



Witness Name: GRO-B

Statement No.: WITN0590001

Exhibits: none

Dated: 4 October 2022

## 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 8 August 2022.

I, GRO-B will say as follows: -

### Section 1. Introduction

1. My name is GRO-B. My date of birth is GRO-B 1947 and my address is known to the Inquiry. I am a retired pilot and married with children. We have four grown up children; two girls and two boys. My son, GRO-B has haemophilia.
2. I intend to speak about my son, GRO-B the nature of his haemophilia and how it has affected him. GRO-B has Haemophilia A and currently has two per cent Factor 8; GRO-B has always been borderline between moderate and severe. In particular, I will discuss the treatment received and the impact risk of infection with Hepatitis C Virus (HCV), HIV and Variant Creutzfeldt-Jakob disease (vCJD) has had on him, his siblings, my wife and I.
3. I would like to emphasise that GRO-B was not infected by contaminated blood products or blood transfusions, but I wanted to relate how we have been

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affected by contaminated blood.

4. I can also confirm that I have chosen not to be legally represented and that the Inquiry Investigator has explained the anonymity process to me. I am seeking anonymity.
5. I can also 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.

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

6. It was always known that my wife was a haemophilia carrier; this was known through the family tree as GRO-B's brother was a haemophiliac. We were informed shortly after GRO-B's birth that he was clear of haemophilia. However, two days later Dr Mathews told us that there had been a mistake and he was in fact a haemophiliac.
7. The very first bleed GRO-B had as a baby was when he was teething. We were on holiday in Cornwall at the time, he bit on something and required blood from Royal Cornwall Hospital in Truro (Treliske).
8. During childhood GRO-B's blood products were issued by Oxford Haemophilia Centre and his consultants were Dr Rizza and Dr Matthews. GRO-B regularly received blood products during his early childhood and even up to the present day.
9. There was never any communication between Oxford Haemophilia Centre and us regarding risks of a possible infection from blood products subsequent to the issue arising. Further, no advice or information was offered to us regarding the matter whatsoever.
10. When GRO-B was a toddler at around two years old, having been unaware of GRO-B being tested, we were boldly asked if we wanted to know GRO-B's HIV test

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result (i.e. to live or die), and we declined. At that stage, we did not want to hear it as it would have been 50/50 as to whether he was infected and it would have destroyed us, if it was a positive result. We then tried to push it into the background and get on with our lives. However, despite Oxford knowing that [GRO-B] was negative, they did not share this information with us.

11. In the later years, when it was clear that [GRO-B] was negative, they still never told us his result.

12. When [GRO-B] was sixteen years old, we received a letter from Oxford Haemophilia Centre to say that a batch of Factor 8 which [GRO-B] had been treated with was derived from a donor who subsequently died from vCJD. When I telephoned Oxford Haemophilia Centre, I was fobbed off with "don't worry about it, it may never happen".

13. My wife and I were devastated and decided to keep it from [GRO-B]. However, the newspapers picked up the story, and he later found out through a local newspaper. This has been the main trauma of our lives.

14. It is twenty-five years later and [GRO-B] is still being tested annually for vCJD. This is a yearly reminder for [GRO-B]

15. [GRO-B] has been part of many various studies. In particular, more latterly opposed to when he was a toddler.

16. [GRO-B] is negative for HIV and HCV, and is annually tested for vCJD. His negative result does not take away the trauma and worry throughout [GRO-B]s lifetime.

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

17. As mentioned vCJD continues to be a concern and [GRO-B] is tested yearly.

#### **Section 4. Consent**

18. [GRO-B] was tested without our knowledge or consent, and we were given no information at all. Maybe he was tested for research purposes.
19. In the later years as an adult, [GRO-B] has told me that he has been part of many research projects, which he consented to himself. I will speak with [GRO-B] to get a list of the names of these research projects.
20. We were not asked if he could be tested for HIV. To be honest, it is almost, because haemophilia is such a challenge and 'they' are the renowned authority in their 'white coats', I would not know what or how to question the clinicians. What questions did we know to ask as the whole thing was just developing and there was so much lack of knowledge. Quite honestly, I still feel this way even now.

#### **Section 5. Impact**

21. The distress on my wife and I in the early years was caused by the uncertainty as to whether our son was infected with HIV, and thus going to die, or whether he was clear, was immense and affected our relationship, as well as the whole family, deeply.
22. When we were asked if we wanted to know the result of the various tests including HIV, we declined, a positive would have destroyed us. We elected instead to hope for the best and eventually pushed it into the background. However, despite Oxford Haemophilia Centre knowing that [GRO-B] was negative, over the years they never felt able to tell us. It was almost as if they asked and therefore it was our choice not to know.
23. My wife and I have endured so much distress and anxiety since the early 1980s and the HIV stress spanned over twenty years. [GRO-B] of course, had no knowledge of this and continued to grow up as a normal boisterous child.

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24. Although we were receiving a non-result, I was around other families that were receiving positive results. GRO-B had a very good friend, who was also haemophiliac, and his cousins were dying of HIV. This had a devastating effect on our pre-existing anxiety.
25. It wasn't really a case of a waiting room full of people in the same situation to discuss what was going on, as when we attended Oxford for our appointments, we would be straight in and straight out. This was until we then went onto home treatment, which didn't require as many appointments. Home treatment was then very traumatic for us all, as in those days, it was a huge syringe and this was very daunting.
26. As the years progressed, we gradually realised and hoped that GRO-B had 'dodged the bullet', and our stress levels subsided, but then we received the letter from Oxford Haemophilia Centre about vCJD, which arrived in the summer of 1997.
27. Despite the brief and bland assurances from Oxford Haemophilia Centre, we were devastated that, after all of this, GRO-B might still be in danger of developing another horrendous disease. The press didn't help matters with their sensationalist reporting, but there was no information forthcoming from Oxford Haemophilia Centre to help us contextualise the risks.
28. We were desperate and both my wife and I sought help from the NHS for our anxiety, which was given in the form of medication, but we were offered no counselling support. Although, we never requested it, as we had to get on with it and we had to be tough for the family.
29. We kept the specific letter from GRO-B but he read the newspapers and heard the news and so was aware of something going on. GRO-B then became extremely anxious and asked me "Dad, am I going to die?"
30. Then sometime during this period, and I am not sure when Oxford Haemophilia Centre must have told GRO-B about the vCJD risk, but from then

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on GRO-B's mental health declined, and this was done without consulting his family.

31. There is no question in my mind that this, along with the day-to-day challenges of haemophilia (for which his school made no allowance whatsoever) severely affected his education. As a child he wasn't allowed to play rugby or enjoy the school sports that he wished to do, and so he would be made to pick up litter instead. He was therefore bullied during his school years.
32. GRO-B is an extremely bright person, but after gaining seven GCSEs, he then dipped on his A levels and gained two passes. He then went on to study Law at the local university, but broke his leg badly and had to leave.
33. He then decided to go back and started another course at Gloucester University, but he caught glandular fever and had to return home. Whilst home, he experienced agonising pains. GRO-B was misdiagnosed by an NHS trainee GP as GRO-B he was sent home and told he "just had a tummy ache". However, it turns out he had a ruptured spleen, and was later rushed to hospital where he was diagnosed and required a splenectomy.
34. A ruptured spleen for a haemophiliac is very serious, and once my wife and I explained that GRO-B was a haemophiliac in A&E, they were shocked and took him straight into surgery.
35. The hospital had no Factor 8 and so GRO-B nearly died waiting for a batch to be rushed from Oxford. On this occasion, he received eight bags of blood and Factor 8.
36. GRO-B was in hospital for quite a long time. He was very unwell and unfortunately experienced a horrific incident when another patient in the opposite bed had a psychiatric event; he got up in the middle of the night and pulled all of GRO-B's tubes out. GRO-B was traumatised by this event and spent

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the next three weeks in a private room.

37. After this [GRO-B] did not finish university, his mental health state spiralled and he was desperately anxious all of the time. It then became apparent to my wife and I that he had started using drugs, which turned out to be heroin.
38. Again, there is no doubt in my mind that this was as a direct result of the growing and desperate anxiety he felt about vCJD; an anxiety which he still has to this day. The effect this had on my wife and I, compounded with the previous anxiety cannot be adequately described. It was, and remains, our deepest grief.
39. [GRO-B] is now forty-one years old and he is in recovery, which is going well. However, he is unemployed, single and now lives in Liverpool; hoping to reset his life, after spending two and a half years in lock-down with us because he was declared clinically vulnerable due to his splenectomy.
40. Although he is now years into cleanliness from drugs, he is still desperately anxious and there is no way these years of unemployment will not have an impact on his future.
41. My daughter was recently staying with us for a couple of days and I asked her how she has been affected by it all. My daughter said to me "where do you want to start dad" and she said "you have no idea".
42. Previously, we never discussed it. I like to think I'm a problem solver but I cannot solve this and I wish I could. It is only now that we have realised how it has been much more impactful to the family than we ever had realised. My other son has severe OCD and is unemployed, and I wonder if this had an effect on his life. Thankfully, I am in a financial position to support my sons. I do not know what happens to those poor people that are not able to be supported and this puts my position into perspective.

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

43. No counselling or support has ever been offered or received by GRO-B from the NHS, or from Oxford Haemophilia Centre. In particular, no support has been offered for the on-going vCJD testing.

44. My wife and I have sought GRO-B private residential detox therapy, as well as private therapy with a counsellor for many years, which has proven a godsend. These treatments have been funded by me.

## **Section 7. Financial Assistance**

45. No financial support has ever been given to GRO-B or the family when he was a child.

## **Section 8. Other Issues**

46. I have nothing to add for this section.

## **Statement of Truth**

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

Signed \_\_\_\_\_  
GRO-B

Dated 4.10.22