

ANONYMOUS

Witness Name **GRO-B**

Statement No: WITN0770001

Exhibits: **WITN0770002-3**

Dated:

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 15 February 2019.

I **GRO-B** will say as follows: -

Section 1. Introduction

1. My name is **GRO-B** My date of birth is **GRO-B** 1967 and my address is known to the Inquiry. I intend to speak about my father **GRO-B: F** ("Dad"), who died on **GRO-B** 1984. Dad received numerous blood transfusions and Factor VIII products in the early 1980s. Although he was never diagnosed with any infection, my family and I have serious concerns that he may have contracted HIV.
2. I am also giving this statement on behalf of my siblings, in particular my sister, **GRO-B** and brother **GRO-B** Our mother, **GRO-B** ("Mum"), died in 2012.

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3. I am a housewife and I currently live in [GRO-B] with my husband, [GRO-B]
[GRO-B] We have one daughter who is 12 years old.
4. Both Dad and Mum were born and raised in [GRO-B] Dad worked as a
Manager in the [GRO-B] department of [GRO-B]
initially at the [GRO-B] branch. After my brother was born, Dad transferred to
[GRO-B] My sister & I were born in Yorkshire and then Dad was
transferred to [GRO-B] We settled as a family in [GRO-B] and Dad
remained at [GRO-B] for the remainder of his career.

Section 2. How infected

5. In 1981, Dad was diagnosed with Thrombotic Thrombocytopenic Purpura ("TTP") and he was admitted to Manchester Royal Infirmary. I can't recall what symptoms he was experiencing before his diagnosis but I believe it started with blood in his urine and progressed from there.
6. The doctors told us that TTP causes platelets to break down and so they thought that they might be able to treat Dad by replacing his platelets. They therefore decided to give Dad blood products and blood transfusions. We cannot recall the brand name of the blood products or the exact dates Dad received treatment. However, my brother and I believe that Dad received untreated Factor VIII and I remember Dad also received several transfusions while he was in hospital. The doctors said that he had received numerous total blood exchanges, which Mum thought was quite barbaric. She was a nurse herself but she had never witnessed anything like it.
7. Dad was discharged from hospital but his health continued to decline over the next few years. In 1984, Dad was readmitted to Manchester Royal Infirmary as the doctors were concerned his TTP was coming back. He was again given blood transfusions and Factor VIII.
8. Dad's health continued to deteriorate while he was at Manchester Royal Infirmary. He died in hospital on [GRO-B] 1984.

9. Dad was never diagnosed with HIV or any other infection. However, given he received untreated Factor VIII and several blood transfusions, and in light of the symptoms he developed after 1981, we have serious concerns that Dad may have contracted HIV.
10. As far as I am aware, my Dad and our family were never told anything about the risks associated with blood transfusions or blood products. We were never told that there was a risk of Dad contracting HIV or any other infection.

Section 3. Other Infections

11. Although our main concern is that Dad may have contracted HIV, I also remember him looking jaundiced in 1983 when we were on holiday in Wales. The whites of his eyes were yellow and his stomach also became enlarged. The doctors did not give any explanation for this but it does make me question whether Dad may have contracted Hepatitis. I am not aware of whether he was tested for it.

Section 4. Consent

12. I feel like we were often drip fed information by the doctors; they only told us what they thought we needed to know. I do not recall the doctors ever asking whether Dad consented to the treatments. The consultant said "our next course of action regarding the patient will be to carry on with blood transfusions". So that is what happened.
13. As a family, we were unaware of how much the doctors knew. We all believed that surely they must have been testing Dad and investigating what was wrong. I wouldn't be surprised to find out they had been testing him without our knowledge given there was so much blood taken from him. I also believe that, had they discovered anything untoward, they would not have wanted to admit this to us as a family.

14. In regards to research, Mum and Dad were both interviewed in a lecture theatre by Dad's haematologist, Dr Wensley, for a paper he was doing about TTP. I have kept the article, which I produce as **Exhibit WITN0770002**.

Section 5. Impact

15. Dad's health deteriorated after he was discharged from Manchester Royal Infirmary in 1981. He became much more unwell than he had been before he was admitted to hospital. He didn't want to eat and he was very distant and quiet. Dad also developed dark patches on his skin. For instance, when Mum was cutting his hair, she noticed he had purple patches on his scalp. My brother and I also recall seeing marks on Dad's skin that one would associate with HIV infection. However, it was not until later, when we found out that people with HIV can have various skin lesions, that we started to wonder whether Dad might have been infected with the virus.
16. Dad also suffered from pulmonary embolisms and bleeds in his brain due to the TTP. I also remember he had petit mal seizures, which caused him to be confused. This was frightening and difficult for my sister and I to witness. He was not acting like our Dad and, at times, we wouldn't even get a response from him. It was as though he wasn't actually there with us. When he was watching television, he would be looking at the screen but you could tell he wasn't computing what was going on.
17. I remember Dad was given large doses of Largactil, which I understand is given to people who are mentally confused in order to sedate them. He was given 500mg five times a day, which would almost knock him out.
18. It was a regular occurrence for me to come home from school and hear that Dad wasn't well. It was as if he was fading away in front of our eyes. Our family didn't know what to do at the time. We felt helpless.

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19. I also recall an occasion when one of the haematology nurses visited our house unannounced. Mum felt it was almost like a test to see how Dad was managing at home compared to at the hospital. At the time, we thought it was very odd for a nurse to visit unannounced and for no particular reason.
20. Dad had protracted periods away from work when he was extremely unwell with TTP. He also suffered from gallstones and eventually had to have his gallbladder removed. I remember Dad's manager from work would visit the house to see how he was. I'm not sure whether Dad's pay would have been affected in those days; however, it made things difficult for Mum, who was trying to keep everything together on her own. As a retired nurse, she became Dad's carer and tried to look after him as best she could.
21. Dad's health continued to deteriorate and so he was readmitted to Manchester Royal Infirmary in 1984. From what I can recall, this was because they were concerned that the TTP was coming back and that Dad's platelets were breaking down again.
22. Dad wanted to see Mum everyday but Mum didn't drive. She therefore had to rely on neighbours for lifts from GRO-B to Manchester Royal Infirmary. Sometimes Mum had to get the train from GRO-B to GRO-B Manchester alone. After visiting Dad she often had to wait in the dark on the platform for the train to come. She would only let my sister and I visit Dad at certain times when she felt he was well enough to be seen.
23. During this second period in hospital, Dad again received Factor VIII and several blood transfusions, including total blood exchanges. I think they were hoping to flush everything out by completely replacing Dad's blood. I can't recall the exact dates he received these treatments.
24. Sadly, Dad's health did not improve. He passed away on GRO-B 1984, whilst still hooked up to a blood exchange machine. The doctors said he had suffered from a cerebral haemorrhage. He was only 53 years old. I still have a copy of Dad's death certificate, which I produce as **Exhibit WITN0770003**.

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25. I remember the afternoon Dad passed away. My brother's mother-in-law had been saying that Dad would be fine but the next thing I knew, my Mum and brother came through the door and said that Dad had passed away. My brother had been at the hospital when Dad died. He said that Dad had been restrained and was violently convulsing and snarling like a wild animal before he passed away. As you can imagine, it was an extremely unpleasant way to die. After dad passed away what followed seemed like there was a mass exodus from the hospital room by the medical staff.
26. Dad's death has been devastating for our family. I was 17 when Dad died and it impacted me greatly. Not having a father figure was extremely difficult. It left such a void. Fathers' day and seeing other people with their fathers only amplified this. I think the worst part is that Dad missed out on seeing his children and grandchildren grow up.
27. My brother and sister also struggled after Dad's death. Until this day, the three of us are extremely close because of what we've been through together.
28. My brother was greatly affected by our father's death. Sadly GRO-B GRO-B after dad died. One cannot say categorically if dad's death had a bearing on the circumstances that led to the GRO-B One can only guess.
29. My sister was very young when Dad became sick and before his death, it was extremely difficult for her to see Dad not acting himself. She was only 12 years old when Dad died. GRO-B says she misses being able to have fatherly chats with dad and Father's day every year is particularly difficult for her.
30. Dad's death really took a toll on Mum. There was a lot of pressure on her when he died and she was very conscious of making sure us kids were okay. Dad was the one who had dealt with the family finances and so, when he died, my Mum had to take over all of this.

31. We were very fortunate that Dad had his pension and life insurance and so we didn't struggle financially after his death. However, it was difficult having to go through the rigmarole of explaining what had happened. Ultimately, it was the emotional impact that hit us the hardest.

32. Dad's death was a great strain on Mum. Several years ago, she was diagnosed with [GRO-B] although we are unable to say how long she had been living with these conditions. She passed away in 2012 on [GRO-B]

Section 6. Treatment/Care/Support

33. I feel we may have been slightly naive by putting our complete trust in Dad's haematologist, Dr [GRO-B] and the Haemophilia Centre at Manchester Royal Infirmary. We assumed that they knew what they were doing. What else could we do? You have to put your trust in the medical professionals, and we did. We implicitly and totally trusted them. For this reason, we would never instigate anything ourselves. It was always a case of them telling us what would be done rather than us having any choice in the matter.

34. There wasn't an offer of counselling or psychological support for Dad during his illness, nor for us as a family after his death. I think this is why my siblings and I became so close. We only had each other to rely on.

Section 7. Financial assistance

35. Because Dad was never diagnosed with any infection, we were never offered any financial support. After he died, Mum had to rely on Dad's pension and life insurance.

Section 8. Other Issues

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36. I have never been involved in any other Inquiry or campaign. I only became aware of this Inquiry when my brother mentioned it to me late last year.
37. Subsequent years after Dad's death, my family and I had independently seen articles in the media about contaminated blood and how some of this had been imported from America. It was then that we started to wonder whether Dad had possibly received contaminated blood or blood products during his treatment. With that realisation we all contacted each other in a state of shock. Our worst fears were becoming a reality.
38. We appreciate that Dad was never diagnosed with HIV. However, we feel as though the evidence was right before our eyes. We could see what was happening to Dad. His health declined so rapidly after the first treatments in 1981.
39. We feel strongly that Dad should not have received that many total blood exchanges in such short succession. The doctors informed Mum that they had not encountered anything like this before, so felt their only option was to keep giving our Dad complete blood changes. However, even for a healthy person, it would have been too much. Given Dad received so many blood transfusions and blood products, and in view of the symptoms he experienced after this treatment, it makes sense to anyone that he could have received blood that was contaminated. Ultimately, we believe that it was this treatment that accelerated Dad's demise.

Statement of Truth:

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

Signed

GRO-B

Dated

14.4.19