had to work full time in order to bring enough money into the house. She originally worked part time but had to work full time when my father was forced to retire and would have to work long hours to support the family.
31. My mother was only 42 when my father died. I was over the age of 18 so she did not receive a widow's pension. I believe she had to give up work for a period in order to look after my father during his illness. She went from a content life, although frugal, to having no stability at all and a very sick husband with a family to support. She had no money and had to deal with losing her husband.
32. Sometime later I moved into my mother's house for a period with my husband as my mother was really struggling. She had a terrible time and ended up getting into debt with her credit cards. I had to step in and help her out financially. When I then moved down south with my husband, my grandparents moved in with my mother in order to offer her support.
33. My mother re-married in 2000 and she married the first person she met in a romantic sense, I don't know if this was a good thing or a bad thing. My mother later passed away of cancer in GRO-B at the age of GRO-B before she even received her state pension.
34. I feel like I have been robbed because not only are neither of my parents alive, but everything could have possibly had a different outcome if my father hadn't been infected and subsequently died. I have had to deal with a lot of

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personal and family issues that I could argue stem directly from my father's death. I am an only child so I do not have any brothers or sisters who can understand this all. I don't have much family outside of my grandmother and aunt who I see occasionally.

35. It was awful for my grandparents on my father's side. They had struggled so much with my father's Haemophilia. He once bit his tongue at the age of 3 and almost died. This was one of many of his life threatening injuries. To think they made it through all of that to lose him in the way they did is just dreadful. It basically killed my grandfather; he was very close to my dad. They had an extremely close relationship and after my father's death he suffered from kidney failure. Although he had a successful operation it seemed like he'd just given up on life. He later passed away and I believe this was a result of my father's death. My grandmother is so strong and is still strolling on at the age of 92.

### **Section 6. Treatment/care/support**

36. I know my father was offered AZT which he refused. He believed it was poison and looking back in hindsight he was probably correct.

37. I am not aware that my father was offered any psychological support or counselling. I was never told of either of my parents receiving any.

38. I was not offered any counselling when I was informed of my father's infection. I have also not been offered and bereavement counselling since he passed away.

### **Section 7. Financial Assistance**

39. I was not involved in any litigation in 1991. I believe at some point my parents received a small amount of money but I am not sure when this was. I believe they received a sum of a few thousand pounds but were instructed to sign a waiver in order to receive it.



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40. We were quite poor growing up. When we needed essential items that we could not afford my father would have to write 'begging letters' which he hated doing. I remember he had to do this for items such as a new table to take his treatment on and a dishwasher. He found having to write these letters very degrading as he would have to go into great detail as to why he needed them. He had to beg for things just to have a decent quality of life.

41. I personally never received any financial assistance in relation to my father being infected with contaminated blood products.

### **Section 8. Other Issues**

42. In my honest opinion I believe those who have been affected by the contaminated blood scandal deserve some kind of financial compensation. There should have been sufficient funds made available for my father and family during and after this ordeal. Considering the way it has all been handled I do not have expectations in regards to receiving anything.

43. I would like to be able to help people who have had to deal with the same thing my family have. I hope sharing this information is helpful.

44. I would like to know if other people have had to deal with death certificate issues. I would like everything that has happened to be revealed.

### **Anonymity**

45. I wish to remain anonymous.

46. I do not wish to give oral evidence at the inquiry.

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**Statement of Truth**

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

Signed. GRO-B .....

Nicola Elizabeth Horsburgh

Dated... 17-5-2019 .....