

# ANONYMOUS

Witness Name: **GRO-B**

Statement No: WITN1147001

Exhibits: WITN1147002

Dated: November 2018

## INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF **GRO-B**

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

### Introduction

1. My name is **GRO-B** **GRO-B**  
**GRO-B** I'm a widower. I have two living children, a son and a daughter. I am retired.
2. I make this statement as the **GRO-B: S** **GRO-B**  
**GRO-B** He was infected with HIV and Hepatitis C following treatment with contaminated blood products.

### How affected

3. **S** was diagnosed with mild Haemophilia A when he was 5 years old because he was covered in unexplained bruises. Initially the authorities thought he was being assaulted by me and his mother. They kept him in hospital in

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[GRO-B] for six weeks. I recall that they tied him to the bed due to the unexplained bruises and to ensure that he did not injure himself any further. Despite their investigations they did not discover what was causing the bruises and wanted to release [S] which was something I would not let them do. It was only then that they realised [S] had haemophilia.

4. His care was then moved to [GRO-B] and The Royal Liverpool Hospital and I believe this is where he first received Factor VIII. He was about 7 or 8 years old. According to his records the Factor VIII was supplied by [GRO-B] at the Royal Liverpool Hospital.
5. From his medical records it appears that the first reference to [S] being given Factor VIII was on [GRO-B] after he fell off his skateboard. His notes state '2 bottles Factor 8 HL1562 given'.
6. He was given Factor VIII in January 1981 following a shoulder injury and in his medical records it states that it was given because there was no cryoprecipitate available. It was after this that he was regularly given Factor VIII rather than cryoprecipitate.
7. At some point [S] was moved onto home treatment. The only instruction we were given was to administer the medication at the first sign of any joints becoming hot or any indication of bruising, no matter how mild. We had to administer it frequently as [S] was very active and would often get bumps and scrapes.
8. [S] took the Factor VIII all of his life, even after he was diagnosed and the doctors knew he had been infected with HIV and Hepatitis C. They informed us that the drug no longer contained any contamination but we could not be sure that this was true. They also told us quite bluntly that even if he had been infected what difference would it make. The risks and consequences of the

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infections were never explained to us. [S] was our life and we would never have agreed to treatment if we had known then what we know now. We thought we were doing the right thing by following medical advice.

9. In September 1983 [S] was admitted for teeth extractions under [GRO-B]. He had had previous extractions in November 1978.

10. On [GRO-B] his notes record that he was tested for Hepatitis B antibodies. We were not asked to consent to this test which came back negative.

11. There is a letter in his notes dated [GRO-B] from John Martin, Consultant Paediatrician, to [GRO-B] which states we had been to see him because we were concerned about the incidence of AIDS. The letter states *"I have discussed this with them. They are very anxious to know whether he should have any tests to see if he could be getting this. I rather put them off but said I would mention this to you in case you felt any tests should be done."*

12. In or about 1978 I came home from work and my wife told me that the hospital had been in contact to inform us that [S] may have been infected with HIV due to contaminated blood products that they and we had been administering. I have since discovered that my wife kept this information to herself for several days as she struggled to accept it. Her father was a haemophiliac and she blamed and tormented herself the whole of her life and never came to terms with it.

13. My wife was extremely upset at the way we were given the news that [S] had HIV. We were never given adequate information about the disease. We couldn't understand it as it was a new disease and we were told that [S] would only last 12 months. The hospital was dealing with a lot of haemophiliacs at that time and the way the news was communicated was very matter of fact as though it was no big deal. We obtained more information from the media than

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we did from the medical staff that were treating [S]. They told us there was nothing they could do for [S] even if he did have the illnesses.

14. On 5 August 1985 [S]'s notes record that blood was taken for HTLV 3 screening. This was the HIV test. We were not asked to consent to this. [S] was 15 at the time.

15. There are notes in [S]'s records which suggest that we refused to accept his HIV diagnosis. In particular, there is a letter from Dr Martin, Consultant Paediatrician, to [S]'s GP which states: *"He is not aware that he is HIV positive and indeed his parents told me they also do not know as the letter I sent them informing them they tore up. I have tried to point out to his parents that it is better to know about events than remain in the dark, but currently they do not wish to alter this situation."*

16. There is also a clinic note dated 16 March 1988 which reads: *"Parents now very anxious because [S] has developed possible HIV symptoms. They now accept the knowledge that he is HIV +, but he does not know. In view of symptoms, see for review."* This is totally untrue as [S] would have been 18yrs old at this point and he most certainly did know that he was infected with HIV

17. In his notes dated 26 March 1987 it is recorded that we said we did not want to know the result of [S]'s HIV test. This is also not true.

18. My view on how the news was communicated to us was that the doctors just wanted to protect themselves and the Government. The way they told my wife was very insensitive and just added to the trauma. They didn't give us any information, not even how to protect ourselves from contracting the infection. We were kept completely in the dark as to the dangers we were all being exposed to and the controls that we should adhere to to ensure that we did not become



infected ourselves. I was given the impression they were experimenting and didn't really know what to do. When we finally told [S] that he was infected he said he was going to move out so that he didn't give us the infection

19. In or about October 1989 the hospital set up a Support Group for the families of those affected by HIV. However, they sent the letter about this to our old address that we had to leave when neighbours / others discovered [S] was infected with HIV and we were all victims of a hate campaign. This made us very reluctant to engage with the social worker or counselling support on offer. We had lost faith in the hospital by that stage.

#### Other Infections

20. [S] also had cirrhosis of the liver, cerebral thrombosis, sub-cortical dementia, vCJD and Antiphospholipid syndrome. [S] also had a number of strokes, the last of which eventually killed him.

#### Consent

21. I believe [S] was treated and tested without his (or our) knowledge or consent. We were not given any adequate information on the tests carried out nor were we properly advised about treatment options.
22. As set out above, [S] was tested for Hepatitis B and HIV without our consent. I note that he was also tested for CMV, EBV and Varicella at the same time. His serology reports for 1988 are now shown to me marked "WITN1147002"
23. I also believe that [S] was used as part of some governmental scientific research that had begun and is possibly still on going.

Impact

24. **S** spent a lot of time seeing a psychiatrist, in Liverpool and in London. His infection affected **S** a lot mentally. He suffered from severe depression. Before the effects of the HIV showed up, **S** went to **S** in **GRO-B** and studied a Masters Degree in IT. He went rock climbing and other sporting activities. He went to India, China and other parts of the world. He went to church a lot and had a close circle of friends. Up until he was 26, he had a good quality of life, but after that it all changed.
25. The physical effects of his HIV slowed him down and made **S** depressed and resentful. It was a terrible time. It was also difficult for him at university; his friends told us that he didn't have any girlfriends because he had HIV. People thought he was gay. He was very caring, he wouldn't hurt a fly. He always looked out for people, if someone was quite vulnerable he'd take them under his wing. It was very sad for us that he wasn't able to have a relationship and share himself with someone else.
26. The mental obstacles **S** faced were quite significant and at one time **S** just stopped eating and he had to be fed by a tube in his stomach. He also stopped taking his tablets properly and I think that he lost the will to live. The hospital wouldn't give him full treatment; they wanted us to care for him but we could only do the basics as we didn't have any medical training. That caused tension within our family because **S** felt that his mother was smothering him.
27. I remember one occasion when **S** pulled a knife out in the kitchen to kill himself. He just couldn't see the point of going on.
28. I felt like he wanted to punish us. Physically **S** looked like a drug addict or a down and out. He looked unkempt and didn't cut his hair. He just let himself go

throughout his illness, it wasn't him, his HIV status destroyed him both in terms of the illness itself and the stigma.

29. He had to take a cocktail of drugs for the HIV which mentally paralysed him. I cannot recall what they were called but there were boxes of them.

30. The Haemophilia Society used to organise trips, but a lot of [S]'s friends died, so he stopped going. It seemed he was going to be tormented for the rest of his life. AIDS and HIV were in the press nearly every day. There was no end to it. No one thought about the families; the Government and medical companies just wanted to protect themselves. Not one person lifted a finger to help them, doctors abused them, bullied them, it was like a game to them. They would continually tell me that 'your son won't last the night'.

31. [S] had numerous hospital admissions in The Royal Liverpool Hospital where he was treated very badly and received extremely poor standards of care. It was horrendous. It was as if the nurses had nothing but contempt for the patients. It was necessary for me to visit him every day to ensure he was eating properly, he was washed properly and that he was receiving and taking his medication. There were many times his medication was strewn all over the floor and I would have to make arrangements to get it replaced. I would shower him when he was too weak to do it for himself and change his bed sheets after he had soiled himself and was lying in the dirt for hours at a time.

32. Despite the horrendous life that [S] had to endure and the constant medication he was taking, he did well to live to the age of 46. My wife died in the [GRO-B] 2015, and [S] died the following [GRO-B] He was in hospital for six months before he died. We had to travel from [GRO-B] and stay in [GRO-B] because he was being treated at the [GRO-B] by then.

33. There were times when **S** would hallucinate; he would say "Dad you're from outer space, aren't you?" He used to see monsters and think that robots are coming to get him it was all the medication.
34. If **S** didn't have HIV, he would have been the healthiest lad in the world. He never drank, never smoked and never did drugs; he looked after himself. **S** would have wanted many kids; he loved children and that was one of the major frustrations in his life that he knew he couldn't have any. When he settled down after university he worked in IT. He was on £90,000 per annum. He used to parachute, go gliding, mountain climbing and sailing, he was so sporting and active. I think he used to be a reincarnation of a Viking.
35. The best way to describe the impact on the family, is that it wasn't only **S** that had the HIV, we all had it. We all felt the consequences of it and we were all traumatised by it. The media said that they should all be sent off those with HIV to an island. The undertakers wouldn't bury anyone who had died from AIDS. We had things written on the car and the side of the house, we were unable to talk to friends or family and that had an impact on us.
36. It also had a significant impact on our other children. My eldest son, **GRO-B**, has got a good job as a chief engineer, but the trauma had a severe effect on his mental health and overall confidence. He always said, "Mem being the eldest son should have got the HIV". My daughter, **GRO-B**, suffered severe OCD throughout her teenage years and into adulthood. I believe that this was as a direct result of the stress on the family with **S** having HIV.
37. When **S** decided that he wanted to move out we got him a flat across the road from us as we had to make sure he took his medication. Sometimes we had to force him. It felt that nothing nice ever happened to us, everything just revolved around **S**'s condition; everything was just stressful and utterly miserable.



38. My wife died when she was 72 years old, - I have no doubt that all the stress killed her. She didn't even know [S] was in hospital; it was a blessing for the whole family that she died before [S] as if she had still been alive it would have devastated her and she would not have coped.
39. My daughter [GRO-B] did everything for me during that time, she would stay in the same hotel with me, she was always there, and she is a star.
40. None of the immediate family could tell anyone what [S] died of. The stigma surrounding HIV was and still is very prevalent and we could not tell anyone as we were unsure how they would react. This situation remains to this day and only my children and my sister know the truth. With cancer you can talk about it to anyone and immediately you get the sympathy. The Government had us all cowered into a little corner, because no one could talk about it and that's where they wanted us.
41. My wife blamed herself; 'if we hadn't had done that' she would always say (meaning that we should not have administered the Factor VIII). [S] could not have had a better mother. But she blamed herself so much, she couldn't talk to anyone; she just couldn't speak about it. The family was taking their frustration out on each other; we just punished ourselves.
42. [S]'s condition had an effect on all the family. My release was coming out of the hospital, going across the road to the pub and having a drink which caused friction and the fighting was horrendous. I had problems with my bowels and incontinence, and my wife lost all her hair with the stress.
43. My eldest son has little if any social skills and despite holding down an important job on the railway he has always struggled to come to terms with the trauma of everything. He is married and has three daughters and I believe the effects on his personality are as a result of what he went through when he was growing up.

44. [S] completed his Masters, and then went to work in [GRO-B]. While most boys were out chasing girls, he was there studying and building computers. [S] got a job in a top firm in [GRO-B], but when the illness kicked in he lost everything and he ended up on benefits.

45. My wife and I never claimed for anything. She didn't want to accept that [S] was ill. Money was quite tight. Any money [S] did get he would give it away. He was taken advantage of by his friends or people that claimed to be his friends. We all suffered because of it; the impact it had on our lives has been horrendous. The pressure has been very difficult. It is one of the biggest miscarriages of justice ever, it's terrible. All [S] ever wanted was for his life to be normal.

#### Treatment/Care/Support

46. All I ever wanted was to help [S] get better. I had to push for the support and treatment that he needed throughout his short life. I sorted out counselling for him with the NHS. The rest of the family was never and have never been offered any counselling. The impression I got from them was that we were rocking the boat. They would ask 'why are you coming to the hospital everyday?' It was a true battle. If they hadn't infected him in the first place, it would not have cost them anything.

#### Financial Assistance

47. No one in our family received any financial assistance directly. It was only when I was in hospital with [S] that one of the other haemophiliacs said to me "do you know you can claim money?" So I got in touch with the Haemophilia Society

and one of the funds gave him a heating allowance. The Haemophilia Society was very good, they would organise days out for the haemophiliacs to meet up.

48. [S] received £20,000, but as soon as he got it, his friends would be there, he would give it to anybody. He went to a meeting in Manchester and he was given some money. He was very vulnerable; he was taken advantage of. I think I made a mistake I should have taken over his financial situation. His mother would say "he is not dead yet, he isn't a cabbage, let him live his life".

49. Later in his life [S]s so called friend took everything he had in order to buy shares even though it was clear to anybody how vulnerable he was. We got in touch with the Police; they said it's a civil matter. I said to [S] "any money you get has got to last you for your future". I feel like him having shares in a company made him feel like a somebody, not a nobody. But this friend totally took advantage of him. Even an Irish man from the Church, took money from him. He was a conman. I called this man and told him. The man telephoned [S] and [S] fell out with me. These people took advantage of his vulnerability.

50. When I was involved with his personal finances I did it to take the pressure off him and did all the forms for him. The hospital wanted me to become Power of Attorney, but [S] would not let me neither would his mother. We tried to protect him really, but we had two hands tied behind our back.

51. The only precondition I am aware of was that he had to sign a waiver to be given the initial £20,000.

52. My observations about the various trusts are that the solicitors were there for the money and the trusts were there for the money. Everything revolves around money. They had these big hotels; I said "this money could be spent on the

parents and the children". MacFarlane Trust's offices are in central London. That must cost a fortune; do their premises really have to be there? All of these offices have such nice furniture. I said "Where did you get all this money from to pay for these offices? Why don't you use this money for the people affected that you're supposed to be helping".

53. [S] may have got money that we did not know about.

#### Other Issues

54. Kenneth Clark was the Minister of Health when haemophiliacs were given infected blood and he allowed the press to destroy the haemophiliacs. He turned people against them. They would go to the hospitals and the medical staff would avoid treating them; some nurses treated them like lepers. There is always going to be a stigma attached to HIV. To be a haemophiliac is bad enough, to put HIV on it is just an extra burden. The Tories allowed the extra stress.

55. You could not even have a nice meal; all the adverts on TV were about HIV and Aids. It was very traumatic for us. I could not imagine what it was like for [S]. Every programme bought up HIV, so you could not watch TV. It dominated your life. I think those responsible should be prosecuted. All the money in the world will not bring [S] back; it won't bring my health back. I would like to see them all locked up. The last thing [S] said to me on his death bed was "don't forget to get the bastards dad"

#### Anonymity, disclosure and redaction

56. I confirm that I wish to apply for anonymity.

57. I do not wish to be called to give oral evidence.



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## Statement of Truth

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

Signed, GRO-B.....

Dated..... 28. 03. 19 .....