Witness Name: GRO-B
Statement No.: WITN0851001
Exhibits: WITN0851002 – WITN0851003
Dated: 19/6/19.

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 4 April 2019.

I, GRO-B will say as follows: -

Section 1. Introduction

1. My name is name is GRO-B. My date of birth is GRO-B 1939 and my address is known to the Inquiry. I am widowed and I live alone. I have one daughter, GRO-B who lives in GRO-B. She is also giving a statement to the Inquiry GRO-B My statement forms the factual basis of GRO-B.

2. I intend to speak about my husband, GRO-B: H He was a severe haemophiliac who was infected with Hepatitis C and HIV/AIDS. I will discuss the nature of H illnesses and treatments, and the impact they had on our lives together.

Section 2. How Affected

My life with H

3. I was 17 or 18 when I met H at a Youth Club, where he used to sing and play guitar. He was heavily involved in music and was a real entertainer for the whole of his life, really – even when we were running pubs.

4. H never let his illness get in the way of his life. He had so many hobbies: aside from his music, H played bowls and darts, forming competitions at the pubs that we ran. When we got married he had a GRO-B dog named GRO-B and he travelled the country showing her. H also loved photography and used to make cine films of weddings.

5. I had known that H wasn't well from the start. My mother wasn't very happy about H haemophilia – especially when we were getting married. But you're just in love. We were married in GRO-B and I had GRO-B in 1962.

6. In 1968 we moved to GRO-B, where H was born. We took on the GRO-B which was owned by GRO-B, and ran a Bed & Breakfast out of there. We also had fuel pumps. These were busy days!

7. H would take sick in bed if he wasn't feeling well. He used to return to work when he perhaps wasn't feeling that good – a day or two earlier than he should have.

8. Things became too much with H illness, so in 1978 we moved to GRO-B, to a pub that was easier to manage. This was the GRO-B GRO-B and I had this until 1989, a couple of years after H died.

9. H was a good, loving husband and a devoted father, he didn't deserve what happened to him.

Nature of H illness and treatments

10. H had severe haemophilia A, with 0% Factor VIII.

11. As a child, H went to Great Ormond Street and probably Northampton Hospital too, where he would receive blood transfusions if he had a severe bleed.

12. In later years, he was receiving blood and blood products (Factor VIII) at the GRO-B and the GRO-B both in GRO-B This was from 1967 through to 1987, when he passed away.

Infection

13. The day before his sister's wedding in GRO-B H was taken to Northampton General after the handbrake snapped on his vehicle and damaged his wrist, causing a severe bleed. The doctor in A & E insisted it was a sprained wrist, and told me to bring him back in the morning.

14. I had to send young GRO-B off to the wedding in the morning as she was being a bridesmaid. H would have been giving his sister away, but I had to take him back to the hospital. They told us that they wanted to send him to this new centre at GRO-B and took him up there in an ambulance. It was GRO-B There, H was treated with Factor VIII and possibly given a blood transfusion.

15. From this point, H would go to the centre at GRO-B whenever he needed treatment. This seemed to be a miracle: that we could ring and speak to a doctor, then take H up to GRO-B for treatment to help stop the bleed and the pain, meaning he would recover more quickly.

16. Eventually H was given home treatment by the family doctor and then himself. He would only go to hospital if he was too ill and needed more care and treatment.

17. I do not recall a specific Hepatitis C diagnosis, although it is reported in various places throughout H medical records. I was only made aware of it after H passed away, when cirrhosis of the liver was confirmed. This is how I recall the Hepatitis C diagnosis.

18. Looking back, H was jaundiced in 1975 and very poorly. A letter from the GRO-B dated September 1985 lists H as having AIDS and progressive dementia, as well as NANB Hepatitis dating back 10 years. This makes it likely that H had Hepatitis C in 1975.

19. H was told that he had AIDS in October 1986. His health declined very rapidly, and he passed away in GRO-B 1987, aged 51.

Information provided to H and I

20. I didn't always go in when H was seeing the doctor, so I do not know what information was provided to him about either infection.

21. I don't know if the information that was provided, was adequate.

22. After reading medical notes, I see that both H and I were told of the possibility of contracting the AIDS virus in 1985, but only the possibility. As it was so long ago, I have difficulty remembering all the details.

23. We were still running a pub at this time. I do think we should have possibly been moved out, but not so much was known about the HIV infection at that time.

24. In the very late stages, possibly after H death, a lady named Mary from the GRO-B tested me several times for HIV. Luckily, to this day I remain OK.

Section 3. Other Infections

25. I think that H was potentially infected with variant Creutzfeldt-Jakob Disease (vCJD) as well. I have read the Haemophilia Society's submission to the Archer Independent Public Inquiry. The section on vCJD refers directly to the symptoms H was suffering before he died.

26. The report lists early symptoms of vCJD as including progressive dementia, loss of speech, withdrawal, behavioural changes and depression – all of which were present in H.

27. H had started suffering from progressive dementia and had certainly gone into his own world towards the end of his life. The dementia had come on relatively suddenly, at the end of 1986. He was basically unable to speak a few months later when he died.

28. H was also unable to feel pain towards the end. I know this because one day when I visited, I had a look at his legs and he obviously had a bleed into the joints. I could see the swelling in the joint and it was very hot. It usually gives the patient a lot of pain because it fills the joints out. I fetched the nurses and doctors who said they could tell that he was no longer feeling pain.

29. Most tellingly, the report mentions persistent pain and odd sensations in the face and limbs. This caught my eye, because I had actually forgotten about this part. H had developed trigeminal neuralgia – a chronic pain condition affecting the trigeminal nerve. Even if he just mildly brushed his face, it triggered a jolt of excruciating pain.

30. I then read about the other symptoms, and I was shocked. You could see that people in charge knew there was a chance that this would come through with the blood as well.

31. I'm glad, in a way, that he didn't know. So many of these things fitted. So, did he have it? I don't know. I wasn't told about a lot of things, and I certainly wasn't told about this.

Section 4. Consent

32. I am not sure whether H was treated without his knowledge or consent.

33. H may have been treated or tested for the purposes of research. I can remember that they seemed to do more tests during 1986. Every time we went up there they were doing more tests and I wasn't told what for.

34. There was a time when I said to a member of medical staff, "Do you think it's AIDS?" and she said, "Oh, we don't use that term around here, it's HIV" – if they'd known they wouldn't have told me anyway. I think this was their way of not telling me.

35. I recall that H told me he had "AIDS" in October of 1986, when we returned from a trip to Spain. We had been looking at purchasing a flat there. H was in bed with a shoulder bleed one day when I asked him for a decision on the flat. He said, "How can I give you a decision on this – I've got AIDS!" I was horror stricken.

36. I note a form in H records entitled *"UK Haemophilia Centre Directors AIDS Committee – Surveillance of possible cases of AIDS Related Illness".* On the first page, the date of first HTLVIII Antibody Status is listed as 31 August 1984, whereas the date the disease was first suspected was 19 October 1986. I produce this two-page document as **WITN0851002.**

37. The fact that H had actually come to Spain and had been looking at the flat, shows that he didn't know that he had AIDS at this stage. He simply wouldn't have come along and kept up with the charade if he had known. After seeing hospital records, he probably knew he had HIV but had not been formally diagnosed with AIDS yet.

38. It would figure that he was told of his diagnosis in October of 1986 (as above) when we returned from this trip, and that is when he had his outburst to me.

Section 5. Impact

Mental and physical effects

39. Mentally, H seemed to go into himself as his health went down. I don't know if he was depressed. I'm sure that he probably was.

40. He never, ever made a fuss about his health. He just got on with it. He never complained or said, "Why me?"

41. I think that, by the time he knew what was happening, his mental state was so bad that he couldn't comprehend it. This is in his last months, with the dementia and other vCJD-like symptoms that I described above.

42. At the end, he got to the point where he knew nothing. He didn't know who I was and he couldn't speak.

43. Physically, H was generally just always very unwell and in bed.

44. The Hepatitis C caused flu symptoms, jaundice, tiredness and night sweats. The night sweats were dreadful – they were so bad that I had to get up in the night and change the sheets.

45. In his final months he lost a lot of weight and was bedridden, unable to do anything for himself: he couldn't wash, eat or communicate with anybody.

46. He also suffered from oesophageal candida, which made it very painful to swallow. It gave a burning sensation and was very painful.

Further medical complications

47. H haemophilia meant he had a constant lack of energy, tiredness and was mostly in bed.

48. The Hepatitis C also made him feel very unwell and caused cirrhosis of the liver. This was only confirmed by me after H death, when I saw some medical papers.

49. Infection in the brain that ended up being progressive dementia – potentially the onset of vCJD.

Course of illness

50. Towards the end of 1986, H required quite a lot of nursing and was mostly in bed. I was either still unaware, or did not officially know, that it was AIDS.

51. The doctor did send in a nurse every day to help with washing, dressing, changing the beds. The washing was enormous. I often had to change the bed 1-2 times a night, owing to night sweats. My lovely cousin used to come and take the washing for me. This probably shouldn't have happened, due to risk of infection, but again, no guidance was given on this.

52. Something happened on GRO-B December 1986, GRO-B GRO-B. As I am a fairly hopeful person, I thought I would take H out for lunch.

53. It was during this lunch that I realised how bad H was. He couldn't read or make sense of the menu. He couldn't speak – he was so lost he just put his head on his arms on the table.

54. I wasn't sure if he had had a stroke – he was struggling to walk and the manager assisted us back over the road to the pub where we lived. I was in shock. This was nothing like dealing with haemophilia.

55. I rang the hospital at GRO-B and I think I took him in the next day. From then on, I couldn't leave him. I didn't want people to see him like that, I needed to protect him.

56. This went on to approximately February – March 1987. I eventually had to take him to GRO-B. After a week or so I wanted to bring him home. He couldn't even get into the car – he didn't know how; his brain couldn't tell him. They took him back into hospital and shortly afterward he was moved to an isolation ward, where he stopped.

57. By this stage, H had pneumonia, he wasn't eating, he lost weight and couldn't seem to talk. He didn't know me or GRO-B. The only other visitors were his sister and her husband.

58. I didn't want anyone to see my lovely, dear brave husband in this state, I needed to protect him and shield him as much as I could. I was told several times that he would not last, but he always seemed to rally. But on GRO-B 1987 at GRO-B he slipped away.

Treatments and their effects

59. I don't know if H took anything for his Hepatitis C. Same with the HIV/AIDS – it's not known what he was taking. Just painkillers at the end.

60. H was in isolation at the end, on the infectious diseases ward.

Impact on private, family and social life

61. Certainly, H had no social life. I kept people, even family members, away from him due to the fear of stigma.

62. Personally, I found it very physically challenging trying to care for my husband, run a pub, and visit a hospital that was one hour away, six times a week. It took me four to five hours there and back.

63. Trying to make out things were not that bad to the customers and putting up a good front, I was exhausted.

64. Without my sister who stopped five days a week, plus some good staff at the pub, I would not have been able to cope.

65. Looking back, I think I should have been advised about the infection, especially given I was providing food and drink to the public. This didn't happen.

66. I had no social life because of H illness and trying to run the pub.

Stigma

67. The stigma associated with HIV gave me feelings of disbelief, fright, being unable to talk truthfully to people, keeping secrets, and uncertainty.

68. We didn't tell anyone at the pub that he'd received contaminated blood, although they did know he was a haemophiliac.

69. I was having to think about what to tell people each day, so that the same message went out. It was another form of protection, really. Both for myself and for H

70. It was exhausting, being in a small community and dealing with this, whilst running a pub. I didn't want to be there – I wasn't able to talk about it because of the stigma. In the end, when he died, I told people that he died of pneumonia, which was listed as one of the causes of his death. I produce H death certificate as **WITN0851003.**

71. I thought the doctors didn't know about the infected blood products, that it had been a mistake and that once they knew, it would be put right. But that wasn't so. It was fairly early though, I believe that H was one of the early haemophiliacs to actually die.

72. Even so, I could never blame the doctors because I'm sure they always did what they thought was right and were always very kind to H.

73. To this day, I am unable to tell people what actually happened to H, I just tell them that he was very ill. I only talk about him to family – four family members know the full story. Isn't that terrible?

74. I left the GRO-B about 18 months or two years after H died. This wasn't a step that I took lightly, because there was no house or security to come to (owing to the lack of life insurance due to H infections). I went into a council flat in GRO-B and was there for three or four years.

Impact on other family members

75. GRO-B had moved away by now and was living with her now-husband GRO-B near GRO-B. GRO-B came to visit when she was able.

76. I always tried to shield GRO-B from the illness as much as I could. GRO-B did meet H several times while he was alive, so he knew the position.

77. GRO-B and GRO-B are grandchildren who I never thought I would have. They never knew their grandfather and he never knew them. One of the biggest losses of this terrible affair.

78. My sister, GRO-B, whom I couldn't have managed without, was my sounding board. GRO-B held the fort when I was at GRO-B, she cooked me meals, and was in every sense there for me. I was so lucky to have her.

79. H sister GRO-B used to visit H on Saturday afternoons. She did a big fundraiser for haemophilia.

<u>Impact on work</u>

80. I still ran the pub at GRO-B, with the help of some extra staff. This meant that when H wasn't very well, I always knew I had somebody coming in.

81. The customers still came, I feel that I was lucky. Mostly they had all got on well with H they supported me and kept the pub as their local.

82. By this time though, there was more about HIV on TV and in the papers. There were a few difficult younger customers. There was a nasty piece of work in the pub one day who was saying "I don't want to be in here, there's AIDS in the family." I think he'd just drawn the conclusion based on the fact of H haemophilia.

83. I moved into the council flat in GRO-B after H died and worked as a driver for GRO-B until I retired.

Section 6. Treatment/Care/Support

84. I don't know if H took anything for his Hepatitis C. I don't know much about it at all.

85. Same with the HIV/AIDS – we didn't even know that he had it, so it's not known what he was taking.

86. There was no general support, just palliative treatment at the end when he was in the infectious diseases ward. The nurses and staff in this ward didn't know H before he became so unwell, which was unfortunate.

87. It was upsetting that he was in isolation by this stage, and had to be alone when I wasn't there.

88. I received some counselling, just before H died. It just made me more upset though, and I had to stop.

Section 7. Financial Assistance

89. I received an ex-gratia payment of £20,000 from the Macfarlane special Payments Trust, on 16 February 1990. I signed a waiver in order to obtain this.

90. I received the following lump sum payments from the Skipton Fund:
    - £20,000 on 6 May 2011;
    - £50,000 on 7 December 2011; and
    - £10,000 on 7 March 2017.

    I used this money to invest in a house, so that I had my own home.

91. I was receiving regular monthly payments for a time after H died, but then they stopped the payments for widows. I can't remember how much these were for. I do remember that they started again around 2007.

92. This year (2019) I received a £500 heating allowance.

93. I never applied for any grants, I only ever had whatever I was entitled to. I otherwise managed on working and savings.

94. I didn't have any difficulties or obstacles in obtaining these payments. I filled in whatever forms and the money came.

95. The doctors completed the forms for the £50,000 lump sum payment, but they did levy a £75.00 fee for this.

96. I would like to think that any financial benefit would help my grandchildren as they set out on life's journey. My daughter has always worked hard and made a good life with GRO-B and the children. She has done so with no financial help from me though, just really hard work.

Section 8. Other Issues

97. I am not legally represented in matters relevant to the inquiry. I haven't done any campaigning in this matter. I did write a letter to Tim Boswell MP in 2007 though, urging him to back the Early Day Motion (supported by Betty Williams MP) in support of the independent Archer Inquiry.

98. In more recent times (post-Archer), I had a general conversation with Andrea Leadsom MP at church one day. She was going to speak with one of her associates about whether or not there would be an independent statutory public inquiry.

99. In 1984, my sister-in-law had written to the Health Secretary asking if blood had been heat treated because her brother was a haemophiliac. She received a response stating categorially that there was no risk involved.

100. We received mixed messages about what was going to happen to the body when H passed away.

101. The day after he died, my sister in law had asked Dr GRO-B whether we had to inform the undertakers about H infection. Dr GRO-B said no – absolutely not, you don't have to.

102. A family member of ours is an undertaker. He sent his boys up to GRO-B to collect the body, and they were sent away. They weren't allowed to touch the body out of fear of contamination. GRO-B went back the next day and did it himself.

103. We were not told initially that his coffin was going to be sealed. I've got a feeling it was my sister-in-law who came over and said that GRO-B said we can't go and see him now because he had been sealed up.

Statement of Truth

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

Signed GRO-B

Dated 19/6/19