Witness Name: GRO-B
Statement No: WITN1537001
Exhibits: WITN1537002
Dated: February 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF GRO-B

I, GRO-B will say as follows:-

Section 1. Introduction

1. My name is GRO-B. My date of birth is GRO-B. I live at GRO-B GRO-B

2. I am the widow of GRO-B: H, who passed away on GRO-B, H was 46 years old when he passed away; his date of birth was GRO-B. He last lived with me at GRO-B.

3. I met H when I started to work in the same factory as him in 1977 in GRO-B. I was a machinist and he was a trader. We did not have any children.

4. I have suffered from a disability since childhood, having had pneumonia when I was seven months old. This has caused me to be unable to use my right arm and has left me with a bad limp. I also suffer from severe asthma, arthritis, as well as pain in my knees and ankles. I have never been given a name for my condition.

5. **This witness statement has been prepared without the benefit of access to H's full medical records.**

Section 2. How infected

6. H suffered from severe Haemophilia A. He would have bleeds approximately 4 times a week throughout the time that we were together. I remember that he would apply a cold compress to his joints to try and ease the pain and swelling. He started to receive cryoprecipitate 3 years before I met him and used to go to Manchester Royal Infirmary. His doctor in 1977 was Dr Charles Hay. He used to receive cryoprecipitate on a drip to treat his bleeds. I recall that in 1979, he was attending hospital for treatment about once a week.

7. H started to receive Factor VIII in 1979 and continued to receive it until 1984. In around 1980, he began self-injecting with Factor VIII at home. He used to keep it in the fridge and used it whenever he needed it. He was very private about his treatment and would go off to a quiet part of the home to inject himself.

8. H's brother, GRO-B: B also had Haemophilia and they both used to go to their various hospital appointments together.

9. In or about 1985, H and B began to have more and more frequent appointments. First it was every three months, then every month and then every two weeks.

10. On one such occasion in or about 1985, H and B were both were called to the Manchester Royal Infirmary to receive tests. When he got home, H did not tell me immediately, but he eventually informed me that he had gone to the hospital and had been told that he was infected with LAV/HTLV-III (now known as HIV) which was likely to develop into AIDS. He was immediately treated with azidothymidine ("AZT").

Section 3. Other Infections

11. H was also infected with Hepatitis B, but I did not find out about that until I was told by the Skipton Fund long after H's death. I am not aware whether

H was ever informed of his Hepatitis infection. He only ever mentioned the LAV/HTLV-III/HIV infection to me.

12. I was also told by B, at H's funeral, that he himself had been infected with Hepatitis B. I had never been told about this by H

Section 4. Consent

13. I am not aware whether the tests at the hospital were done with H's knowledge. In the months that led up to him being told, he was having more regular appointments. First it was every 6 months, then every 3 months and then every 1 month. We were never told by the hospitals that he was infected as a result of receiving contaminated blood.

Section 5. Impact

14. The only information given to H about his infection by the Hospital was a couple of leaflets he was given, telling him to avoid coming into contact with blood. No other information was given about contact with other people. There was not much information about how the infection could be passed on by sexual contact. The hospital issued us with condoms and cream to use along side the condoms but didn't explain why this was necessary.

15. I do not believe that H was told how to deal with his condition or how it was going to develop.

16. I had to have a blood test myself, which came back negative. There was a delay of 4 months in me getting the results and I heard from the hospital that certain medical notes had gone missing. At the time, we were not married and I was using my maiden name. I believe that having two names might have caused the confusion. I was not tested for any other infections at the time. No information was given to me by the hospital about H's condition.

17. H began taking anti-viral drugs immediately in 1985. When he first started, he was sick a lot but once he got used to them, the doctors told him to try and persevere and after about three weeks he began to feel better.

18. I had always wanted to have children and because we could not, it put strain on our relationship and caused tension between us. H once said to me "*I know other people take the risk, but I could not live with myself knowing that I could possibly infect a child*". I was only 24 years old when we were told that we could not have children.

19. I believe that had H not been infected with HIV, we would have gone on to have a family together.

20. H was very sociable before his diagnosis, but after he was told he was HIV positive he changed. He stopped wanting to go out and wasn't the same person. However, even with the infection, H still tried to live his life to the best of his ability.

21. H did not want to tell any family members about his infection. I do not know whether this was because he was ashamed or because he just didn't want them to know he was ill. He put it all on my shoulders and I did not know how to deal with it. We had a very close family but I could not speak them to or confide in them about it. Not even H's mother knew anything about his infection until the day he died.

22. H carried on working in the factory, but became really withdrawn and quiet. He said on one occasion: "*It feels like a rope is around my neck and it keeps getting pulled tighter and I do not know what to do about it*". When he started to be really poorly, the GP said that the best thing he could do is to cease working. I then developed arthritis. Since neither of us were working, we started to live on savings. We both received benefits from DVA and incapacity benefit (ESA).

23. In or about 1986-1987, H began experiencing multiple infections such as thrush in his mouth, pneumonia and, ulcers. Once this happened, the doctors

said that H had moved on to the next stage of his infection, which was full-blown AIDS. Eventually, his immune system became virtually non-existent and he could not get rid of his infections.

24. Although H and I knew that we may not have long left together, we were still very much in love and so we got married in 1989. It was a happy day, but not the joyous occasion that it should have been because he was becoming so unwell.

25. After H had stopped work, we relied on income from my employment. However, I had to stop working in June 1990 due to my own ill-health. I have been unable to work since. Fortunately, H had always been a good saver and so we were able to manage.

26. In the last year of his life, H contracted Pneumocystis Carinii Pneumonia ("PCP") a number of times. By that stage, he was going into hospital every few weeks with an infection. I cannot remember much about that time: it has become such a blur.

27. Eventually H suffered from a further bout of PCP from which he did not recover. He went into hospital and stayed there for a week before he passed away. He had been placed in a side ward because he did not sleep very well and because other patients had begun to gang up on him, not wanting him there because they had found out that he had AIDS. Although this was really horrible, and demonstrated the stigma surrounding his infection, H was pleased to be put in a more private ward as this meant he could watch TV and I could visit at any time.

28. H passed away on GRO-B. He was 46 years old when he died. I was the only other person present. We had been married for 13 months.

29. After his death, I was so distraught that I could not function in any meaningful way. I could not understand what had happened or why: I wanted answers for how he had been infected but I could not get them.

30. I cannot clearly remember H s funeral: I seem to have "blanked" it out, due to the emotional trauma I was experiencing at the time.

31. An inquest took place on 6th March 1991, 3 weeks after H s funeral, at which the Coroner was Leonard Gorodkin. The hearing lasted 3 hours but felt much longer. The Inquest heard evidence that H had been using Factor VIII between 1979 and 1984. It was found that this how he must have been infected with HIV.

32. I was questioned very aggressively by the coroner who was very unpleasant to me and made me feel like I was a fool for not knowing various dates relating to H s treatment. It was the most awful experience and it made me feel as though I was on trial for murdering H .

33. The Inquest recorded H s cause of death as "*misadventure*" along with "*septicaemia*", "*Acquired immune deficiency*" and "*Contaminated Factor VIII*". This was recorded on H 's death certificate, which I now produce as **Exhibit WITN1537002**. I cannot remember the reasons given for the finding of "*misadventure*" but I found this finding deeply upsetting: it made it sound as though H was in some way responsible for his own death when the truth is that he, and all the other haemophiliacs who lost their lives, were killed by the wrongful use of infected blood products.

34. I believe that H was one of the last people that had to have an inquest after dying of AIDS related illnesses.

35. When I got home from the inquest, there were people from the press surrounding my house. I locked my door and wouldn't answer any questions but they continued to bang on my door and the back wall of my house. They then went around the neighbourhood, knocking on everybody's door on the street, asking "*Do you know you live next door to somebody who died of AIDS?*". I had to stay with my sister at the time as living in my house was not safe because of the press and because of the way that my neighbours reacted to the news that H had

died of AIDS. The stigma surrounding the disease led to fear and isolation for me and my family.

36. After H's death, I felt numb and did not understand what was happening and why. I was only 30 years old. I walked around like a zombie and just went through all the motions of living. I would only eat and drink what I needed to survive. I stopped seeing people and wouldn't socialise at all.

37. For about 7 years after H's death, I simply didn't function normally. Things only started to improve when my sister had a son and asked me to look after her whilst she was at work. This began to give me a reason to get up in the morning.

38. I eventually remarried to an old school friend who I got to know again after we bumped into each other in a local shop in town. If it hadn't been for this chance meeting, I do not think I would ever have as I was not thinking about another relationship after H's death. At the beginning, I compared them to each other but I knew this was unhealthy and I had to stop doing that. My second husband and I had a good marriage which only ended when he passed away in August 2018. He and I never had any children.

Section 6. Treatment/Care/Support

39. H was treated very quickly with anti-viral medication and I do not believe that he had any difficulty obtaining that treatment.

40. When H was still alive, I could not get it in my head why I could not have children. As a result, we both went to see a counsellor called Emil Morgan at Manchester Royal in 1987 who offered couple's therapy. It did not help me because I thought that he just was trying to put me off the idea of having children.

41. In the last year of H life, he received counselling from Alison Amscot. She was in our house every week and was with me when he died. She also came to the inquest to give evidence. I think this helped H but it was too little too late

in my opinion. We should have been offered support earlier as I believe that it would help us better understand his condition.

Section 7. Financial Assistance

42. After H's death I got in touch with the MacFarlane trust who I believe put me in touch with the Skipton Fund.

43. In around 2009/2010, I received £50,000. I got a letter from the McFarlane Trust, saying that this money would be sent to us. I had to fill out a questionnaire and I was informed that I qualified for the payment.

44. The other lump sum I received was four years ago, of £10 000 from the Skipton Fund. I now receive regular monthly payments of £750 a month from the English Infected Blood Support Scheme.

45. There were not any obstacles or difficulties in obtaining financial assistance and there were no preconditions to my knowledge.

Section 8. Other Issues

46. I feel like all of this should never have happened to H. He was having treatment to stop him from being ill, but instead, it killed him. Even though this happened a long time ago, having to answer the questions for this inquiry brought everything back to the surface and I felt all the old emotions all over again.

47. After H passed away in the hospital I never got to see him again, and he was returned to me in a sealed coffin. I honestly don't believe that H was in there.

Anonymity, disclosure and redaction

48. I would like to apply for anonymity and I understand this statement will be published and disclosed as part of the Inquiry.

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

Statement of Truth

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

Signed.. GRO-B ....

GRO-B

Dated....16th march 2019.