

Witness Name: **GRO-B**

Statement No.: WITN0112001

Exhibits: **WITN0112002 - 023**

Dated: 7 November 2018

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 22 October 2018.

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

Section 1. Introduction

1. My name is **GRO-B**. My date of birth and address are known to the Inquiry. I am a married woman and I live with my husband, in a house that we own. I intend to speak about my deceased son, **GRO-B: S** **GRO-B: S** and his infection with Human Immunodeficiency Virus (HIV) and Hepatitis C, which he contracted as a result of using blood products when he was a child.
2. In particular, I shall discuss the nature of if his illness, how the illness affected him, the treatment he received and the devastating impact it had on him and our lives together.
3. I have been asked if I am currently legally represented. The answer is no. I am more than happy for the Investigators attached to the Inquiry to take my statement.
4. **S** was diagnosed with Haemophilia in 1976 and he contracted HIV and Hepatitis C from the use of Factor VIII treatment in the 1970's

and 1980's. He was my only son and he died on GRO-B 2006 aged 34. S was lovely, sociable, intelligent young man.

Section 2. How Affected

5. As a child, S suffered from severe bruising. He was 6 months old when I first noticed a really black bruise on his body. I took him straight to hospital but the doctor didn't tell me what could be wrong.
6. When he was about 3 years old, I was bathing him and noticed a "L" shaped bruise on his back. Again, I was concerned and took him to GRO-B surgery. Dr GRO-B examined him; he said that it looked like a heavy blow that had been caused by a hand. I think he thought that I was mistreating him, and he sent social workers round to the house. The social workers came once a month.
7. I was a very young mother and I got scared and questioned what I was doing wrong. I thought that I wasn't feeding him right.
8. When he was 4 years old, he 'cockled' over a curb and sprained his ankle. It wouldn't heal so I took him to see Dr GRO-B. He asked S to walk around the surgery, but he couldn't do it. The doctor then rolled up his trouser and saw bruising that was not normal. S was referred to Kingston General, which was in Hull for a blood test. {It has since been knocked down} I called up for the results and was told over the phone that he had Haemophilia. I really did not know much about this; we have no history of Haemophilia in my family.
9. I arranged to see another doctor by the name of Dr Raper at Kingston General. S had further blood tests, which confirmed that he had mild Haemophilia A. I feel that this diagnosis only happened because I kept pestering the doctors.
10. I received no apology from the doctors regarding the false accusations of mistreating my son and when I told another doctor about this, he said it was understandable that they had come to other conclusions, as Haemophilia was a rare disease.
11. Initially, I took S to Kingston General Hospital in Hull for treatment whenever he had a bleed, where he received injections of Factor VIII

concentrate. He was frightened and the doctor said that I caused the fear by trying to shield him from the needles. (WITN0112002). We were later told that [S] could have the treatment at the local hospital in [GRO-B: S] {again this hospital has been knocked down} as this was much closer to home and we had no transport of our own. At the age of 12, [S] began injecting himself with Factor VIII at home. He was very brave and just managed the whole process very well.

12. [S] mainly received Factor VIII in the late 1970's and the 1980s. We were told that the Factor VIII he received came from a few different companies and originated in America, however I never received any batch numbers for the products given to him. The consultant haematologist at Kingston General in Hull explained that Factor VIII was a "wonder drug", which was much quicker than other treatments for Haemophilia. He never explained any risks of using the blood products.
13. In 1981, I received a telephone call one afternoon when [S] was at school. It was Dr Raper; he said he was ringing to tell me that [S] had been infected with HIV. I vaguely knew what this was, but thought it was a gay disease. I didn't know you could catch it from blood. "But how?" I asked. He told me it was from a bad batch of Factor VIII but I can't quite remember what he said; my head had gone by this point. I then asked how he knew, as he hadn't had blood tests. He said he had them at Hallamshire Hospital in Sheffield.
14. I remember going to Sheffield in an ambulance car for [S] blood tests, but I had been told that this was because the Factor VIII had stopped working properly and they wanted to work out why. I was told it was to test for inhibitors, not HIV.
15. I went into shock on the phone. The news was communicated poorly and I felt as Dr Raper was trying to rush me off the phone. It was very abrupt. I asked him what we should do and he said just take more care when looking after him. He told me it was not easy to pass on and that we could talk about it more during an appointment. He said to tell the dentist and informed me that he would tell the other doctors. I was not warned of the risks of others being infected as a result of [S] infection and no information was provided about HIV. It never really has been.

16. I never got anything in writing, which I can't understand. I didn't think much of it then, but looking back I think, "how strange, why was I never told something so important in writing".
17. I put the phone down and broke down. I was in a right state and couldn't calm down. I thought my young son was going to die. I didn't want to tell [S] in case it ruined his life. I wanted to give him as much fun as he could have. His dad was in denial, he was angry and thought they had got it wrong. We decided not to tell him. At that stage I thought [S] would only have about two years to live, he was my little boy, it was heart breaking.
18. Eventually, I decided it was time to tell [S] he had HIV. I got the doctor to tell him because I couldn't face it; I felt like such a wimp. This was in 1990, when [S] was 18. He was so upset, he thought it was the end of the world, we all did. From 1990 onwards, his life was one crisis after another.
19. In 1991 [S] told me he had been diagnosed with Hepatitis C. The date of this diagnosis isn't consistent in the evidence I have and the paperwork from the hospital is very vague (**WITN0112016, WITN0112019 and WITN0112020**). I don't know anything about this diagnosis other than that he was devastated. I imagine he was told in person as there are no letters about it, but I'm not sure. This infection must have happened after I was told in 1986 that he had been changed onto heat-treated concentrate and that it had much less chance of infection.
20. It was only when we were going through the papers with you yesterday that I found out that [S] had also been diagnosed with Hepatitis B on 21 February 2006.

Section 3. Other Infections

21. I don't believe that [S] received any other infections. He had the worst, namely HIV, HCV and HBV (**WITN0112010**) as a result of being given infected blood products. That said, [S] did receive a letter warning him that a blood donor had been found infected with CJD

(WITN0112012) and he had received Factor VIII from this persons blood donation. This caused more fear but thankfully he didn't have it.

Section 4. Consent

22. [S] was too young to consent to tests himself, but I believe that [S] was tested for HIV without my knowledge and consent in Sheffield.

Section 5. Impact

23. [S] suffered mental and physical effects of being infected with HIV. In the 90's he had spates of depression and anger. The doctor said he needed to see a counsellor. (WITN0112008) He would rage, well of course he would, anybody in his situation would. He couldn't believe that this could happen in this day and age. He felt that he had nothing left to live for. There was so much he wanted to do and couldn't. It drained him. It stressed him out so much and he constantly worried about things. He was always having infections, chest problems, night sweats and stomach problems. He had shingles twice, got skin infections and lost lots of weight. He never had chance to have children and he would have loved children.
24. [S] was diagnosed with Non-Hodgkin lymphoma in 2003. I believe the HIV caused it. He had chemotherapy. He received treatment once a fortnight, on a Monday. By the Wednesday he would feel tired and angry, on Thursday and Friday he'd be violently sick. He would then have a week of recovery. It was a constant cycle.
25. He was given the all clear from Non-Hodgkin in 2004. He was thrilled and made lots of plans.
26. On 5 August 2005 he came to see me. He had a shocking cold and a bad cough. He told me he was going to the doctors because they had always told him anything wrong with his chest needed to be reported straight away. He was on and off with colds until Christmas.

27. The Non-Hodgkin lymphoma came back on Valentines Day 2006. He went into Hull Royal and the doctor couldn't understand why it had taken hold so fast. He went home again after the appointment. He looked shocking; he was so ill and had lost so much weight. He said to me, "I think I'm dying". He couldn't sit down, he was just skin and bone and in so much pain.
28. He went into Castle Hill hospital on Friday morning (GRO-B 2006) the week before he died, for blood transfusions. It was horrible. They weren't expecting him and wanted to do all sorts of tests. I said please stop it and just give him the transfusion or transfer him to Hull Royal. They transferred him at 5:00pm.
29. He got the transfusion and he seemed better the following day but then it just got worse. They put a Hickman line in on the Tuesday. On the Wednesday evening I went to see him, took him some food and sat chatting in his private room. He kept getting shooting pains in his back and asked me to get a nurse. I asked the nurse why he was in so much pain and she asked if I could get to the hospital for 5:00pm the following day to speak to the doctor. I said yes.
30. I left work early the following day and two young doctors took me into a private room and asked if I knew what was happening. I said no, that's why I'm here. They said they were sorry but there was nothing more they could do and that he had a couple of days max. He was conscious and I think he knew what was happening. He even said, "don't come to tell me I'm dying" to one of the doctors.
31. At 2:00am he pulled out all of his tubes and said, "Mum, the Americans killed me". He always blamed the Americans. I told him to let them put them back in and he said, "no, they're killing me". Eventually he let them. I sat with him and he told me he loved me, that he loved everyone and that he didn't want his name in the paper. I didn't really know what he meant by this.
32. On (GRO-B 2006) he was given a diamorphine pump for the pain and a catheter.
33. On (GRO-B 2006) we were told that he wouldn't last more than a few hours. (S) was in and out of consciousness as I sat with him, his

dad and girlfriend. I held his hand and spoke with him. At 5:30pm I think his body let fluids go. I wanted to preserve his dignity so we left the room whilst the nurse changed him. The three of us went upstairs for coffee and 5 minutes later the nurse asked us to return to [redacted] S room. I went to kiss him and felt him going cold. I told the nurse and she said "I'm so sorry, he must have passed away". She said, "this often happens, it's like they seem to wait". I stayed with him and said my goodbyes for 20 to 30 minutes. I was so upset, devastated that I had lost my son.

34. When I went to pick the night clothing he had been wearing off the floor, I was told to leave them as they were infected. They wouldn't let me have them. I wanted to take them as a mum, a last memory of him alive, and I wasn't allowed to.
35. The next day I went to collect his death certificate. The doctor said "I have put down on the death certificate recurrent Non-Hodgkins lymphoma for you". I can't get this out of my head. I think she meant it was probably HIV in the end, but I just don't know. There's no mention of HIV or Hepatitis C on the certificate. (WITN0112021) There wasn't in relation to his funeral arrangements either.
36. I don't know if he developed AIDs. I was never told but I assume he had. A post mortem was never carried out on his body.
37. [redacted] S didn't face any difficulties in accessing treatment. For HIV, he took FTC (200mg once a day), Tenofovir (300mg once a day) and Atazanavir/ Ritonavir (300/100 once a day). He refused treatment for Hepatitis C. By this point he had lost faith in the NHS and he also felt too ill to cope with the treatment. He had heard how awful it was. (WITN0112011)
38. Being infected with HIV affected [redacted] S private, social and family life. He had a number of long-term girlfriends and a wife who knew about the HIV and were lovely about it. However, his wife was very nasty in the end. She left him just before he was diagnosed with cancer [redacted] GRO-B [redacted] GRO-B (WITN0112015) He couldn't tell many people about his infection and always felt on guard. He was so fearful of others finding out. Friends that

he did tell were devastated. He rarely went out because he was often ill. Few family members knew. He felt like it was his "dirty little secret".

39. [S] infection also impacted my life. I married [S] dad in 1971 but we separated in 1989. I think it had a great deal to do with [S]
40. When [S] was first diagnosed with Haemophilia, his dad was very angry. He said it was all my fault, as women carry it. He wanted a football-playing son, not an ill one. He did calm down. He loved [S] and was a good dad when sober. However, when the HIV diagnosis came, he was in denial and would not accept it. He stayed out drinking all the time, often from 8:00am to 12:00am. He wouldn't even know I had taken [S] to hospital a lot of the time. He stayed out late drinking after work and didn't want to believe it. I resented him because he was on a good wage and I felt that if he hadn't drunk, I wouldn't have had to work and I could have cared for [S] more.
41. I left him in 1989 when the drinking became unbearable. I met a new partner but I never told him about [S] infection because I once heard his sister talking about HIV and saying that they should all be put on a blood island. All the time I lived a lie. We split in 2001. I then met my future husband.
42. When [S] was 5 years old, Dr Raper and Dr [GRO-B] both told me that I really shouldn't have any more children. They advised me to get sterilised. They both said it would be wrong to have more children because of the risk of Haemophilia. At 28 years old, I was sterilised. (WITN0112004)
43. I couldn't tell my family about the HIV. I couldn't risk it. If they said one word about it to anyone, [S] life wouldn't have been worth living. [GRO-B] was and still is a very small community. Even my own mum and dad didn't know and died in ignorance. This is probably a good thing, as they doted on [S] and it would have killed my mum to know.
44. After we lost him, I was quite suicidal. I just couldn't believe what had happened, what they had done. I didn't want to go on. It was just so unfair. [S] was a bright, clever, talented, funny young man and a great musician; he played the electric guitar in his band.

45. He was such good company and I missed him so much. I went from seeing him every day to never again. I was angry at the world and at doctors. I lost all faith in doctors and wrote to Tony Blair telling him that they had murdered my son. I tried to get through each day and I try to keep busy, but it is only in the last couple of years that I feel as though I can do things again. I talk about him a lot and try to keep his memory alive.
46. My husband said that when [S] died he lost me too. I am so, so tearful and I can't listen to a lot of music or watch certain films. It has wrecked and totally broken me.
47. In 2005 [S] best friend had a baby. [S] adored her and was going to be Godfather, but he died a month before her birthday. The family put off the Christening and a few years later asked me if I would like to take his place and be Godmother. This kept me going.
48. The stigma we faced was everywhere. There were tombstone adverts, HIV, AIDs and death written everywhere. I feared for [S] and what would happen if people found out. I was scared he would be ostracised and beaten up. [S] had to go to clinics where he sat amongst drug addicts and all sorts. Someone once assumed he was on drugs and asked "what are you on mate?" He didn't want to be seen picking up prescriptions in [GRO-B] as I have said, it's a small place and nothing is private.
49. [S] was tormented at school in the 1980's for being a Haemophiliac. Dr Raper had written to the school headmaster about his Haemophilia. The letter is wrong regarding the time frame of the Haemophilia and also states that [S] would have a "normal life span". If only that had been true. He had tested positive for HIV at this point so I know that was wrong information.
50. The headmaster made an announcement at school, without my consent, stating that everyone had to be careful around him. This made it worse. Other pupils assumed he was gay and called him a "little bleeder". They would shout, "you're gay, you'll have all these germs". No one even knew about the HIV. (WITN0112005)

51. He was behind in his studies, however he did achieve two A-Levels. He also completed Open University courses. He didn't work. He applied for jobs but his Haemophilia went against him.

Section 6. Treatment/Care/Support

52. I was never offered any care, counselling or psychological support in consequence of what happened. [S] was offered and he did go a couple of times to help with his anger. On occasions he was angry, he had every right to be.

Section 7. Financial Assistance

53. In 1990, one of [S] doctors told him about the Skipton Fund. He was advised that he could claim £20,000.00. He did this and received the payment in 1991. His doctor said "why don't you buy a burger van and get on with the time you have left". I think this was Dr Raper.
54. In 2008 I got a telephone call from a lovely nurse that used to look after his case. She said [S] would have been due an extra £25,000.00 because of liver damage and sent it to his dad and me instead.
(WITN0112023)
55. He also received numerous payments from the Macfarlane Trust, but I don't have the details of these payments. I do give the Inquiry my consent to look at those records if they so want.
56. I don't believe he faced any difficulties in getting this assistance. However, I would like to add that the compensation he received was not sufficient for him. No amount of money can make up for wrecking his life, but he should have had the compensation to live a decent life where he didn't have to worry about money. £20,000.00 goes so quickly. He was diagnosed in 1979 and died in 2006; that's less than £1,000.00 a year.
(WITN0112006, WITN0112007, WITN0112018)

Section 8. Other Issues

57. [S] was a member of the Haemophilia Society and found out about the Irwin Mitchell litigation against the American pharmaceutical companies including Bayer. He became involved in this in 2004 and I continued it after his death. He wanted someone to be found responsible and held to account so I wanted to keep fighting it. I have a lot of correspondence from Lieff, Cabraser, Heimann & Bernstein, LLP, the law firm representing the pharmaceutical companies, telling me that I wouldn't win and should give up. In 2006, I was told if I wanted to continue I would have to fund it myself. I thought about selling my house to do this but was told that it wouldn't touch the surface. (WITN0112013, WITN0112014, WITN0112017)
58. In 2006 I decided to sign a settlement agreement. I was given \$37,000.00 and had to sign a document releasing my rights to pursue any claim against the defendants in the future. They did not admit liability. (WITN0112022)
59. I waive all my legal privilege over these documents and am content for the Inquiry to view or take copies of the correspondence as they see fit.
60. I also have a few concerns that I would like to address:
61. Within the doctor's letters, there are a few things I think are very unprofessional. In a couple, I am described as an "overprotective mother". There is also a letter in which [S] is addressed as [GRO-B] (WITN0112002, WITN0112003, WITN0112019) Finally, [S] was first diagnosed as a mild haemophiliac, but later referred to as severe.
62. The hospital seemed overly bothered about costs. On one occasion, a doctor refused to inject [S] for a bleed in his big toe due to the cost of the treatment. I was told to take him home and keep an eye on him. I called [S] doctor and he said take him back. By this point, the bleed had spread to his ankle and more Factor VIII was needed than

would have been for the toe. Another time, **GRO-B** forgot to order **S** Factor VIII. He was sent to Hull Royal and they argued with me over whether the Factor was needed. The doctor said it wasn't. This time I got the doctor to call **S** doctor. 30 minutes later the Factor arrived and **S** was injected and sent home. I also have a letter showing concerns about the cost of caring for **S** if he were to have a major bleed. (WITN0112009).

63. **S** was tested positive for HIV in 1979 (WITN0110208, WITN0112016). Why was I not told until 1981?
64. There is a letter dated 5 July 1981 from **S** doctor to another doctor, asking if he would see a young haemophiliac boy. There is no mention of his HIV positive status in this letter and I can't understand why.
65. I watched the World in Action documentary and I don't understand why this was still going on after 1975. The Government knew so early. **S** hadn't even been diagnosed then. It felt like genocide.
66. I paid £50 for **S** medical records, but there are areas blanked out. I am content for the Inquiry to request his records on my behalf, in their entirety. There are also records missing between 1976 and 1987 and lots of contradictions regarding the HIV and Hepatitis C diagnosis.
67. This Inquiry has been a long time coming and I hope that those responsible are held accountable for the damage and heartbreak that the use of infected blood has caused to me and my family.
68. To confirm, I have given the Inquiry the following documents:

- **WITN0112002** – One (1) letter from Dr Raper, Consultant Haematologist to Dr **GRO-B** and Dr **GRO-B** of **GRO-B** **GRO-B** Letter concerns treatment of **S** (DOB: **GRO-B**/71) in which he says he had great difficulty obtaining any blood as both **S** and his mother are frightened of venal punctures. Letter continues to say "I think the

main problem here is the mother's attitude and the mother is very protective".

- **WITN0112003** – One (1) letter dated 3 November 1978 from Dr Raper to Mr Edwards, dental surgeon, re: [redacted] s (DOB: GRO-B 71). Letter concerns dental treatment and the fact his mother did not wish her son to have a minor operation on his birthday. Dr Raper states [redacted] s is a rather over protected only child". Letter contains mother's annotations.

- **WITN0112004** – One (1) letter dated 6 July 1981 from Dr Raper to Dr Eric Preston, Hallamshire hospital from Dr Raper, re: [redacted] s (DOB: GRO-B 71). Letter refers to future treatment and also comments that he is an only child and is likely to remain so.

- **WITN0112005** – One (1) letter dated 4 December 1981 from Dr Raper to Mr [redacted] GRO-B Headmaster, [redacted] GRO-B Letter explains the fact that [redacted] s is a Haemophiliac and states the diagnosis was made "about 3 years ago". Letter also states "it is likely he will have a normal lifespan". There is no mention of HIV.

- **WITN0112006** – One (1) letter dated 1 November 1990 from C.G.L. Raper, Consultant Haematologist to Mr [redacted] s Letter refers Mr [redacted] s to the Macfarlane Trust. "Date of your positive HIV test was 16/04/87".

- **WITN0112007** – One (1) letter dated 9 May 1991 from The Macfarlane Special Payments to Mr [redacted] s

- **WITN0112008** – One (1) letter dated 25 August 1995 addressed to Dr [redacted] GRO-B [redacted] GRO-B Letter states [redacted] s at the age of 8, was diagnosed as HIV positive.

- **WITN0112009** – One (1) letter dated 6 June 1996 from C.G.L. Raper to Dr S. Jaliha questioning who was going to “pay the large bill should he [redacted] S [redacted] ever require a major operation”.
- **WITN0112010** – One (1) letter dated 16 December 1996 from Chris Valentine to Dr Elaine Baguley. Letter states “as a consequence of these blood products he has been infected with Hepatitis B, C and HIV”.
- **WITN0112011** – One (1) letter dated 16 August 2000 from Dr Raper to Dr [redacted] GRO-B [redacted] GRO-B Letter confirms that Mr [redacted] S [redacted] does not want any treatment for his Hepatitis C infection.
- **WITN0112012** – One (1) letter dated 22 January 2001 from Dr Raper to Mr [redacted] S [redacted] Letter refers to risk of infection of CJD from blood products.
- **WITN0112013** – One (1) letter dated 20 March 2001 from Dr Alan Anderson to Dr Raper with reference to Helixate NexGen having been stopped (Bayer).
- **WITN0112014** – One (1) letter dated 21 March 2001 from Jon Hemphill to Dr M.L. Raper re: releases for KOGENATE BAYER.
- **WITN0112015** – One (1) letter dated 11 February 2002 from Dr Peter Moss to Dr Kurtis stating “probably acquired his infections in late 70’s early 80’s from infected blood products”. [redacted] GRO-B [redacted] GRO-B
- **WITN0112016** – One (1) page of hospital notes. Entry dated 16 April 2003 states “HIV disease since 1979”.

- **WITN0112017** – One (1) letter dated 17 February 2004 from Lynne Wilson to Mr [S] re: US litigation.
- **WITN0112018** – Remittance advice dated 13 July 2004. Confirms payment of £20,000.00.
- **WITN0112019** – One (1) letter dated 24 August 2004 from Kate Trower to [S] with first reference to being Hepatitis positive.
- **WITN0112020** – One (1) letter 10 September 2004 from M.L. Shields to [S] Letter confirms "Hepatitis C infection is clearly documented in the laboratory reports from 1992".
- **WITN0112021** – One (1) death certificate in the name of [S] showing cause of death "I (a) Relapsed Hodgkins Disease" certified by S. Dawi MRCP.
- **WITN0112022** – One (1) letter dated 14 September 2009 from American Solicitor's LIEFF, CABRASER, HEIMANN & BERNSTEIN, LLP. Letter signed by Heather Foster ([GRO-B] waived all legal privilege).
- **WITN0112023** – One (1) letter dated 7 January 2014 to from Nicholas Fish to Mrs [GRO-B] (Skipton Fund re: top-op payment of £25,000.00).

Statement of Truth

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

Signed

[GRO-B]

7. 11. 18.