ANONYMOUS

Witness Name: GRO-B
Statement No: WITN3335001
Exhibits: Nil
Dated: 20 February 2020

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 22 November 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 GRO-B 1947 and my address is known to the Inquiry. I live in GRO-B with my wife, GRO-B, and we are both retired teachers.

2. I intend to speak about my treatment for haemophilia and my infection with hepatitis C ('HCV'). In particular, the nature of my illness, how the

illness affected me, the treatment received and the impact it had on me, my wife and our lives together.

3. I am not legally represented and I am content for the inquiry investigators to assist me with the writing of my statement. During the interview, my wife has been present and has contributed to the content.

Section 2. How Infected

4. I was born in Manchester, in a Salvation Army hostel because of a snowstorm that day. I grew up in GRO-B with my mother and father, who served in the Army just after the Second World War and subsequently trained as a printer, he eventually became a civil servant.

5. My mother's father was a haemophiliac, and my mother was a carrier. Her uncle (her father's brother) died as a result of his haemophilia when he was an infant.

6. When I was aged approximately 2 years old, I suffered a cut to my tongue from biting a barley biscuit. The bleeding did not stop, and I was diagnosed with severe haemophilia A. I was home educated by a private tutor because of this until I reach the age of 11.

7. I incurred a lot of knee problems as a child due to regular internal bleeding in my knee joints. My mother would hush up my bleeds as best she could.

8. Family remedies included putting a hot poultice on the bleeding joint, coupled with a dose of aspirin. This did not prove helpful. On one occasion in my early teens, I returned from a football match between Stockport County and Workington where I collapsed as soon as I got home. I had suffered a stomach bleed as a result of taking aspirin in conjunction with my severe haemophilia.

9. My mother was very highly strung and felt a lot of responsibility for my haemophilia as a carrier of the condition. This caused a lot of rows at home, and I began to play down the severity of my haemophilia. If I had a minor bleed I would avoid telling my parents as this would cause a big fuss and I did not want to cause any trouble. This caused a lot of damage to my elbows and knees as a child, which remains to this day.

10. On those occasions where I had a more serious bleed, I would need to go to hospital to receive treatment. I was treated regularly at the Manchester Royal Infirmary where I would receive intravenous injections of fresh frozen plasma ('FFP'). This was described to me as 'plasma injections'. I would do my best to avoid going to hospital whenever possible, and when I was forced to go I would be in there for up to a week. At the time I gave a lot of my blood for research.

11. I passed my 11 plus which allowed me to go to my local grammar school just outside Manchester. At the school's insistence, I wore bright red armbands to identify me in case someone knocked me over. At any opportunity I would take the armbands off to stop me being singled out.

12. I was also forced to go to school on a bus with children who had severe educational needs. These children were either abused at home or had severe learning difficulties, which was obvious to me even at 11 years old. I was very relieved when I was allowed to use public transport like the rest of the school children.

13. I was singled out further by the school when they prevented me from taking part in sports and P.E. classes with the other kids. I learned to accept this and simply got on with it.

14. In the build-up to my O-Level exams I suffered a serious bleed in my arm. This forced me to delay my O-levels by 12 months as I received treatment at the Manchester Royal Infirmary to stop the bleed.

15. My mother, metaphorically wrapped me in cotton wool to stop me from getting injured. Looking back, she had me under lock and key as she overcompensated for my welfare. On one occasion, I returned home just after 11pm having been at the local church youth club. When I got home I found that my mother had phoned the police to report me missing.

16. By the time I had finished sixth form, things had got so bad at home that I just wanted to get away and go to university. I went to Manchester University aged 19, having been held back a year due to my arm bleed, on the condition that I would not stay at home if I went there. I longed to be free of the shackles of my mother's parenting. I gladly accepted the offer to study Geography and Geology in the knowledge that I would not have to remain at home with my parents.

17. The freedom of university went to my head straight away. I had a wild first year, until I met my now-wife GRO-B ('GRO-B') at a dance. We were both studying geography and had a lot in common. She had a sobering and calming influence on me.

18. Whilst at Manchester University, I would go to the Manchester Royal Infirmary nearby to receive cryoprecipitate as and when required. I would also get a prophylactic injection of cryoprecipitate prior to taking my exams.

19. I chose to stay on at university to undertake research, though I now regret not submitting my MSc paper. I then went on to do a further year's teacher training, before qualifying to become a teacher. GRO-B meanwhile went home after university to care for her mother, who had suffered a stroke when GRO-B was aged just 16. Due to the doctor's negligence, she was advised to wait for 24 hours, which resulted in her being paralysed on one side.

20. GRO-B and I decided to get married soon afterwards. When I told my parents of our engagement, it was like a death sentence. There was

total silence, and my father said to GRO-B 'I hope you know what you're letting yourself in for'. This only goes to show how defeatist my parents were. My mother was a jealous woman, and when I told her that we were going to buy a house, she threw herself on the floor and cried.

21. In April 1970, I was admitted to Manchester Royal Infirmary with a severe bleed in my left knee. I was not given enough cryoprecipitate, which only made the knee worse. The knee soon became septic, and both my legs were put in plaster. The surgeon told GRO-B and I that he would have to amputate the leg. He then changed his mind considering how young I was. He had a son of 18 and I think that resonated with him.

22. The treatment showed no signs of working for some time. I was conscious throughout all of this, and I remember the extreme pain and the dreadful smell. It was a truly awful time.

23. Eventually my knee and the sepsis recovered. I remember the sepsis coming out of my leg in a brown liquid form. I then had to learn how to walk again, having been bedbound for 6 months. Having been admitted in April, I left the hospital in October 1970.

24. Whilst in the hospital, I had been interviewed for a job at GRO-B GRO-B and was offered a position as a teacher. I was supposed to start work in September 1970, though this was postponed until January 1971 when my walking began to improve.

25. After all this trauma, I thought I had to make sure that GRO-B was happy and still wanted to marry me. Thankfully she did, and we set a date for July 1971. However, I put the date back until GRO-B, as I wanted GRO-B to be absolutely sure. We eventually married on GRO-B GRO-B.

26. Between 1972 and 1976, I continued to attend the Manchester Royal Infirmary for cryoprecipitate. I would avoid having a prophylactic

injection as I knew it was expensive and I did not want to burden the NHS. If we were ever planning on going away somewhere, I would always check the local hospital facilities to ensure that they treated haemophiliacs and were stocked up with cryoprecipitate.

27. In 1976, I became aware of a teaching opportunity in GRO-B. GRO-B's mother had died in 1975, and her father had a friend nearby so he was happy. My mother was still alive, and she had become increasingly demanding, interfering and a general pain for us both. GRO-B thought that I should stand up to her more. We decided to come down to GRO-B to get away from her.

28. I got a job at GRO-B in GRO-B as head of the geography department. I started there in Easter 1976 and was very happy with the job and the working environment. I would end up working there for 22 years.

29. From arriving in GRO-B, I was treated for my haemophilia by Dr Barrie Murphy at Torbay Hospital. Dr Murphy was Head of Haematology at the hospital and was a brilliant doctor who took into account the whole patient, not just the treatment. He encouraged me to register with the Haemophilia Society.

30. One day, Dr Murphy suggested to GRO-B that I should go on home treatment. He showed GRO-B how to administer factor VIII product to me. This was quite complicated at first, in particular mixing up the right amounts. He showed GRO-B how to inject the butterfly needle into me; once he was satisfied that GRO-B could do this she was allowed to treat me at home.

31. It was wonderful knowing that I did not need to go into hospital anymore to get treatment whenever I had a bleed or a bruise. GRO-B felt happy to be of assistance to me whenever I had a bleed. We both saw it as much more convenient than having to go to hospital for treatment.

32. Not long after starting home treatment, I began to get nervous about factor VIII blood products. We watched a TV programme on BBC2 with an investigative journalist who notified us of the potential danger of blood products being imported from America. The programme showed the risks associated with blood being collected from high-risk persons such as drug abusers and prisoners who were paid to donate.

33. The very next morning I called the Haemophilia Society to alert them of the programme. The person I spoke with said that they were not aware of the programme and I heard nothing back from them.

34. When I first started to receive home treatment factor VIII, the AIDS scare had not yet really begun. Then, around 1983 onwards things changed, it made GRO-B feel awful and petrified that she could kill me by infecting me with the AIDS virus.

35. We both knew that the blood product was pooled from multiple donors, thus increasing the risk of infection. This made things extremely difficult for GRO-B who was understandably worried about injecting me with HIV-infected blood product.

36. I continued to avoid taking factor VIII when I had a bleed unless absolutely necessary. This, I now realise, stems from my childhood and not wanting to cause a fuss with my parents. I also did not want to traumatise GRO-B by asking her to administer the factor VIII to me.

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39. We had an interview GRO-B from an awful woman called Ms GRO-D. She came from the Church of England, as we have a Christian background. Ms GRO-D was the decision-maker, and we knew we had to get on with her. After many interviews we were allowed to GRO-B on 30 November 1978.

40. GRO-B GRO-B GRO-B GRO-B GRO-B This matter had gone on for over 18 months by the time it reached the High Court.

41. The court hearing was a traumatic experience for both of us. I had to stand in the witness box and give evidence for 30 minutes, which felt like a lifetime. We later learnt that Dr Barrie Murphy showed up at the hearing to give evidence in support of our case. He claimed that he had to be in London that day for a conference and had some spare time, though I do not believe this was the real reason.

42. During the hearing, the Claimant's legal team brought my haemophilia under scrutiny. They questioned whether a haemophiliac should be allowed GRO-B. Eventually, after all this trauma, we won the case and GRO-B.

43. We began to notice that GRO-B behaviour was a bit odd when he was around 18 months old. He was always a livewire, and as our first child we were a bit uncertain about this. Then, when we went to collect GRO-B from GRO-B's friend's house, we saw GRO-B playing in a play pen. He looked up at us, and then looked back at his toys and carried on with what he was doing.

44. GRO-B knew right away that something was not quite right with this behaviour, and noticed that his responses was different to other children's when they see their parents. GRO-B showed autistic traits

from a young age, and was always obsessive about things. He was eventually diagnosed with Asperger's syndrome aged 17. This was very difficult bringing him up as no schools wanted to take him.

45. GRO-B eventually ended up at the private primary school where GRO-B was working at the time. He began to steal small items of no value from other children. Though a kind and loving boy, this behaviour continued throughout his life. He saw an educational psychologist, and then to everyone's surprise, passed his 11-plus aged just 10 years old.

46. GRO-B went to the local grammar school, which turned out to be an unhappy experience for him. He continued to steal small items for no apparent reason. Eventually, he was asked to leave at the end of lower-sixth form. GRO-B then left home, got a job and rented a flat nearby. He got worse rapidly, and ended up in the Psychiatric Unit at Torbay Hospital on a few occasions.

47. We gave GRO-B permission to GRO-B Brazil. He visited him a few times between ages 18 and 22. He always seemed to be worse when he came back. Now aged 41, GRO-B recently said that the best thing to ever happen to him was GRO-B. He has recently had a baby girl with his partner, which has been transformational for him.

48. We decided to GRO-B, in 1983 when GRO-B was 4 years old. We were initially turned down, and I did not know why. I believe it may have been because of the AIDS scare around that time, and the stigma associated with being a haemophiliac. Then, Reverend Andrew Tanner, who was connected to the Haemophilia Society, intervened on our behalf. He queried why we were turned down for GRO-B after all we had been through with the High Court case GRO-B.

49. GRO-B GRO-B. GRO-B and GRO-B were our children, GRO-B GRO-B. GRO-B was quite an ordinary child in comparison to GRO-B, and

she was fine academically. When she went on to grammar school, another child on her first day said that GRO-B was GRO-B. She was labelled as GRO-B from then on.

50. GRO-B was very close to GRO-B growing up, and I would help her and make sure she did her homework. Then, aged 18, she left abruptly. She was friends with another GRO-B girl who had Asperger's, and they both decided to leave together. GRO-B leaving really affected GRO-B. We did not know where she was and she did not keep in contact with us.

51. She went onto marry and had two children. This marriage ended and since then she has had another two. At the moment we don't have a lot of contact with her, that said we are always there for her.

52. In the early 1990s, Dr Murphy advised that I should have a test for HCV. I believe it had recently become available to identify the virus through such a test. I was not given any reason or explanation as to why I should have a test for HCV, and I had no obvious symptoms of the virus.

53. I had previously been tested for HIV in the late 1980s. I recall that I did not receive the results for 12 months. Thankfully, this came back negative; it was a very worrying time. GRO-B also had to have the test.

54. When GRO-B was in the hospital one day, I believe to collect more factor VIII product for my home treatment, she bumped into Dr Murphy in the corridor. Dr Murphy told GRO-B discretely that I had tested positive for HCV. He told GRO-B to inform me of the results. GRO-B tells me that he informed her in a gentle and sympathetic way. We had a good relationship with Dr Murphy, and I have no qualms with the way in which we were informed of my diagnosis.

55. When GRO-B came home from the hospital and told me I was infected with HCV, she was in a complete state. She felt incredibly guilty as she

had been the one injecting me with the factor VIII product that had caused the infection. Although it was a body blow for me, I just thought that I would have to get on with it and deal with it.

56. I knew the significance of my infection with HCV, although with hindsight I did not know the full extent of the implications HCV would have on my body. Since I have not requested my medical records, I am unsure which particular batch of factor VIII was the cause of my infection.

57. After my diagnosis, I was referred to Dr John Lowes, a senior gastroenterologist at Torbay Hospital and a specialist in hepatitis. Dr Lowes had a diffident air, though was a nice person underneath this and a brilliant doctor to me.

58. Dr Lowes called GRO-B and I in for a meeting to discuss my HCV infection. He said that we have to get something done about my infection. He told me about a new trial for interferon-B but that there was currently no funding available for me. When I asked why that was, Dr Lowes just gave me a wink and said 'leave it with me', implying that he would get me on the trial. I believe that he felt sorry for me because he was used to treating intravenous drug users. Sure enough, I was put on the trial with 20 other people soon after.

59. The interferon-B trial began in 1996, when I was aged 49. Dr Lowes allowed GRO-B to administer the injection to me at home, knowing that she had done so for many years with the factor VIII. I was administered one injection every weekday for a total period of 18 months.

60. The side-effects of the treatment hit me almost immediately, and I constantly suffered with severe flu-like symptoms. I had one day's respite on Sundays as the treatment was not administered on weekends. Dr Lowes had warned me that the treatment would be a bit grim, but I was unprepared for the severity of the side-effects.

61. Throughout this 18-month period I experienced extreme fatigue, flu-like symptoms, and I often feared that I would die in the long term. GRO-B recalls that I was low and depressed, though I put a brave face on this and tried to battle through it. I also suffered from a lot of aching and muscular pain. Though this is normal for me because of the pain in my joints, this pain was certainly exacerbated by the interferon.

62. GRO-B remembers that I was very low throughout this time, and she began to notice a personality change in me. She said that I was very snappy and short tempered, which is completely unlike me. Despite all these side-effects, I managed to continue to work during the interferon trial. My usual defence mechanism came back into play, meaning I responded by fighting through the pain and working hard. This was also helped by my passion and commitment to teaching.

63. I completed 18 months of the interferon treatment, after which I was told that I was 'all clear'. I continued to have annual check-ups for 5 years afterwards, and have been confirmed as 'all clear' of the HCV.

64. Dr John Lowes told me after completing the treatment that 10 out of the 20 people on the interferon trial had given up part of the way through due to the severity of the side-effects. Of the other 10, I was the only person for whom the treatment had worked in clearing the HCV. I believe that Dr Lowes was appalled at what had happened to haemophiliacs and others, and wanted to help me.

65. I have not had a liver biopsy, though I have had liver function tests that showed my liver is fine. I continue to have blood tests every year to monitor this.

66. GRO-B continues to administer Advate recombinant factor for my haemophilia as and when needed. I have an annual check-up with Nichola Rymes at Torbay Hospital, though she did want to see me every 6 months, I preferred this to be every 12 months. I am also seen

annually at the Comprehensive Care Centre at Bristol Royal Infirmary for a diagnostic check of my joints.

Section 3. Other Infections

67. As far as I am aware, I have not had any infections other than HCV as a result of receiving infected blood products.

68. I received a letter around 10 to 12 years ago from Nichola Rymes at Torbay Hospital informing me that I might have been exposed to vCJD. This dropped through the post one morning with no warning and no advice. I was shocked by the insensitivity of how this was communicated to me.

Section 4. Consent

69. I consented to receiving all treatment pertaining to my haemophilia.

70. I consented to being tested for both HCV and HIV.

71. I consented to receiving interferon-B treatment in respect of my infection with HCV.

Section 5. Impact

72. Throughout all the fear and alarmist adverts surrounding AIDS at that time, I was petrified at the thought of transmitting any sort of infection to GRO-B and others. Albeit I was trying to limit the amount of blood product I was receiving for my bleeds I knew that I was likely to be at risk of receiving contaminated blood.

73. The biggest impact it had on our marital life was the decision I took to abstain from any form of sexual relations that a husband and wife would normally have, the fear of infecting GRO-B was huge and the consequences would have been devastating.

74. The extent of the AIDS scare in the 1980s meant that our social contacts were detrimentally affected. We felt stigmatised by the media campaign surrounding AIDS and because of a general ignorance of haemophilia as a disorder.

75. On one occasion, a friend of GRO-B's refused to come into our house for a cup of tea as she was afraid of contracting AIDS. This stigma was all borne out of a misunderstanding of haemophilia. I even remember seeing a sign that read 'Death to all haemophiliacs' whilst travelling in France one year.

76. As we were both socially conscious, the social side of life became increasingly unpleasant for us. We started to close up and shut ourselves away from other people. There was a fear factor amongst society, which led me to withdraw from people, and I did not want people to know about my haemophilia.

77. As teachers, we were both very conscious of the risk of transmitting any form of infection to the schoolchildren. I did not tell anyone at the school of my infection with HCV, though some teachers knew that I am a haemophiliac.

78. I decided to retire soon after the completion of my HCV treatment in 1998. This was approximately 5 years earlier than I had intended. I never thought I would make it that far anyway because of the risk of infected blood products and my regular injections. Taking an early retirement meant that I got about half of the pension I would have got had I worked for a further 5 years as intended. Luckily, we have not

overly struggled financially as we have invested wisely and saved as a family.

79. My health has suffered massively as a result of my treatment for haemophilia and my infection with HCV. As I was aware of the risks of injecting infected blood products, I did my best to avoid administering factor VIII unless absolutely necessary.

80. I was also affected by my mother's influence during my early years, meaning I would ignore a minor bleed in my joints so as to avoid the fuss of needing hospital treatment. My reluctance to administer factor product persists to this day. All of this has had the effect of causing grade 4 osteoarthritis in my joints. This subsequently led to septic arthritis (joint sepsis) on three occasions.

81. My wife, GRO-B, has been stoic and determined throughout the entirety of this ordeal. She always wanted the best by me and to do what was right for me. It has been very hard for her to come to terms with, as she administered the factor VIII treatment which caused my HCV infection, through no fault of her own.

82. GRO-B GRO-B GRO-B. Though we do not regret this decision, for a woman it was very hard for GRO-B not to GRO-B GRO-B. GRO-B GRO-B. We deemed this too much of a risk to take.

83. Despite all these difficulties, GRO-B has been of tremendous support to myself and our children, GRO-B and GRO-B. When GRO-B left aged 18, this had a terrible impact on GRO-B, especially considering how close they had been.

84. Within a year of GRO-B leaving, GRO-B was diagnosed with breast cancer in 2003. She found a lump in her breast and this was found to be cancer soon after. Thankfully, GRO-B had a fantastic oncologist and was successfully operated on in 2003. She is in now in full remission.

85. I have not been refused dental treatment as a consequence of my HCV infection. My dentist is aware of my previous infection with HCV, though this has not influenced my treatment in any way. Whilst I was HCV positive, the dentist was understandably a bit cautious, though I was still treated when necessary.

Section 6. Treatment/Care/Support

86. I am grateful to Dr John Lowes for getting me on the interferon-B trial in 1996. Although I was initially told that there was no funding available for me to be part of the trial, I believe that he pulled a few strings so as to get me on this interferon treatment.

87. I have not been offered any form of counselling or psychological support in consequence of my infection with HCV. GRO-B and I have bounced off each other and supported one another throughout the many crises we have had to deal with. We have learnt how to deal with this, and are able to cope ourselves.

Section 7. Financial Assistance

88. I made an application to the Skipton Fund after I received a form advising me of my eligibility. I then received a one-off payment of £20,000. I cannot remember if I had to sign any pre condition to accepting this money. It was a one off payment.

89. In 2017, as a result of the transfer to English Infected Blood Support Scheme (EIBSS), my haematologist, Nichola Rymes, verified my medical records, though I do not think they were all up to date. My records did show that I was treated at Torbay Hospital, that I received blood products and that I was infected with HCV.

90. In April 2018, I was informed that my stage 1 payments would increase to £4,000 per annum, excluding winter fuel allowance to be paid separately in December of each year. I thereafter received £333.33 per month.

91. On 21 June 2019, I received a letter from the English Infected Blood Support Scheme ('EIBSS') informing me that my stage 1 payments would increase to £1,538.17 per month. These increased payments began in July 2019, as well as a backdated payment of £3,590.47. My annual payments from the EIBSS now total £18,772.

92. I am aware that other people have been a lot worse affected by infected blood, and I am grateful for the amount I receive. I was surprised by the big increase of £1,200 per month in July 2019, but I am aware that for a lot of people this has come much too late.

Section 8. Other Issues

93. I would like the Inquiry to make sure that all those people infected and affected are compensated as much as they can be for all the suffering they have endured.

94. I believe that somebody, or a group of people, made the decision to import blood products from America, in the knowledge that they carried a high risk of infection associated with using paid donors such as drug addicts and prisoners, rather than choosing to spend money on

updating and increasing capacity at the laboratory at Elstree. If that is the case, these people should be brought to justice for making that decision. Though I was grateful for the convenience of receiving factor VIII treatment, these blood products should have been safe.

95. I also feel that it has taken far too long for this Inquiry to be held. Part of me feels lucky to be alive having seen so many others in the haemophilia community suffer to a much worse extent, and in many cases die. It is imperative that this Inquiry now establishes the full truth of what happened.

96. We have decided to provide this statement to the Inquiry as we thought we should put forward our own unique story to assist with the inquiry's investigations.

97. We would like the inquiry to be concluded as soon as possible but appreciate that it must also be thorough and will take some time.

Statement of Truth

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

Signed GRO-B

Dated 20.02.20