

# ANONYMOUS

Witness Name: GRO-B

Statement No.: WITN7144001

Exhibits: Nil

Dated: 08/10/22

## INFECTED BLOOD INQUIRY

### WRITTEN STATEMENT OF GRO-B

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 26<sup>th</sup> July 2022.

I, GRO-B will say as follows: -

#### Section 1. Introduction

1. My name is GRO-B My date of birth is GRO-B 1966 and whilst I reside in Hampshire full details of my address are known to the Inquiry.
2. I intend to speak about my late fiancé, GRO-B: F and his infection with HIV. In particular, the nature of his illness, how the illness affected me, the treatment he received and the impact it had on him, our son and our lives together.
3. F was born GRO-B 1966 and died GRO-B 1986 when he was just 20 years old. He passed away with his parents in Newcastle.

## ANONYMOUS

4. [F] and I met in 1981 when I was 15. At that stage of my life I was in a children's home in [GRO-B] and he was in a 'special' college near Alton, Hampshire. I believe this was called Lord Treloar College. [F] was there because he had haemophilia.
5. [F] and I have a son together, [GRO-B] who was born in [GRO-B] in 1983 when I was 16. We were together for 4 or 5 years before [F] died.
6. I remarried on [GRO-B] My husband, [GRO-B] and I have been together for many years. He is a civil servant working in [GRO-B] [GRO-B] [F] still and will always have a special place in my heart and I miss him every day.
7. I can also confirm that I have not chosen to have legal representation and that the Inquiry Investigator has explained the anonymity process to me. [GRO-B]
8. Additionally I can confirm that the Inquiry Investigator has explained to me the 'Right to Reply' procedure, and that if I am critical of a medical professional or organisation, they will have the right to reply to that criticism.
9. I wish to acknowledge that naturally as time passes, memories can fade. I have been able to provide approximate time frames to matters based on life events. However, these timeframes should be accepted as 'near to' rather than precise dates.

### **Section 2. How Affected**

10. [F] had severe Haemophilia, Type A. I believe his mother was the carrier of the disease. When he had first told me that he had haemophilia, I had no idea what it was.

## ANONYMOUS

11. [F] had been using Factor 8 as treatment for as long as I knew him. I presume he started being treated with Factor 8 at Lord Treloar's school. [F] had an older brother, [GRO-B: F's B] who also had haemophilia. I don't know whether or not he had also gone to Lord Treloar's school.

12. [F] was under the care of the Royal Victoria Infirmary (RVI) in Newcastle. His haemophilia social worker was Jean Lovie and he was under the direct care of Dr Peter Jones.

13. The Factor 8 came in two small bottles, one had something that looked like water and the other was some sort of powder. I learned how to administer the Factor at the RVI. As part of the training process we learnt how to inject the mixture on an orange and then I had to inject saline solution into my own veins. I would inject [F] with Factor 8 when he needed it, particularly when he was too unwell to administer it himself. [F] would sometimes self-administer the Factor 8.

14. The amount of Factor 8 he needed would vary a lot. Sometimes he would go for almost a week without treatment. He would need it whenever he injured himself and for any internal bleeds. He would also take the treatment prophylactically.

15. At some point, they had told [F] that there could be a risk that he could get hepatitis but this was after [F] had undergone much of the treatment. [F] didn't have HIV when we met and he developed it whilst we were together, presumably after the birth of our child, [GRO-B]

16. The RVI told [F] s parents that he had contracted HIV. I assume it must have been Dr Jones and he confirmed that he got HIV from the infected blood. [F] was the third person who was confirmed to have contracted HIV through blood products.

## ANONYMOUS

17. I am unsure if his brother also contracted HIV but if he did, I believe **F's B** had a history of taking intravenous drugs. **F** never took drugs, nor had any tattoos, piercings or any treatment abroad.
18. There was certainly less dialogue between Dr Jones after **F** got HIV. **F** would ask questions but found he was hitting a brick wall all the time. I think they knew a lot more than they were letting on but they wanted to cover it up and at the same time I feel they just didn't know the answers to the questions
19. **F** didn't take the HIV diagnosis well and he felt like they were still keeping things from him and his parents. It seemed that they just wanted to push it all under the carpet as if it was going to go away.
20. I also tried to contact the hospital and they would never speak to me or get back to me. They seemed uninterested in our concerns and appeared as if they didn't want to know. We were young at the time but I don't think they were giving any information to anybody.
21. I couldn't speak to his parents about it because it upset them a lot and they had been really good to me already. But again, maybe, they were keeping stuff from us as well. I felt they knew a lot more than I knew. The hospital was talking to them a lot and as I was, at the time, only 20, they may have been telling **F**'s parents..
22. After being diagnosed with HIV, he was told he had AIDS shortly after. He was given just 6 months to live but he died after three months.
23. After **F**'s death, I went back to **GRO-B** so **GRO-B** could see his grandparents. Whilst I was there, **GRO-B** **F**'s dad, said we needed to go to the RVI so that **GRO-B** and I could get **GRO-C**. **GRO-B** was only three at the time.
24. Waiting for **GRO-C** was the hardest and longest week of my life. I kept overthinking and blaming myself. I was also

## ANONYMOUS

worried in case  had haemophilia as well. I felt like it would all be my fault because I had fallen in love with his dad who was given  as   was worried about this too. Thankfully, we both came back

### Section 3. Other Infections

25. I am unaware of any other infections other than HIV that  received as a result of being given infected blood products.

### Section 4. Consent

26.  was definitely treated and tested without his knowledge or consent, without being given adequate or full information, and I believe for the purposes of research.

27. Even before his diagnosis with HIV, the RVI always put a lot of pressure on him to take treatment and I don't fully understand why. I don't know if they thought it may be the best for him but there was stuff going on and it was all kept very quiet.

28.  would say they were giving him more Factor 8 than he was usually taking but he never went into detail as to why. I don't think he wanted to worry me. He would say he didn't want more Factor 8 and they would keep coming back and asking him again and again. I think  felt pressured into having the Factor 8.

29. It felt like an experiment; he said he was a guinea pig and they wouldn't leave him alone. Had he been well enough, I would have taken him away from the hospital but he wasn't well enough to go anywhere.

**Section 5. Impact**

30. Underneath I always knew something was wrong [F] went from being a right chatter box and then he started to become quieter. He would blame himself and even on his deathbed, he said that I deserved better. He was worried about [GRO-B] and not being a dad for him. I assured him I would be both his mum and dad. I reassured him [GRO-B] would never forget him.

31. When [F] and I had our son, [GRO-B] I was initially in the children's home for a while but then we moved up to [GRO-B] with [F]'s parents. I was, however, still under the support and care of the social workers until I was 18. [GRO-B] and I eventually moved back down to [GRO-B] to live in a flat together. [F] lived with us for a little while but went back up to [GRO-B] as his health increasingly deteriorated.

32. It all affected me really badly. [F] and I had planned to get married the year after he died in 1987. [F] and I threw a little engagement party. During the party I burst into tears because [F]'s dad had said he was happy for our engagement and had he had a daughter, he would love me to be his daughter.

33. When [F] got really poorly, I said to him that I would marry him in our pyjamas next to his hospital bed. I wanted to marry him in hospital but he was adamant he would get better. He said his dad could walk me down the aisle. I don't know whether he genuinely thought he was going to get better or whether he was just looking for something to look forward to. He kept saying he was going to beat this but I think he may have been saying this because of [GRO-B] and I. Reassuringly I think he thought that's what I needed to hear.

# ANONYMOUS

34. Following [F]'s death, I was all alone looking after [GRO-B]. Neither my parents, nor [F]'s parents, would ever really care to help. [GRO-B]'s grandad [F]'s father, was the only one who would put in some effort initially, but when he died no one really cared. [F]'s mum didn't seem to want to keep in touch with their grandchild.
35. [F]'s dad died of a heart attack about a year after [F] had died. His dad just didn't seem to want to carry on anymore. He was never the same after [F] had died and he was a good man. I was unable to get up to the funeral as I had to work.
36. It affected [F]'s dad a lot more as they were very close. [F]'s mother didn't live far from where [F] was buried but she would never go to the grave at all. It was only a 10 or 15 minutes' walk from where they live. I would go every day when I was up there.
37. Our son [GRO-B] has really been impacted by [F]'s death. It has been really hard on him. We used to travel from [GRO-B] to [GRO-B] to see his Nan and grandad, and we used to go and get flowers and take them to [F]'s grave.
38. We would visit the grave two-three times a year and I had to try my best to save up in order to travel to [GRO-B]. We had to take the 12 hour coach journey as it was the cheapest way. We would often stay with [F]'s parents but there was always an atmosphere. They didn't want anything to do with [GRO-B]. It felt like they blamed me and felt as if it was my fault.
39. [GRO-B] referred to [F]'s grave as the flower garden when he was younger but as he has got older, it has become harder to visit. The last time [GRO-B] went to his dad's grave was when [GRO-B]'s Nan, [F]'s mother died. [GRO-B] wasn't working at the time so [GRO-B] and I brought his outfit to wear and paid for him to go up, including the flowers.

## ANONYMOUS

40. My new husband [GRO-B] has been great and when we had the money, he would drive us from [GRO-B] all the way to [GRO-B] I haven't had the money to go and visit [F]'s grave for a while.
41. It took time but [GRO-B] accepted that his father had died and when he got older I told him about HIV. [GRO-B] is 39 in [GRO-B] and it's sad to know that [F] has missed out on [GRO-B] growing up and he has also missed being a grandad. [GRO-B] didn't have his dad around as his friends did to play football or do other things. He kept saying it wasn't fair and I would tell him that there wasn't anything we could do about it. It still has a lasting impact on him now. Whenever we try and speak about it, he finds it too difficult.
42. After his diagnosis, [F] was unable to work at all. We were surviving on benefits at the time. When he died, I had to get three jobs to put a roof over [GRO-B] and my head. At one stage I had two factory jobs and one cleaning job in a shop. I worked six days a week and only had Sunday off to spend with [GRO-B]. We would always go to the park if the weather was nice. When I was at work, [GRO-B] would be looked after by my neighbour. She would take care of him on Saturdays and pick him up after school. We helped each other out a lot and her child would sometimes come and stay over at ours as she worked nights.
- 
43. We were living in a two-bed council flat and it was very difficult to get by and survive in those days. I would sometimes try to make a little picnic for us to save some money. If the weather was horrible, we used to build a tent in the front room. We'd also take all the canned food out of the cupboard and make a little shop. We rarely could afford to go out, but Sundays were always our day together and they were very special.
44. [F] had become extremely unwell as his HIV developed into AIDS. I wish I could have taken the pain away from him, he was suffering so much. He used to say to me that he didn't know what it



## ANONYMOUS

was like to be normal; he was always worried about knocking himself or having a bleed. It was a horrible time and to add to this pain, we faced a lot of stigma as a result of his and his brother's HIV diagnosis.

45. I don't know what, if anything, the RVI did to manage **F**'s infection with HIV. I was back down in **GRO-B** so I wasn't fully aware of what was going on. He was always in the hospital and I couldn't bring myself to go to visit him.
46. **F** tried to ask Dr Peter Jones for information but he never seemed to be getting anywhere. If **F** wasn't well I would phone the RVI and try to get an ambulance when he was poorly. It was like trying to get blood out of the stone and I would just end up ringing 999 every time. I remember people used to write things on the wards like 'AIDS live here', amongst many other horrible things.
47. We had trouble burying **F** as the undertakers were too scared to touch him so he was buried in a metal coffin. He was taken out of the hospital in a closed metal coffin and was buried in the same one. We weren't even allowed to see him when he died. They also had trouble trying to find someone to bury him because no one wanted to bury someone with AIDS. Churches would also be saying no.
48. Soon after **F** was diagnosed with HIV, people would repeatedly smash in our windows in **GRO-B**. Once **F**'s Nan was staying at the house so I could look after her and someone threw a brick into the living room where she would normally sit. Thankfully she was in the bathroom when the brick was thrown through the window. It would definitely have hit her had it been thrown ten minutes earlier. People would also spray the house with the words 'aids live here' and 'aids'.
49. We kept on having to move and change our names. We were forced to move four or five times. I changed my name four times due to the stigma. I was **GRO-B** **GRO-B** and now **GRO-B** I would change it

## ANONYMOUS

by deed poll every time and it was costing me money I could ill afford, money that could have been spent on [GRO-B] [GRO-B] at his young age, had to change his name each time too. He hated it. He also had to keep changing school as we moved address. I also had to keep changing jobs as I was scared they would find out.

50. We believe it was [F]'s brother, [GRO-B]'s first wife, [GRO-B] who was behind all this. She had told everyone that [F] had AIDS as she wanted people to feel sorry for her. She kept going on about money and [GRO-C]. She would also ask [F]'s parents for money and would be there for hours until they gave it to her. We couldn't pursue anything as we had no proof. Every time we got somewhere, she would tell people where I had gone. She wasn't in a happy marriage and got herself into drugs as well.

51. Even down here in [GRO-B] the word was getting out. My windows were repeatedly damaged. The bathroom and separate toilet windows were broken and the three windows in the kitchen were also smashed. They even smashed through my front door. [GRO-B] was young and didn't understand what was happening. He kept saying he wanted to go home and play in his bedroom. I couldn't take him back to the flat, it wasn't safe and I couldn't show him what they had done to the place.

52. Every time we moved I would have to settle back in and find someone to help me look after [GRO-B] as I worked a lot. No one would help us. The police wouldn't help, nor the council. I had to sell loads of my stuff to try and put us in a bed and breakfast when our flat was smashed up.

53. [GRO-B] was having nightmares and constantly wetting the bed. Sometimes he would be too scared to leave the house. I was having nightmares too and could not fathom out why this had to happen to us.. I was depressed and never given any support. My GPs failed to support us, I had no one to turn to at the time. I confided in one person and they told other people. I lost my trust in others and had to live a

## ANONYMOUS

secretive life moving house, changing my name, all to protect my son. I would have and still would do absolutely anything for him.

54. If I didn't have  I have no doubt I would have taken my own life. I have attempted to take my own life on a few occasions. I would take tablets and then go to the hospital to have my stomach pumped.
55.  was a teenager when all the damage, moving around and everything else stopped. He was about 12 but the psychological damage was already done and it had carried on long after  had died.
56.  had to also endure bullying during primary school and the start of secondary school.  wouldn't tell people why he didn't have a dad but he was called a 'bastard' all the time. He was forced at this age to understand what would happen if the issue of AIDS would come out. Every time we moved he would have to go to a new school, and make new friends each time.
57.  s death and the events following it, ripped me apart because he was the love of my life, my first love. We were young and I will always love and miss him. I always feel extremely down and sad near his birthday. It still affects me 30 years later and I'm never myself around the time of his birthday.
58. There has been great difficulty getting any paperwork or medical records from the hospital. I now wonder what they are hiding. There were always delays and then they would ask me loads of questions, directing me to go to other places for the hospital records. They have never said the records were destroyed or that they wouldn't provide them, they just aren't sending them. We have also had trouble getting any paperwork proving that  and I were tested for HIV. However I have subsequently had proof of a HIV test

**Section 6. Treatment/Care/Support**

59. I didn't face any issues getting medical care as down here they wouldn't have known. I don't know whether  faced any difficulties or obstacles in obtaining treatment, care and support in consequence of being infected with HIV.
60.  wasn't offered any psychological support but I don't think he would have taken it even if it was offered. I believe that psychological help may have been beneficial for me in the years following s death.

**Section 7. Financial Assistance**

61. I didn't know there were any financial support schemes until recently when I found out about it on the TV. I have just applied for the scheme and am waiting to hear back

**Section 8. Other Issues**

62. I felt let down by the RVI. They never gave us any information and they never took responsibility for their actions. I was just cut loose and left to deal with it all.
63.  and I were under the impression that the medical professional, particularly Dr Peter Jones, would have known about the infected blood for a long time before they told us. Looking back, it seems that they could have stopped it at this point. It probably wouldn't have saved  but many more thousands of people may have not been infected.

# ANONYMOUS

## Statement of Truth

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

Signed

GRO-B

Dated

8-10-202