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Witness Name: GRO-B

Statement No.: WITN3786001

Exhibits: WITN3786002 – WITN3786009

Dated: October 2020

Infected Blood Inquiry

WRITTEN STATEMENT OF GRO-B

I, GRO-B will say as follows:

Section 1: Introduction

1. My date of birth is GRO-B 1939. My address is GRO-B
GRO-B I am married to GRO-B who has
also provided a statement to the Inquiry GRO-B and together we
had two sons. Our eldest son, GRO-B:S had haemophilia and died as a
result of being infected with HIV. Our son GRO-B did not have
haemophilia and is now married with a son of his own.
2. I am providing this statement in relation to S and also my brother GRO-B:B
who was also infected with HIV and died as a result of his treatment for
haemophilia with blood products.

Section 2: How Affected

My brother, B

3. My brother, B was born on GRO-B 1947. My family was
living in Ireland when he was born. When he was a baby he got a mighty

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bruise on his forehead and our mum took him to the doctor. Our parents were planning to move to England at this time, so the doctor told us to go to King's College Hospital ("King's") when we got to England. [B] was diagnosed with haemophilia at King's College.

4. There was no treatment for haemophilia when [B] was a child; it did not become available until he was a teenager. Before treatment became available, he had an incident with a scooter and was off school for nine months. The doctor told him to take aspirin, which is probably the worst thing he could have done.
5. He was first treated with Cryoprecipitate in 1973 when he was 16 years old. I recall that he received treatment from 15 donors. Following this he began treatment with Factor VIII. The records which I have recovered from the United Kingdom Haemophilia Database ([B] Records") indicate that he started receiving Factor VIII in 1977 (WITN3786002).
6. [B] friends all knew about his haemophilia. One evening he was on a night out with some friends when he felt a bleed coming on; they all piled into a van and took [B] to the hospital to get treatment.
7. In later years, [B] received home treatment so that he could inject his Factor VIII himself. He would treat himself as soon as he felt a bleed coming on. The pain [B] experienced with bleeds was dreadful.
8. At the time, [B] was not told about any risks of being treated with Factor VIII, we thought of it as a godsend.
9. The first time my husband, [GRO-B] and I became aware of any issues with the treatment was when news of HIV came on the 10 o'clock news. This would have been in or around 1983. I was completely speechless but once I found my voice I called my husband and said, "*listen to this*". We were both in complete shock as it said that haemophiliacs who were classed as severe would be infected. [B] and [S] were both severe

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haemophiliacs. Following this, [B] came round to see my husband and me. He was more worried about our son [S] than he was about himself.

10. Shortly after this, [B] was told he had HIV. He was under the care of Dr [GRO-D] at King's College Hospital. He was informed at the hospital and took it in his stride. I do not recall exactly when this was but [B] Records state that the date on which he was first positive for HIV was 2 May 1985 (WITN3786003). A document, Form AIDS/3, "*Surveillance of possible cases of AIDS Related Illness*" dated 2 April 1986, contained within [B] Records also shows that [B] tested positive for HIV on 2 May 1985. (WITN3786004).
11. A further entry in [B] Records shows that a diagnosis of AIDS was made on 15 February 1987 (WITN378005). A second Form AIDS/3 contained within [B] Records, dated 23 April 1987 and titled "*Surveillance of possible cases of the Acquired Immune Deficiency Syndrome (AIDS)*" states that on that date, his full clinical diagnosis was AIDS. This form shows that [B] had had symptoms of AIDS since July 1985 (WITN3786006).

My son, [S]

12. My eldest son, [S] was born on [GRO-B] 1973. He was diagnosed with haemophilia when he was three months old. He was bruised and, having grown up with [B] I recognised the signs although I did not want to believe that he had haemophilia. At that time, I did not know haemophilia was hereditary as [B] used to joke that he was a mutation as my other brother, [GRO-B] did not have haemophilia.
13. Until we moved to [GRO-B] in 1986, [S] was also under the care of Dr [GRO-D] at King's. He was initially treated with Cryoprecipitate; he did not like this because it was given intravenously. [B] said that he would be glad of it in the future. The records my husband has recovered from the National Haemophilia Database ([S] Records) indicate that he

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began treatment with Factor VII from at least 1977, as the records do not go back any further than this (WITN3786007).

14. Initially we were open about the fact that [S] had haemophilia. As a child [GRO-B] talking about haemophilia.
15. When [S] was about nine or ten, before we heard about HIV on the news, he came out of school limping one day. As that was a sign that he had had a bleed, I took him straight to King's College Hospital for treatment. This was a regular occurrence, but on this occasion the doctor said that he would give [S] a blood test "to make sure they hadn't given him anything else." I didn't question this at the time as I had [S] younger brother with me and had to keep an eye on him.
16. We were told that [S] had HIV when he was 12 years old. By this time, we knew that [B] had HIV. It was my husband who was told by Dr [GRO-D] that [S] had HIV; I was not present. However, I recall the doctors saying that he may build up antibodies to it [S] Records state that the date he first tested positive on 15 September 1986, but this must be incorrect as [S] was diagnosed before we moved to [GRO-B] A document titled "UK HDOC Working Party AIDS Surveillance and HIV Clinical Death Report Form" which was completed by Dr [GRO-B] following [S] death indicates that [S] first tested positive in October 1984 (WITN3786008).
17. When we moved to [GRO-B] [S] was treated at [GRO-B] Hospital and he was under the care of Dr [GRO-B]

Section 3: Other infections

18. I knew both [B] and [S] liver must have been failing as they were both completely yellow before they died, however, Hepatitis was never mentioned in relation to either of them.

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19. [S] Records indicate that he tested positive for Hepatitis C in 1993. This became evident as part of a "look back" exercise conducted of his records (WITN3786009).
20. As described below, my siblings and I were entitled to a payment from the Skipton Fund in respect of [B] therefore he must also have been diagnosed with Hepatitis C.

Section 4: Consent

21. I believe all haemophiliacs were tested for HIV soon after the news report described above. However, my husband and I were not made aware that [S] was being tested for HIV or Hepatitis C.
22. I am not sure if [B] was aware he was under the surveillance referred to in paragraph 10 above.

Section 5: Impact

Impact on [B]

23. In the mid-1980s, he began to show signs that he was unwell. He became emaciated and developed psoriasis on his elbows. At the time of his diagnosis, [B] was enjoying life. He loved cars and was in charge of a car-parts warehouse. He played the [GRO-B] and had [GRO-B] with some friends and [GRO-B]. However, his health deteriorated gradually and he had to give up his job. He also had to give up [GRO-B]. After [B] was diagnosed, he had a different attitude to things. He became a person that lived for the present day.
24. [B] was put on AZT medication. A form contained within [B] Records titled "*Form/AIDS 3 Follow-up*" dated 29 March 1988 indicates that this commenced on 7 July 1987 and he showed some initial clinical improvement as a result of this.

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25. Our family and his friends were supportive. His friends knew that he had haemophilia and HIV; they were all adults and were understanding. He never married but he did have a few girlfriends. The only time I can think of that **B** experienced any stigma was when he was working in a **GRO-B** television shop and people did not want to touch the papers that he had touched.
26. My husband and I moved from London to **GRO-B** in 1986, after **B** and **S** had been diagnosed with HIV. **B** came to visit us once in **GRO-B** but the journey of an hour and a half was too much for him and he had no energy when he arrived, he just sat in a chair.
27. **B** died on **GRO-B** 1988 at The **GRO-B** Hospital; he was 42 years old. He spent the last week of his life there and all our family went to visit him. His condition was dreadful; he was all tubed up. He was completely yellow and very emaciated. However, when I last saw him, **B** was more concerned about me getting backing to **GRO-B** than he was about himself; that is the type of person he was. Our family was devastated when he died; completely heart broken.
28. **B** death certificate states that he died of overwhelming septicaemia, AIDS and haemophilia.

Impact on **S**

29. When **S** was about 11 years old he developed an awful dry cough which never went away. Soon after his diagnosis his mouth was encrusted with candida (thrush); the inside of his mouth was completely cream and crusted over. I have to say he never complained.
30. We did not tell **S** for years that he had HIV. He was at secondary school when we eventually did tell him, and he was completely shocked.
31. He always enjoyed a laugh, especially with his brother **GRO-B** who was four years younger than him; they were always great pals. When they

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were teenagers they were out with friends. [S] friend [GRO-B] made a joke and said "perhaps [S] got AIDS". After this [S] told [GRO-B] that he had HIV. I think [GRO-B] may have told people in the village but we were lucky that [GRO-B] was a bit of a 'Walter Mitty' character who used to tell stories all the time and no one would believe what he said. We live in a small village and there was a lot of stigma around HIV.

32. As a teenager he loved going out with his friends. He was very popular and enjoyed a few drinks. He was never a moody teenager and was always ready for a laugh. I do not think he ever told his friends about his health problems. They knew he had something wrong with his blood and they accepted that.
33. On one occasion he was in Ireland on his own and noticed something on his neck. He returned immediately and I took him to see Dr [GRO-B] in [GRO-B]. It turned out he had shingles.
34. After school he went to [GRO-B] College to do a HND in Business Studies. He then went to work at [GRO-B] in [GRO-B] and got on really well there. I think he was only there for six months before his health really started going downhill but he was given a couple of promotions during this time and was working in statistics before he died. He liked his job and was popular there. When [S] died, the manager gave the whole floor the day off to attend his funeral and they all came.
35. In the April before he died he went skiing with [GRO-B] but in the summer he developed a chest infection which would not get better with antibiotics. The last two weeks before he died he was very ill. He did not want to see any of his friends and told them that he was busy with his cousins who were over from Ireland. This was not true; he was in fact in bed. His eyes were blood red; there was no white in them, and he was completely yellow. He could also barely breathe. We kept him at home, upstairs in bed, although trips to hospital were required.

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36. [S] died in hospital on [GRO-B] 1996 at [GRO-B] hospital.
He was 23 years old.

Impact on the family

37. We were all devastated when [S] died; especially [GRO-B] who was only 19 years old at the time.
38. I have tried to deal with the loss by joining things and keeping myself busy, however my husband prefers to be on his own. [GRO-B] has recently had a son who has brought a lot of joy into our lives
39. My husband and I still do not tell people about the cause of [S] death and have asked to give our evidence anonymously because we consider we would still suffer stigma within our small village if people were to find out how [S] died. [GRO-B] is married and we are close to his wife and her family. However, [GRO-B] has not felt able to tell his wife that his brother had haemophilia or HIV.
40. Recently I was joining a choir and when I gave my name to the lady who was running it she said that [GRO-B] was an unusual name and that she had only ever known one other person with this surname and he was a [GRO-B]. She was obviously referring to my brother [B] however, I did not dare say anything as I did not want her to make the connection between HIV and my family.

Section 6: Treatment/Care/Support

41. [B] dentist was reluctant to treat him and he had to go back another time in order to receive dental treatment. I remember this as he always had good teeth.
42. I have never had any psychological support to deal with my son and brother being infected by contaminated blood products and dying as a

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result of this. My husband recalls attending one session but he did not find this helpful.

Section 7: Financial Assistance

- B**
43. **B** died before the Macfarlane Trust was established. He received an attendance allowance from the Department of Social Security. After he died, our mother got an ex gratia payment from the government.
44. My siblings and I applied to the Skipton Fund in 2011 as the Trustees of **B** estate and received a payment of £20,000, which we split between us. I had a letter from Dr Roopen Arya, a consultant haematologist at King's College Hospital, attached to the **GRO-B** Haemophilia Centre, in relation to this process.

- S**
45. **S** received an ex gratia payment from the government when he was a teenager. He used some of the money to go to Ireland to visit his cousins.
46. My husband dealt with the application process for the Skipton Fund for **S**. We received an initial payment of £20,000 and a further payment of £50,000.

Statement of Truth

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

Signed **GRO-B**

Dated 24/10/20