

# ANONYMOUS

Witness Name: GRO-B

Statement No: WITN1763001

Exhibits:

Dated: August 2019

## INFECTED BLOOD INQUIRY

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FIRST WRITTEN STATEMENT OF GRO-B

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I, GRO-B will say as follows:-

### Section 1. Introduction

1. My name is GRO-B of GRO-B  
GRO-B My date of birth is GRO-B I used to  
work on the pipelines until I injured my back when I was around 62 years old  
and I subsequently retired on medical grounds.
2. I make this statement in relation to my late son, GRO-B: S who was  
born on GRO-B and passed away on GRO-B at the age  
of 47. He was infected with Hepatitis C as a result of receiving contaminated  
blood products.
3. This witness statement has been prepared without the benefit of access to my  
late son'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.

4. I am aware that my step children, [GRO-B], also provided their own statements to the Inquiry. Their witness numbers are [GRO-B] and [GRO-B].

## **Section 2. How Affected**

5. [S] was my youngest child and the result of my second marriage to [GRO-B] and [GRO-B] mother.
6. [S] was diagnosed with Von Willebrand Disease (VWD) which is an inherited genetic bleeding disorder that prevents the blood from clotting properly.
7. [S] received Factor VIII Concentrate as treatment for his VWD. He was treated at the Royal Shrewsbury Hospital and Princess Royal Hospital in Telford.
8. [S] was approximately 13 years old in 1981 or 1982 when he sustained an injury to his leg whilst playing rugby at school which caused severe bruising to his leg. The GP sent him to hospital and after a number of tests and investigations [S] was diagnosed with Von Willebrand Disease (VWD).
9. [S] was infected with Hepatitis C at the Royal Shrewsbury Hospital.
10. We were not told of any risks associated with taking Factor VIII. We were told that [S] needed the treatment and it was normal, like any other procedure. We put our trust in the doctors, we did as they advised and we would never have questioned them.
11. Having reviewed some medical documentation recently since [S] death it appears that [S] blood count was borderline and it may have been that there was no real evidence to suggest that [S] actually required the treatment. A previous clotting screen in 1977 "revealed no abnormalities whatsoever" and a further clotting screen in 2005 also showed normal clotting.

12. From the notes, it appears that [s] Hepatitis C test results were available on the 9th December 2005 however he was not told until the 13<sup>th</sup> December 2005.

13. It wasn't until [s] collapsed in December 2005 at the age of 37 that he discovered he had been infected with Hepatitis C. He was told by one of the doctors that were treating him who explained that he had been given contaminated blood. We did not know what it all meant at the time and the severity of the diagnosis.

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

14. [s] was only infected with Hepatitis C as far as I am aware. There was no other way for him to become infected other than the blood products because he had a blood transfusion.

### **Section 4. Consent**

15. I do believe that [s] was tested and treated without his consent. We were never consulted in relation to providing our consent. As far as I am concerned [s] was just given the Factor VIII.

16. In my opinion, I absolutely believe that [s] was used for the purposes of research. The doctors kept pumping this blood product into [s] for about a month and I do not know why. There was no proof that [s] even needed it but it was still given to him. There must have been a reason for doing it and now I question whether it was for money, or to prove something, or for the purposes of research.

**Section 5. Impact of the Infection**

17. [S] was gobsmacked and just bewildered when he found out that he had been infected. He was very intelligent and I suspect that he was not telling me the truth about how he really felt. He just told me that he had been infected with bad blood, but he didn't tell me at the time what he had been infected with. For me, as his father it was bad enough to just hear that, but it wasn't until later I found out the full extent of the diagnosis. I was always under the assumption that whatever was wrong with [S] the doctors would be able to cure him.
18. [S] got on really well with the doctors and would discuss his condition in detail with them. [S] became very knowledgeable about Hepatitis and it did not take too long for him to work out the severity of the infection and his condition.
19. I really believe that before the hospital staff told [S] about his condition they tried to hide something because they did not tell him straight away.
20. During that time we were repeatedly asked if [S] had taken drugs or if he abused alcohol. [S] was a big man and he weighed approximately twenty stone. It really felt like the medical staff just assumed it was all down to drink and drugs.
21. [S] was never told how to manage the infection, only that he had it. I do not recall the doctors sitting us down and telling us about out any precautions that we should take or what it meant for [S] going forward. We were never told of about any risks and we as a result we were not worried about it.
22. Some days [S] would be fine and it would seem like nothing was wrong with him, but then the next day he could turn significantly and he would be very ill. Gradually, the turns became more frequent. Initially it would be months between good and bad days but it soon became months and then just days in between.



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23. [S] suffered from further health conditions due to his Hepatitis C infection such as cirrhosis of the liver and Encephalopathy. [S] required regular abdominal drains due to the build up of fluid in his body. He also had severe leg edema which required ongoing treatment and latterly he suffered with incontinence of both the bowel and the bladder due to high levels of diuretics and lactulose he had to take.
24. [S] had very poor mobility which was not helped by an umbilical hernia and the surgeons decided not to operate because of [S] poor health. Instead the hernia was just left and over time the hernia expanded to the size of a football.
25. [S] was always isolated for his numerous hospital admissions and nobody other than his immediate close family visited him and I can only assume that this was due to the stigma attached to the Hepatitis C. [S] felt very vulnerable, he was always in a low mood and he felt unsupported by the community around him.
26. [S] suffered further medical complications such as endocarditis which was caused by a tooth extraction that [S] needed due to the hepatitis damaging his teeth.
27. [S] received treatment for his Hepatitis C infection and he had the first treatment in 2006, which consisted of daily injections. I cannot remember the details very well but I do know that it was one year of treatment and after 10 months his infection levels came down a lot. However the hospital refused to let him continue with the treatment and [S] was devastated. He had some complications but [S] desperately wanted to carry on with the treatment. Our family believes that those remaining 2 months would have been crucial in helping [S] clear the infection.
28. The next treatment that [S] received for the Hepatitis C was many years later in 2015 I believe. He had a new Consultant called Dr Kara Rye who fought for [S] to get on the treatment because the hospital originally

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refused as it was too expensive. I offered to pay for the treatment myself but Dr Rye told me that she would sort it and that is exactly what she did do. I was told by a friend that the treatment cost approximately £3,600 a year which is nothing when you consider that it could in the long term save a life. I cannot believe that the hospital wanted to block the treatment for such a little cost. Dr Rye really fought [S] corner and even got him across to Birmingham for an assessment for a liver transplant.

29. [S] did clear the Hepatitis C and we were told it was undetectable, however we were also told that there was no guarantee that it would not come back.

30. By that time [S] had so many complications, his severe hernia served as an obstacle to any transplant. The anesthetist blocked the transplant due to [S] ascites and the massive hernia. The doctors said they could perform the operation but that the final decision was with the anesthetist and he had said no. There were definitely other treatments that [S] could have had but he was denied.

31. I find it very hard to talk about this and very hard to explain how I felt other than to say it shattered me really. As time went on and I watched [S] deteriorate I knew what was coming but when [S] started the treatment we were told that he would have ten years of a good life. We believed what we were told because everything was relatively stable during the treatment.

32. I used to think that I was a tough man but losing [S] made me see myself differently. In my lifetime I have seen men die but nothing has ever shaken me the way this did.

33. When we took [S] to A & E we were constantly being asked about what he had taken and what had he been drinking. This continued even up to a few months before he passed away. It made my blood boil that they just repeatedly asked this and wouldn't just accept that it was a result of being given contaminated blood.

34. I recall an occasion when one of the student doctors did a ward round and the Consultant asked the student for their view on what they thought was wrong with [S] and they commented that it was alcohol. The Consultant hit the ceiling and kicked the student out and said not to come back. The nurses told me about it and said that the Consultant was fuming.
35. I gave up work due to my back primarily and it was the right time for me physically. I had been off work sick for 12 months due to my back problems and in the end they made me redundant. It was very convenient because it meant that I was able to be with [S] although no one at work knew about [S] diagnosis.
36. I was with [S] twenty four hours a day. We went everywhere together and I attended all his appointments with him. On one occasion I stayed in the hospital for 72 hours because I didn't like to leave him and I constantly felt I was just up against the system.
37. [S] was in a coma for a week before he passed away and it was only at that point when I realised that it was the end. I had just been getting on with it and looking after him, taking one day at a time.

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

38. I was never offered any counselling or support. Back then I just accepted it all and did not think there was anything I could do.
39. [S] had carers come in every morning and this was organised by the hospital, although we had to pay for it. We used the money that we received from the Skipton Fund and money from the council to pay for the carers.
40. [S] also had to pay for someone else to assist him generally. It was daily care and in addition to the carer's. We paid for any other care that he needed and I was on my own with [S] at that point.

41. We made sure that [S] received good care whilst he was at home and the Skipton Fund paid us the allowance every month.

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

42. I believe [S] received financial support from the Skipton Fund and no other financial support. However I do not know the details of his financial situation.

43. I am aware that [S] did apply to have a wet room installed through the Local Authority because he was unable to access the bath or shower, but it was refused.

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

44. I want to know why and how this Scandal was allowed to happen, especially when it became known not to use the blood products and they still did.

45. I want to see someone held accountable and I want to know who made those decisions.

46. I want the Inquiry to know how it felt to lose a son and how it has destroyed me. I wonder how their families would have felt if this had happened to them.

### **Anonymity**

47. I wish to remain anonymous.

48. I do want to give oral evidence to the Inquiry.



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## Statement of Truth

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

Signed..

GRO-B

Dated..

20<sup>th</sup> August 2019.