Witness Name: GRO-B
Statement No: WITN1811001
Exhibits: 0
Dated: December 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. I live with my life-long companion and carer, GRO-B whom I met in 1979.

2. I was infected with Hepatitis C, as a result of receiving contaminated blood products.

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. Haemophilia A has always been in my family and I knew I had the bleeding disorder from a young age. My clotting factor is 9% which means that my blood clots five minutes after a non-haemophiliac's blood would clot.

5. I was also diagnosed with Von Willebrand Disease (VWD); however five years ago I was informed that I have been misdiagnosed.

6. GRO-B and I met in 1974. We enjoyed music and climbing and soon after became partners. In 1995, we split up, but remained extremely close friends because we preferred to be that way. I agreed to help bring up GRO-B son, GRO-B (who was four years old when we met) and who allowed me to give him two parents in his life. We have never been in a sexual relationship and continue to see ourselves as a partnership.

7. During my lifetime, I have been treated at the Bristol Royal Infirmary (BRI), Southmead Hospital and Bristol Dental Hospital. I received a number of products at each and the earliest I was treated was in 1975. My consultants at the time of my diagnosis were GRO-B and GRO-B I did not have a good relationship with GRO-B

8. I do not know which blood products I received as part of my treatment. Unless there was an emergency, that absolutely necessitated life saving blood treatment, I did not go to the Haematology Centre. This was quite simply due to my dislike and distrust in the staff.

9. As such, from the 1970s, I only received a number of blood products. Once for a dental extraction in 1975, for my vasectomy in 1977, for dental work in 1978 and beyond.

10. During the ensuing years and throughout my investigations during the early 2000s, I discovered that batch numbers were not kept for the 1970s.

11. The products I received whilst having my teeth extracted in the 1970s were cryoprecipitate and other Factor VIII concentrate substitutes. The dental clinic had to consult the haemophilia department at the hospital, to assess the likelihood of my bleeding and decided to take the risk, without giving me blood products. If I bled the haemophilia department advised that I be sent there straight away.

12. In 1985, I had a bad climbing accident, through which I sustained a head injury. A rock the size of a microwave fell on my head. Consequently I was taken to the BRI. I believe that I was infected during this accident where I received Factor VIII concentrate products.

13. Since the late 1990s, the blood products I received have been at the Bristol Dental Hospital. My GP at the time was GRO-B and who is now over 90 years old.

14. Aside from the above blood products, I have never received regular treatment as a matter of course. Currently, I store tranexamic acid in the house, but very rarely do I use it. In fact, a senior doctor at Southmead Hospital mentioned to me that if you are not a very active person, then tranexamic acid may cause a stroke. I am not an active person at all; therefore I only use the product if I am in severe pain.

15. Almost immediately after my incident in 1985, I became severely ill and suffered from drastic weight loss and turned completely yellow. GRO-B was so worried that she called the emergency doctor, who upon arrival, said he was calling an ambulance. In July 1985, I was admitted to the BRI for ten days. The doctor however, simply brushed my health aside and said it was a touch of jaundice, which would eventually go away.

16. The next thing we knew, doctors arrived dressed in white suits and took GRO-B and I into a broom cupboard, where we waited seven hours for a nurse to finally say she would tend to us. Nobody wanted to touch me or my blood. After this incident, my symptoms became less prominent.

17. Between the years 1985 and 1995, no medical personnel understood the impact my infection had on me. It seemed as though they did not understand the virus itself. My health was very on and off during this time. I could go weeks feeling unwell and then soon after be well again. By that time I would be ready to attend hospital but because I was well, it seemed like I no longer needed medical attention. I had been for several blood tests but later found that my blood samples went to a lab and were binned prior to testing. At one point I had to give 11 samples in order for a result to be obtained.

18. In 1992, I stopped working due to ill health, namely extreme flu like symptoms and fatigue. During the early 1990s, GRO-B and I got into many arguments so we decided to split in 1995 and distance ourselves from each other. I went to Germany for a break, but returned to the UK later that year.

19. In 1995, GRO-B received a letter addressed to me and phoned to ask if she should open it on my behalf. I said yes and the contents of the letter revealed that my test results showed that I had been tested positive for Non A Non B Hepatitis. The letter was sent by GRO-B GRO-B who advised that if I needed to talk to him I could get in touch.

20. I had a conversation with GRO-B about this; however I do not recall spending a lot of time with him.

21. No information was provided to me regarding my Hepatitis C positive status. If it had not been for GRO-B I would have been in the dark for about ten years about my condition. She intervened and looked after my care. She gathered and sourced information from doctors around the world on what she had heard regarding contaminated blood. When GRO-B and I confronted the haematologist and hepatologist, they were in complete denial.

22. GRO-B also discovered at this time that GRO-B had, like many GPs, received prior notification in the early 1990s from the Department of Health that their Haemophilia patients may exhibit signs of infection and possible HIV and Hepatitis C. This notification had been sent out a considerable number of years prior to my diagnosis, yet I was never put on watch despite being obviously unwell. I had not attended the Haematology Centre as frequently as I was not a severe haemophiliac.

23. In 1996, I attended a meeting arranged by the Haemophilia Society (HS) and found it horrendous that they were offering refreshments such as fish fingers, chips and beer. By providing beer they were indicating to people that they were allowed to drink. GRO-B was extremely well read and had conducted a massive study on the liver; therefore she was aware of the dangers associated with drinking. GRO-B was a journalist then and could have easily reported this. At this meeting, we felt they were still trying to cover up the scandal and were not giving people honest and reliable information, which was available then.

24. Adequate information was not provided to help me manage or understand the infection. All GRO-B said, was to see our doctors at the BRI. GRO-B didn't know much about the virus at all, or at least, that is what it seemed like. Nobody wanted to give me information or prepare me. Instead they were trying to cover their own backs.

Section 3. Other Infections

25. The Department of Health sent me a letter stating that I was at risk of vCJD. Three days later, I was scheduled an appointment at the Haemophilia Centre. Once there, all the Sister asked was whether I was happy with the information provided in the letter.

Section 4. Consent

26. I believe I was treated and tested without my knowledge, without my consent and without being given adequate or full information.

27. In 1985, I was not capable of giving consent. GRO-B wanted the hospital to wait until I was conscious to give me blood but they told GRO-B to stop interfering with my care.

28. I do not believe I was treated or tested for the purposes of research. However on one occasion, GRO-B the Dean of the hospital, said that we were all part of a gigantic medical experiment; like mice being tested.

Section 5. Impact of the Infection

29. When I was younger and prior to my accident in 1985, I was a very active and fit man. I enjoyed climbing, cycling and generally living life to the full. I rarely saw the doctors, because I did not trust them. GRO-B and I got on our bicycles and rode around the country. We lived a very high quality of life and took everyday as it came. This changed drastically after becoming ill with the symptoms of Hepatitis C.

30. I became very ill within two weeks of my blood transfusion in 1985 and started to suffer from jaundice. My body reacted very badly. I lost an excessive amount of weight within the first ten days of the transfusion going from 15 stones to 8.5 stones. My urine was the colour of beer. I was readmitted to hospital as an outpatient, but was only given painkillers. In total it took me a year to recover from this bout of poor health.

31. From 1992 onwards, I continued to suffer from poor health and had to give up my job. I could go for six weeks feeling absolutely dreadful, but get up one morning and be as good as new. I would randomly fall asleep at any given time and struggled to cope with severe fatigue, joint

pains and brain fog. Even whilst sat on the sofa, my mind would drift off and get lost in my own thoughts. This could be for hours at a time, though to me I had no indication of time. Next thing I knew it would be tea time. I took up reading to pass time. At least from the page numbers I could track what I was doing.

32. I am now unable to walk and suffer from a muscle wasting disease called cachexia, which was diagnosed last year whilst hospitalised for another illness. Physically, I am unable to walk far. I am now severely underweight with a height of 6 foot 4 inches and a weight of 45 kilograms. For this reason, I am extremely frail and have been bedridden for the last ten years. I am in constant pain in my joints and regularly suffer from bruising on my wrists. My normal daily routine consists of 9am starts, eating breakfast and sleeping again until 4pm. I suffer from chronic fatigue and loss of appetite. I also suffer from terrible headaches, but not migraines.

33. During extreme weather conditions, it is near impossible to control my body temperature. I get extremely cold during winters, but in extreme heat I find it difficult to breathe, not only through my nose and mouth, but through my skin too.

34. Ten years ago, at the pain clinic, I was informed that very little could be done to treat me, due to my ill health and weakened immune system. To follow on from this, I also have to seek dental treatment as a result of getting constant gum infections.

35. From 2002 until 2016, I fell into chronic low level depression. I would not get out of bed and would get extremely frustrated whenever GRO-B tried to help me. The curtains were permanently drawn and even my dogs would not come inside. If GRO-B came in, I would tell her not to bother me. She contacted the doctors on my behalf and they said that I was depressed. No matter what GRO-B tried, I refused to go to a hospital for help. Unfortunately in 2016, I fell and broke my rib so I had no choice but to go. Due to the cracked rib, I could not breathe so I was kept in an incubation unit.

36. Currently, I suffer from acute chronic emphysema. In the past I used my inhaler twice a day, however more recently I have to use it almost every 15 minutes. When I saw my doctor about this, he said that he hadn't seen a body like mine, since working with tuberculosis patients in India. Even the doctor was shocked at the state of my health.

37. I decided not to undertake the Interferon treatment that was being tried out on people with serious addiction issues, because, frankly, I did not trust the health authority. They were the ones that had infected me in the first place, so I did not trust them to be honest in their approach at this point either.

38. In general, I chose to use very little drug intervention. Instead I used self-help/homeopathic remedies such as acupuncture and milk thistle, which have been scientifically proven to help the liver. I also paid a lot of attention to my diet, eating only organic food as much as was possible. To help my mind, I pursued meditation and yoga. GRO-B has been excellent in making many of these recommendations to me. The GP clinic I am currently registered with, delivers advice on homeopathic remedies as well.

39. For the acupuncture, I had an incredible doctor named GRO-B who informed me that brain fog was extremely common in patients with Hepatitis C. He learnt his techniques from China and helped me understand what was going on inside of my body. I found this treatment incredible.

40. When I first started acupuncture treatment, it cost around £40 per hour and the NHS was partially funding it; however the NHS eventually stopped contributing. This was ridiculous as I had saved the government so much money from not pursuing the Interferon treatment and only minimally had I used the NHS services throughout my lifetime. In total, the homeopathic remedies cost around £200 to £300, which we self funded using our meagre income.

41. Since I did not accept the Interferon treatment, I did not face any difficulties or obstacles, other than having to deal with the pressure of doctors trying to convince me otherwise. Ironically, many of those who were infected and went on Interferon treatment have died; yet I am still alive. I questioned the doctors on this and said that I did not trust them. The doctors always said that I would be "cured" of the virus, but that was not true! The Hepatitis C virus may have been cleared, but the impact of the virus remained and this was evident. This meant that it could still adversely impact my liver.

42. Now, I no longer possess the physical or mental strength to pursue normal medical treatment, aside from the routine Fibroscan or ultrasound on my liver.

43. To increase my weight, I received advice from doctors to eat a lot more and to include junk food in my diet. However I spent my life eating a good diet, involving only organic food. I cannot simply start eating fish and chips everyday, as that would impact my health in other ways.

44. In terms of other treatment for other conditions, I always received dental care at the hospital.

45. From the early 1990s, my infection was heavily impacting my private and family life. As I have mentioned above, GRO-B and I decided to part ways in 1995. At the time we were raising GRO-B who was 25 years old then. We were both getting extremely short tempered. I was no longer able to do simple things like pick up bread from the bakers. This impacted on our relationship and since we did not know what was the cause was, GRO-B was not empathetic and it did not take a lot for both of us to get angry.

46. Then came the phone call in 1995. It was awful. I was on my way to France to live near the Alps. People who work on CERN lived in that area and it was a leading technological city. I wanted to find another life there and learn new things. Unfortunately, due to shock, I returned home immediately. I was utterly disgusting at how the UK health authorities had treated me. I moved back to the UK and from then on, GRO-B and her family cared for me as though I was their own.

47. Since my diagnosis, I stopped engaging in all physical relationships. Due to the fear of cross contamination; I never engaged in a sexual relationship thus denying me the right to enjoy my private life.

48. With regards to my social life, I do not drink and never have, contrary to the medical advice the doctors provided. Apparently, I was permitted to drink in small quantities; however I do not believe this, so I chose not to drink at all.

49. It is difficult to socialise as I have a weak immune system and am more susceptible to infections. If someone visits and they have a cold, I would also catch it. For that reason, before hosting a dinner or a social gathering, GRO-B had to ensure that none of our guests had infections, even if those guests were my grandchildren. It was almost like a care

home and as a precaution we stored flu jabs in the house. This is still the case today. It is a shame, as GRO-B and I love to host parties and we entertain big.

50. GRO-B is now 48 years old and I am a grandfather to his daughter. I cannot engage in or enjoy life as I should with my family, due to the impact of the virus.

51. In the past, my granddaughter had to stay in a Bed and Breakfast when they wanted to visit. I remained by the door as she stood by the gate. We would wave at one another and talk on the phone. This was disheartening as I adore her. In fact, to me, the most magical word in the world is 'Grandad.'

52. As I was a climber who had long hair, people would often ask if I had contracted Hepatitis C through drug abuse and if I was using heroin. This was a common misconception and I suffered great stigma as a result.

53. When I was well, I used to be the general manager of a furniture shop called GRO-B I would make furniture from scratch and create special designs unique to each customer's needs. I would have to come up with a collection of furniture three times a year. Unfortunately, I struggled to cope with my work, due to the brain fog and physical exhaustion. Not only did my job entail physical labour, I also had to think a lot about my designs, such as where I would purchase materials from, the specifications provided by the customer and how to best assemble the furniture itself. There were so many aspects I had to consider before successfully creating a piece of furniture.

54. In 1992, my final year working for GRO-B I earnt £35,000. Considering inflation and the fact that everything was handmade, that value would have been at least £60,000 now. The financial loss alone is incalculable.

55. Initially, I was offered a council home but it was appalling. The council remit was to move drug addicts across the whole estate and that was making me mentally ill. GRO-B said that I could move into her home as flatmates. She, upon consulting her family, agreed to look after me and I have lived with her ever since.

56. In 1997, we chose to move from that property to a better location that was quieter (our current address in GRO-B. It was a much needed change; however on the sale of the

property GRO-B did not receive much. Our current property is rented and we pay £800 monthly. It is the landlord's father who still owns the house.

57. The property was derelict at first and required a lot of work. Nevertheless financially, it was difficult to raise the money as I retired in 1992 due to ill health and GRO-B did not qualify for Carer's Allowance until 2018. I also received minimal Personal Independence Payments (PIP).

58. As I am unable to care for myself, I had a full time live in carer and was awarded Disability Living Allowance (DLA) for life in 1997. For the application, we liaised with a representative from the DWP who was training to be an occupational therapist. He was only 22, but was extremely rude and ignorant. By way of example, he asked me when I had caught haemophilia. It was outrageous! Furthermore, he refused to accept that GRO-B was my spokesperson and kept asking that she leave. They should have known that GRO-B speaks for me from my previous PIP application. I was distressed and unable to comprehend what he was saying.

59. Recently, instead of giving GRO-B a Carer's Allowance, the DWP gave her Pension Credit. This means that instead of getting £64 weekly, she now receives £32 monthly. This is only a small increase.

60. As previously mentioned, instead of relying on the NHS for treatment and thus saving government funds, I chose to use homeopathic remedies and incurred a considerable cost. As we didn't think we need them, we didn't keep any receipts or proof of such treatments.

61. My own family barely acknowledged that I was ill and my own mother died when I was only 15 years old. Their attitude wasn't great and I later became disassociated with them. Thankfully GRO-B family took me in and included me as their own family member. She comes from a big Italian/English family who took to me from day one. When she first invited me to her family gathering, GRO-B mother could not believe my own father's disinterest in my health.

62. GRO-B and her family have never even discussed compensation. They are all about living life to the full and having a good time. This has been a real benefit to me and without them, I wouldn't even be alive. Her parents, siblings and extended family all loved me from day

one. If there was to be any form of compensation payable at the end of this Inquiry and I am not around to receive it, I want everything that I would have been entitled to, to go to GRO-B

Section 6. Treatment/care/support

63. I had some counselling after the first transfusion and decided not to have children of my own, because I didn't want to pass haemophilia on to my daughter. I was happy to co-parent GRO-B

64. All psychological support was self-funded and private. My acupuncturist was also a registered counsellor and really helped me.

Section 7. Financial Assistance

65. I have never received any financial support, compensation or any other funding help, aside from one lump sum of £4,000 received in 2007 from Michelmores LLP.

66. An action was being pursued in the USA by a large firm in San Francisco against a Pharmaceutical Company regarding contaminated blood. Michelmores LLP were dealing with infected persons in the UK. GRO-B fought this action for me and had to find a letter from the hospital confirming that I was diagnosed with Hepatitis C. This proved difficult as we were first informed it had been archived. Nevertheless, we eventually obtained the letter and were permitted to join the action. Unfortunately, the action was refused by US courts and discretionary payments were made in 2010 to all participants.

67. 35% of the award was paid to me and 65% retained by the solicitor firm. I did not consider this fair, but I had no strength to argue against solicitors, especially given how many confrontations I had experienced with various firms and institutions already.

68. I do not receive any support from any of the related trusts like the Skipton Fund.

69. GRO-B made an application to The Manor House (TMH) on my behalf. TMH eventually became the Skipton Fund. When she spoke with their representative, she was informed that I was not eligible for financial assistance refused treatment and self-medicated.

70. I consider this to be obscene as I saved the NHS a fortune by not using their services. All I want is that they give me what they owe me. I don't want to rely on them for anything and wish to be financially independent like I was prior to my ill health. Given what I was earning and what we lived on and comparing that, to what our income is now is ridiculous. GRO-B and I are almost 70; we have no savings in the bank and only have a small pension policy.

71. I want to know what help is available to me. Until now we have scraped by with rent and regular expenses, however if I were in need to make a large one off purchase, I want to know who to apply to for a grant. Where should I go if my washing machine broke down or my fridge? I want information that I was never given, about where to go for help when my infections caused me extreme financial difficulties.

72. I have no faith in the idea that I will ever receive financial compensation. There are over 4000 of us and the extent to the monetary damage, I estimate, could reach £400,000 per person. With our current Government, how are they going to top up the money they owe us all?

73. My suffering is mild in comparison to someone whose children, brother or husband have died. How do you compensate that person and how will the Government quantify the loss we have all suffered? We need the Government to make an overarching decision on this.

Section 8. Other Issues

74. I have spent my entire life having to defend myself, constantly having to explain why I can't do something, or eat something, or go somewhere. If I need something, I also have to justify myself before I can obtain any sort of assistance.

75. As a haemophiliac who was infected during the 1970s/1980s, I am appalled at the lack of support on the scandal, beyond lip service from our political parties and the like. Many of us are also angry that the very charity that was set up to help us, The Haemophilia Society, who had a constitution and a 'duty of care' to do so, did not represent us in the way that would have made an impact.

76. When we challenged the Haemophilia Society in 1995 at a public meeting, we spoke of the lack of support and spoke with the then CEO, GRO-B. We questioned possible

links with funders who may have pharmaceutical links and direct donations from pharmaceutical companies where there could be a conflict; this was denied. We now know we were right!

77. We also know that the charity used the information from the infected members to gain funds. In effect, the members who were infected became 'outcomes' and ticked the box for funds for the charity. Many naive and trusting members did not know this and those funds were spent on young people, family 'reduced fee holidays' and large salaries for the CEO and others. Funds were not used to support a full Inquiry, proactive press, or any other form of awareness that made a difference. The support was minimal to say the least.

78. The issue of the Society taking funds from pharmaceutical companies involved in the supply of blood and the Society actively promoting a product we now know to have been contaminated, is appalling.

79. It is simply not enough for staff member GRO-B to say; 'that was then, this is now and we should 'draw a line under it.'

80. The real scandal is that the Government, the treatment plant at Elstree, the NHS consultants and many GPs had been warned of the risk of contamination, the risk of infection and yet many of us were only told in 1995. In my case that is a year after I became very ill.

81. The issue now is to fully open up the investigation in an honest manner, to reassure all of us that there is no other agenda and whoever leads will not be in the purse of the Government, politicians or others. Additionally, that they will not withhold information, that they will see this through with openness, transparency and ensure compensation for those infected and those whose lives and the lives of their families have been destroyed.

82. People have passed away and those alive become sicker by the day, overridden with depression and physical disabilities. These people have spent their lives waiting for compensation, hoping that one day they will get some. GRO-B and I took the decision that this is our quality of life now. We never lived in the compensation culture and I do not believe this was ever going to be about compensation. It is political suicide for the

Government to give adequate money and fully compensate each individual's loss. I am not going to wait for it. If I live another year, I will count myself lucky.

Anonymity

83. I wish to remain anonymous.

84. I would not like to give oral evidence at the Public Inquiry.

Statement of Truth

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

Signed GRO-B

Dated 16th December 2019.