

ANONYMOUS

Witness Name: GRO-B

Statement No.: WITN7370001

Exhibits: WITN7370002-3

Dated: 3/1/2023

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 26 October 2022.

I, GRO-B will say as follows: -

**Section 1. Introduction**

1. My name is GRO-B My date of birth is GRO-B 1959, and my address is known to the Inquiry.
2. I am married and my husband GRO-B and I have a daughter. I work at a scanning company which scans doctors' surgery and hospital files.
3. I intend to speak about my infection with the Human immunodeficiency virus (HIV) due to contaminated blood. In particular, the nature of my illness, how it has affected me, the treatment I have received and its impact on my family and our lives together.

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4. I confirm that I am not legally represented, and I am happy for the Inquiry Team to assist with my statement. I wish to provide my account anonymously for personal reason and family reasons.
5. The Inquiry Investigator has also explained the Inquiry's statement of approach and 'Right to Reply' procedure. I understand that if I am critical of a medical professional or organisation, they will have the right to reply to that criticism.
6. I currently receive treatment at the Royal Free Hospital, and my company usually handles files from the Royal Free Hospital. Therefore, I have prevented my files from being scanned, as this would mean my colleagues may have access to my confidential records.

### **Section 2. How Infected**

7. On GRO-B 1982, I was six months pregnant, and I attended a routine scan appointment at the GRO-B Hospital in GRO-B. My waters had broken just before the appointment, so the doctors decided I should remain in the hospital and I was admitted to the maternity ward.
8. I was rushed into the theatre for surgery because I had begun contracting, and the doctors could not stop it. It happened so quickly. The plan was to perform a caesarean section because I had given birth to my daughter via caesarean around a year before, and no one realised that it was an ectopic pregnancy until I was in surgery.
9. The doctors had to remove the baby, and the baby did not survive. No one explained what was going on to us at the time. They also performed a partial hysterectomy, which meant they took out a part of my womb.

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10. My husband **GRO-B** was with me the whole time, watching them running in and out with bags of blood. I was sedated, so it was all a blur. **GRO-B** cannot recall if any doctor spoke to him about what was happening or what they were doing. They told him that the operation was going to take a long time and that he should go out for a coffee.
11. When I came to, I was on a normal ward and no longer in the maternity ward. There was a bag of blood still connected to me via a drip. The doctors did not tell me how much blood they had transfused, but **GRO-B** believes someone, either a doctor or nurse, mentioned that I had received nine pints of blood.
12. When I gave birth to my daughter **GRO-B** I received a maternity record card which continued to be filled out even after she was born. However, this time, the maternity record card stopped recording details following this final visit.
13. I exhibit, as **WITN7357002**, my maternity record card, which demonstrates the number of times I visited the hospital, along with other details of the pregnancy and includes comments about my last visit.
14. I remained in the hospital for about a month after the operation. My daughter was only about a year old at the time and looked at me dubiously when I finally returned home because I had been away for so long. It is something I will never forget.
15. No one informed me about the blood transfusion or any potential risks associated with receiving blood. Perhaps they did not anticipate that I would require blood which is why I was not informed before the surgery.
16. Life carried on as normal after the operation and my return home but after a few years, I began experiencing various symptoms of ill health. I was suffering from joint problems and arthritis particularly in my fingers but which also seemed to affect me all over my body. I suffered weight

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loss and hair loss as well as problems with my appetite and was experiencing black spots in my vision - for which I was referred to an ophthalmic specialist following my later confirmed diagnosis of HIV. For the most part, during the 1980s and 1990s, I put up with my symptoms and did not think much of them as a whole just putting the way I felt down to motherhood and looking after a family.

17. I visited my GP practice, GRO-B on many occasions over the next twenty years, and the doctors carried out tests and considered different possible causes for this, such as lupus as I recall but nothing conclusive came to light.
18. From the mid-1990s onwards, I was referred to the Royal Free Hospital and was under the care of the rheumatology department. The doctors seemed to have run out of options and were considering taking out a gland from my mouth.
19. It had gotten to a stage where I did not know what it felt like to be healthy anymore. It was now 2003, and I was feeling very poorly. I attended the Royal Free Hospital for what was meant to be half a day appointment, but instead, I was admitted for a week, so I could undergo intensive testing.
20. Following this testing period, the doctors informed me that there was another blood test they wished to run. They took some blood, and then I was discharged to return home.
21. A few days later, I received a phone call from the hospital inviting me to return to the hospital the following day. They explained that I had to attend a different clinic at the hospital, which turned out to be the HIV clinic, but I did not know that at the time.
22. I believe my husband and I were informed that I had contracted HIV at the face-to-face appointment. I cannot remember in precise detail of



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what happened. However, I think there was a counsellor in attendance who took me to one side, and someone else also discussed it with

GRO-B

23. I do not remember the name of the doctor who informed me of the diagnosis. I believe he was only at the Royal Free for about six months. However, he tried to reassure me and handed me some leaflets to take home. I was in shock and had so many questions so the memory is a bit of a blur. I could not understand how I had contracted the infection.
24. At this point, they took blood from GRO-B so he could also be tested for HIV. We had to wait for about a week to receive the results, and although he was very worried as was I, there was nothing we could do about it. I felt terrible that I may have passed on what was thought then to be a life-threatening disease. Luckily the results came back negative.
25. No one informed us that our daughter might also need to be tested for HIV, although I vaguely recall being asked to confirm that she was healthy.
26. I believe that the doctors at my GP practice were aware that my white blood cell count was low for many years before I was diagnosed with HIV and that this was why I was referred to the Royal Free Hospital in the first instance.
27. By 2003, the media regarding HIV had improved, but I still believed that it was like I had a death sentence hanging over me.
28. Almost immediately after the diagnosis, I was prescribed medication and have been on various regimes since 2003. I was informed that my viral load was high, and I attended the hospital frequently in the first few months. I went every other day, then once a week until gradually, it became once a month.

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29. I take three tablets daily, one blue and two orange tablets. I have recently been informed by my doctor of the last 15 years, Dr Gabrielle Murphy, that there are plans to amalgamate the tablet regime into a single injection which you would only have to take once every six months.
30. Following my diagnosis, I had to have a liver scan, which confirmed that I had a fatty liver. I have never had a liver biopsy. There has been no specific follow up on my liver although I suspect it is monitored on my 6 monthly visits to the Royal Free
31. I do not have any tattoos, nor have I ever been an intravenous drug user. My husband and I have been happily married for over 40 years, and I have never received medical treatment abroad. The only way I could have contracted HIV was through the NHS blood transfusion I received in 1982 at the GRO-B Hospital in GRO-B. It is the only blood transfusion I have ever received.
32. I was informed by the doctors that it took so long for them to arrive at the diagnosis because I did not fit into the criteria and did not seem to be "that type of person".

### **Section 3. Other Infections**

33. I do not believe that I have received any infections other than HIV due to being given infected blood. However, I do believe that it has been in part responsible for the many ailments and conditions I have suffered from over the years.

### **Section 4. Consent**

34. I was unaware that I may require a blood transfusion before my operation in 1982.

35. When the doctors were carrying out the tests in 2003, I consented to the blood tests, but no one informed me that they were testing specifically for HIV.

**Section 5. Impact**

36. The news of the HIV diagnosis came as a huge shock to me. As soon as I was informed, I made an appointment to see my GP Surgery to inform them of the diagnosis. On the day of my appointment, I suddenly became nervous about standing next to people. I even saw my brother-in-law at the GP, but I would not go near him because I was concerned about other people contracting the infection from me.
37. At one stage, a week or so after being diagnosed I went to the Citizens Advice Bureau to see where I stood but I could not bring myself to talk about what had happened and I broke down and had to leave.
38. Before I was diagnosed with HIV, I suffered from various issues that I now realise may have been connected to the infection. I regularly suffered from internal thrush and various stomach related problems. Although the doctors have suggested that the internal thrush is due to my asthma, I have been asthmatic all my life and never had such problems before my operation.
39. The doctors believe that the stomach problems are due to the medication regime I take to keep my HIV viral load down. However, the stomach issues have persisted, irrespective of whatever HIV regime I am on. I have now been prescribed permanent medication for both of these conditions.
40. Two years after my partial hysterectomy, I had surgery to have my ovaries taken out due to large ovarian cysts described by doctors as the size of oranges. I do not know if these developed due to HIV or if they resulted from damage to my ovaries during the surgery in 1982.



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41. I had to take a year off work because I was very ill and adjusting to the news of the diagnosis and my new medication regime. The hospital signed me off work so I could get back in good health. I contacted the executives at my workplace because I wanted to inform them about my diagnosis, and they came to visit me at my house. I explained the diagnosis, and they were fine with it. It was a relief to be able to keep my job. I received normal sick pay during this period.
42. After returning to work, I suffered from really bad shingles and had to be signed off work for another two weeks. No one at the Royal Free attributed the shingles to the HIV diagnosis. However, I believe this is due to HIV because the infection has compromised my immune system.
43. When I had shingles I saw my local doctor, GRO-B who prescribed antibiotics which cleared it, only for it to return a week later, so I had to see her husband, and he prescribed a further course of antibiotics and I was fine after that.
44. My current employer has employed me for 38 years. When I took a year off, someone else covered my role. On my return, I had to take a lower position, but my salary remained the same as it had been before.
45. GRO-B believes that it has affected my career progression prospects because I have to take a day off to attend hospital appointments on a regular basis. He also thinks that because I am aware of how kind they have been with regard to how much time off I have, I also do not push myself forward or demand more from them.
46. Nobody knows in my family aside from my husband. It is easier to keep it just between the two of us. We are of an era when HIV and AIDS came to the fore and are all too aware of the stigma it can attract. It did not affect my relationship with my husband when we found out because we are a team.



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47. When my daughter had our first granddaughter, I was conscious about being careful, but it did not affect my way of dealing with her. I still give her hugs and kisses. My daughter as I've said, is not aware of my HIV diagnosis.
48. There was one incident where I fell over and cut my lip. The entire family was around, so GRO-B and I immediately rushed to deal with it ourselves to ensure that everyone remained safe. In a way, it affects your life as you are always conscious of that there could be a risk to others and the last thing you want to do is to cause someone to go through what we have had to.
49. I do not drink alcohol, but this does not stop us from socialising. I am not the type to let myself go that way. GRO-B does not drink among other people because he would not want to divulge any information and would prefer to remain in control.
50. At the beginning of the treatment, I lost my sense of taste and had to adjust my diet. It is back now. I have no sense of smell, but that is something I have always lacked. There were no other symptoms that I recall.
51. I deliberately did not go to the dentist for many years because I did not want to have to disclose my diagnosis to the dentist. Someone recommended my current dentist because they were known to be willing to deal with people who have been diagnosed with HIV. I have been with them for a while and have had no issues with them.
52. I do not think I have experienced stigma or been treated adversely by other medical professionals because, aside from those who have to know, I do not disclose this information.

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53. When I took a year off work, we suffered some financial loss because there was a big difference between the sick pay salary and what I earned normally. I was on about £1000 a month, and sick pay was £200, so I lost nearly £10,000 for the year I was off sick. It has also had a knock-on effect on my pension.
54. Regular travel to the Royal Free Hospital is expensive and then there is the parking as well. I have made numerous journeys in the last 20 years and never missed an appointment.
55. My doctor at the Royal Free is retiring soon, and we are considering moving to a different hospital which may be closer to home, such as GRO-B or GRO-B. However, that would mean we are more likely to run into people we may know. I would not want a situation that causes people to ask questions about why we are visiting the hospital. Even though I know it is not my fault, there is still a sense of shame because of how people still perceive the illness and I would not want others knowing my business.
56. Even at the Royal Free, I am uneasy about walking into the HIV clinic because of the stigma attached to HIV and being associated with unsavoury types of people. I worry about someone we know seeing us walking in there and the assumptions they would make.
57. We have a second mortgage on our house now, and there was no issue obtaining this. GRO-B has life insurance, but I cannot obtain this due to the HIV diagnosis. No one will provide cover.
58. We generally do not declare it on forms if we have to travel abroad. Since being diagnosed, we have only been to see GRO-B's brother in Australia. In order to travel with the HIV medication, we obtained a letter from the GP and did not have any issues with customs.

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59. After our daughter and my pregnancy in 1982, we could no longer have children. I was left with the fact that my womb was taken away from me. I was in the hospital for a month and was not offered counselling to deal with such a monumental loss. Aside from being infected with HIV, this was the most devastating thing.
60. I had come in into the maternity ward to have a child and came round on the general ward. It was like the doctors had abandoned me and **GRO-B** believed it was wrong for them to do so. I think they said their reason was that they did not want me to see all the other people with their babies when mine had not survived.
61. However, on the maternity ward, there was more care for the patient, but the general ward was not nice. It also felt to me like they were rubbing it in my face that I no longer had a baby although the intention was probably the opposite.
62. The baby was a boy, and we would have had a daughter and a son, but we have had to just get over it. We had an 18-month-old daughter who took up a lot of time, so we focused on raising her.
63. **GRO-B** was also self-employed. He ran a fish and chips van and was busy between ferrying me back and forth to the hospital for various tests and appointments and running his business. His business did suffer to an extent but losses are difficult to speculate on.
64. It felt like a relief for him when I was finally diagnosed because at least they had an answer for why I had been so ill, and things started to slowly get better. He was so supportive when I was ill and all during my hospital appointments but it must have been a strain on him as well no knowing exactly what my problem was and balancing the commitment to me with running a business to support the family.



**Section 6. Treatment/Care/Support**

65. I believe that I was informed of my diagnosis in front of a counsellor and the Royal Free advised that counselling support was available to GRO-B and me. They were very good in that respect.
66. The Royal Free were concerned I would go on to develop depression, but I don't believe I did, although I often felt low and under a cloud. I was not prescribed any medication. I was already on too many tablets and just dealt with these feelings myself.
67. GRO-B has never been depressed or had to go to the GP to discuss his mental health.
68. GRO-B and I may have heard about the Terrence Higgins Trust regarding providing psychological support but not financial assistance.

**Section 7. Financial Assistance**

69. I may have been made aware to contact the Terrence Higgins Trust for counselling assistance but not in respect of financial support. I have never applied or claimed support from any of the trusts and schemes set up for people affected by contaminated blood. Nothing was ever mentioned to me by any medical staff.
70. I have tried to obtain my medical records from the GP and the GRO-B GRO-B Hospital in GRO-B where I received the blood transfusion. I am now aware that the hospital records have been destroyed. The GP gave me a subject access form to fill out to begin the process. I have now received a letter from my GP which is a copy of a discharge letter dated 20.01.83, signed by Dr GRO-B. In the last paragraph it confirms that I required a blood transfusion. I produce this as **Exhibit WITN7370003**.

71. I am now aware of the English Infected Blood Support Scheme (EIBSS). I learned about the EIBSS from the news, the internet and the Inquiry registration form. I downloaded the form and filled in what I could before leaving the form with my doctor at the Royal Free Hospital to fill in their section. That was in late September and apparently their legal team are having difficulty authorising the endorsement from the doctor although we have been assured that it will be done.
72. When I spoke to the Royal Free initially, they did not seem to be forthcoming with information, and we had to conduct our own research. It would also have been helpful for someone to approach us to inform us that this was a type of support available to us.

#### **Section 8. Other Issues**

73. Due to what has happened to me, I would not go back to the GRO-B in GRO-B if I had a choice, but I have been happy with my care at the Royal Free. It has not affected my faith in the NHS as my treatment on the whole has been good. I do not believe that I was deliberately infected – I needed the blood at the time, or that any possible treatment had ever been denied to me.
74. I was dubious about coming forward to tell my story to the Inquiry because I did not at the time have any records to prove my story. I am lucky that I have recovered proof of my transfusion but what about the others who have not?
75. I would like someone to acknowledge that a mistake was made. The way I look at it, I went into the hospital pregnant to have a baby, and I came out infected with HIV. I have had to live with that for many years and the prospect of death was never far from my mind, albeit life is now fairly normal. But it wasn't always. In the early years there was the worry of what would happen to my husband and my daughter and how long did I have left? This all takes a huge physical and emotional toll.

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76. The infected blood scandal is terrible. The government has to acknowledge that it has not just been haemophiliacs impacted by this, and there were many other reasons people were given infected blood.
77. Why did we have infected blood in the UK? I hope they have learned from what has gone wrong and never make the same mistake again.

### **Statement of Truth**

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

Signed

GRO-B

Dated

3/1/2023