

Anonymous

Witness Name: GRO-B

Statement No: WITN6943001

Dated: 18 March 2022

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 30 November 2021.

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

Section 1. Introduction

1. My name is GRO-B and my date of birth is GRO-B 1960. I live in GRO-B London and my full address is known to the Inquiry. My late wife GRO-B: W and I got married in GRO- and we had two children together.
2. I lost both my wife W and my daughter, GRO-B: D, to HIV/AIDS. I intend to speak about the loss of my wife and my daughter to HIV and my family's infection with HIV, which I believe W got as a result of receiving a blood transfusion or blood product during childbirth. My son and I were also infected with HIV as a result of my wife's infection. I will speak about the nature of our illnesses, how it affected us, the treatment we received and the severe impact it had on our family and our lives together.

3. I confirm that I am not currently legally represented and that I am happy for the Inquiry Team to assist with my statement. The Inquiry Investigator has explained the 'Right to Reply' and that I understand that if I am critical of a medical professional or organisation they will have the right to reply to that criticism.
4. I have had the Inquiry's anonymity process explained to me and I wish to remain anonymous because of the stigma associated with HIV and to protect my son and his family.
5. I wish to acknowledge that naturally as time passes, memories can fade. I have been able to provide approximate timeframes for matters based on life events. However, these timeframes should be accepted as 'near to' rather than precise dates.
6. My late wife's name is and her maiden name was . She was born in Italy on 1962. We got married in in Italy after meeting in London. She was working here at the time because her brother owned a restaurant. I came to London in 1987 to study English because I needed to speak English for my work. I was an artisan pasta and biscuit maker. As there was a near where I come from in it was important for me to learn English properly . There were lots of different kitchens and I needed to be able to speak English in order to take my products there. So that was the reason why I came to England, to learn English.
7. I met my wife the year after I came here in 1988. later we got married in Italy in . After we were married, we stayed in Italy for nearly a year and then returned back to England in . In 1992, we bought our own house in . I was studying and working part-time at the same time. After I met my wife, I started working at her family's restaurant.

8. I am not currently working because I have a lot of medical problems, including a trapped nerve in my arm that causes a lot of pain as a result of carpal tunnel syndrome. The nerve is trapped in my spinal cord which might require surgery at some point. I also have pain on the left side of my leg because of a stroke I suffered in the past where I lost sensation in my left hand. I have arthritis in my hands and knees. I am also diabetic and I have severe heart problems. Having suffered a heart attack in 1998, I had a stent inserted to open up a main artery. I am HIV positive for which I take medication every day.

Section 2. How Infected

9. When my son was born on [GRO-B] 1993 at Lewisham Hospital, my wife lost a lot of blood during the delivery having suffered from a haemorrhage. As a result, she was put on a line to give her a blood transfusion to replace the lost blood. She was on these transfusions for at least two days. After the second day of the transfusion she was a little stronger and we were allowed to go home. She had follow up visits at home.
10. We both found out that we were infected with HIV in 1994, one year later following the birth of our son, under incredibly tragic circumstances which I will explain fully later in this statement. At that time, I didn't make the connection between HIV and the blood transfusion. Even in our discussion with the doctors about [W] HIV, we did not discuss that it could have originated from a blood transfusion and as I recall the route of infection was not discussed. My view at the time was that we had it and we couldn't change that fact. It wouldn't have given us any help in that moment, that was my instinctive reaction. The main thing at that moment was to look after ourselves.
11. Now, however, I realise that the blood my wife received must have been infected. Other sources of infection are very unlikely. I never took drugs and I don't even drink. My wife was the same. In that regard we were

quite an unusual family for that era. Neither of us had any tattoos. We were both heterosexuals and we didn't get infected through any previous relationships.

12. The only other remote possibility is that we contracted it from the dental surgery in GRO-B as I always feared that they weren't disinfecting the equipment they used properly and I didn't think the dental nurse was very hygienic in her practices. Initially, I thought that was the source of the HIV infection, that was one of my suspicions at the time. It was only later after the initial shock of being given the news that I started to think about how we might have got it.
13. Even later on, when I heard on the news about the scandal of infected blood, I thought that it only referred to events that happened in previous decades. However, now with the benefit of hindsight, I am confident that my wife was infected via her blood transfusion during childbirth. Looking back, and hearing about the work of the Inquiry, has allowed me to connect the dots. This is especially true because I remember my son was strangely and inexplicably ill when he was a young child. That is why his spleen was enlarged and was causing him problems because he was fighting an infection. However, an HIV test was never done at that point and we didn't know about the HIV infection until later on, but my son had health problems before D and W were diagnosed with HIV.
14. I was getting more prone to colds and skin problems which I had never had before. W used to say maybe the London air is not good.
15. To the best of my knowledge, my wife had never had any previous operations requiring a blood transfusion, other than following the birth of our son, when she haemorrhaged. Neither have I had any operations or transfusions.
16. Therefore, I think there is a strong possibility the route of infection was when my wife received a transfusion when she haemorrhaged during the birth of our first child.

17. I don't know of any other way we got infected and I know there is no other way because I knew my wife and I know about my life and our life styles, we never did drugs and all the people we knew back then are all fine. We discussed whether it could have been someone either of us had been with before we were married, but they were all fine.

18. My wife breastfed our son for at least 3 months before she fell pregnant with our second child and I believe that is how he became infected with HIV. When she was breastfeeding [D] she sometimes let him breastfeed and have a cuddle too as he was a little bit jealous of the baby. We were later told that HIV can be passed to a child through breast feeding [W] blamed herself thinking that maybe our son got infected that way but he was having some problems already and we had to take him to the hospital because of an enlarged spleen which I mention in more detail later. She blamed herself for [D] as well because [D] was the point at which we learnt that we were infected.

Section 3. Other Infections

19. I do not believe that my wife was infected with any other infections other than HIV as a result of her treatment with blood and blood products during the birth of our son. I also don't think that I was infected with anything other than HIV as result of my wife's infection.

20. I have been told by King's College Hospital that I have Hepatitis B antigens but it doesn't cause me any problems and I have never been formally diagnosed with Hepatitis. I think maybe I had a Hepatitis B vaccination at some point hence the antigens.

Section 4. Consent

21. I do not believe we have been tested for anything against our will or without our consent for the purposes of research. I consented to all the

medical trials for the HIV treatments that I was offered. In fact I actively asked to be put on trials as there was no cure I wanted to try new medication routes.

Section 5. Impact

22. One day in 1994, when my wife was breastfeeding our daughter who was about GRO-B months old at the time, she woke me up and told me that D was not breathing properly. D's lips were purple and we knew that there was something terribly wrong. It looked as if she was drowning. We went to King's College Hospital immediately. They measured her oxygen levels which showed they were very low. She was admitted to a paediatric ward called the Variety Ward, where she stayed under observation because she was not responding to treatment up until her death. They started to do various tests to understand what was happening to her. Initially, they didn't find anything wrong other than her breathing problems. Then they discovered she had fluid in her lungs, so they told us that were going to puncture her lung to try to drain the fluid. They drained the fluid from her lungs, but she still wasn't getting any better. Her face had become swollen and she had a large haematoma on the back of her head as she was constantly lying in bed.

23. Dr Colin Ball, a Consultant, from King's College Hospital told us that he did not know what was happening to her. At that point, he asked us if he could do a test and explained what the test was and told us that he was obliged to ask for our permission before carrying out the test. He said he didn't think that it could be that but he didn't know what else to think as she was not responding to other treatment. We consented to the test and he did an HIV test which came back as positive.

24. He advised us that we also needed to be tested, including our young son. My wife was absolutely distraught.

25. [D] was just [GRO-B] months old when she died on [GRO-B] 1994. On her death certificate, the cause of death is stated as 'interstitial pneumonia' but it does not mention HIV/AIDS or any other cause. I think this was the correct decision given the era she died in and society's view of HIV at that time. The doctors suggested the cause of death didn't need to be listed as 'HIV/AIDS' on the death certificate because of the stigma surrounding it at the time but they did ask us and give us the option to include it if we wished.

26. All three of us, me, my wife and my son also tested positive for HIV. They told us that they were really sorry and that the virus was incurable and that our life expectancy for the entire family, was just six months. They tried their best to reassure us. They told us that we would get help from the government under a 'special rule' for people with a terminal illness and a very short life expectancy with HIV/AIDS.

27. By this point, [W] was already understandably very unwell and depressed because our baby had died. She was crying every day and was totally destroyed by it, as was I. She would dream about our daughter every night. I remember vividly that she would tell me stories about how she dreamt that [D] was there with her.

28. [W] immediately started treatment for HIV. However, the medication she took wasn't effective. Subsequently, she got Cytomegalovirus. HIV totally destroyed her immune system. At that point she had gone on to develop AIDS. She completely lost her eyesight about one year before she died. On one occasion [W] dreamt that [D] had scratched her eye. She would take lots of injections to manage the condition including injections actually into her eye to get straight to the infection. Unfortunately, nothing worked because her immune system was so compromised.

29. I remember at one point I saw maggots coming out of her intimate parts shortly before she died. She was at home at this point but I didn't mention

this to the hospital. She went back to hospital but when this episode happened she was at home. She had lost so much weight and she was just skin and bones.

30. [W] died in hospital and I was with her when she passed away. I remember holding her hand and feeling it going cold. I knew she had died. I remember calling to the nurse, "I think that my wife has died."

31. When [W] died on [GRO-B] 1997, I went crazy. I was inconsolably upset. We were the perfect family and we were really happy. We had one daughter and one son; that was the perfect combination, especially for us as Italians. But then, all of a sudden, within just a few years, both my daughter and wife died. My son who was only three years old, had lost his mother. I cried for five years after my wife died.

32. Now it was just me and my son left. So, I had to think about living our lives as best as we could. I had to explain to him that his mother had died. I told him she was in the sky and was looking over us. I explained the concept of angels and heaven to him. I told him it was okay if he wanted to cry because I wanted to cry as well. We cried together. I told him we had to get our strength to carry on because that is what his mother would have wanted. I put all my energy into my son and taking my medication to get better.

33. When he was around 7 or 8 years old, I explained to my son the implications of his HIV diagnosis. I explained that his mother had died from it. I also told him not to tell anyone about it, including his friends and teachers, because people would treat him badly if he did tell them. I told him he had to take his medication and that it was a serious responsibility. That is the part where I think he needed a female figure in his life to help explain everything to him.

34. It was really tough for me to look after my son by myself after [W] died. At one point, soon after [W] passed away, I even considered having my son adopted because I felt I was unable to bring him up as a single

male by myself. I felt that I couldn't cope in the way that he needed me to. I didn't have much family support because they were afraid of getting infected themselves. The family helped a little by for example, sometimes looking after him one day a week often at the weekends. That was when I realised that I needed to find a woman in my life as my son needed a female figure in his life. I could be a good father but I couldn't be a good mother which is what I felt he needed.

35. After realising this, I made efforts to meet someone. I made my own website for people living with HIV. I knew that I could only date someone who was also HIV positive as I could not risk infecting someone else and this is something I felt very strongly about. What the virus had done to me I didn't want it to happen to anyone else, for me it would be like attempted murder to infect someone. There were groups in London at the time for people with HIV but they were for a different target group and it was not for me.

36. I met my second wife through the website that I set up and we got married in GRO-B My son was only ten or eleven years old when she came into our lives and they have a very good relationship and they bonded with each other. He calls her 'mum' and he has a half-brother too, as I had a child with my second wife, who is now 14 years old. However, unfortunately, I am currently going through a divorce with my second wife as we are not compatible.

37. Now that my son is himself a dad, he still makes efforts to remember W He even superimposed a picture of his mum along with a picture of his new born baby, with them both smiling. The picture looks like she is holding his baby. He took a picture of his baby and a picture of W which I had in my loft, and combined the two pictures. He paid someone to make it into a watercolour which is beautiful. When he showed me the picture, I didn't realise who it was at first. It made me incredibly emotional to see that. He also has a tattoo dedicated to his mum on his chest. He has a very fervid memory of his mother and it is still very much alive today.

He remembers every single moment, even though he was so young. There was a lot of crying when she died because of that.

38. When my son was growing up, I gave him everything he wanted, all the games and all the toys. I did that for him because he had suffered so much by losing his mother, so I never hesitated in getting him what he wanted. At one point, we even got a dog called Rex to help make him more responsible, as he would have to take care of the dog too. He did it really well for a year, but then he didn't want to continue looking after the dog, once he was bored of doing it and the novelty had worn off. So, eventually, we gave the dog away as we couldn't look after it. I really missed the dog, he was a beautiful white German Shepherd cross but I wasn't able to look after him, so I had to find a home for him.

GRO-B

GRO-B

39. My son has suffered physically and psychologically as a result of having been infected with HIV and losing his mother at such a young age. He was a clever boy at school but it had an impact on his schooling because he didn't always do his homework. I wasn't able to keep on top of his homework, I think if his mother was there he would have been a more proficient student.
40. Imagine going to school when you are very young and not having a mother to collect you. He just had me to pick him up and the children noticed that and picked on him.
41. We had to attend hospital regularly for medication and check ups to monitor his viral load. If he had to miss school for medical appointments we had to provide a letter from the hospital for the school. They didn't state the reason on the letter as we were not obliged to tell the school.
42. We suffered from some stigma associated with HIV and AIDS. I completely lost touch with many of my friends because they were afraid of getting HIV themselves. We found out who our real friends were through this experience. My brother-in-law's wife told us that she could

no longer visit us because me and [W] had HIV. She was too afraid. Before we got HIV, [W] brothers would come to our house every day. As she was the older sibling, she was like a second mum to them. After the diagnosis, they stopped coming so there was a definite change. Also the wives of the brothers would be at my home most days but this all stopped after our diagnosis.

43.No one knows that my son is HIV positive except his partner. His partner is not HIV positive. As his virus is undetectable, he cannot infect her with it. That is the medical advice from the doctors. However, we had previously always agreed that he should only be with someone who was already HIV positive so that he couldn't risk infecting that person too. Luckily, his partner is very understanding and it is not a problem for them. As we have tended not to tell people unless they needed to know about our HIV status, the stigma we have suffered has been limited. For example, there was no impact for my son when he was at school as the school did not know. Neither the teachers or other parents knew.

44.The other area this impacted my family was in relation to my career prospects. Before we were infected with HIV, I was studying to become a computer engineer and qualified as one. I was on track to get a good job with a decent salary. I had completed my Diploma and my NVQ's. My qualifications were exactly what they wanted at a site in Essex which was going to be a base for the European Commission. In the end, I never applied because of everything that happened soon after I qualified. I enquired about jobs and at that time the salary was £50,000 with a car, holiday pay and benefits. However, everything got derailed and the opportunity vanished as [W] was not well.

45.HIV has also, in my opinion, changed my metabolism. In turn, this has affected my eating habits and caused significant weight gain. As a result of this I underwent bariatric surgery in 2019 because I was basically dying as I was too overweight and was diagnosed as being morbidly obese.

46.I also developed diabetes Type 2 as a consequence of being obese.

47. My son's viral load is undetectable, he takes his medication but sometimes he isn't punctual with his hospital appointments. Sometimes the hospital call me to remind him that he has an important appointment. They phone me because they have known us both for so many years and because I am his dad. He also has to attend appointments for his damaged kidney.

48. My son doesn't want his name to be published in my statement because he has a family and doesn't want people to know about his HIV infection, but I have nothing to be ashamed of as none of this was my fault and our family was destroyed. I wish to respect my son's wishes and have chosen be anonymous and I don't want my name published.

Section 6. Treatment/Care/Support

49. The medical support and treatment we received at King's College Hospital has been first-class. After our diagnosis, the hospital directed us to a charity, the Terrence Higgins Trust, who have helped us greatly over the years. They even provided us with respite holidays and helped financially with bills and advising us on what benefits we were entitled to. They signposted us to a lot of information and support even more than what we needed. Whenever they offered support for my son, I accepted it. The hospital and the Terrence Higgins Trust also organised psychological support for us.

50. As mentioned earlier when we were given our HIV diagnosis we were told that our life expectancy at that time was 6 months. As a result, we were provided with a lot of help and we were told that we wouldn't need to worry about bills, everything was taken care of, and the government benefits we received covered our bills and outgoings. We didn't have to pay for our mortgage as the Terrence Higgins Trust advised us how to get the right housing benefit which paid the monthly mortgage.

51. For treatment and tests we attended the Caldecot Centre which is a sexual health clinic at King's College Hospital, usually every month. We attended on a day that was specially designated for families. We were given a separate room away from others. I feel that we were treated respectfully.
52. Initially, after we were diagnosed with HIV, they told us there was some treatment available, but ultimately that the infection was incurable.
53. When my son was about three years old, he had to take medication called Septrin which he inhaled, to protect his lungs. It came in powder form and had to be mixed with some transparent liquid. It was very harmful to him so we stopped it. He would constantly throw up after he had inhaled the medication. I thought that the medication could kill him. It was actually discovered afterwards that it had in fact killed some children and it was discontinued.
54. My concentration and focus was on finding new drugs and I was constantly doing my own research. Sometime after my wife died, I found out on the news that a doctor in Milan, had produced an experimental injection drug to treat HIV. I did my research and discovered there was this experimental vaccine developed by Professor Gringeri, and who had discovered the medication. I told King's College Hospital about it and asked them to access those drugs. Fortunately, the doctor in Milan and King's College Hospital collaborated so that me and my son could get the drugs.
55. I contacted Professor Gringeri and he told me to come and see him in Milan. So my son and I went to Milan as my sister lived nearby. He suggested that he asked Kings College Hospital if he could send the batches of the medication there, otherwise, we would have had to travel to Milan for the injections.
56. I spoke to my Consultant, Chris Taylor at Kings and explained the situation to him and told him that the professor in Milan was willing to

send the injections to Kings College. He agreed to this and there was no money to paid for the treatment because it was given on a compassionate basis. The transfer of the medication from Italy to the UK was arranged and handled by the 2 consultants. My consultant Chris Taylor was a saint to me because he was always willing to help and accommodate my requests in any way he could.

57. The medication had to be transported to the UK in dry ice and was delivered to King's College Hospital where we had to go and collect it. The hospital would not administer the drugs but they showed me how to inject it and wanted to see that I could administer the injections. I was then allowed to administered the drugs at home.

58. We had to store them at the right temperature in the fridge. We completed the entire course. At that time, although we were doing fine, our HIV viral load – although decreasing - was still present but under control. We continued to take the medication.

59. At this point, I wanted to work out which course of medication, my normal combination pills or the injections, were the effective treatment in controlling my viral load. To do this, after I had finished my course of injections and waiting for a further two months, I stopped taking my combination pills. As soon as I did that, I noticed my viral load increased on my next blood test results. That implied to me that it was the combination pills, not the injections, that were responsible for controlling my viral load. I took this unusual course of action of temporarily stopping one of my treatments, because I was desperate to find out which set of medications was working for me to find a cure. I didn't tell the doctors that I did this until afterwards. They told me that they would not have sanctioned what I did, but were interested in the results it showed.

60. At the beginning there were only 2 drugs at the disposal of the NHS; one was AZT and I am unable to remember the name of the other one. Some of the medication offered to me under the NHS, to treat HIV was offered on drug trials for which I was willing to take part as I wanted to clear the

virus. I was always willing to try any new trials if previous drugs were not working. It was a collaborative effort between patients and clinicians.

61. Eventually we found a combination that worked for me so it was no longer experimental. They check for resistance and try to determine which one is right for you. My viral load was decreasing.
62. My son was about 7 or 8 years old when he first started taking medication to treat HIV. My son was one of the first, indeed if not the first, to take HIV medication for children in this country. I asked for him to be treated with the same combination I had at that time because it was working. They provided the same medication as me but in syrup form and in a proportionately smaller dose.
63. One of the side-effects of the medication is that he grew crystals in one of his kidneys which gave him kidney damage. Unfortunately, it was not picked up on the blood tests before damaging his kidney. It should have shown up on the test but there was some anomaly there. His kidney was punctured when he was still at primary school by the crystals and he has serious kidney damage as a result. I stopped taking that particular HIV treatment because it also gave me similar problems, whereby it became very painful to urinate and caused me bladder problems.
64. My viral load for HIV is currently undetectable. I take my medication regularly and I never miss a dose. I know that it works because when I stopped taking the medication my viral load shot up. I have been taking the same medication since the end of the 1990s.
65. I think the reason why my wife was unable to respond to HIV treatment was down to her genetic make-up, whereas mine and my son's viral load did come down. Although our CD4 cells would often go lower than normal, our CD8 cell levels were always very high. CD8 cells are those cells which trigger immune defence by causing cell death, and thereby, killing off infections.

66. My wife was very thin and frail when she died. I decided that I was going to keep weight on to stay strong as most people who died of AIDS were very thin.

67. Overall, I have found the level of service and treatment at my hospital to be fantastic. I can't say anything negative about the NHS.

Section 7. Financial Assistance

68. I have not applied to access any financial assistance from any schemes other than the Terrence Higgins Trust who have helped me. I also receive government benefits. As mentioned before the Terrence Higgins Trust advised and directed me as to which benefits I was entitled to apply and they also helped fill the forms in.

69. I am not aware of any other support schemes that may have been available to me and I was not given any information by anyone about any other schemes other than the Terrence Higgins Trust.

70. There is a welfare worker based at the Caldecot Centre who helped me to get the benefits I am entitled to.

71. When I had to give up working because of the virus, I received incapacity benefit, income support and Disability Living Allowance which is now called ESA but I am no longer entitled to ESA because they say I haven't worked for 4 years, despite my Welfare Officer telling me I am that I am entitled to it .

Section 8. Other Issues

72. My view is that everyone who has been infected and affected by contaminated blood should get compensation because they ruined our lives. If they kept using the same companies to source blood despite

previous incidents of blood-borne infections, then that is unforgivable and they should be convicted for that. If they used a company that was unreliable and didn't carry out tests to see if the blood and blood products were safe then that is criminal and unforgiveable.

73. I want to know where the blood products came from and why it was used for such a long period of time. It is not just about me and my family. I want to know if this is still happening to other people who still are not aware that they have been infected. Maybe there are still people being infected today, I don't want to think about that.

74. I have been looking at how other countries in the European Union and the wider world, handled their blood scandals and in Italy the Terms of Reference included infection in the nineties.

Statement of Truth

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

Signed

GRO-B

Dated

18-03-2022