

Witness Name: GRO-B

Statement No: WITN3052001

Exhibits: WITN3052002- WITN3052013

Dated: 10 January 2020

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF GRO-B

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

1. I am the mother of the late GRO-B: S who was born on GRO-B 1967. I was 24 years old when S was born. My husband, GRO-B and I had a daughter prior to this in 1965.
2. S was approximately 9 months old when he was diagnosed with haemophilia. I did not know what haemophilia was at the time. S had hurt his knee and he would not stop crying so I brought him to Northampton General Hospital where he was transferred to the Oxford Haemophiliac Centre. It was there that Dr. Matthews explained to me what haemophilia was and the fact that S was a severe haemophiliac.
3. After S was diagnosed with haemophilia, Dr. Bruton (who was another doctor involved in S's care) got a book on haemophilia to enable him to understand the condition a bit better. Since I am a carrier of the gene, S's sister was subsequently tested to see whether she was also a carrier and she too was found to be a carrier. In terms of our family medical history, no previous known haemorrhages had ever occurred.

Treatment:

4. When the children were old enough to go to school, I would work in the morning time and take care of the children in the evening while [GRO-B] was at work. Throughout [S]'s childhood, I had to bring him to the hospital frequently if he ever sustained an injury. We would always go via the ambulance and cryo precipitate was the treatment that was available at the time for haemophiliacs. This would be prescribed and would be given to [S] in the hospital.
5. Factor VIII then became available. [S] would go to the hospital regularly to obtain his treatment and subsequently, [S]'s GP started to administer the treatment. Soon after, I learned how to administer it. Nobody ever spoke to [GRO-B] and me about the risks associated with blood products. Eventually, [S] took over and would administer the treatment himself; he was very good at taking his treatment and he took this very seriously.

Jaundice episodes:

6. When [S] was 4 years old, he developed jaundice. In total, he had 2 jaundice episodes and during the second episode in July 1973, when he was 6 years old, he was admitted to the [GRO-B] Hospital. [S] was very ill during this episode and he was vomiting and having regular nosebleeds. His nose bleeds were not responding to the local use of Russell viper venom in the blood products given. I noticed that [S] was passing high-coloured urine the day before his admission and he became jaundiced on the morning of admission.
7. [S] was given a lot of Factor VIII during this period. During this incident, I was told that he had a very bad bout of jaundice but overall, I was not given much information. [GRO-B] and I visited [S] every day while he was in hospital. It is clear from [S]'s medical records that the [GRO-B] Hospital believed his diagnosis to be as a result of both haemophilia and serum hepatitis. (Exhibit WITN3052002).

Incidents in January 1979 & 1982:

8. In January 1979, [S] slipped on the ice and banged his head. He suffered from pain and dizziness afterwards and he was admitted for observation the day after this incident on the 24th January 1979.
9. There is a note on [S]'s medical records (**Exhibit WITN3052003**) which says that blood products such as Factor VIII Concentrate can cause viral hepatitis, but [GRO-B] and I were not aware of this and the doctor didn't mention anything to us about this. This record also describes how [S] was treated 'with large doses of Factor VIII' during this period.
10. From [S]'s medical records in **Exhibit WITN3052004**, it is now clear that [S] did, in fact, have Hep B from a pathology report dated the 17th July 1974. Later medical records dated the 5th July 1978 again indicate that the Hep B antibody was detected in [S]. (**Exhibit WITN3052005**) However, I have no recollection of anything regarding Hep B ever being mentioned to me at any stage and neither does [GRO-B].
11. In March 1982, when [S] was 15 years old, he suffered from multiple bleeds to his right knee and was admitted into hospital as an emergency. On this occasion, [S] received a lot of factor concentrates. (**Exhibit WITN3052006**) In June 1982, [S] suffered from a further bleed to his right knee and was admitted to the orthopaedic ward at Kettering and District General Hospital where he, once again, received a large amount of Factor VIII. (**Exhibit WITN3052007**)
12. A letter from the Oxford Haemophilia Centre to [S] dated the 18 July 1986 states that a list of batch numbers of Factor VIII were recalled from a number of patients on this date. This is likely to have been as a result of inadequately heated factor products. (**Exhibit WITN3052008**)

Nursing and potential careers

13. [S] left school at the age of 16 which was very normal back then. He had enjoyed his time at school but if he ever sustained any injuries, he had to remain at home until he had fully recovered.
14. [S] considered a number of career paths. He wanted to be a policeman at one point and he even wrote a letter to the Duke of Edinburgh about this to which he received a response. At another stage, [S] wanted to train as a pilot and was interested in working with Air Traffic Control because he loved the RAF; however, they were not interested in hiring him. (**Exhibit WITN3052009**)
15. [S] also developed a strong interest in becoming a nurse and he wrote a letter regarding a possible career in nursing to Dr. Matthews. [S] volunteered in [GRO-B] Hospital at one stage and the nursing tutor there wrote to Dr. Matthews stating that he was very impressed with [S] but that nursing would be a very demanding career for him because of the long hours and having to lift patients regularly. [S]'s tutor said that he might be successful if he applied for some of the smaller centres which would not have been as demanding and which would have accepted lower grades.
16. From [S]'s medical records, it is very clear that he was actively trying to pursue a career in nursing and that he was taking this goal very seriously. It is also clear that everyone was working with [S] to try and get him into nursing school. A letter from Dr. Matthews dated the 26th June 1984 (**Exhibit WITN3052010**) states that [S] was planning on taking the equivalent of a pre-nursing course with the intention of entering nursing school the following year.
17. However, [S] ultimately ended up doing a youth training scheme instead which he ended up getting let go from. For his next job, [S]'s employers were initially reluctant to employ him because he was a haemophiliac. However, he got the job in the end in September 1984 and started working as a Packing Inspector. [S] enjoyed going to work and he held this same position until he passed away.

HIV diagnosis

18. [S] was diagnosed with HIV in March 1985 (**Exhibit WITN3052011**). However, the hospital kept his diagnosis from him for over a year. From his medical records, [S] was not told about his HIV diagnosis until the 2 April 1986 (**Exhibit WITN3052012**) after he had indicated in February 1986 (**Exhibit WITN3052013**) that he wanted to know the results of his HIV testing. [S] had a girlfriend at the time and although he was not having a physical relationship with her, it was important for him to have been told of this diagnosis as soon as it was discovered.

19. When [S] was diagnosed with HIV, he rarely complained as he did not want to worry [GRO-B] and me. However, [S] did disclose to us that the HIV campaigns caused him stress and anxiety. He told [GRO-B] and me that he did not want the family to know about his HIV diagnosis, so we kept it a secret and we still have told no one else to this day, including [S]'s sister.

Death

20. [S] passed away on the [GRO-B] 1987. On the day he died, [S] went for a haircut and afterwards, he went over to his girlfriend's house. [S] became extremely ill after he had arrived at her house; it looked as if he was having a fit but he actually was having a haemorrhage bleed. As soon as I received the phone call, I went straight to the hospital and was brought into the family room. There, I was told that [S] had passed away in hospital. I had been warned previously that something like this could happen.

21. The conclusion on [S]'s death certificate was that he died from a subarachnoid haemorrhage due to haemophilia. When I went in to identify [S] I was told not to touch him but I did anyway. No inquest was conducted and [S]'s funeral was held on the same week he died.

22. It was devastating going home to an empty room after [S] died. I can recall that Dr. Matthews was totally shocked at [S]'s death and could not understand it.

The present

23. It has now been 32 years since [S] died and although you learn to live with it, it is still very tough. As [GRO-B] says, when his son died, he died as well because his name died.

24. I miss [S] hugely and to this day, I carry photos of him in my purse. I also have a photo of him as my screensaver on my phone. I have 1 daughter, 3 grandchildren and 2 great children who live nearby. One of my grandsons was given [S] as his middle name as my daughter felt that it would be too difficult to give him [S] as his first name. Two of my grandsons are haemophiliacs but neither have Hep C.

25. [S] was young and was living at home when he died [GRO-B] and I lost care, support and companionship for all of the years after his death and our home became a very quiet place. Parents should not bury children and life has been difficult without him [GRO-B] retired in 2001 and has greatly missed having [S] around him during his retirement. [S] lived his short life to the full.

Compensation

26. [S] died before compensation was given. However, I received around £25,000 from the McFarlane Trust. I also received a payment of £20,000 from the EIBSS.

27. I want justice for [S] and I want answers as to how he became exposed to viral infections. I would like to ask the inquiry the following questions:

Questions for the Inquiry:

1. Why was I not informed about [S]'s Hep B diagnosis?
2. From correspondence to a GP in 1979 (**Exhibit WITN3052003**), it is clear that GPs were informed that blood products could pass on Hepatitis. Why were GPs informed of this risk but not parents of young patients?

3. Why was there such a delay in telling [S] that he had contracted HIV? He was diagnosed in March 1985 but he was not made aware until April 1986. He had a girlfriend by this stage and should have known.
4. Why was there a scaremongering campaign on the TV regarding HIV? This scared [S] and caused him a great deal of anxiety and worry.
5. Why has the government not acknowledged the failing that occurred and apologised? There was a reliance on the government to provide safe products to all patients and the government failed in their duty.

Statement of Truth

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

Signed

GRO-B

GRO-B

Dated

10/1/20