Witness Name: GRO-B
Statement No.: WITN0448001
Exhibits: NONE
Dated: 05.02.2019

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 30 October 2018.

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

Section 1. Introduction

1. My date of birth and address are known to the Inquiry. I am the father of a son who contracted both Hepatitis C and HIV. I am the husband of a wife who contracted Hepatitis C. I am the father of a daughter who, although a carrier of haemophilia with a slight bleeding disorder, is fortunately not infected. What follows is **my** story; **my** experience. I am not affected by any bleeding disorder myself.

2. I can confirm that I have chosen not to be legally represented and that I am happy for the Inquiry team to assist me in drafting my own statement.

Section 2. How Affected

3. Many years ago my wife was diagnosed with Von Willebrand Disease. This was later changed to Haemophilia. Based on the original diagnosis we were informed that, if we had children, they might suffer some mild bleeding disorder.

4. In 1973 our son was born via a forceps delivery, which resulted in bruising to his head. This was possibly the worst kind of delivery and he went straight to intensive care and was eventually diagnosed with severe Haemophilia A. There was at that time a very real chance that he a) might die or b) might suffer brain injury.

5. My son survived and, apart from his haemophilia, was a healthy child. So, with help and support from our local Haemophilia Centre, life (with a new baby and haemophilia) settled into its new routine.

6. During the next few years our son made many visits to the Centre during the day and the Children's Ward at the Hospital at night. It almost became a home-from-home where we were made welcome and treated with respect.

7. We did occasionally get accusing looks from people in public because of our son's visible bruising and we did, on one occasion, have to offer an explanation to a particularly uninformed doctor on a hospital ward.

8. In 1976, after much soul searching, our daughter was born. She was diagnosed as a carrier of haemophilia disorder with a mild bleeding disorder herself. Fortunately, over the years, she has needed very little in the way of treatment so has escaped any potential infection.

9. However, shortly after our daughter was born, my wife suffered post-natal depression and her and our new baby were hospitalised. This, coupled with dealing with our son's haemophilia, her own difficulties

and operations and the **guilt** she would later feel, led to my wife suffering a series of depressions over many years.

10. Somehow, with lots of help and my wife's determination to get well, we survived these very difficult episodes. Our children were always our priority.

11. When our son was 3-4 years old, he was diagnosed with Non A/Non B Hepatitis (later to become Hepatitis C). All information regarding my son's diagnosis came from the Haemophilia Centre who provided us with ongoing help and advice.

12. Then the **"bombshell" – HTLV3** (now HIV).

13. A lecture was given by the then Director of our Haemophilia Centre preparing us for the threat of a new virus that could pose a risk to those who were being treated with some blood products.

14. A short while after (May 1985) our son was confirmed to be infected with this potentially deadly virus. This diagnosis was made by the Haemophilia Centre who, once again, provided help and advice. He was GRO-B years old. Once again we were in a "would he live or would he die" scenario – how do you tell an GRO-B year old child that he might die a dreadful death? We didn't.

15. In 1989 my wife became ill and was diagnosed with Non A/Non B Hepatitis. This diagnosis was probably made by the hospital haematology department but I can't be sure. Initially it was suggested she must have contracted it during a recent holiday in America. Later it was determined it was due to having received contaminated blood treatment. My wife felt dirty and unclean – something not to be discussed in public therefore **secrecy** was necessary.

16. I believe we were informed of the risks associated with HIV and Hepatitis C when my wife and son were diagnosed. However too much time has elapsed to be certain of any of these things.

17. Our son approached his GCSEs and eventually moved on to A Levels. Because of illness some of his school work had suffered so we employed a tutor to help improve his maths. He struggled through a bout of pneumonia and later a difficult bout of tuberculosis. Against the odds our son recovered sufficiently to enter university (1993). His aim was to study Computer Sciences.

18. His health was at this point rapidly deteriorating. We were informed that he might not make it to Xmas. We were then informed that he might not make it to Easter.

19. Our son attended university for as long as he could but, on GRO-B 1994, succumbed to a tragic, lingering, wasting death that was HIV related.

Section 3. Other Infections

20. As far as I am aware, the only infections contracted via infected blood by my wife and son are those detailed in paragraph one of this statement. However, I suppose it might be possible that, if my son's immune system was compromised, perhaps it could have had a bearing on him contracting pneumonia and/or MAI.TB – I don't know.

Section 4. Consent

21. The only information I am prepared to offer here is a modified quotation copied from notes my wife made during our son's treatment:

1977 date 1 – "Informed…our son has Hepatitis".

date 2 – "More blood tests…Our son is Australia Antigen positive. Sample of blood taken from my wife."

date 3 – "Blood tests, liver function tests, myself, our daughter and our son.

Possible Anti-Hepatitis Globulin for myself, our daughter and my wife…"

The notes do not show any record of us actually receiving Anti-Hepatitis Globulin. Would it have helped us if we had?

1983 date 1 – "Our son has to go….There is a 3 stage family injection available which would cover us against Hepatitis for 5 years". The notes do not show any record of us receiving this injection. Would it have helped us if we had?

Section 5. Impact

22. As a result of his Hepatitis C infection my son was removed from his nursery school. With help from our Haemophilia Centre he was temporarily placed in another school prior to going on to Infant's school.

23. The headmistress of the local Infant's school wasn't too keen to accept him, but again with much persuasion and help from the Centre, she relented.

24. This was our first experience of **stigma** but, once again, a routine was established.

25. Haemophilia could be discussed openly but depression and Hepatitis Non A/Non B were taboo subjects and best kept **hidden**. So, secrecy and **shame** were now added to the stigma and guilt.

26. As time passed, both my wife and I were given training so our son could be treated at home. I was a coward and couldn't do it so it was left to my wife to administer. What should have been a shared effort became my wife's sole responsibility. Ultimately this would lead to more guilt being heaped on her shoulders.

27. Home treatment was arranged by and administered in accordance with instructions from the Haemophilia Centre. It gave our son a near normal life until HIV reared its ugly head.

28. Whilst we struggled to come to terms with the new body blow of our son being diagnosed as HIV positive, the press and media were having a field day. People were dying and questions were being asked: could this be something akin to plague? Should the victims be quarantined, perhaps on prison-type ships or something akin to Anthrax Island? Could it lead to a worldwide pandemic? The label "Gay Plague".

29. Then the Government campaign – leaflets through every door – the **"AIDS"** tombstone – the continuous stoking-up of panic. We, the affected and those, the infected, had to endure this constant bombardment of information and misinformation. We were very, very **afraid**. The shutters came down, the drawbridge was raised and **fear**, secrecy and **self-preservation** became the order of the day. We had two children to protect.

30. The only people we could confide in were the medical professionals, their staff and associated social workers. We relied on them for help, advice and support but how were they being supported? Patients young and old were becoming ill or dying. Our local Haemophilia Centre was trying desperately to help and advise where and when they could but who was supporting them? What was the toll on their physical health and mental wellbeing? Did they receive any extra resources to assist in dealing with this tragedy? How did they cope?

31. How did the victims cope? Not only were we living with the fear of a family member dying but now the fear of discovery by members of the press and the general public. What might be the consequences of discovery? Yes, we were **afraid**. This was an ugly, dirty and potentially deadly virus. We were living with guilt, shame, fear and secrecy.

32. The sword of Damocles hung over our heads – would our son die? If so, when and how? It was our last thought at night and the first the next morning. And still we struggled to maintain a near routinely normal life.

33. Where were the authorities? Were they helping? Had we, the victims been forgotten? Perhaps we were expected to just get on with it! Had we been dumped; left to suffer in silence; left to flounder? Should this be so then shame on them!

34. But, no matter how difficult, life goes on. For both my wife and myself depression and anxiety were never very far away. We did what we could and, with lots of help from the Centre and our GPs, we survived.

35. The kids were growing up and were better able to understand some of the problems we were all facing. We were trying hard to live a normal life in very abnormal circumstances.

36. My wife's diagnosis had the effect of bringing to an end any further intimate relations between us. Amongst other problems, she has difficulty walking (mainly due to arthritis) so, because of this and Hepatitis C, I no longer have a wife, I have a companion. Similarly my wife no longer has a husband she has a carer. This, of course, has resulted in even more guilt. She is also concerned that her Hepatitis C status could lead to her dying prematurely – more fear.

37. **1994** – what a wondrous year! We were expecting our son to die. I was facing potential redundancy. My mother-in-law was ill and died in GRO-B My daughter was doing A Levels. My son died in GRO-B My daughter left for university in September/October.

38. With help, my wife nursed our son at home until he died. Her grief was overwhelming, she was weary and exhausted both physically and mentally. She had given her "all" and just "gave up" – she wanted to die.

39. I believe (although I am no longer sure) that, for her own safety, she was sectioned under the Mental Health Act. Over the next couple of years, she spent a considerable amount of time in hospital trying to come to terms with the loss, grief, shame, secrecy and the guilt.

40. Guilt for having passed Haemophilia on to her children. Guilt for giving our son treatment that might have been responsible for killing him. Guilt because a significant part of our marriage had been taken from us. Guilt because depression and mental torment has had such a devastating effect on the whole of our family. Guilt that our daughter might not want children because of what she has witnessed and experienced over the years.

41. She was eventually discharged from hospital but was ill for many years after. She was in the care of various psychiatrists, the Crisis Team and our excellent GP. The medications she was prescribed, including ECT, were powerful and substantial.

42. With significant help from our GP and her own strong will and determination she managed to recover.

43. With a great deal of further help and determination she weaned herself off all medication associated with depression. She started to "feel" again; to "live" again.

44. But, even during her recovery, concerns about recurring depression and the black pits of despair far outweighed any concerns regarding Hepatitis C treatment. My wife considered the risk too high so Hepatitis C treatment was a non-starter (especially the Interferon based products, depression being a major side effect).

45. During this lengthy period the staff at the Haemophilia Centre were changing. It is difficult to explain but we were losing touch with the Centre – the atmosphere had changed and I felt we were being a bit let down and, to some degree, abandoned.

46. Contact with the Centre became less and less frequent and has more or less ceased.

47. My wife's Hepatitis C is being managed by a very understanding hospital consultant. He keeps a watchful eye on her and stresses the

fact that modern treatments for Hepatitis C carry little side effects and are considered quite effective.

48. However, nothing can be guaranteed 100% safe and effective. My wife is still fearful because a) her treatment might fail and the bitter disappointment could trigger more depression and even guilt; b) the treatment itself might trigger another serious bout of depression. Therein lies the dilemma: the fear of depression versus the fear of the consequences of Hepatitis C. Only time will tell.

49. Who then is prepared to assess the <u>impact</u> this has had (and continues to have) on my wife's life and wellbeing (and on my and our daughter's life and wellbeing)?

50. We often tell each other that nothing else bad can happen, but it does. Even after 30 years and more our lives still continue on a downward spiral.

51. A simple example of this concerns the Alzheimers Society. Not many years ago they commissioned a hard hitting TV advert which included the AIDS tombstone. But who did it hit hardest? The people it was aimed at or those of us who had already suffered (and were still suffering) from the Governments HIV/AIDS campaign.

52. Another example is when my wife received a letter, out of the blue, suggesting there might be a risk of her contracting vCJD.

53. Writing our individual statements and/or experiences is, in itself, forcing us to relive those tragic circumstances over and over and over again: hence the downward spiral continues.

54. Our son carried the heaviest and most tragic burden of illness and death. My wife and I carry the burden of losing our son. Our daughter carries the burden of losing her only brother.

55. My wife also carries the burden of Hepatitis C and its potential consequences. She also bears the responsibility of motherhood.

56. Mothers are the glue that holds families together. Regardless of the difficulties she has faced (and is still facing) she has dragged herself up from the dark pits of despair and has put her family first. Our children have been loved and nurtured and have been a blessing to us both. With significant help from the Centre and our GPs, she nursed our son at home through his dying days without thought for herself. She was his rock and his comfort.

57. Even though she has suffered many bouts of depression she has always put her children first and been a proud, capable, caring and exceptional mother.

58. I have referred several times to my wife's fragile mental state, her depressions and the added stress inflicted by our son's Hepatitis C/HIV and her own Hepatitis C diagnoses. What I have not mentioned is the courage, determination and fight she has shown, pulling herself out of these dark places and soldiering on.

59. As mentioned later in my statement, I have suffered my own waves of depression and anxiety. I have tried to love and support my family. I have watched us all struggle, often with things outside our control.

60. Like my wife, I am very tired and very weary. It would be nice if this all just "went away" but I know it won't – it will always be there to haunt us.

61. Who can quantify the additional physical damage and mental strain these events have put on our lives? Only those involved from the beginning can understand the mental torture and heartache that this tragedy has inflicted on us. We have more ahead of us and it is my belief that this torture will cease only when we die.

Section 6. Treatment/Care/Support

62. I have skipped over my periods of depression and anxiety – the amount of time I have spent with psychologists and talking therapists – the monies spent on hypnotherapy and Relate.

63. Most referrals to these services came from our GPs via the NHS. One particular NHS psychologist was suggested by the Haemophilia Centre. Other services e.g. hypnotherapy and a Relate counsellor, although suggested by a GP, were made (and paid for) privately. At least one other session with Relate we arranged ourselves.

64. I have also attended ad hoc group voluntary sessions organised by clinical psychologists in our local library.

Section 7. Financial Assistance

65. In or around 1989 a group legal action was being organised to claim some form of compensation for those infected with HIV. We weren't entitled to legal aid so, having taken advice, had to back away or risk losing what little savings we had.

66. Fortunately our son reached his GRO-B birthday that year and automatically became entitled to legal aid in his own right. This eventually resulted in a compensation payment.

67. My wife, because she is registered with the Skipton Fund (and possibly the Macfarlane Trust), is receiving the relevant payments for her Hepatitis C status.

68. Information leading to my son's compensation and/or my wife's Hepatitis C payments would probably have been relayed to us via social workers attached to the Haemophilia Centre, our associations with the Macfarlane Trust, the Skipton Fund and possibly the Haemophilia Society.

Section 8. Other Issues

69. **We** didn't ask for this **Inquiry**. It is raking up the past and causing us to remember events that we have tried to push to the furthest recesses of our mind. It is causing us a great deal of grief and heartache.

70. With or without us the Inquiry will continue. There is no escape. On that basis we are, in our own individual way, trying to contribute what we can either as experiences, information or formal statements.

71. Those still infected face uncertainty. Marriages and relationships have suffered. Families have been seriously affected and/or destroyed. Some, I am told, have experienced financial hardship.

72. The Inquiry will not bring us peace but will, in fact, bring more grief and heartache. What we have been forced to endure should not have happened – perhaps the Inquiry can shed some light on **why** it happened!

73. It won't tell us what my wife's future will be with regard to her Hepatitis C status and it certainly won't repair the damage this whole fiasco has caused.

74. What it might do is answer some lingering questions:

Why did my son have to die this way?
Why were we seemingly left in the dark and forgotten about?
Why were we left to suffer in silence?
Why were we left in fear?
What happened to self-sufficiency in blood products?
How were decisions reached regarding the importation of blood products to meet requirements?
What role have the product suppliers played?
Have they been questioned?

Do they accept any responsibility?
Who amongst the medical/scientific community knew what and when?
Were any questions raised by this community?
Were any answers given?
Why has it taken so long to get to an Inquiry?
Is there a case to answer?

75. This has plagued us for over 30 years. I don't know how we have survived this far! We still have a long way to go. Will it ever end? Will we still be here to see the end?

76. I have spent many, many hours writing this statement and the associated modifications. I have relived the grief and unhappiness over and over and over again. I am tired and weary: I am old and need to rest.

77. This has been **my** experience. These are **my** recollections. There will be gaps. There might be mistakes. It's the best I can do and it **constitutes my statement to the Inquiry**.

78. My wife has requested I inform the Inquiry Team that she has submitted details of our son's home treatments to that Team but, **please note** – the information contained therein is **not** part of, and is **separate** to, **my** statement.

79. If some of it is useful good; if not, then at least I have tried and can do no more.

80. If possible I wish to remain **anonymous**.

Statement of Truth

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

Signed GRO-B

Dated 05.02.19