

ANONYMOUS

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Witness Name: GRO-B

Statement No: WITN0930001

Exhibits: WITN0930002 - WITN0930006

Dated: 11th September 2019

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 25th April 2019.

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

Section 1. Introduction

1. My name is GRO-B. My date of birth is GRO-B 1951 and I live in GRO-B. My full address is known to the inquiry. I am retired and I live with my second husband, GRO-B GRO-B who is a retired teacher. I have one daughter from my first husband, GRO-B: D, GRO-B who was born on GRO-B GRO-B 1976.

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2. I intend to speak about my daughter's infection with HIV, which she contracted as a result of a blood transfusion in 1981 during open-heart surgery to treat an Atrial Septal Defect. She was 4 years old.
3. In particular, I intend to discuss the nature of her illness, how the illness affected her, the treatment she received and the impact it had on our life as a family.
4. Prior to the infection, my daughter was a confident young lady who was happy and healthy and full of life.
5. I am not legally represented, I am happy for the Inquiry team investigators to assist me with my statement.
6. Both my daughter and I request full anonymity.

Section 2. How Affected

7. I married my first husband [GRO-B], in [GRO-B]. Shortly after we were married, I had [D] on [GRO-B] 1976 at [GRO-B]. [GRO-B] She was three weeks early and was a small baby, only weighing about six pounds.
8. I knew that something was wrong early on as she didn't feed very well, she didn't have the energy to suckle and after about three or four months I had to change to bottle feeding. This did help a little but she wasn't growing properly and she wasn't putting on weight well. She would also sleep for what appeared to be 20 hours a day. On reflection this was not normal for a healthy baby.
9. When she was six months old, our GP detected a heart murmur and she was referred to [GRO-B] Hospital in [GRO-B]. [GRO-B] They monitored her there for about six months, but after about a

year it was clear that she was not progressing or thriving, and so they referred her to Paediatric Cardiac Department at GRO-B Hospital under Magdi Yacoub.

10. They put her under investigation and they admitted her for a cardiac catheterisation under general anaesthetic. They diagnosed her with an Atrial Septal Defect with a hole the size of a penny and an enlarged heart.
11. The registrar told me that without an operation, D wouldn't live past thirty years old. It was terrifying to think of my daughter having such a short life, and it was agreed that she would have the surgery but that it would have to be delayed until some time before she started school.
12. My husband had just taken a new job in the local government in Northumberland at the time and so we moved up there. D's care was transferred to the Freeman Hospital in Newcastle upon Tyne.
13. In early May 1981, I signed the surgery consent forms and D was admitted to the Freeman Hospital for the open-heart surgery to treat her Atrial Septal Defect.
14. The staff were fantastic and they were very kind to us. Prior to the operation, they gave us a tour of the intensive care unit (ICU) so that we knew what to expect and so that we wouldn't be shocked. They gave me accommodation while D was there as well so that I could be with her at all times.
15. The surgery itself went fine and D was in the ICU for about two or three days and then she returned to the ward. After the operation, the ward staff told me that she had received four units of blood during the procedure to replace blood loss and to prevent anaemia.

16. The staff on the ward were excellent and encourage me to be involved in D care. They showed me how everything worked and explained what would happen to D .
17. She was on the ward for just over a day, and then, while I was with her, her lips started to go blue and so did her fingers. She was just lying there, not responding, she had gone into cardiac arrest. I called for help immediately and a crash team came in straight away and revived her with a shot of adrenaline. It was terrifying. D was only just over four years old and they said that she was on the verge of slipping into a coma. I was so scared, I thought that my worst fears were being realised and I was losing her in that moment.
18. Eventually, D recovered and they allowed her to come home after spending ten days in hospital. I was so relieved after everything that had happened, I remember my mother coming up from Suffolk with a bottle of champagne to celebrate the success of the operation.
19. A few days after we had come home from the hospital, D became very unwell. She had a high fever, sore throat, headache and aching limbs. I phoned the ward at the Freeman Hospital and they told us to bring her in immediately. We drove straight to the hospital where they were waiting for us at the door and they took D straight up to the Paediatric Cardiac ward.
20. They kept her under observation on the ward for two days where she improved. They told us that they couldn't find anything specific wrong with her and that it was just a viral infection. Upon reflection and having spoken to my current GP, I and he now believe that this was seroconversion and the HIV beginning to take effect.
21. She came home after a couple of days where she carried on making good progress.

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22. As I have said earlier, before the operation [D] was very tired and slept for most of the day, she was not very sickly. After the operation, she had significantly more energy but she suffered from a lot of infections after that point. She had whooping cough a couple of months after she had come out of hospital. It was very painful for [D] as it put a lot of pressure on her chest, it was absolute agony to watch her go through it and I would have given anything to take the pain away from her.

23. She contracted all of the normal childhood infections such as ear infections, throat infections, roseola, chicken pox, tonsillitis and she had her adenoids removed. She was always getting coughs and colds and she would often faint at the drop of a hat and have heavy nosebleeds.

24. The long list of infections went on and on and that became the normal for us, there was nothing strange about the infections in themselves but it was the frequency that she had them, which was a concern for me.

25. She was still making good progress though when my husband took up the position of [GRO-B] and we moved down. [D] continued to have her heart check-ups at Derriford Hospital and when she turned eighteen, they decided that she was well enough to be discharged from these check-ups.

26. I never thought of [D] as a sick child, it was when she had her third set of grommets put in that I became really concerned. I didn't have anything to compare her illnesses against, she is my only child and I didn't have any close friends who were mothers, so at the time I didn't think that it was particularly unusual.

27. She took time off school when she was sick, but I wasn't aware if she was spending more time off than the other children. The school never made any comments about it, it just became normal over time. I never

thought or suspected that these infections were as a result of her operation.

28. D did well at school and went on to study GRO-B at King's College in London. In 1996, towards the end of her second year at University, she had a lecture on blood borne diseases. This was around the time when people first began discussing contaminated blood, when she heard the timescale she realised that she fell into the group at risk of infection. She got herself tested straight away, and she tested positive for HIV. This was when our life changed.
29. She came back home for the weekend to see me as soon as she could, and she stood in the kitchen and said "I've got something to tell you". At that moment, I thought she was pregnant, then she told me that she was HIV positive. I was devastated. I couldn't believe it, I asked her how it had happened and she said she didn't know.
30. I was so shocked and completely battered, at this point HIV was still considered to be a death sentence. I didn't understand at all, she didn't fit any of the risk categories, she didn't have any piercings or tattoos and never took any kind of drugs. She told me that she had always been sensible in relationships and she was never promiscuous.
31. I thought I was going to lose her when she went into cardiac arrest and when she told me that she was HIV positive I was scared that this was the time that I would lose her. I'll never forget that weekend, we were both like zombies, in constant tears and total bewilderment.
32. I was at a loss when she went back to London, I couldn't process what was happening and I still don't know how I managed to carry on with my life at the time. D told me that she had an appointment at St. Thomas' Hospital in London and I said I would go with her, I didn't want her to go through any of this alone.

33. I remember sitting in the waiting room of the HIV clinic at St Thomas', it was a shock to be sitting there. It was a horrendous experience and [D] was horrified to be sat there. I really felt for her at that time, we had been suddenly thrown into this completely different world that was so far away from our own. It didn't feel like we should be sitting there, it was an entire part of life we had never been associated with or ever expected to be, and now we were part of it.

34. I cannot remember seeing any other women in the waiting room, it was clear that [D] stood out.

35. The woman at the HIV clinic was very nice, and she told us that [D] infection wasn't severe and that she probably wouldn't need treatment for a while. They said that they would monitor her with regular blood tests.

36. I remember asking specifically if the infection could have come from the blood transfusion, which [D] had in 1981. We had just begun to hear reports of people being infected with HIV and Hepatitis C from infected blood and blood products and that had been my first thought when [D] had told me that she was HIV positive. The female consultant said that it was extremely unlikely that it was from the blood transfusion and was very emphatic about that; she said that [D] had "just been unlucky".

37. [D] carried on with her degree and came out with good results. She was and still is a very determined young lady. She got a job working in environmental health as soon as she graduated. She always kept her career moving, even doing a post-graduate degree and loved every minute.

38. She moved out of London to [GRO-B] and met her now ex-husband. They got married and [D] became pregnant. She had a truly awful pregnancy as she had to take specific drugs to prevent the HIV from transferring to the baby. They made her physically sick throughout

the pregnancy, but as always, she was very determined and wouldn't let the HIV stand in her way. She never wanted to be a victim.

39. She had to have an emergency caesarean in Birmingham as GRO-B Hospital couldn't handle the HIV, and her daughter GRO-B was born three weeks early in GRO-B 2006. Fortunately, GRO-B tested negative for HIV. D was unable to breastfeed because of the HIV and she soon developed post-natal depression. Her caesarean wound also became severely infected and she had to receive treatment for that.

40. After a while, her marriage started to deteriorate and she decided to move back to GRO-B and got a job with the local council. She was still experiencing a lot of infections. She had pneumonia, kidney infections and ear infections, it was another long list of things that were going wrong with her.

41. She went to the HIV clinic at Torbay Hospital where they insisted on testing her for syphilis and other STIs. It made her feel awful and they insinuated that it was her lifestyle that caused the HIV infection. We could never understand where it came from, and every medical professional we spoke to refused to acknowledge that it could have been a result of the transfusion she had received.

42. It was not until D applied to the EIBSS, which I will explain in detail later in my statement, that we finally received an answer. After the laboratories at the Freeman Hospital confirmed D blood transfusion, she received an email from the EIBSS dated 13th February 2019 saying 'that they were pleased to inform you that your application for HIV payments has been approved'

43. It was incredible. All those years of D blaming herself, thinking that she had picked the wrong guy at the wrong time and been unlucky, were so unnecessary and finally over. It was a truly amazing moment

to hear that the transfusion was the probable cause. We were over the moon to hear that what we had suspected all these years was true.

44. is on anti-retroviral drugs now and her HIV is undetectable, but she still suffers from a lot of problems even now. She has had terrible gynaecological problems and terrible migraines. Most recently, she woke up and one of her eyelids had drooped. Her whole immune system has been weakened and every time she has any kind of invasive treatment or procedure, she gets an infection. We both know that she will always have to live this way.

Section 3. Other Infections

45. I am not aware of having received any infection other than HIV.

Section 4. Consent

46. I consented to the open-heart surgery, which had to treat the Atrial Septal Defect.

47. As far as I'm aware consented to all tests and treatments and was not tested or treated without her knowledge or consent.

Section 5. Impact

48. Until 1996, I had a happy daughter who was about to start her life out in the big world. Everything changed completely when told

me about what had happened. After the first appointment at the HIV clinic at St. Thomas' Hospital, I was overwhelmed by the feeling that my daughter's life would be over in a matter of years. I was completely battered and shell-shocked. It was incredibly difficult to deal with as a mother, especially as I didn't ever expect to feel this way again after her heart surgery as a child.

49. I noticed a change in after her diagnosis with HIV, she was prone to depression and anxiety. I didn't see her much as she was studying in London but there was an obvious difference. These problems have only progressed and worsened over time. now also suffers from Post-Traumatic Stress Disorder (PTSD) and experiences flashbacks. I was not shocked when she was diagnosed because of the truly horrific experiences she has had to endure.

50. As a mother, it has been very difficult to see how this virus has affected my daughter. I saw her confidence and self-esteem shattered because of how the HIV made her feel. She still feels as if she does not deserve a good relationship and that she is damaged goods. She believes that she can only have bad relationships now and that she has to live with that. I love my daughter dearly and I hate to see her think of herself in this way.

51. I do feel some responsibility for the infection. I'm her mother and I took her to the hospital hoping that it would make her better but it just caused more problems. I know I couldn't have stopped it but it doesn't help the way I feel.

52. After told me about her infection with HIV, I started drinking too much. I have a long history of anxiety which I have had treatment for on various occasions. Fifteen years ago, I took an overdose as I couldn't cope. I just wanted it to end, I wanted to go to sleep and never wake up. I would never do that now, but I was in a very bad place at the time.

53. I stopped drinking after that and I have now given it up completely. I don't remember much about this time as I have tried to block it out.
54. Things don't get better as time passes, everything is still as raw as the day she told me. I can accept what happened but it is what happened afterwards which makes me angry. Everything that she has been through could have been avoided, all of the stress she has endured, the anxiety, the feelings of worthlessness are all unnecessary. I wish that my daughter didn't have to go through any of that.
55. I have always been aware of the stigma surrounding HIV. Everyone is understanding as long as it is in the abstract and not happening to someone they know. As soon as it becomes personal, they don't know how to handle it.
56. I haven't experienced any extreme prejudice but that is because I have learned to keep quiet and not tell people. We haven't told many people about [D] infection with HIV, including our family. [D] has a good relationship with her father but still does not want him to know. I have only recently told my older brother but I do not want anyone else to know. This is the main reason for our request for anonymity.
57. Shortly after [D] found out about her infection with HIV, I told a close friend of my mother who I grew up with as a child and used to be a nurse. She couldn't handle me telling her, despite being a nurse and a close family friend, it was too much for her. I didn't tell anyone after that. She actually said that she wished I hadn't told her.
58. When I visited [D] in hospital when she had given birth to her daughter, I was horrified to find her in a side room which had yellow tape across the door saying 'Biohazard – Do not enter'. I was disgusted at the way in which they were treating my daughter. Luckily, a new ward sister came on duty and ripped it off saying that she didn't think it was necessary. I know that the stigma of the tape really got to

D she felt awful. She had been labelled quite literally and very insensitively.

59. **D** had to wait six months before **GRO-B** could be tested for HIV which caused a great deal of anxiety for her. It was an agonising wait. Fortunately, **GRO-B** is HIV negative but the stress of waiting for the results helped to cause **D** post-natal depression.

60. At the moment **GRO-B** does not know about her mother's infection with HIV. She knows that her mother had a heart operation which didn't go to plan but that is it. I know that **D** will have to tell her daughter eventually and that **GRO-B** will start asking questions soon. We know that she will be shocked and so we want to make sure that she is old enough to understand. The thought of the conversation is easier now that we have the acknowledgement about the transfusion causing the HIV infection.

61. I have had to handle everything that has happened in **D** life alone, which has been incredibly difficult and isolating. Even when **D** had her open-heart surgery, her father came in occasionally but never told me that he was coming, I always found out from the nurses. I have always gone to **D** appointments alone and handled everything by myself. It is only now speaking with you that I truly realise how much I was alone.

62. **D** and I have always been a team and we have gone through everything together. My husbands have always been on the side-lines throughout, and so shouldering all of this on your own makes you feel like you are on your own.

63. I have always taken the responsibility of what was happening on myself. I felt very isolated without having anyone to lean on and knowing that I couldn't talk to anyone out of fear of the stigma. It has caused my self-esteem to drop.

64. My relationship with my second husband, GRO-B has suffered immensely because of everything that happened with D infection with HIV. We were married in 1990 and he found out about D infection when she was diagnosed. He told D very early on in our marriage that he felt as if he had lost me. This was not very helpful for D as it was another burden that she had to shoulder.
65. There was a gradual wedge that came between GRO-B and me, he was very sceptical of everything. I think he felt as if we were clutching at straws throughout and that we were just trying to find another reason to avoid the possibility that D had made a mistake.
66. GRO-B kept saying that there was no proof that the transfusion was the cause of the HIV infection. It wasn't until that D received the money from the EIBSS that his view changed. Even then he said it wouldn't stand up in a court of law.
67. He is a very analytical man but all I wanted was some support and someone to put their arm around me. After my divorce from my first husband I spent five years as single parent, I have always felt like a single parent and still feel like one today. When D told me about her infection with HIV, I think I became withdrawn and I isolated myself from GRO-B and everyone else. No one really seemed to understand, there was always the implication that we should be moving on and that we should get over it.
68. GRO-B and I get on but we live separate lives very much as a result of everything that happened. We don't argue but we have separate bedrooms and separate holidays, we lead our own lives.
69. D is not well at the moment, even with the anti-retroviral drugs. She still suffers from a litany of different problems for which she needs

lots of different treatment. I am very glad that she has financial support from the EIBSS, as I know that if she did ever need to give up her work then she and GRO-B would have that financial security. It is one area of D life that I know she does not have to worry about anymore.

70. D had to have an MRI scan recently because one of her eyelids has drooped and there was concern that she was having a stroke, I felt everything all over again. I thought that would be the moment that I do lose her. I live my life in fear that moment will come.

71. There is not a day that goes by that I don't think about what happened and what D is still living with, I constantly find myself awake at three o'clock in the morning thinking about all the unanswered questions there are. For example, what about those other babies who were also having operations in the hospital at the same time, as D was, how many of them became infected?

72. I do not believe in conspiracy theories but I am left wondering if anyone knew, when they knew and if what they knew could they have stopped what happened to D. I have many sleepless nights going over what happened in my head. I am constantly waiting for the phone to ring and for D to tell me what has happened now.

73. I go away to Italy by myself quite often but it is never an escape. Even when I am away, I am always worried about the phone ringing and what she will say. It is always there, constantly coming to the forefront and receding again but never leaving me.

74. I try not to think too much about the future and instead just take each day as it comes. I feel as if I am always waiting for the next thing, the next call from D to tell me about what has gone wrong. I still live in that mindset that something awful is about to happen and that we are all just waiting for it to hit.

Section 6. Treatment/Care/Support

75. We were always made to think that [D] had been unlucky and that she had unfortunately had a relationship with the wrong guy. The possibility of being infected through the transfusion was never even considered by any doctor, consultant or nurse we saw.

76. My daughter spent over twenty years of her life thinking that her infection with HIV was her fault, despite not falling into any of the risk categories. At the HIV clinic at Torbay Hospital, they treated her as if she was sexually promiscuous and it was an awful experience for her. Someone should have at least discussed or acknowledged the possibility of being infected from the transfusion instead of just denying it outright.

77. We were advised that it would be necessary for [D] to take antibiotics before she would have any surgery when she was younger, but as far as I am aware she has never been refused treatment because of her infection with HIV.

78. No one has ever told me or advised me to get tested and I never have been tested. It never entered my head that I might have to be careful about blood with [D] I was never informed about precautions to take regarding wounds or cuts. [D] often had nose bleeds when she was younger and it is only now that I realise that I may have been at risk.

79. When [D] and I went to the HIV clinic at St. Thomas' Hospital, to the best of my knowledge, the consultant didn't provide any information about the risks of transmission or how to prevent it. This conversation could have happened without my presence though. I know that she

knew enough about the risks, because of her profession, to keep herself and others safe.

80. I was given an appointment to meet a counsellor at the Sexually Transmitted Diseases Unit at Derriford Hospital. This in itself was degrading, by the very location. Again this was another world that I had never been part of.

81. I had one appointment with the counsellor who was very sympathetic and understanding, and who praised me for continuing to support my daughter. I said that I would support D as much as I could and for as long as I could. I didn't go back as I didn't feel like I needed the counselling. I don't have much faith in it.

82. I have had the opportunity to join a support network throughout my experience, but I don't feel that it is right for me and I prefer to process everything that has happened in my own way. I didn't want it to rule my life any more than it already does.

Section 7. Financial Assistance

83. D first found out about the EIBSS from her mortgage adviser when she was selling her house during her divorce. She had to tell them about her infection with HIV for insurance purposes, and that is when her adviser asked her if she had applied for financial aid.

84. This was just about the time that the Infected Blood Inquiry had started to be mentioned in the press and D looked into it. She sent off her application explaining what had happened, but she was refused because she couldn't provide evidence that the blood transfusion had taken place. Even though I had supplied a letter confirming that she had had a blood transfusion when she was in hospital for her heart operation.

85. The EIBSS were very helpful and sympathetic and said that if she could find confirmation of a blood transfusion then they would consider her application again, as shown in the letter from the NHS Business Authority to [D] dated 10th October 2018, exhibited at **WITN0930002**.

86. [D] contacted the Derriford Hospital requesting her medical records but received a response from Mel Thomas from University Hospitals Plymouth NHS Trust on 12th October 2018 stating that they had been destroyed in 2008, exhibited at **WITN0930003**.

87. She also asked the Freeman Hospital on 18th October for a statement from a member of staff verifying the need for her to have a blood transfusion as part of her open heart surgery in 1981, exhibited at **WITN0930004**. She received a reply from the Subject Access Request Team at the Freeman Hospital saying that they had destroyed her case notes on her 25th birthday and that they were unable to help, as exhibited at **WITN0930005**.

88. This was a very frustrating process. It seemed ridiculous to us that her records had been allegedly destroyed after she had undergone a significant surgery. [D] was one of the first groups of patients to have open-heart surgery for an Atrial Septal Defect and it never made sense they would destroy her records after that kind of surgery. It was just unbelievable that there were no medical records going back more than a few years ago.

89. A month later, [D] received a response from the laboratories at the Freeman Hospital which confirmed that she had been given a blood transfusion on 11th May 1981, that she received three units, her medical record number [GRO-B] as well as the fact that the blood had been donated on 10th May 1981 and the ID numbers of the donors: [GRO-B] and [GRO-B] as shown in exhibit **WITN0930006**.

90. This was the letter that changed everything. We finally had confirmation that [D] had received the blood transfusion.

91. After [D] submitted that information, everything happened very quickly from then on. She received a lump payment of £80,000 and an annual payment of £18,000 which recently increased to £28,000.

92. The money is amazing but it is not compensation for what has happened to my daughter and it does not make it better. It does give my daughter a choice and the freedom to cut back on work if her illnesses get worse.

Section 8. Other Issues

93. I would like the Inquiry to find answers to the many questions which still plague me. I want to know what information was available about the contamination of blood, who knew it, when did they know it and did they act on that knowledge as soon as they had it?

94. I would like to know why there was no follow up with recipients of blood transfusions and blood products once there were suspicions of contaminated blood.

95. [D] found out about her infection with HIV because she took herself to get tested. If she hadn't heard about the risk of transfusions and the possibility of infected blood then she may not have found out for several more years. I do not want to think about what could have happened if she had been tested later on. This has affected so many people and I am sure there are some who still do not know.

96. I think it is terrible that we were told that all of my daughter's records have been destroyed. It should not be the policy to completely destroy such important information, especially when it may stand between someone and financial stability.

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97. I would like to commend my daughter, as she has been incredible at handling her infection with HIV, and everything else that she has experienced because of it. I am very proud of her.

98. This is the first time I have ever spoken to anyone in this detail about what has happened to D and the impact the HIV infection has had on our lives and sadly will continue to do so. The realisation that all of her post heart operation childhood infections she suffered and the procedures she had to go through were, as a direct result of her immune system being compromised.

Statement of Truth

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

Signed

GRO-B

Dated 11th September 2019.