

# ANONYMOUS

Witness Name **GRO-B**

Statement No: WITN3509001

Exhibits: 0

Dated: September 2019

## INFECTED BLOOD INQUIRY

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FIRST WRITTEN STATEMENT OF **GRO-B**

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

### Section 1. Introduction

1. My name is **GRO-B** I was born on the **GRO-B** 1959. I live at **GRO-B**  
**GRO-B** I work in the local hospital  
as an assistant technician. I have three daughters, **GRO-B**, **GRO-B** and **GRO-B**  
as well as eight grandchildren.
2. I make this statement in relation to my late husband **GRO-B: H** who  
was born on the **GRO-B** 1959 and who passed away at the age of 38 as a  
result of receiving contaminated blood products **H** and I met at school and  
we married in 1978.

3. This witness statement has been prepared without the benefit of access to my late husband's full medical records.

## Section 2. How infected

4. [H] had severe Haemophilia A. He was diagnosed when he was around 6 months old as [H]'s family have a history of Haemophilia. I understand he had lots of problems as a child in relation to his Haemophilia and spent most of his early life in and out of hospital.
5. When [H] was young he received Cryoprecipitate (Cryo) to treat his Haemophilia. I believe the Cryo was produced in England.
6. When [H] turned 16 years old he was given Factor VIII (FVIII) blood products. I believe it was given to all Haemophiliacs when they reached a certain age. [H] administered the FVIII at home after being taught how to inject himself.
7. [H] was treated at the Haemophilia Centre at the Manchester Royal Infirmary (MRI). His consultant was Dr [GRO-D]
8. I don't believe [H] or his parents were ever told that there was any risk in relation to receiving any blood products.
9. [H] was infected with Hepatitis C (HCV) and the Human Immunodeficiency Virus (HIV) as a result of receiving contaminated blood products.
10. We were not made aware that [H] had received contaminated blood; we did not know anything about it. We only found out [H] was possibly at risk when a Panorama documentary was televised in 1985. The documentary was in relation to imported blood products and the devastating affect it had on those

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who had received them. Before this we had no knowledge at all. I know his parents were not told either.

11. The documentary showed they were importing blood from the US that had been taken from prostitutes, prisoners and people who were paid to give blood. I remember how unbelievably shocking it was. I was stunned and angry that we had never been told or even been warned that the programme was to be televised. If I had not seen the documentary I would have never known anything about contaminated blood.
12. As a result of watching the documentary [H] realised that he was at risk of infection. He collected together all of his FVIII, put it in a bag and took it to MRI. He told them he would not be using it anymore and if he had a bleed would come into the hospital. He also said from this point onwards he would only accept Cryo treatment.
13. Dr [GRO-D] labelled [H] as mentally unstable after this incident. I know this because Dr [GRO-D] put it in his notes and another doctor told [H] about it. [H] took Cryo until he found out he had already been infected. Once [H] learnt of his infections he started using FVIII again through home treatment. The damage had already been done and FVIII was easier to access.
14. [H] was diagnosed with HCV, then known as Hepatitis Non-A Non-B and HIV a few months after the documentary televised in 1985. He went to the hospital for a check up and he was told in passing that he had been infected. He came home and was really upset. I believe he was told he had both viruses at the same time.
15. I do not believe [H] was given adequate information in relation to either of his infections. Also no practical advice was given as far as I am aware, although [H] was told not to let blood come in contact with anyone else and to practise

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safe sex. Nobody really helped him. [H] was a very intelligent man he took it upon himself to keep his family safe.

16. I believe [H] should have been told of his infections earlier than he was. We should have all been contacted before the documentary was televised so as we were prepared, it was an enormous shock. To find out he had two infections was awful. That's what MRI was like, they never told anyone anything. His blood results must have shown there was something wrong, they must have been aware, but they never told us anything. They treated us really badly.

17. I remember [H] was worried that I had been infected through him. I was pregnant in 1983 and the documentary was not shown until 1985. I was summoned to MRI to get my blood tested. Luckily, I was clear. I was not told of the results directly, I was actually told through [H].

18. I was not happy about the way we were treated at MRI. Sometimes I was treated really badly. I would not attend if I could avoid it. When I was summoned for blood tests they told [H] if I did not go they would take his home treatment away from him so I had no other option. I do not believe any medical institution should be run in this fashion.

19. [H] received a liver transplant in September 1995. After his transplant he was no longer a Haemophiliac as his blood clotted naturally meaning he did not require any blood products. The last time he received FVIII was the day of his transplant.

20. After [H]'s transplant I remember the surgeon who performed the operation said to me he had never seen a liver as bad and that it was rock hard, like a stone. He said [H] would not have lasted till the December without the transplant.



21. [H] passed away in Ninewells hospital on the [GRO-B] 1997.

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

22. The only infections I am aware that [H] had were HIV and HCV.

### **Section 4. Consent**

23. I believe [H] was tested without his knowledge. They took blood tests all the time but he was not told why they were taking so much blood or what they were doing with it. [H] assumed it was to test his platelet levels but they must have known what they were looking for.

24. Every time [H] went to get home treatment or had a consultation they would take his blood. They used to threaten him all the time, they told him they would take away his home treatment if he did not do what they asked.

25. I personally believe [H] was tested without his consent. I believe they must have tested his blood and known that something was wrong but decided to try and protect themselves rather than tell us.

26. I do not know if [H] was tested for research purposes.

### **Section 5. Impact of the Infection**

27. HCV caused [H] to suffer physically, he did not have as many problems with HIV, but HCV caused him liver related problems. His liver function tests were not normal. He became jaundiced. His legs and feet would be swollen and full of fluid and he his stomach was swollen, ascites.

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28. [H] suffered from constant nose bleeds that came without warning. Once his nose would begin to bleed it was like a running tap and there was no way to stop it. The nearest hospital was an hour and 15 minutes away and his nose would bleed the whole way there, this happened on a regular basis. They would have to give him nasal packs or cauterize his nose to stop the bleeding.
29. [H] also lost his appetite and was constantly fatigued. His skin was terribly itchy. He lost a lot of weight and became weaker and weaker as time progressed.
30. [H] also suffered mentally as a result of being infected by contaminated blood. He was devastated that he had received infections; he was very upset and shocked. He could not believe that this had happened to him and that the MRI had never told him. The only relief came from the fact that he had not infected me or our daughters unknowingly.
31. We were a very strong as a couple and helped each other deal with the situation as best we could. At first [H] was not too unwell but in the last few years of his life his health declined. You could tell that he was unwell just by looking at him, he used sunbeds so he would not look so yellow.
32. [H] would try to be active and to eat well and we did things as a family. It was only in about 1996 that he started to become really ill again. The HIV infection started to put a strain on his new liver and his health started to decline once again. He started to have fits, oedema in his legs, jaundice, ascites, constant fatigue and nose bleeds. His body could not cope and he started to reject his liver. He had liver failure towards the end of his life. He also had renal failure and had to have dialysis three times a week.
33. In the last week of his life [H] decided to refuse dialysis. The consultant at the local hospital wanted to speak to me. They sat me and [H] down and told us that [H] would not survive another week if he stopped having dialysis. We discussed this and I knew [H] could not cope anymore, he had had enough.

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He refused dialysis on Monday, the **GRO-B**. On Friday of the same week, **GRO-B** I was with him all day and night and he was sleeping and awake most of the night. He passed away on Saturday the **GRO-B** 1997 peacefully in his sleep around 10 am.

34. **H** received medication for HIV, I believe it was AZT. Unfortunately he suffered from many side effects and as a result he had to stop taking it.

35. I am not sure if **H** was given medication for HCV. He was on a lot of tablets at the time so it is possible that he was.

36. **H** had a liver transplant in 1995 and was therefore on anti-rejection tablets.

37. Mentally, going through the transplant, **H** was very worried. He was scared that he was not going to make it through the operation. I remember the surgery took 8 hours. I went with **H** to Kings College Hospital in London. He was scared but he thought it was a chance to have a better life and to spend time with his family. **H** was a positive man, he did not dwell on negativity. I was with him all the way. He believed his transplant was going to give him a chance for a better quality of life. Our daughters were young at the time, 15, 14 and 10 they did not know anything about **H**'s infections. They knew he was having a transplant but did not know why.

38. I do not believe there was any treatment that was not made available to **H**. The care he received from Edinburgh Royal Hospital (Edinburgh Royal) when we moved to **GRO-B** outstanding. They were always researching his condition and seeing if there was more they could do. It was so much better than that offered at MRI. I think with Edinburgh Royal if there was anything further that could have been done it would have been. Professor Ludlum was amazing. He would come in from home just to check on **H** and to see if there was anything more he could do.



39. There was huge backlash in the 1980s in relation to HIV/AIDS. When we found out about [H]'s infection we did not tell anyone, not even members of our family. We made sure that [H]'s Mum never found out. Her brother was a Haemophiliac and fell off a swing, hit his head and died at the age of six. As [H] was also a Haemophiliac she metaphorically wrapped [H] in cotton wool. We did not tell her as she would have found it too difficult to deal with.
40. The only friends we told were also Haemophiliacs. Our daughters did not even know [H] was a Haemophiliac, never mind that he had HIV or HCV. They only found out [H] had Haemophilia when our eldest daughter was around 18, as they needed to be tested to see if they carried the Haemophilia gene. We could not tell them in case they accidentally let slip. [GRO-B] has a very high drug use rate and we knew people would make assumptions as to how [H] was infected. We kept it to ourselves and we supported each other. We tried to carry on in as normal a fashion as we possibly could.
41. People were hounded as a result of having Haemophilia. At the time there were a lot of news articles and press highlighting a correlation between Haemophiliacs and HIV. [H] was actually fired by his boss at a music shop as a result of having Haemophilia. He worked as a shop assistant at the time and he was told that they did not want people who had blood diseases working there.
42. Once [H] was made redundant he did his A-levels and worked for an agency which led him to do a multitude of jobs. He drove a security van, worked in a bingo hall, you name it he did it. We then moved up to [GRO-B] in 1988 and obtained a university flat and later on when he qualified from university we bought a house together. I worked part-time when the girls were at school.



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43. We did not face any stigma because we did not discuss it with anyone. However, we did hear horror stories of people who had been affected which led us to worry about the possibility of people finding out.
44. [H]'s mother could not cope as a result of his death. He was her only son and she was absolutely devastated. She had a terrible time when he was young he was always in hospital due to his bleeds. We moved her up to live in [GRO-B], I looked after and cared for her. She died in [GRO-B] of this year. She never recovered from his death.
45. My three daughters were obviously affected by their father's death. At the time they were 17, 16 and 13 years old. The week he died they spent all of their time with him and they played together for example dominoes they took it in turns to spent time with him. The girls have missed out on having their dad there. They have since married and had children and not been able to share these experiences with their father. You take things for granted when you have your parents there.
46. [H] missed out on watching his daughters grow up, walking them down the aisle and meeting his grandchildren, especially the two boys. They both have Haemophilia and he could have helped them. He would have been over the moon to have so many grandchildren; it is heart-breaking to think about what we have all missed out on. It has been devastating.
47. [H] still received payment when he had to stop working as he was on sick leave. [H] worked for a few months in 1997 but it became too much, in the end he was medically retired in 1997 because he was not well enough to work. He had to cash in his pension and received a lump sum. Not long after he cashed in his pension he died. He just wasted away.

48. The plan [H] and I had was that I would support him during his A-levels, his degree (which he did at [GRO-B] University in 1988) and the start of his career. Once he had achieved this, the plan was that I would then sort out my career as I wanted to be a mid wife. I had started my studies but [H] became very ill and I had to give up my studies.
49. When [H] received his transplant and he was well for a few months I was able to study again. I had to do the first year again, which they allowed due to the circumstances. I went back to do my first year of midwife studies. However [H] became really ill and passed away while I was studying.
50. I tried to return to my studies but I began to suffer from really bad depression, it hit me like a ton of bricks. The loss of [H] and everything I had been through while trying to look after three children just became too much for me. I woke up one morning and could not stop crying. I sat there in my dressing gown for a few weeks and did not know what to do. I did not wash or change. My youngest daughter took me in hand, she made me coffee and fed me, she was an absolute rock. One of my daughters would clean, the other would cook while I was in a world of my own.
51. I had never had depression before I did not know what it was until I went to my GP and I was prescribed medication. This all happened in 1998, I took the medication for a few weeks and then stopped as I do not like taking medication. I like to deal with thing myself. I do still have periods of depression now and then and I find dates such as Christmas, birthdays, anniversaries etc difficult but I cope. My daughters find some days difficult as well.
52. The lump sum [H] received from his pension paid a few bills but it was not enough for us to live from. I had to finish my studies and go to work as I needed to provide for my daughters. We used to go to a music shop in Dundee where you can sell old CDs and similar items. We had to sell things at the shop just to

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keep our heads above water because we were struggling financially. I became a care assistant in a nursing home and then obtained the job I have now.

53. At the time we had a mobility vehicle. We could not afford to make the payments to keep it so they just came and took it which was devastating for me and the girls; it had been [H]'s pride and joy.

54. I have never had another relationship. [H] was my soul mate, my life. He was my everything, I would never want to be with anyone else.

### **Section 6. Treatment/care/support**

55. My GP offered me counselling but I prefer to deal with things myself, I just get on with it. Other than that nothing else was ever offered.

### **Section 7. Financial Assistance**

56. We received £20,000 in 1988 from the MacFarlane Trust but that was it while [H] was alive we did not receive any more financial assistance.

57. I received financial assistance from the Skipton Fund in 2011. I received the Stage 1 payment of £20,000 and then the Stage 2 payment of £50,000. Other than that I have never received anything else. The Haemophilia Nurse, June at Ninewells Hospital in Dundee informed me about the Stage 1 and 2 payments as she thought I would be entitled too them. We were never told by any medical professionals. June obtained the forms and filled them out, I just signed the application form

58. I did not know you could get financial assistance in the form of grants, I was never told.

**Section 8. Other Issues**

59. This has happened to so many people and it is so sad. I cannot believe this has happened on such a large scale it is mind blowing. When you are going through it, it seems like a secret you have to keep to yourself. But the scale of this scandal is absolutely terrible.

60. People who were being told they would have a better quality of life as a result of receiving blood products have had their lives cut short. It is dreadful. You expect medical professionals to care for you and prolong your life, they are the ones who have caused this to happen.

**Section 9. Anonymity, disclosure and redaction**

61. I confirm that I do wish to apply for anonymity and that I understand this statement will be published and disclosed as part of the Inquiry.

62. I do not wish to be called to give oral evidence to the Inquiry.

**Statement of Truth**

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

Signed... GRO-B .....

GRO-B

Dated ... *7th December* ... 2019