Witness Name: GRO-B

Statement No: WITN0421001

Exhibits: WITN0421002-10

Dated: 13 May 2022

INFECTED BLOOD INQUIRY

STATEMENT OF GRO-B

I, GRO-B, will say as follows:

Section 1: Introduction

My name is GRO-B GRO-B.

1. I am a mother of 2 sons infected with HIV and Hepatitis, my son GRO-B: S1 has already provided his own written statement to the Inquiry and my youngest son GRO-B: S2 sadly passed away aged 11.
2. There is no history of Haemophilia in our family.
3. GRO-B.

Section 2: How affected

4. When my oldest son was born, we were unaware that there were any issues until he was circumcised at 2 weeks old. After the procedure, he continued to bleed without stopping so we rushed him to the hospital to get stitched.
5. His diagnosis of haemophilia was missed at this time and came at 7 months later when he fell and required hospital investigation.

6. It was found that he was Factor VIII deficient. He was considered a severe haemophiliac and at that time his level was less than 1%. My third son S2 was born in 1983 and again it was found that he was a severe haemophiliac **Exhibit W0421002**. Our daughter was born in 1980 and our eldest son GRO-B was born in 1979 and is not a haemophilic.

7. It was found that I carried the gene, my siblings had been tested but I was the only carrier among them.

8. S2 received his first concentrate before his circumcision in 1983 **Exhibit WITN0421003.** The circumcision was carried out in Great Ormond Street Hospital. At this stage, S2 was being given concentrated product that came from bottles which contained the blood of various people. Around that time, I read in the Haemophilia bulletin of a hospital in Wales where they were screening every blood donor and the blood products (cryoprecipitate) and that no patients from that hospital were infected.

9. As a baby, S2 attended Great Ormond Street regularly for minor bleeds mainly from his lips/mouth. During these attendances he was treated with Lister Factor VIII. **Exhibit WITN0421004.**

10. I cannot recall when we found out that the blood products were contaminated. We had so much going on that we just got on with it. We just wanted to get on with our lives and look to the children's future.

11. Whilst I had no awareness of the infected blood products at the time of S2's birth in 1983, I was astounded to find out that the medical profession were aware of this fact in 1982.

12. I sought information from the hospital regarding when my son was first infected with HIV, as I could not recall when I was informed of his diagnosis. From review of his notes and the letter that I received, he tested positive in October 1985. **Exhibit WITN0421005.**

13. My children attended Great Ormond Street Hospital and when there were indications that there may be people infected by infected blood products, we and other parents

attended a meeting which I believe was around 1987, where Professor Hardisty Haematologist told us all that it was more than likely that our children would not be affected. No other advice was given. There was no mention of HIV or Hepatitis C.

14. S2 got very ill in or around 1987 **Exhibit WITN0421006**. He became ill very quickly. He developed hepatitis and he had liver failure. He had a procedure at one stage to clear his lungs. It also affected his lungs and he was found to have pneumocystis pneumonia.

15. Throughout his early childhood, I recall S2 suffering with intermittent chest infections. **Exhibit WITN0421007.**

16. As we were given no information regarding where the blood products came from, I was not aware if it was US product that was given to S2. However, I do know that at one stage I was told there was a shortage of blood products in the UK but I never asked or questioned the situation. The hospital has all of the batch numbers for the concentrate product that S2 was given.

17. I am not sure when this took place but I do not recall being asked to sign a consent form to say that we were aware of the risks associated with the products being given, however it was never explained to us how the treatment would affect our boys, side effects, or any of the risks involved. We were not asked to sign.

18. In the year prior to S2's death, he spent a great deal of time in the hospital and it seemed that his health was on a downward spiral. **Exhibit WITN0421008.**

19. On the night before he died, S2 was very ill so I had no option but to telephone Great Ormond Street Hospital and was told by a doctor to wait until morning to see how S2 was.

20. I rang again the next morning to let them know S2 had died and Kate (the haemophiliac nurse) could not believe that the doctor had not told us to come in with S2 the night before. **Exhibit WITN0421009.** We received an apology from the hospital but that is all.

21. We did nothing further about it because we just wanted to get on with life, reluctantly we let it go. We had enough going on without anything further getting in the way. S2 was very weak and very ill for the last year of his life. At that stage S2 had had inhibitors. I remember that he was on something intravenously at that stage. The Nurse (Kate) administered this.

22. My son S2 died at home on GRO-B 1995 aged 11 years.

23. S2 was diagnosed with Hepatitis C after HIV. All care for S2 came from Great Ormond Street. His death certificate sets out that he died from pneumonia, AIDS and Haemophilia. Our GP certified his death. **Exhibit WITN0421010.**

24. His funeral GRO-B and occurred as soon as possible after his death GRO-B 1995.

Section 3: Other Infections

25. Please see section 12 above. He was consistently coughing, extremely weak, missed a lot of school and was extremely behind in his school work.

Section 4: Consent

26. None whatsoever.

Section 5: Impact

27. I am currently employed as a head teacher of a local school. I was offered this position when S2 was dying and I sought assurances from the school board that if there were any issues with my ill son that they would have a temp to step in and take over my role so that I could tend to S2 without any unnecessary delays. This was agreed and I took on the role at that time because I felt I needed something to distract me from severe anxiety. It distracted me from what was happening at home and helped keep me sane at that time which was very difficult. It affected my social life and career as I could not work full time. My husband had to take care of the children while I was at work and could not work full himself.

28. My husband and I never told anyone at the time that S2 had AIDS or how/why he died. At the time I felt that some people were aware that it was a result of his being haemophiliac, but they never voiced their suspicions in any way.

29. Not even my siblings knew about his HIV infection. We decided to deal with the matter in our own way and on our own. I felt that this was the best way to deal with it for fear of being stigmatised. My son S1 remembers that at one stage our GP told us that he thought haemophilia had died out, that it was an ancient illness. One doctor actually asked how you caught haemophilia. This was the mentality at that time of some people. When I finally disclosed S1's situation to family one cousin suggested that there were alternative methods out there.

30. My husband, GRO-B, shared the responsibility of looking after our dying son. Family were very good while S2 was so ill in the last year of his life.

31. I continue to suffer anxiety as a result of the situation, and I need to take regular breaks and exercise to deal with my anxiety. As a result, I can only work part time.

32. I developed breast cancer over 13 years ago but thankfully I have made a good recovery. I feel that all of these health issues arose from the stress of our sons' viral status, health issues and in the case of S2, his death.

33. In our community, it is common for most couples to have large families. Because of the stress and the full time consuming risk of taking care of S1 and S2, my husband and I made the decision not to have any more children. This made is feel very different from our family and friends and now that we are getting older, we have fewer children to look after us and keep us company.

Section 6: Treatment/Care/Support

34. S2's treatment history consisted mainly of Factor VIII concentrate. As a young baby, he experienced spontaneous bleeds usually into his mouth, which settled rather quickly when treated with Factor VIII concentrate. I believe that the Factor VIII concentrate S2 received as a young boy was the cause of his HIV infection.

35. With respect to his HIV infection, I cannot recall when we were made aware of this – see paragraph 12 above.

36. From review of his records, at one point his CD4 count had dropped and he had no symptoms.

Section 7: Financial Assistance

37. My husband is a freelance scribe and works for the GRO-B. We lost income as a result of the situation.

38. We received compensation of £29,000 on S2's death and the Skipton fund awarded us £30,000 per child so we were given £60,000. S1 also received £30,000 himself personally.

Section 8: Other Issues

39. I hold the NHS/British Blood Company responsible for my son's death and for my other son S1's status.

40. There was never any proper screening of the blood product, we were never told of the dangers of the blood products. If we knew about the people being infected in 1982 (a year before our son S2 was born), our path would have been different. Families were never made aware of it and it was the responsibility of the blood companies to screen the product.

41. I do not want children to suffer like my children or parents to suffer the way we have as a result of our sons' HIV and Hep C status. They were born with haemophilia but we should not have to worry about other treatments. Haemophilia is manageable but compounded with HIV and hepatitis makes leading a normal life impossible.

42. I would like to see full justice, i.e. full compensation. Money can not bring our son back but it can help us improve our quality of life.

Statement of Truth

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

Dated 13 the 5th 2022

Signed: GRO-B

GRO-B