Witness Name: GRO-B
Statement No: WITN1155001
Exhibits: 0
Dated: August 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. I live at GRO-B GRO-B. My date of birth is GRO-B 1960. I currently live with my wife, GRO-B and my grandson, GRO-B, GRO-B and I have two children, GRO-B born on GRO-B 1981 and GRO-B born on GRO-B 1983. GRO-B has another child from her previous relationship born on GRO-B 1973.

2. As a result of receiving contaminated blood products, I have been infected with the Human Immunodeficiency Virus (HIV), Hepatitis B (HBV) and Hepatitis C(HCV).

3. This witness statement has been prepared without the benefit of access to my full medical records. If and in so far as I have been provided with limited records the relevant entries are set out in the medical chronology at the end of this statement.

Section 2. How infected

4. I suffer from severe Haemophilia A and have a clotting factor of less than 1%. When I was three or four years old I started getting a lot of bruises and I was diagnosed with Haemophilia at GRO-B Children's Hospital. I was then transferred to Manchester Royal Infirmary (MRI) in 1964. I was under the care of Dr I.W. Delamore and Dr R. Wensley.

5. I was treated initially for bleeds with plasma and then Cryoprecipitate. From around 1974 onwards I received Factor VIII Concentrate, more specifically Kryobulin, Koate, Kogenate by Bayer. This was non heat treated and I was informed that I would have to use up the old stock of Factor VIII before I could get heat treated products for my Haemophilia. At one stage I recall we were told that this was because we had been infected in any event. As a child, I was often taken into hospital via ambulance to receive plasma treatment. Overall, I went to hospital quite often, every few weeks or so. I was taught how to inject myself with Factor VIII in 1977 so that I could home treat. If I had a particularly serious bleed, however, I would need to go into hospital.

6. When I was younger, we moved into a new housing estate. Soon after I needed to go to hospital for a bleed and I called for an ambulance. When it arrived they were also picking up a boy from across the road who was also a haemophiliac and who had had a bleed. We became close friends and went to the same school being picked up by coach together.

7. We had quite a lot in common; we would go for treatment to the same hospital and both of us were offered Factor VIII treatment. We did move away around 1969 with my dad's work where I attended the Oxford Haemophilia Centre until we returned. At the time we were living with my Grandma and until I returned to school I went to live with my friend's family to make things easier until my parents found a house for us all to live. Prior to my HIV diagnosis, the issue of contaminated blood had garnered a lot of media attention and we raised these concerns with the hospital and tried to refuse Factor VIII treatment. in response the hospital said that if were not going to accept home

treatment we would have to come into hospital every time we had a bleed. I remember discussing this with my friend about not taking Factor VIII but it was not easy to do. Whilst my friend found it convenient to attend the Manchester Royal Infirmary as he worked nearby, I lived further away and could not access the MRI as easily as he could. I continued with home treatment.

8. Olive Redding sent me a letter to attend the MRI on 31st May 1985 to discuss the results of a test for HTLV3 antibodies and I was taken into see Dr Wensley; Olive Redding was there as well. They told me that I was HTLVIII positive. I was told that it was not a good prognosis. I was told that I had a couple of years to live and they asked me who I would like informed. I was on my own at this appointment as GRO-B had to stay at home to look after the children. Eventually the HTLVIII diagnosis was changed to HIV in later correspondence from the hospital. As far as I can remember I was given no advice with regard to the infection.

9. They told me that I could live without it impacting me for a while and that I could be okay and it could be years before it developed but the possible prognosis was roughly two years and I could live quite long without it seroconverting to AIDS. Overall, they didn't talk about it for long and I went away thinking I wouldn't really have long at all, it was like a ticking time bomb in my mind. They did not really know what they were dealing with.

10. I do not recall going home after that appointment; I was in shock. It was very upsetting and there was no advice given to help me manage or cope with the virus. The hospital gave no indication of when I was actually infected. When I came home, I told my wife. Until GRO-B was tested herself, we were so worried about the children and whether they had been infected.

11. In terms of advising us on the risk of transmission, I was told that I should refrain from having unprotected sex, but that was all and nothing else was mentioned about managing the infection. He told me that I was HTLVIII positive. I don't know when they started referring to HTLVIII as HIV, but it changed I recall in later correspondence from the hospital.

Section 3. Other Infections

12. I received a letter in the post regarding vCJD asking me if I would like to be informed if I had received any implicated batch. I responded saying I wanted to know and they replied that as far as they knew, I had not received any such batch and was not implicated but they could not be one hundred percent sure.

13. In addition to being infected with HIV, I was also infected with Hepatitis B. I cannot remember when I was given that diagnosis. I was never actually diagnosed with Hepatitis C. However, in the early 1990s, after my knee replacement surgery I attended the Royal Liverpool Hospital (RLH) for a routine blood test, and the nurse let slip at that time that I had contracted Non A Non B Hepatitis. I was not given any information about it other than being told that it was nothing to worry about it. This was never followed up in later appointments. I was later told that I had self cleared the virus.

Section 4. Consent

14. Before I was given my HIV diagnosis, I was asked to have a blood test. They had told me what they were testing for I think but as I say my recollection is not all that clear in this regard. I do remember consenting to a blood test.

15. Whenever I went for routine blood tests, particularly in the early days, they always took a lot of blood. Once I commented on the amount they took, as they used a large syringe, 20 or 30 milligrams. I wanted to know why they needed so much of my blood, but they did not provide any adequate answers. I never knew what they were doing with my blood and they may have been testing it for research purposes. If so this would have been without my knowledge and consent.

Section 5. Impact of the Infection

16. GRO-B and I were married on GRO-B 1980. We had only met each other in the January and our parents frowned upon us living together so we got married. We had our daughter GRO-B on GRO-B 1981 and our son, GRO-B GRO-B on GRO-B 1983.

17. When I found out that I was HIV positive I was annoyed and in shock. We had had the children by that time and we were concerned that I had passed on the infection to them. When GRO-B tested clear it was a massive relief, although I was still wary as I knew that I could still pass on the infection to them. I had no idea that the risk of transmission was low; as nobody had ever told me of the risk and the hospital themselves did not understand the gravity of the risk.

18. I was frightened so we made sure to isolate any utensils and towels I used and to minimise every possible risk of transmission we could. In turn, I also ended up pushing my family away. I would not let my children get too close. I saw the adverts and documentaries about AIDS showing images of people with lesions on their faces and looking skeletal. I was scared and did not want to be close to people and started pushing everyone away thinking that this was easier as in my mind I was going to die a terrible death.

19. Furthermore, due to the stress of the infection, I was always angry and suffered from mood swings. At times I got very lost in my thoughts. When I sat at my computer, my mind would often drift and I would find myself wondering why I was there in the first place.

20. At times, I also struggled to get out of bed. Even today, I am riddled with health complications.

21. When I was at the MRI, I had an awful experience. Dr Wensley did not treat me well. I needed a knee replacement because of the damage to the joint due to bleeding. He said I could not have one as I was too old. I was very

annoyed about that and I believe that my HIV status may have influenced his decision.

22. In the late 1980s, I attended a Haemophilia Society meeting in GRO-B and met Dr Hay who said that he would perform the knee replacement surgery if I got referred to the Royal Liverpool Hospital. I was transferred and had the knee operation on GRO-B 1990. I was still quite well at that point.

23. In early 1991 I was told that I had a hyper para thyroid causing high calcium levels. Dr Hay referred me to a surgeon who wanted to operate on my thyroid. I resisted at first and asked for alternative treatment to surgery. I was concerned about my lymph nodes and I knew that the HIV was dormant in my lymph nodes. I had had a few lumps and I thought to operate on my neck might be dangerous. Dr Hay assured me that they would use Methylene Blue would be ok to use to identify the thyroid gland and this reassured me a little as the surgeon had concerns that it can affect bleeding. I agreed to have the surgery which went ahead in early 1991. The surgeon proceeded to operate but he was concerned about my Haemophilia and decided not to use Methylene Blue. As a result he missed the thyroid gland and took out the lymph node tissue. It got very messy and they wanted to do it again but I was stressed and I refused.

24. Within a few weeks my condition took a bad turn. My viral load for HIV went up and my T cell count went down. I became very poorly. I came home and had a violent episode of sneezing which caused my neck to open up. I had a bad external bleed and treated myself at home with Factor VIII. I was seeing a solicitor at the time with regard to the HIV litigation and I mentioned this negligent treatment to him. He came to see me in hospital and eventually I was awarded £10,000 out of court settlement for the failure to use the dye to locate the thyroid. Later the solicitor was putting pressure on me to sign the waiver in the HIV litigation to accept the settlement.

25. I was quite ill and I had a massive breakdown. I tried to leave the hospital with all my notes; I wasn't thinking straight. A security guard and a nurse took

me back to the ward and I was sectioned and put on a secure ward for about a month.

26. They put me on psychotic drugs and then left me to the care of my wife.

27. My health went down hill fast and I ended up with sepsis and pcp. I also had something wrong with my ear. They put me in a separate room and put signs on the door which read "no entry without gowning up" and signs on the door indicating "high risk".

28. They said I had manic depression and attributed this to the stress of moving house recently. That was not the case at all; we had moved house several times without issue. I had another breakdown and they then diagnosed it as AIDS related Dementia.

29. I received no treatment for Hepatitis B or C and was told that I had self cleared those infections. I was given no treatment for HIV until 1994 when I was given AZT and DDI.

30. The HIV drugs came with bad side effects. DDI in particular were massive horse pills and you had to physically break them up to ingest them. I remember we went on holiday; GRO-B was in her first year of secondary school. I experienced some really bad side effects with severe swelling in my leg due to fluid retention. I was poorly but remember that holiday as I was with my haemophiliac friend GRO-B who has since died from co-infection of HIV and HCV.

31. It affected my mental state and I had episodes after which GRO-B told me that I didn't know what was going on around me. One time after taking the drug, my condition had gotten so bad that for three days, GRO-B had to move me around in a wheelchair. She tried to get me admitted into hospital, but they said that there were no beds available. We were desperate so we asked the bed manager at the hospital. However we were told to go home as there were no beds. Contrary to my recollection, in my medical records it states

that they had a bed, but we refused to take it and went home. This was simply untrue. We had to get home so my wife could look after the children after school.

32. I had to come off both AZT and DDI in about 1995/1996 as I was gradually getting worse. I suffered from pneumonia episodes. Dr Hay tried other treatments but I was unable to tolerate anything well.

33. GRO-B had enough of the hospital and contacted Body Positive in Manchester and the Terrence Higgins Trust. Volunteers were sent to our home and they suggested that we contact North Manchester General Hospital (NMGH) as there was a very good doctor there called Dr Wilkins. We asked to be referred and moved to NMGH in or around 1995-1996. GRO-B had to convince my GP to refer me to Dr Wilkins. My GP told GRO-B that I was going to die anyway so what did it matter where I was treated. My wife responded by saying what had he got to lose then. Later on the GP apologised.

34. Dr Wilkins admitted me into NMGH for months. He got me on triple therapy. I lost so much weight; weighing less than seven stone; I looked skeletal. I was on various combinations of drugs. I remember that there was a clay pill that I had to drink with a glass of milk and overall, I was taking approximately eight tablets a day. It was horrible and made me feel very sick. Sometimes I would vomit the pills back out. Dr Wilkins was excellent though, and whenever a new drug was released, he would try to get me on it.

35. At the time I was also suffering from neuropathy which caused mobility issues. I had to sleep downstairs on a reclining chair as I could not walk.

36. I am currently on therapy for HIV and take the following combination of drugs: Abacavir; Lamivudine and Efavirenz. I have got used to whatever I am taking and the accompanying side effects. One significant side effect of these drugs is osteoporosis. I was told I had brittle bones and therefore have weak ankles. Also, the tips of my fingers and my thumbs go numb.

37. I get neuropathy very badly in my hands and legs. I was told that it was the HIV drug that caused this but since then I have been told it is the Hepatitis C.

38. I feel the hospital have played down the HCV. I have never been sat down and given advice about it. At one point I was informed that I had self-cleared the virus. I was offered to go on Interferon treatment; however I refused as I was aware of the side effects. Some days I cannot function at all and in terms of using my brain; I am not all there. I am told that this could be attributable to Hepatitis C. I feel a discomfort in my mid abdominal area and once I went to see Dr Hay and mentioned it. He just said you have self cleared Hepatitis C and dismissed my complaint. I do remember Dr Wilkins gave me a fibro scan and told me the results were fine but in the past the nurses at my GP surgery have told me that I had cirrhosis of the liver. However, nothing was followed up. Another scan revealed that my liver had enlarged and had got fatty but again there was no follow up. Dr Hay certainly never referred me to a liver specialist.

39. I have had a lot of problems with my gallbladder and have been told that I have gallstones. These used to cause pain but I have changed my diet and these have got a lot better and have not bothered me for some time. I have had a lot of problems with kidney stones and I had a large one removed from my left kidney as it was causing bleeding. After it was removed I had a scan which showed a few smaller stones which had been left and I had to have lithotripsy to shock them into smaller stones that would more easily travel through the urinary tract and pass from the body. This was not a nice procedure and even though I had Factor VIII to stop bleeding I still was left with a large bruise to my lower back. During the operation to remove the kidney stone they caused a stricture to my urethra with damage from surgical tools which they used and I now have to self catheterize.

40. I am currently under the care of Dr Morgan at GRO-B Hospital. My T cells are fine and my viral load is undetectable. I still take tablets at very set times everyday and my condition is monitored closely, but I have had to change my lifestyle to stay as healthy as possible. I do not drink or smoke and everything I do is part of a strict routine.

41. I didn't go to local dentist like normal, and had to see Dr Wilson at the MRI for all dental care. It was fine whilst she was there, however she retired and after that she was never replaced. They brought in a temporary dentist who created a fuss over sterilising the equipment. It was embarrassing as he came into the room suited up and placed signs on the door stating high risk. He made a show of everything and completely overreacted. I feel that even today I am prejudiced against. I am always the last appointment of the day, even though I arrive at the same time as other patients. Furthermore, on one occasion when I was admitted to the MRI, a nurse told me not to use the toilet as other people had to use it. Instead she asked if I could use a bottle.

42. I still try to go out as much as possible. I see my parents and do the supermarket shopping. I have a mobility scooter and a car which helps me get around. However I am limited in what I can do as I cannot walk far at all due to arthritis in the ankles and a low bone density. After being diagnosed with HIV I feel I have not really lived.

43. Due to the stigma associated with HIV, we have kept very quiet about my infections and we tended to socialise less and subsequently lost most of our friends. Once my son had a gland problem in his neck and he required a minor operation to sort it out at GRO-B Children's Hospital. The surgeon appeared to make a big fuss about my HIV status. At the Haemophilia Centre, Sister Shaw intervened and sorted it all out and the operation went ahead successfully.

44. Through the course of my life I have strived to do well in whatever role I was offered. In whatever I did I excelled but due to my Haemophilia and ill health resulting from HIV I have always become too ill to carry on a role and have ended up losing jobs.

45. Before my marriage I had a job at a pizza restaurant and within one week I earned the responsibility to run the whole place on my own. Unfortunately, the area manager came into the restaurant, sat me down and told me to go home as I had Haemophilia. He explained that the job involved working with knives

and with my condition the risk was too high. The manager kindly rang my parents to apologise as well, which was a nice gesture. I also obtained employment as a Baker and Confectioner but because of the regular bleeds in my knees I could not continue. I tried being a hairdresser and did that well, but again I was let go. After my marriage I was held back by the tiredness and fatigue.

46. In order to cope, I am in receipt of Employment and Support Allowance. Initially, when I started attending the Job Centre, they kept sending me for interviews and I would get the job, but then get fired. In 1984, I got a job as a labourer but they laid me off too. The Job Centre said it was a waste of time and told me to go on a preparatory course as I was unable to secure employment. I think if I had been on prophylactic Factor VIII treatment I may have been able to work but at the time it was not available to me.

47. At the time of my breakdown GRO-B, my daughter, was at secondary school. GRO-B had focused her attention on caring for me which meant that my children did not get as much attention as they should have. GRO-B fell into bad company and started drinking alcohol and taking drugs. She went off the rails and is still an alcoholic today. I very much believe this was a direct result of my infections and subsequent mental health issues and that we were not there to support her and explain the difficulties with my health. She became pregnant very young, and due to alcohol she was unable to care for her son, GRO-B Social services wanted to take GRO-B away and initially gave him to his birth father. Eventually we were granted custody and he has been living with us ever since. As GRO-B had been drinking during pregnancy, GRO-B was born with Foetal Alcohol Syndrome and therefore requires a lot of care and attention. He is now in a special school. Meanwhile, GRO-B has been getting help from the local church and she is doing a lot better than she was.

48. I would also like to mention that my friend, whom I grew up with, passed away as he needed a liver transplant. He too was infected by contaminated blood and we could always confide in one another as we were going through the same thing for most of our lives. This was very heart breaking for me as we were very close.

Section 6. Treatment/care/support

49. No counselling or psychological support was made available to me in consequence of being infected. I saw a Hypnotherapist named GRO-B at GRO-B Hospital. I met her at a Haemophilia Society meeting and she was very good. I saw her every few weeks or so and she taught me self hypnosis and relaxation techniques. It was by chance that I met her and no hospital every offered me any counselling themselves.

50. I did not go to our local dentist for fear of my HIV and HCV status coming out. I do remember being given dental treatment at Manchester Royal Infirmary under Mrs Wilson who was great until she retired. Thereafter, the dentists appeared to make a show of things by approaching me all gowned up with masks.

Section 7. Financial Assistance

51. In or around 1991 I was involved in the HIV litigation and had to sign a waiver stating that I would not pursue any further claims. I cannot remember the exact amount I received from it. I didn't really want to accept the money but I felt pressure to do so. I thought the money implied we should all go away and die and of course so many have done. However, at the time I was in no condition to make up my own mind so GRO-B dealt with a lot of harassment on my behalf and in the end I reluctantly signed it.

52. We invested some of the money on advice from the Royal Bank of Scotland and lost a good amount on the stock markets and also used some towards buying a property. However we were unable to afford the upkeep and we had to sell.

53. I am currently in receipt of Employment Support Allowance. I also receive monthly payments from the EIBSS. There has been a recent uplift of this following the start of the Inquiry. I receive £3416.66 per month.

54. On GRO-B 1993 I was awarded Disability Living Allowance. This was later changed to Personal Independent Payments (PIP) and I had to go for an assessment. I arrived in my wheelchair because of my mobility and I had a drinking bottle for water. They concluded that because I was able to drink out of a bottle myself during the interview that I was not entitled to the full daily living of PIP award, only mobility. As I was grateful to continue getting my Motability car I did not appeal although I think it was unfair as they only awarded PIP for four years which means that I have to go through all this again and nothing is going to get better.

55. I received the Stage 1 payment from the Skipton Fund of £20000. I handed over the application form to Dr Hay who completed and sent it off for us.

56. Recently I found out about the Special Category Mechanism payment; however I have not applied for it. On the file there is a list of symptoms to be eligible for SCM payments, but I cannot apply for them without Dr Hay's approval and I do not believe that Dr Hay would approve as I have not complained about those symptoms to him. Each time I see Dr Hay some symptoms I forgot to mention and though the symptoms are worrying he always discusses my haemophilia and bleeds. When I do mention having pain in my mid abdominal area his reply is you have cleared Hepatitis C and nothing more is done. Therefore I lack evidence to support the application.

57. Since my grandson started living with us recently, my personal circumstances have changed. The EIBSS have given us a top up. In June 2019 I received £2398, in May 2019 I received £1024 and in April 2019 I received £1898. Prior to April I was paid £1898 monthly. I take whatever they have to offer as I do not want to question them. I hate talking to them on the telephone.

58. In addition to the monthly payments and lump sums, I have also applied for one off grants which I have done by email so I did not have to talk to anyone. Just before EIBSS took over from the MacFarlane Trust I needed a mattress for an electric bed which I had purchased. This was done by email and they sent me the money after I had to show it was a competitive cost. When you

feel so sick and ill the last thing you want to do is look for the cheapest product. Most of the time in any event when you get the cheapest it shows as you get what you pay for. I wanted an air mattress as I had lost a lot of weight and weighed only 7 stone. The people at the fund were awful and I was so annoyed with them in the end I gave up. I have also applied for a grant to have a chair lift installed but prior to them releasing the money they required me to get three different quotes. They took the cheapest and the one I got was an old model and did not last long.

59. Since the EIBSS took over, I have not really bothered contacting them. I cannot physically handle filling out application forms and struggle just to hold a pen for a long time. For a top up payment, the EIBSS wanted me to send them a Child Tax Benefit form for the year 2020; I only had the 2019 one. They insisted that I had the 2020 form but I most certainly did not and I kept trying to tell them that but they were adamant. It was a week later when the 2020 form arrived in the post. It is stressful and painful going through all these procedures.

60. We try to buy what we need ourselves and struggle on without having to make applications.

Section 8. Other Issues

61. I took out a life insurance policy when we were first married with Liverpool Victoria but it became too expensive and I could no longer afford it. This was before my HIV diagnosis and at that time, both GRO-B and I were unemployed. As a result my life is not insured. I am worried about my wife and grandson financially should anything happen to me. Every day if I feel ill or get an infection I think that this is my time. I am paranoid if anyone close by to me has a cold or chest infection and I will try to avoid them.

62. What I would like to know from the Inquiry is why it was necessary to put us on Factor VIII treatment. They insisted Factor VIII was a fantastic drug which would change our lives and it did; for the worse. I remember being told that we had to use all the old Factor VIII treatment up before we were put on to heat treated Factor VIII and I remember the reason given was that we had already been infected so it would not make any difference.

63. Furthermore, if they did make a mistake, I would expect them to own up to it and apologise in detail and not to cover things up. I have some of my medical records but I do not believe that I have them all. For example there is a letter to my GP from the hospital dated in 1983 letting him know that I was admitted to hospital with a hip bleed but there are no notes from the hospital with regard to my admission. I have been treated with different Factor VIII treatments but I have never been told what treatments I was being given nor was I given any warning of risk.

Anonymity

64. I would like to remain anonymous, as I would not want local people to find out and cause problems for my grandchildren. For the same reason I do not want to give oral evidence. I understand however that my statement will be disclosed and published by the Inquiry.

Statement of Truth

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

Signed GRO-B ....

Dated 09/08/2019..............................