

Witness Name: GRO-B

Statement No.: WITN3648001

Exhibits: **WITN3648002-003**

Dated:

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF GRO-B

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 9 October 2019.

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

Section 1. Introduction

1. My name is GRO-B. My date of birth is GRO-B 1938 and I live in London. My full address is known to the Inquiry.
2. I am a widower with three daughters and seven grandchildren, and I am a housewife.
3. I intend to speak about my late son, GRO-B: S who was born in GRO-B 1961 and passed away on GRO-B 1991, at the age of 30. My son was infected with HIV through blood and blood products. In particular, the nature of his illness, how the illness affected him, the treatment he received, and the impact it had on him and our lives.
4. I confirm that I have chosen not to be legally represented and that I am happy for the Inquiry team to assist me with drafting my statement.
5. The process of anonymity has been explained to me and I have opted to remain anonymous.

6. My daughter, GRO-B, was present at the meeting with the Inquiry team and assisted with translation process.

Section 2. How Infected

7. S was our first child and only boy. As a baby he had lots of severe nosebleeds and bruises that took a long time to heal. We took him to see the doctor and it took the doctors around a year to find out what was wrong with him. In 1962, when he was around one and a half years old, S was diagnosed with haemophilia. I am not sure what type of haemophilia S had, but his death certificate (**Exhibit WITN3648002**) does say 'Haemophilia A'. It was very severe and sometimes he had to use crutches or a wheelchair when he had a bleed, because his knees would swell up and he would not be able to walk.
8. As a child he was treated for his haemophilia at Great Ormond Street Hospital, and started having injections when he was around two or three years old. I do not remember the name of the injections, but they came in packets that would need to be soaked in water. Whenever he had a bump he would take these injections, as well as painkillers. We would put a cold pack on his knees to help with the swelling. S took these packets for his whole life.
9. S was also treated with blood transfusions from the age of three, because he would lose a lot of blood and feel very weak when he had a bad bleed. His nosebleeds were so heavy that the pillows would be soaked through with blood. When he was a child these blood transfusions were administered at Great Ormond Street Hospital and were given as and when he needed them.
10. I do not remember whether they informed me of the risk of infection before he had these treatments or how much blood he was given, because the doctors mostly talked to my husband. I do not remember the name of his treating doctor at Great Ormond Street Hospital.

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11. When my son became an adult his treatment moved from Great Ormond Street Hospital to the Royal Free Hospital. He continued to be treated with injections and blood transfusions. Again, I do not remember if the doctors told me about the risk of infection before he was given treatment at the Royal Free. My son and husband would talk and often would not tell me what the doctors had said; it was between father and son.
12. At the Royal Free Hospital, Dr Katherine Dormandy, the consultant in charge of the haemophilia centre, treated [S] [S] had missed a lot of school and college due to going to the hospital for treatment, so Dr Dormandy suggested he attend the Lord Mayor Treloar's College because everything was there – he could study and receive treatment at the same time.
13. [S] started going to Lord Mayor Treloar's College at some point before 1979 while he was in his [GRO-B] teens (possibly from the ages of [GRO-B] to [GRO-B]). While he was at the college he had regular appointments and would receive treatment both there and at the hospital. He stayed at the college during the week and came home on the weekends. I do not know the details of the treatment he received at Treloar's as he was an adult and did not share all of the details with us, because he did not want us to worry. I do not know if there was a particular doctor or teacher who supervised his care at Treloar's.
14. We cannot exactly pinpoint when [S] received the infected blood because he had received so many blood transfusions; every time he had a bruise, nosebleed or pain in his knee they would recommend a blood transfusion.
15. He was diagnosed with HIV at the Royal Free Hospital when he was around 23 or 24 years old. By this point Dr Lee had taken over his care from Dr Dormandy. Dr Lee had asked us all to come to the hospital and we were all in the room together when the doctor told us about the HIV. The doctor mostly spoke to my husband and I did not understand the whole conversation, but they were talking about blood and infection; all I heard was that they had given him blood and it was infected. I also remember the doctors telling [S] that it was terminal and he would die, because that is when I started to cry.

16. We later found out that [S] actually knew about the HIV before we did. He told us that Dr Lee had come to speak to him in his room and had to leave for a moment to do something. She left his medical file on the desk and [S] had looked at it when she left the room. This is how he accidentally found out that he had HIV. He said that when Dr Lee came back into the room he had asked her about it and Dr Lee explained what it meant as best as she could. I think that the doctor told him how he could manage the infection and explained that it could develop into AIDS. He kept all of this to himself until the doctors told my husband and I.

Section 3. Other Infections

17. I do not know if [S] was infected with any other infections. My late husband would have known, as the doctor explained everything to him.

Section 4. Consent

18. As far as I am aware, [S] consented to all treatment he received and was not treated without consent.

Section 5. Impact

19. [S] died 6 or 7 years after he knew that he had been given infected blood. There was a period in his life where he was doing well, but he spent the last few years in hospital. He was a very intelligent young man and was studying [GRO-B] at the Polytechnic of East London (now called the University of East London). At the end of 1990, during his final year of his [GRO-B] degree, his health really deteriorated. At this point [S] mostly stayed in the hospital, although we would bring him home on his birthday and special occasions. He even took one of his exam papers in the hospital. His skin turned black and he lost a lot of weight; he was very skinny and had sunken and hollow cheeks. His veins were very prominent and his skin was covered in open lesions. I have lots of big photo albums of [S] being happy, however it was very sad

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near the end. Although he never told us how he felt and tried to put on a brave face with his sense of humour, he had a frightened, hurt and angry look in his eyes. We have an extract written by [S] that gives an insight into the impact the illness had on him (**Exhibit WITN3648003**). During the last few months he was on a lot of medication and if you asked him a question he would just look at you and nod or shake his head – he just wasn't there anymore.

20. Although I know that [S] was receiving HIV treatment, I do not know what that treatment was, as it all happened in the hospital. As far as I am aware I do not think that [S] experienced any obstacles or difficulties in accessing treatment. I also do not know whether his medical or dental treatment was affected by his infection with HIV.
21. [S] was very popular, so the whole family would go to the hospital to visit him. The students he tutored also came to visit him. People knew what had happened and were all very empathetic and sympathetic. The Asian community is very close knit, so we did not experience any stigma; people still visited [S] at the hospital and touched him. I do not think that we experienced any prejudice or stigma on account of the HIV and our close friends and family were very accepting of it. [S] also had some very good friends who would hang out with him and comfort him – he had a lot of support.
22. Four to five weeks prior to his death, [S] was moved to a hospice in [GRO-B] called the [GRO-B]. He was very quiet by this point and did not talk to me very much – he talked more to his father. [S] passed away on [GRO-B] 1991. His death certificate (**Exhibit WITN3648002**) states as the cause of death: 1a) bronchopneumonia and 1b) haemophilia A. I do not know why HIV is not listed as a cause of death on his certificate; this is just what was given to my husband.
23. [S] was a very determined and motivated young man. He was a good student who was well loved by all of his teachers and lecturers. Following his death we received a letter from the college of Polytechnic of East London expressing sorrow at the news of [S]'s passing. He wanted to open his own [GRO-B]

and used to tell his sister that she could be his assistant. I have no doubt that he would have succeeded in this if not for the HIV, but he was unable to have a job because he was in and out of the hospital too often. He had dreams and so it is really sad that he never had the chance to achieve his goals.

24. [S]'s infection with HIV and subsequent death had a huge impact on our family. I felt helpless and my husband and I would blame each other. After [S] died we were very depressed and became quite insular, avoiding contact with the outside world. Two of my daughters were married and living with their husbands at this point, so it was just my husband, one of my daughters and I living at home. I lost a lot of weight, and my husband took on a lot of the emotional impact and got really depressed. He had been a lecturer at [GRO-B] College, but he really lost his drive once [S] died and he was less focused. He decided to take early retirement, and eventually lost the house and his business. My husband passed away in 1998.

25. The hardest part is the loneliness – my life is empty now. [S] was my only son, and although it has been 28 years since his death I am constantly still remembering different things about him all of the time. I feel the loss of my son every day and the close bond we shared was so special. He would talk to me every day and always supported me in my life. I constantly think of the life he could have had as a [GRO-B] and the family he could have had. Being of Indian origin means that I would have lived with him and my daughter-in-law when he got married. I used to have a suitcase that was filled with things that I had been saving for [S]'s wedding day since he was a boy. I remember opening that suitcase up after he died and giving everything inside of it away. It was like all my hopes for the future were gone. I feel I have lost out on a normal family life with my dear and loving son who I miss immensely.

26. [S]'s treatment was covered by his benefits, however the main financial impact is the lost potential for him to become a [GRO-B]. If my son had lived to become the [GRO-B] he aspired to be, he would have earned a lot more and I would have more financial stability. Now I live on my pension alone in a high-rise council flat. I suffer with arthritis and other ill health that prevents me

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from leaving my flat. Thankfully one of my daughters still lives close by, and she helps me with my shopping and looks after my needs. My husband losing the house and business due to our son's death also had an impact.

Section 6. Treatment/Care/Support

27. I do not think that the doctors offered our family support or psychological counselling. However, the doctors talked to my husband more than they did to me, so they may have offered it to my husband and maybe he just didn't tell me.

Section 7. Financial Assistance

28. My son received financial assistance around 2-3 years before his death. I think he found out about the assistance from a doctor who gave us all of the forms to fill in. I do not recall the name of the organisation providing this assistance because my late husband would have dealt with all of the paperwork. I remember that once [S] applied for it, he received the payment quite quickly. I do not know the total amount [S] received but there was around £46,000 left in his account a few months prior to his death, and he put this remaining money in my name. I later consented to give my husband half of this sum.

29. I do not recall there being any preconditions imposed on [S] making the application, nor do I recall there being any conditions to him accessing the money. I do not have anything else to say about the money – it's just money and I gave quite a lot of it away to charity or friends or family back in India. I also gave some of it to help people go to Mecca. My daughter thinks that I did not spend this money on myself because the money was meant for [S] not for me, but he did not live long enough to spend it.

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Section 8: Other issues

30. It wasn't just my son; there were lots of people who had infected blood. I feel great emotion and sympathy to the other people who have gone through this and to all the other mothers who have lost a child through this.

31. There are no other issues that I would like to discuss.

Statement of Truth

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

Signed GRO-B

Dated 07-02-2020

Statement of Truth

As my mother, GRO-B is not fluent in the English language (but she can sign), I, GRO-B, confirm that I have read and translated the statement to her.

Signed GRO-B

Dated 07-02-2020