

Witness Name: **GRO-B**

Statement No: WITN1586001

Dated: 28 April 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF **GRO-B**

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

Section 1. Introduction

1. My name is **GRO-B**. I was born on **GRO-B** 1946. I live at **GRO-B** **GRO-B**. I am divorced and widowed and I live alone. I have 2 children **GRO-B** and **GRO-B**.
2. I am writing this statement in relation to my son **GRO-B: S**. He suffers from severe Haemophilia A and was infected with Hepatitis C (HGV) and the Human Immune Deficiency Virus (HIV) from contaminated blood products.
3. This witness statement has been prepared without the benefit of access to my sons' medical records.

Section 2. How Affected

4. **S** was born on **GRO-B** 1977 with severe Haemophilia A. The initial diagnosis of haemophilia was difficult and prolonged. **S** bruised very easily. As he was regularly seen at the health clinic as a baby they suggested that I took him to see a doctor to see what the problem was. Dr **GRO-B** gave me a

look and asked me what the clinic thought the problem was. I got the sense that Dr **GRO-B** was thinking that I may be the cause of it and he told me to come back in three weeks.

5. I went back to the doctors with **S** around 3 weeks later because of the bruising and he was referred to Dr **GRO-B**. **S** was sent for a blood test at the local hospital.
6. The doctors took blood from his arm. After this his arm went solid and purple. This initial blood test result came back negative.
7. When **S** was 9 months old he was walking around the coffee table and he bit his tongue. It would not stop bleeding. I took him to the doctor and Dr **GRO-B** told me to give him ice cold lollies. After 4 days the tongue was still bleeding and **S** was admitted to hospital.
8. He had a further blood test which again came back negative for haemophilia. The hospital wanted to do further tests but **S**'s blood count was too low; he was anaemic. The hospital gave him whole blood followed on alternative dates by cryoprecipitate. The bleeding stopped on the days he received Cryo but then it would start bleeding again. He was taken to theatre to look at the tongue and they found he had a lump which they removed. He had 3 stitches and was given more plasma.
9. Blood clots then started to develop in his mouth because they were not adhering to the wound itself.
10. After four weeks in hospital the consultant from **GRO-B** Hospital discussed **S**'s condition with a consultant from **GRO-B** Children's hospital. We took him to **GRO-B** Children's Hospital **GRO-B** for further blood tests. I remember that they had to take blood from his heel as they could not find a vein.
11. The results from this blood test showed that **S** was in fact a severe haemophiliac. He began treatment at **GRO-B** Children's hospital.

Sometimes he would have treatment three times a week and at other times we were there for a whole week. He had cryoprecipitate at the **GRO-B** Hospital but after his diagnosis he received Factor VIII concentrate.

12. When **S** was about 10 or 11 years old he started home treatment. **S** had always hated needles. I took him to a hypnotist for treatment to accept needles which worked but still to this day he doesn't like needles.

13. I cannot remember the specific date when we were told about HIV but I do recall that there was a meeting I was asked to attend. I cannot remember specifically where it was but I think it was at the Children's Hospital. It was in a big room and there were quite a few parents there. We were told that some of the children had been infected with HIV and some had not. We were told that if we wanted to find out if our child had then we would have to ask for the information individually.

14. I think **S** was possibly 9 or 10 at the time but I am not sure. I did not want to ask. In a way I did not want to know because I did not want the result. I felt that I could not do anything about it if the result was positive. I was very worried. I decided not to ask at the time.

15. Sometime after, and before **S** started home treatment, we were at the haemophilia unit at the Children's Hospital. **S**'s notes were out of the filing cabinet and were open on the desk in the unit. There was a white sheet of paper stapled to the inside of **S**'s file with some results on it. As I was nosey and inquisitive I read this sheet of paper and felt numb. It showed that **S** was HIV positive.

16. I discussed it with my husband and we decided not follow it up as such. I did not tell anyone or question it, nor did I tell **S** at that stage. I had a chat with Dr **GRO-B** at the clinic when **S** was around 14 years old. I decided that now was the correct time to tell him about his status as he was old enough to understand and I wanted him to get used to the fact whilst he was growing up.

17. Dr **GRO-B** told **S** after I gave my consent. I was too emotional about it all so I had to get Dr **GRO-B** to tell **S**. It may have just been a meeting in his office. My memory for some of the finer details and dates are all a bit hazy; I have tried to put it all to the back of my mind.

Section 3. Other Infections

18. We were told that **S** had contracted Non A non B hepatitis later to be known as Hepatitis C (HCV). I remember that the whole family had to have an immunisation which we had to pay for ourselves.

19. I remember that **S** who by this time was living on his own, did receive a letter that indicated he could be infected with vCJD. This arrived on a Saturday morning. I remember this because he could not follow it up over the weekend and talk to anyone about it straight away.

Section 4. Consent

20. I had never consented for **S**'s blood to be tested for any of these viruses. I also did not have any knowledge or give my consent for **S** to be tested for the purposes of research.

Section 5. Impact

21. When **S** was told, he seemed to take it relatively well. Dr **GRO-B** was very accommodating. He said that **S** could ask him anything if he wanted to. **S** has never really discussed his infection with anyone. Many years later he told his girlfriend who is now his wife.

22. We were not told at the initial meeting of the risks of HIV and how to deal with it. We were not given any sufficient or proper counselling. I remember that all the mums had a meeting with the sister in the haemophilia unit but I never felt that they were speaking openly to us. They seemed evasive and not fully upfront with us.

23. [S] seemed to cope well having been told about his infection. However I do remember that he had nightmares but he used to keep them to himself.
24. I told a couple of close friends about [S] and they were shocked when I told them.
25. The school were aware of [S]'s haemophilia but I do not know whether they linked this to HIV. They had always known about his haemophilia because when [S] was at nursery, the nurse would tell [S] that he could not go to certain classes or he would have to be brought to particular classes in a wheelchair. He had a nursery nurse assigned to him. When he was moving classes he was going to have to go in to a pre-fab building. He was told that he couldn't go into that class because he was in a wheelchair. I went at that stage to the Director of Education and sorted it out for him. I do not know if there was any prejudice with [S] because of the stigma attached to haemophilia and HIV.
26. When [S] was in school he would have to put 'sharps' in a yellow bin so as to not cross contaminate. He was told he could not go on school camp because of his haemophilia. They told me that they could not take responsibility because of his haemophilia. In the end I told the Director of Education and he said he would either stop the whole camp for everyone or [S] could not go. Eventually it was agreed that [S] would attend the camp during the day and I would take him home in the evening.
27. I remember when we went to America on holiday when [S] was about 12 years old. We were told at that stage that we could only take 12 bottles of Factor VIII which obviously was insufficient but I understand at the time there was a shortage.
28. I remember at some stage there being a recall of Factor VIII concentrate but I cannot give specific dates.
29. [S]'s life would have been very different had he not been co-infected; people are afraid of it. There was such bad publicity at the time that it was something you

could not openly discuss. If he had been diagnosed with cancer then we would not have had to keep secrets and people would automatically be sympathetic but with HIV and HCV he cannot talk openly to friends and his employers about it.

30. I remember when he was young that it was difficult to let him go to other friends' houses. I don't believe that he was treated in any way different to the other children but I was afraid if he had an external bleed. I remember that a friend of his father took a group of boys to the forest at **GRO-B** one day **S** had a fall and grazed his knee which bled and the father mopped it up. I did not know what to do about telling the father he was HIV; it made me feel very uncomfortable. I did not tell him in the end but **S** was not invited again.

Section 6. Treatment/Care/Support

31. At one point before we knew about his HIV when **S** was in hospital, someone had noticed him bleeding onto his pillow. He had had a tooth out. They sent him to an isolation ward and had different crockery to everyone else. He was not even allowed to use the ward toilet. I presume this was because of his HIV status. He was treated poorly by the medical staff then which I now know was because of his HIV and the fears which surrounded it.

32. I also noticed that when **S** needed dental work done, the surgery would have everything covered in plastic wrap; the tools and taps included.

33. At Christmas in 2003 **S** had pleurisy. He was told it was to do with AIDS. He was admitted to hospital. He was not allowed to use the shower and was not allowed to sit in the day room. I remember complaining to the hospital and saying that if your patients are at risk then you should be looking after them and not preventing my son from using the facilities.

Section 7. Financial Assistance

34. In 1991 there was a settlement package offered. This required me to sign a waiver. There was an offer of 21,000 for those haemophiliacs infected under the

age of 18. I think if you were over 18 and single you were offered 45,000 and if you were married 65,000. I did not agree with it. I signed the waiver at the very last minute as we were told all had to sign the waiver or no one would receive anything. I remember this being such a paltry amount and I felt that it was disgusting for what had been done to them. I remember thinking it was so unfair that they were not offered the same amounts as they were all infected with the same product. Money would not put it right but you could use money to make things better. I feel it is very unjust; other countries have paid much higher sums.

35. I recall at the time that the Herald of Free Enterprise had sunk and those that had received damages got much more than the haemophiliacs infected with HIV.

36. I do not know of any other payments as [S] is now an adult and is married and living with his wife.

Anonymity, disclosure and redaction

37. I do wish to apply for anonymity and understand that this statement will be published and disclosed as part of the Inquiry.

Statement of Truth

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

Signed [GRO-B]
[GRO-B]

Dated. 28-4-19.