Witness Name: GRO-B
Statement No.: WITN0237001
Exhibits: **Nil**
Dated: 24 July 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 13 May 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 1960 and my address is known to the Inquiry. I am a business owner and currently reside in the USA with my wife and son.

2. I have Type A haemophilia and I intend to speak about how blood products used to treat my haemophilia infected me with HIV, Hepatitis C ("HCV") and Hepatitis B ("HBV"). In particular, I will speak about the nature of my illness, how the illness affected me and my family, the treatment I received and the impact it had on me and our lives.

3. 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 writing my statement.

4. My brother GRO-B has also provided a witness statement to the Inquiry. He also has Type A haemophilia.

Section 2. How Infected

5. Soon after I was born, I was circumcised in accordance with my family's religious practice. The circumcision caused me to bleed and it wouldn't stop. I was unable to leave the hospital for 3 months as I was constantly bleeding. My family was living in Lebanon at the time and the doctors were running tests on me to try and determine the cause, but no one knew why I was bleeding. I was eventually diagnosed with Type A haemophilia.

6. It turns out that my mother is the carrier of haemophilia; she had 9 brothers and sisters, but none of them had haemophilia.

7. Growing up in Lebanon, there was no treatment for haemophilia, I would just be given a pack of ice and bandaged up if I had a bleed.

8. My family moved to the UK in 1975. By the time I moved to the UK I had very damaged joints; bad knees, elbows and arthritis. Not too long after arriving in the UK, I had a bleed in my joints and was taken to the local hospital. I explained to the doctor in charge that I was a 'bleeder', but they weren't equipped to deal with haemophiliacs. I remember being in a lot of pain, but they were unable to help me. As far as I am aware, my brother and I were the only haemophiliacs in the area.

9. In 1976 or 1977 my brother and I were then referred to a hospital in London where we were seen by the head of the haematology department. Initially I was treated with cryoprecipitate, but then he introduced my brother and I to Factor VIII. We were taught how to inject ourselves so we could use it at home. As I was a severe haemophiliac I would have to treat myself every 2 or 3 days.

10. I recall I started using Cutter's brand of Factor VIII; I remember the packaging was brown with an orange strip. I was later introduced to Armour Factor VIII product.

11. My local GP was not familiar with haemophilia treatment so I had to go to London on a weekly basis where they would take blood and do tests but they never discussed what was going on with my health with me. I was just told to keep injecting Factor VIII and deal with whatever issues arose as they came along.

12. I was never given any warnings or told of the risks and side effects of using Factor VIII, I was only told that it would make me feel better. There were, however, side effects including rashes, stomach ache and increased body temperature. My body adjusted after a while, but I was never told to expect side-effects. I was also never told about the possibility of getting an infection from using the Factor VIII.

13. I believe it was in 1981 or 1982 when the head of the haematology department was retiring, and I remember him asking me if I wanted to know the results of my vCJD test. I told him 'no', I didn't want to know, so he didn't tell me. Thinking about it now, many years later, I wonder if he was also going to ask me if I wanted to know the results for HIV, HCV and HBV. I'm unsure, because I don't think he finished his sentence, but I assume if they were testing me for vCJD, they must also have been testing for other infections as well.

14. I knew vCJD was lethal, and just as bad as HIV or even worse, so if they knew about me having vCJD they must also have known about my HIV infection as well. I had a feeling they wanted to tell me about HCV, HBV and HIV but he wanted to 'test the water' first by casually mentioning vCJD to see if I could accept it. When I said I didn't want to know about vCJD, it was left at that. I'm sure he must have known more, however, there was no treatment for it at the time anyway.

15. In 1983 or 1984 I had an opportunity to move to the US. When I arrived in the US I found a local haemophilia centre that referred me to a hospital to see a haematologist. The haematologist tested me for HCV, HBV and HIV right away. The results came back positive for all tests. I felt like I had been punched. I didn't know where or why I got these infections. I had so many questions, this was really my first introduction to these diseases.

16. The haematologist sat me down and asked me some questions about my lifestyle that I didn't appreciate. He asked if I'd had sex with a boy or a man, and if I had lead a promiscuous life. I said no to all his questions. I had never even been to discos or pubs, I'd lead a boring lifestyle, all I did was go to school, go to the hospital and go home. Despite my answers, the haematologist kept repeating the same questions. It felt like he wanted to push the idea that it was my lifestyle that had caused me to contract these diseases. He didn't want to hear that I could have contracted these diseases from Factor VIII. Although this haematologist was sceptical, other doctors eventually realised that contaminated Factor VIII was the cause of my infections.

17. I had experienced symptoms from HIV and hepatitis' diagnosis. However, in the early 1980's, I started to get sick from HIV and Hepatitis c virus, I had diarrhea, stomach bloating and ache, liver pain, fever & body rash, my platelets dropped, lost weight, also my liver enzymes were high, etc. Perhaps I should say that I was very sick and I did not know about it and did not give it much thought.

Section 3. Other Infections

18. To my knowledge I have not received any other infection, apart from HIV, HCV and HBV, as a result of being given infected blood. However, I believe there was no test for vCJD in the UK, so I am unaware result.

Section 4. Consent

19. I know that I was tested for vCJD in the UK without my knowledge. Blood was taken regularly from me when I visited the hospital in the UK, but I was never told that this blood was being tested for these infections. I also believe that I was tested for HIV, HCV and HBV without my knowledge, as mentioned in paragraph 13. The head of haematology at the hospital in London was a kind man and I respect him, but I do believe that he or other medical staff should have told me about the infections I had. I understand that there may not have been any treatment available at the time for these infections, but I still should have been informed about the status of my health.

20. I did consent to undergoing tests for HIV, HCV and HBV in the US.

Section 5. Impact

21. I underwent treatment for HIV, HCV and HBV all at the same time, while still managing my haemophilia.

Treatment for HIV and physical impact

22. After I was diagnosed with HIV, I was put on AZT treatment, which had just been approved by the US FDA. I was aware that AZT had been given to people with cancer in the 1960s and didn't often work for them. I understand that for HIV it was intended that AZT would weaken the virus.

23. I was prescribed a high dosage of AZT. I would take 3 pills in the morning and 3 pills at night and suffered terrible side effects. It caused me to get sick, get rashes, stomach aches, weakness, sleepless nights, and headaches. It was such an awful medication to take. I had to take pain relief medication (Tylenol, Panadol and Aleve) to combat the symptoms, however, they only lessened the symptoms they didn't make them go away. AZT is like chemotherapy, but you are given such high doses despite the fact that your body can't handle it. I have

friends who couldn't cope on AZT so had to stop taking it and unfortunately passed away as a result.

24. I believe it was around 1987 when my haematologist retired, and a doctor from the infectious disease department took over my HIV treatment. This doctor also took over my haemophilia treatment and he was a very kind and understanding man. When he took over my HIV treatment, he tested me again for HIV, to which the results came back still positive. The new doctor took me off AZT and introduced me to protease inhibitor combination therapy. This involved taking 3 different medications in one month, then the doctor would take one out and replace it until he found the right combination. It seemed to work; my viral load dropped, I felt healthier and my appetite came back.

25. I now only take 2 pills once per day to treat my HIV. I currently take Symtuza, this is a combination of 4 drugs: 800mg of Darunavir, 150mg of Cobicistat, 200mg of Emtricitabine and 10mg of Tenofovir. I also take 50mg of Tivicay. I am registered with a pharmacy and they deliver my medication via UPS or FedEx which makes it easier.

26. I have been undetectable for HIV since 2000, but will be taking medication for life. I have built up a resistance to various HIV medications and therefore can't go back to taking medications that I have been on previously, so it is necessary for pharmaceutical companies to continue to develop new drugs.

Treatment for HCV and HBV and physical impact

27. I underwent combination therapy to treat HCV and HBV it was around 1992. I had Alpha Interferon injections and Ribavirin. I was initially supposed to complete 6 months of the combination treatment, but the side effects of this treatment were so bad I couldn't stay on it. I had headaches, diarrhoea, stomach aches and experienced weakness. Sometimes I was so weak I couldn't walk. I couldn't tolerate these symptoms so I had to stop.

28. I later had a second attempt at this treatment on a lesser dose, but again had to stop the treatment. This I believe was in 1993.

29. Around 5 years ago I managed to clear HCV on my third attempt at treatment. This time the treatment consisted of Interferon injections twice a week and a Solvadi pill daily for 3 months. Although the symptoms were unbearable, I didn't want to get sicker or get liver cancer, so I knew I had to tolerate the treatment.

30. I have been told that the HCV and HBV have cleared and that my health is stable, however, I still suffer the agony of wondering if I am getting worse. I worry a lot and after a while it really knocks me down. I now have fibrosis of the liver and my liver is functioning at less than 50% capacity because of the damage caused by HCV. I undergo regular ultrasounds and CAT scans to check the state of my liver.

Mental health

31. After my diagnosis with HIV, HBV and HCV, I was depressed. At times I was suicidal and had to take anti-depressant medication for a long time. I just couldn't believe what was happening to me. I was a boring guy, with an ordinary lifestyle I never expected something like HIV to happen to me. You always think it will be someone else, but not you.

Family and Personal

32. My HIV diagnosis devastated my wife at the time, she just couldn't accept it. She was told that she should forget about having children, which was a big issue for her. We were told by the treatment center staff and the doctors, both infectious disease and hematologist. She was also afraid that I would infect her. This caused us to separate which was devastating. We had been high school sweethearts and married one year after we finished college.

33. I have since married again, and now have a 4 year old son. My wife knows all about my medical history which sometimes puts a pressure on our relationship. We sometimes argue because she is scared of being infected. She knows that she can't catch HIV through touching or sharing eating utensils, but we still have to be really careful of what we do.

34. We are very careful when it comes to being intimate and use protection. If I were to cut myself, I am putting others in danger. I have a responsibility to not cause hurt my family or cause them pain. I love my wife and want to protect her. Unfortunately HIV is always in the back of our minds.

Immigration

35. I was almost deported from the US due to my HIV status. I originally came to the US on a business visa (B1 category). At the time I applied for permanent residency (a green card), the law was that they couldn't accept a HIV positive person into the US. I recall undergoing a physical assessment and being told that I couldn't proceed as I was HIV positive.

36. In 1985 or 1986, I saw a local lawyer and paid him over $3500 USD to assist with my case. This lawyer wasn't any help and I felt as though he just took my money. I remember seeing how thin my file was, it was as if he hadn't done any work. I then found another lawyer who understood my situation and helped me significantly for a fee of around $2000 USD. This second lawyer found a waiver that would allow me to stay on the condition that I stay healthy and prove that I was taking medication. The waiver came into place when the Clinton administration came in and HIV medications were working.

37. I understand that the US government was worried about infections spreading and the safety of the population but it was a very stressful process to go through.

38. I am now a citizen of the USA.

Work and Education

39. After I completed my diploma in the UK, I moved to the US. I was really interested in political science and computer studies and for a while I was hoping to pursue a career in diplomacy. I applied for a few jobs to embassies but no embassy would take me when they found out I had haemophilia.

40. I wanted to do my Masters, but figured wasn't going to be around as HIV meant a death sentence back in the 1980s. Sickness has held me back, I could have gone for a higher degree, and gone for a job with higher pay, but instead I stayed working for my dad. It was easier as he allowed me to be flexible with my working hours. If I had to take time off, it wasn't a problem, and sometimes it would take a day or 2 to recover from a bleed.

41. In the 1990s I was approached by a homecare company to work for them. They had seen me at the haemophilia centre and knew that I knew the community. I started working for the homecare company part time and at the same time they would supply me with my medication as they are affiliated with pharmaceutical companies. I stayed working in this role for a couple of years and it involved signing up new patients and meeting with doctors and the community.

42. I remain working for my father's company, and since my father has now passed, I run the company with my brother.

Stigma

43. I haven't told many people about my HIV or HCV diagnosis as I'm worried they will treat me differently. People at the hospital know that I am HIV positive, but not many people outside that category of people know. I'm not 'out' with it, and don't see the need to tell people. I have only told a few friends that I'm a haemophiliac. There were 2 people at work who knew that my brother and I were haemophiliacs and may have suspected that we were also HIV positive because we often took sick days, but I never told them.

44. There was a point when there were many newspaper stories which would report on haemophiliacs being attacked with diseases. It was a thing to talk about and it was everywhere. So when people found out I had haemophilia they would ask about whether I'd also contracted other diseases. I don't think people knew any better and were just being curious, but I found it easier not to tell anyone even about having haemophilia.

45. One time I got pulled over by the police when driving. It was a hot day so I was wearing short sleeves which revealed a bandaid on my arm. The police officer asked if I was a druggy. I responded by telling him I was a haemophiliac and he let me go.

Section 6. Treatment/Care/Support

Knee surgery

46. Due to the severity of my haemophilia I needed knee surgery, but was refused as I was a 'bleeder'. When I was around 15 years old I was stretched out and put in cast where I was on back for 6 months. This helped to an extent but as I got older my knees became totally damaged and I relied on a cane. I couldn't go up stairs, run or barely walk.

47. It eventually got to a stage where I couldn't walk. I was introduced to a surgeon at the hospital I attended for my HIV and haemophilia treatment. He was a wonderful man and suggested I undergo knee reconstruction surgery. At this point my right knee was locked at a 45 degree angle. He knew about my HIV and HCV and still said willing to take the risk to do the surgery. He wanted to do both knees at once, but I told him just one at a time as I was uncertain about how it would go.

48. I underwent the first surgery on my right knee in 1995. 10 years later, in 2005, I went back for my left knee to be reconstructed. The surgeon said 'I told you so'. Following each surgery I had 3 months of physical therapy, which took a lot out of me. I was also treated with Factor product for 2 weeks straight following the surgeries. It was a very painful recovery and I relied on a walker and cane.

49. Before meeting this surgeon I had been seeking somewhere that would take on my case, but as soon as mentioned having haemophilia, HCV and HIV, I was rejected.

Dental care

50. I have had trouble obtaining dental treatment as a result of being HIV positive. I needed a root canal so visited a local clinic but the dentist refused to treat me. I informed him that the law says that he has to treat me and if he refuses, I have the right to sue him. In the end I didn't end up pursuing legal action and just went somewhere else. I really didn't want to go back there anyway.

Counselling

51. When I attend hospital for my HIV appointments, I am also asked about how I am; it's more of a chat about how I'm feeling so I wouldn't call this formal counselling. I understand the treatment centre can only do so much and I'm lucky to have the support of my family.

Section 7. Financial Assistance

Medical insurance

52. Living in the US means that it is necessary to have medical insurance in order to afford medical treatment. It's a complicated process navigating it, but my medical insurance covers the cost of 80 percent of the cost of the medication, and the other 20 percent is my responsibility. I currently pay $399 per month for my insurance policy. I pay a higher insurance premium because of having haemophilia and HIV. Someone healthy wouldn't pay as much.

53. My HIV medication costs approximately $1400 USD per month; most of the cost of this medication is covered by my insurance. My factor prophylactic medication costs $52,000 USD per month. I infuse with factor product twice per week. If I need to go over my normal dosage I require pre-approval from the insurer that they will pay, which also involves my haematologist providing an explanation to the insurer the reason for the change. Permission also needs to be sort if the type of medication I'm prescribed changes.

54. In order to cover the cost of the 20 percent for my haemophilia, I'm on a monthly payment plan, which is like a mortgage but no interest needs to be paid. Sometimes the insurer will waive the 20 percent payment. The insurer will look

at how much money you make and make a decision on how much you can pay. At the beginning of the year you have to tell them if can afford medication or not. They put you on a list and help with payments according to income. It is a headache of a process to navigate.

<u>Payment funds</u>

55. I was told about the Macfarlane Trust, through the UK hospital in about 2003, When I first started to receive payments, I was given around £300-350 per month, but I now receive £1500 per month.

56. The McFarlane Trust then told me about the Skipton Fund. I believe I made my application to the Skipton Fund in the late 1990s. I received the Stage 1 payment, a £20,000 lump sum payment, as I had contracted HCV. I also initially received a monthly payment of £500, I now receive £1500. I was refused the Stage 2 payment as my liver was not 100 percent damaged. I had to get a report from my doctor but as I was cleared for HCV I wasn't eligible.

57. There has recently been a change to Skipton and Macfarlane, and now my monthly payments are made by EIBSS. I receive one payment in the middle of the month, and one at the end. Only recently changed.

58. In the past I have tried to apply for grants for medical bills and other requests from Macfarlane but have mostly been denied. Macfarlane would say the payments for my requests were not in the budget and told me that my monthly allowance is enough. I asked for assistance to fix my back deck. I am happy that Macfarlane came through but it was like pulling teeth to get them to assist. There was a lot of emailing back and forth but they eventually provided the funds for it.

59. For a while I wasn't working and therefore not receiving an income. I tried to apply for benefits but this only amounted to $160 USD per month, but that amount is not enough for my family. It was back when I was receiving £300 per month, I applied to Macfarlane to seek an increase in my monthly payment so I could buy food for my family, but they wouldn't increase my payment.

60. I am appreciative of the payments I receive, but it is not enough. I pay out a lot more than I am compensated for.

Section 8. Other Issues

61. I feel it is right that the Inquiry is taking place and believe whoever made the decision to distribute Factor VIII should be held accountable, whether that be the UK Government, pharmaceutical companies, NHS or doctors. Someone should be held accountable for the damage done to us.

62. I understand in the early days of manufacturing Factor VIII, they didn't heat treat or freeze dry it. I was told when the heat-treatment started, but I was never told where the blood was collected from. In the 90s evidence started to come out in newspapers, including the New York Times and the Washington Post, about blood being collected from prisons due to shortages. There were also articles about haemophiliacs being infected with viruses because President Clinton and pharmaceutical companies were collecting hundreds of pints of blood from prisoners and didn't care how safe the blood was. As a recipient of a blood product I was angry. I felt cheated. The pharmaceutical companies knew what was in the blood but still decided to distribute it rather than withhold it. I believe it should have been my choice to treat with factor or to decline treatment had I known fully about the risks.

63. When we needed help those who infected us walked away. At the moment I pay out a lot more money than I am receiving from the funds. I am fearful that there is always a threat hanging over us that the government could turn around one day and say there is not enough money and I could be cut off. My expenses are mind-boggling and medical costs are extreme. If I didn't have insurance I would die. I am grateful for the assistance from the funds, but I believe the way money is distributed from the funds should be changed to a flat rate across the board to make it fair, because at the moment if you live in the UK you are at an advantage.

Statement of Truth

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

Signed GRO-B

Dated 7/24/2019