

## 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 and I live alone at GRO-B  
GRO-B I was born on GRO-B 1929.
2. I make this statement in relation to my son, GRO-B: S who was born on GRO-B 1954 and who was infected with Hepatitis C (HCV) through contaminated blood products.
3. This witness statement has been prepared without the benefit of access to S medical records.

**Section 2. How Affected**

4. S suffers with Christmas disease, a type of Haemophilia caused by a deficiency of Factor IX. He has suffered bleeding into his joints from birth.
5. From when he was born until he was about 12 years old there was no treatment. When he suffered bleeds he would be hospitalised or would have bed rest. He has arthritis in most joints as a consequence of his bleeds.

## ANONYMOUS

6. He was under the care of Great Ormond Street Hospital until he was 12 and then he was transferred to the Royal Free Hospital (RFH) for treatment. Originally he received care from Catherine Dormandy but after her death **GRO-A** he was treated by Dr Kernoff.
7. As a child he received treatment by full blood transfusion because occasionally he became anaemic due to blood loss.
8. When he was 4 or 5 he went to a special school in **GRO-B** It was a school for children with disabilities and it was thought that he would be safer there. However, there appeared to be a lot more accidents there because there were fewer lessons and they were allowed to play more! Later aged about 7 or 8 he went to a hospital at **GRO-B**
9. A teacher at **GRO-B** recognised that **S** was very bright but lacked the power of concentration. She could see his potential and helped him in his education.
10. After 6 months he went into the ordinary education system and went to a school where the head teacher was very supportive. He liked having **S** at the school as it was good for the other children to be aware of his needs. **S** was very clever and finished up in the top set. He passed his 11+ and went to grammar school.
11. **S** loved sport; he wasn't meant to partake but he did. He was the type of child that would not be bullied.
12. From around the age of 12 onwards he started receiving cryoprecipitate and we used to take him back and forth to the RFH for his treatment
13. In his late teens **S** was taught to administer treatment himself. From approximately 1970 onwards he was treated with Factor IX concentrate. I believe they had enough of this treatment in this country but for some reason they imported it and this was the Factor IX that **S** received. The treatment was stored at home. At the time we did not think about the fact it was imported; we were just grateful that the treatment was available and helped **S** to lead a normal life.
14. **S** did not go away to University; he studied law at **GRO-B** London and lived at home so that he was near to the RFH for treatment. We were worried if he went to another University away from home that there would not be a haemophilia centre.

15. I do not know the date when he was told that he had contracted hepatitis C (HCV) but he only told me later on when he became ill. I remember that I was relieved he had not contracted HIV.

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

16. I am not aware of any other infections.

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

17. I do not know whether his blood was tested without his consent or whether he was used for the purpose of research. As he was an adult when he was advised of his HCV status I was no longer involved in his treatment.

### **Section 5. Impact**

18. From the age of 15 [S] had wanted to be a solicitor. My cousin was a solicitor in the City and [S] went to his office during holiday periods for work experience. When he left university he assisted with a solicitors practice in [GRO-B] called [GRO-B] and eventually he ran the practice.

19. He was married in 1980 and had two sons.

20. In about 1993/1994 [S] became ill; he could not work. He was very tired and lethargic; he lacked energy. He was told that he had contracted Hepatitis C. He told us sometime in the 1990's.

21. [S] whole life changed with his illness. I am sure that his diagnosis was the cause of his marriage breakdown. I am not so sure about how his marriage was affected but I'm sure that it would have affected his marriage and his sex life. His ex-wife [GRO-B] is still part of our family although they are no longer together.

## ANONYMOUS

22. [S] had two knees and one ankle replacement and when undergoing this surgery required a considerable amount of Factor IX. During 1993/1994 [S] became very ill with symptoms. I was caring for my sick husband at the time; it is difficult for me to remember specific dates.
23. I remember that he saw all kinds of doctors to help him; he even attended a pain doctor.
24. After [S] had been told he had hepatitis C everything in his life went wrong and he started taking cannabis which he felt was the only thing which assisted with the pain.
25. For the last 15 years or so [S] has suffered from depression. His sons help him. He doesn't appear to do any of the normal every day things and lives an almost hermit life. However, he is very intelligent and plays bridge which is his saviour.
26. [S] was hopeful that he could receive gene therapy to cure his haemophilia but when the time came for treatment they said that he could not receive it because of his HCV. They told him that he would have to eradicate the HCV to enable him to have treatment.
27. He started with Interferon treatment. He suffered some gruelling side effects. It gave him psoriasis and as a result of this he got psoriatic arthritis in his hands. They stopped the interferon; it did not cure him. The Professor treating him at the time said that [S] had had the worst side effects he had seen from the drug.
28. A couple of years later he was offered further treatment. I think it was called Harvoni and consisted of an injection. I believe that he is in remission.
29. I do not know whether he will have gene therapy. I keep asking him about it but I feel he is having second thoughts about it.
30. We do not keep his condition a secret; I do bury it. I live with the guilt that through me he has this problem but I do not let myself think about it too much as it is sad and heart breaking.
31. My husband [GRO-B: H] was [GRO-B] of the Haemophilia Society and used to go to world congress meetings. [S] was never interested in mixing with other haemophiliacs but



## ANONYMOUS

wanted to lead his own life. He wanted to do normal things. My husband died in 2001 aware of HIV and HCV. We have known many children the same age as **S** who have passed away from HIV.

32. **H** would face up to everything and had a much better knowledge of what was going on. He was my backbone. He would be angry to know that it has taken so long for the Inquiry to start but he would be pleased that eventually it has. He was a very sensible man and very close to **S**.

33. As a mother it is hard to see your son in pain all the time. He has to start his day with a dose of drugs that cannot be bought over the counter and it takes time for these to kick in before he is able to start his day. Most of the time he is unwell but **H** always used to say to me that we had to live our life and that is what I am trying to do. I have and always will be here to help him and have tried to give him as normal life as possible.

### Section 6. Treatment/Care/Support

34. I do not know how his liver is now; I think he is checked regularly. I do know that he is left with psoriasis that they do not seem able to clear up. Whilst he has tests on a regular basis; he is always tired and lacks energy.

35. I do not know whether he has received or is receiving counselling. I know that many years ago there was a wonderful social worker and nurses at the RFH that he could talk to. I have never received counselling and have never requested it.

36. I do not suffer with depression; I am a strong in character.

# ANONYMOUS

## Section 7. Financial Assistance

37. I am not aware of any payments received by  I know that he is now receiving benefits.

## Section 8. Other Issues

38. I have been devastated and sickened by the fact that some people must have known what was going on; they knew that the blood was infected as they had taken it from infected people. I believe our wonderful transfusion service had enough Factor IX product but they imported foreign treatment which has in turn infected him.

39. Between the ages of 40 and 60 my life was normal.  was living a normal life, treating himself, married with children and employed as a solicitor. It did not seem to happen in a day; it all seemed to happen insidiously.

## Anonymity, disclosure and redaction

40. I wish to apply for anonymity. I understand that this statement will be disclosed and published as part of the Inquiry. I do not wish to give oral evidence.

## Statement of Truth

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

Signed.....  .....

Dated..... 16/5/19 .....