

Witness name:

GRO-B

Statement No: WITN2574001

Dated: 16th January 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF

GRO-B

I provide this statement in response to a request under Rule 9 of the Inquiry rules 2006 dated 12th December 2018. I adopt the paragraph numbering in the Rule 9 request for ease of reference.

I, will say as follows:-

1. Introduction

1. My name is GRO-B My date of birth is GRO-B and my address is known to the Inquiry.

2. How Affected

1. I am the mother of GRO-B both of whom have haemophilia and have been victims of contaminated blood products. I am not married and I am retired.
2. I will first refer to my GRO-B: S1 son and then my GRO-B: S2

3. I found out that my **S1** son was a haemophiliac when he was 1 and half years old. He was rushed to hospital as he had a tongue bleed. My father **GRO-B** at the time and he had to **GRO-B** in order to take **S1** to the hospital. He drove **S1** to **GRO-B** I remember that day very clearly. We returned the next day and **S1** had undergone some testing and was diagnosed with haemophilia. **GRO-B** said "I am the top doctor and I will sort him out." To begin with, the boys would receive plasma injections such as cryoprecipitate. Later on however, I would inject **S1** with Factor VIII blood products. I was only shown how to do this once and considering I injected **S1** regularly in the house you would expect more training than that.

4. **S1** stayed in **GRO-B** for a few days. He must have had four pints of blood we did not know what was happening. **GRO-B** had his arm amputated during the war but he never required that much blood and did not have haemophilia.

5. I found out that my **S1** was infected with Hepatitis C ('Hep C') in the 1990s when everyone else started to find out. He was not told how to manage the infection and did not have any form of counselling upon hearing the news. I do not know the circumstances under which my son was told he had haemophilia.

6. We did not have a clue initially where the Hep C could have come from. I was in tears when I found out he had Hep C, however you were told you could live forever with Hep C. It was only recently that my **S1** **GRO-B** found out that he is a haemophiliac and **GRO-B**

7. My **S2** is a severe haemophiliac. We found out he had haemophilia when he was **GRO-B** They carried out a blood test to find this out. The sister explained what it was to me but we just wanted him to live life to the full. My **S2** was always worst behaved and less careful than the **S1** My **S1** son did not have an inhibitor like my **S2** My **S2**

would have to stay in the hospital at length whereas my **S1** son would not be required to stay at the hospital for long periods of time.

8. One day I remember very clearly was when my **S2** was **GRO-B** years old he was **GRO-B**. His arm went gangrene. The doctor told him he would have to have below the elbow of his arm cut off. **GRO-B** **GRO-B** the operation could not go ahead due to the severity of his haemophilia. The operation was cancelled and miraculously his arm started going back to normal.
9. The day my **S2** was told he was infected with HIV is one I remember vividly. We were on **GRO-B** when he had a terrible bleed in his ankle. My **GRO-B** were on holidays with us as well. I spent £117 on the phone to **GRO-B** team at **GRO-B** as they kept trying to put my **S2** son **GRO-B**. They did not understand what was wrong with him at all; they did not have any Factor VIII to give him either.
10. The hospital in **GRO-B** then told us that there weren't any haemophiliacs on the island. They had been giving my son over the counter Anadin for the pain.
11. My **S2** was told the next day back in **GRO-B** by **GRO-B** that he had HIV. He was told not to call me. The phone call I did get from him to give me the news not only changed his life but my life also changed from that day on.
12. My **S2** son was initially told that he had 18 months to two years to live. It was terrible hearing them telling him he was going to die. It was like a game of Russian roulette with his friends. One-by-one they were dying. He and his friends had a little community where they could all chat with one another and discuss what was happening. We had lovely nights together. The group was called the **GRO-B**. The members of the **GRO-B** would go for meals and drinks together.

13. I was never told or guided by **GRO-B** or anyone else on how to deal with the news. My son was not given counselling until two years later. He took the news of his diagnosis very badly and began to take drugs. I felt like I was also taking the sentence for him.
14. I thought I was waiting for my **S2** son to die. I gave him his Christmas presents early one year as we thought he was going to go. I told a few friends who were good as gold and they knew that he did not get AIDS from messing around with drugs.
15. In relation to the Hep C. My **S2** was told he had cirrhosis of the liver. However a later scan came back and it was confirmed that he never had this. The physiotherapist down the hospital was great with him and she got him seen to straight away. His wife was with him when he had the Hep C diagnosis not me.
16. My **S2** became paranoid in those two years about whether the cirrhosis was going to kill him. I just kept thinking he was going to die but as long as I am alive I get the feeling nothing will happen to him.

3. Other infections

1. My **S1** now has a terrible chest; however I am unsure if this is linked to the Hep C. My **S1** did have a fibre scan, the results for this came back fine and he was given the all clear in terms of any complications with his liver.
2. My **S2** was diagnosed with pneumonia a few years after his AIDS diagnosis and I was very concerned when he had been told he had pneumonia.

4. Consent

1. I never provided any consent. They knew that my **S2** had HIV months before they told him and this is shown through his Haemophilia Database records where it states that my **S2** was diagnosed in 1984 but told in 1987.
2. I remember **GRO-B** on the ward saying that she always made sure that my **S1** had the British blood product, she would say 'make sure he has the British one'. I did get suspicious why did she keep saying this about **S1** I know she said this to another family.
3. I get the feeling she knew what was going on. She finished working there all of a sudden. I feel like all of it was too much for her. She came and visited us at home one day and it was lovely. She finished working there in the early 1980s and before my **S2** son was told about what his infection she was firm that she did not want the U.S blood products in the haemophilia Centre.
4. The way she talking about everything to us was as if she knew about the scandal that was taking place.
5. In regards to research, I believe there is a possibility that they could have been treated with infected blood for research purposes.

5. Impact

1. The mental effects of my **S2** son's diagnosis were huge. I did not want to go out. If people were coming to the house I was warned by nurses about the stigma they might have attached to my son's condition. My mental state was bad upon hearing the news. I would think that my son's life had gone and so had mine.
2. As a teenager my **S2** **GRO-B** for a period with my **GRO-B** **GRO-B** He was not able to work for very long as he kept having bleeds. For example when he was **S2** he was in a **GRO-B** The only thing he could do was **GRO-B** and he still enjoys doing this.

3. I would go out on a Saturday night and even in the summer I would put the heating on to make my **S2** sleep, even when it was baking hot in the summer I would make sure that the house was boiling. The diagnosis that he had not only ruined his life but it also ruined mine.
4. I don't really know what else to say apart from that my own mother could not stop crying for years. However, all the family were brilliant with my **S2** son nonetheless.
5. I never thought my **S2** would come live a happy and productive life but I think my father is with him. I carry God in my heart and I believe my son's granddad is with him at all times.
6. My nerves have been terrible. I would have killed myself if my **S2** son had not have gotten better. I felt guilty. I always thought, "why him?" He was always in the hospital and it was horrible.
7. Another point I would like to add is about the character of **GRO-B** He was money mad. He would make my **S2** son feel guilty for having a bleed, he would say things like 'don't you realize how much this treatment costs' and was always repeating to him about being extra careful.
8. I had to take Valium for my nerves. I took it to try and calm me down. I would go to bed crying and I would wake up and it would be on my mind again. However my **S2** son's **GRO-B** took a weight off my mind.
9. My **S2** son has been to hell and back. I would worry he would be dead if he did not have his tablets.
10. If anything came on the television about AIDS people would call me and ask me about it. It was intrusive. The stigma was just terrible. It felt dirty, people

used to think my **S2** son was gay. I was glad he was able to take tablets that made him sleep.

11. My **S2** son did not go to school. A tutor would come to my house. However he struggled to concentrate so he did not progress much at all. He would talk to the tutor and try and distract her to avoid getting his work done.

12. My **S1** son used to work on the market when he could. He was not and is still not able to do manual work. My **S1** son had **GRO-B** and it's not fair to my **S2** that he could never have kids. I know it went through his head that he always wanted children and it therefore went through my head. It was wonderful when my **S2** son met his **GRO-B**

GRO-B

6. Treatment/Care Support

1. The tablets my **S2** son was prescribed for his HIV have debilitated his joints. He is stiff and struggles to walk very far.
2. A treatment he had received for HIV called Indinvir caused him to have nightmares. I know he still gets very tired a lot from the HIV drugs and he really struggled to wake up in the mornings.
3. Some of the tablets he has taken have made him violently sick. He has also developed OCD. I know he has had counselling for his OCD. He would even hide his toothbrush, he was so scared of passing the HIV onto someone.
4. The main treatment my **S2** son had for the Hepatitis C was Interferon and then Ribavirin. The Interferon treatment was dreadful for him and had a terrible impact. He told me that people had asked him if he had been in a car crash as the side effects of the treatment had been so bad. My **S2** son had to take sleeping pills after the Interferon treatment.

5. A fibre scan for cirrhosis in 2006 showed that my S2 had a severely damaged liver; the doctor told him that he needed to have a liver transplant. After another scan two years later and after being placed on the transplant waiting list he was given the all clear.

7. Financial Assistance

1. When the boys were younger I had some money from the Round Tree Trust to put towards a car.
2. I had to give £2000 back to social security when they found out I had the car. They took my partners income into consideration even though I was looking after my son's full time.
3. I feel like I lost my life too but I feel like I have struggled over the years. I really think they should've given mothers something when they were awarding payments, especially mothers who have lost children through this.

8. Other Issues

1. Those responsible know the truth. They have been dragging their heels for years. There should be a payment for people now. The victims of this should enjoy life whilst they can, especially years ago they struggled. 2-3 years is too long for the result of an inquiry, something should be given to those who have lost and who are still suffering.
2. They should bring the money forward now and help these poor people.

Statement of Truth

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

Signed.....

GRO-B

Dated.....

16-1-2019