Witness Name: GRO-B
Statement No.: **WITN6478001**
Exhibits: **WITN6478002-4**
Dated:

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

I, GRO-B will say as follows: -

Section 1. Introduction

1. My name is GRO-B I was born on GRO-B 1970 and my address is known to the Inquiry. I am currently a volunteer chaperone. I live in GRO-B I intend to discuss my infection with HIV, Hepatitis C (HCV) and Hepatitis B (HBV) which I contracted from blood products for treatment for my Haemophilia.

2. This witness statement has been provided without the benefit of access to my full medical records.

3. I can confirm that I have chosen not to have legal representation and the Inquiry Investigator has explained the anonymity process to me. My family has been involved in some prior litigation which I will discuss further in Section 8. I do wish to be anonymous as I have two stepchildren who have only recently been made aware of my status, and I therefore do not wish to cause any further distress to them.

4. I can also confirm that the Inquiry Investigator has explained the 'Right to Reply' procedure, and that if I am critical of a medical professional or organisation, they will have the right to reply to that criticism.

5. I wish to acknowledge that naturally as time passes, memories can fade. I was a young child when I was infected, and a teenager when I found out about my HIV infection. I have been able to provide approximate timeframes for matters based on life events. However I can only recall to the best of my ability, and these timeframes should be accepted as 'near to' rather than precise dates.

Section 2. How Infected

6. I was diagnosed with haemophilia at a very young age. When I was a few months old, I was taken for a routine immunisation. By this point, the factor levels I had inherited from mother had worn off. I had an injection in my buttocks, and I bled profusely. I ended up black and blue from my chest down to my knees.

7. As with many other haemophiliacs, the bruising was initially put down to abuse. However eventually one of my GPs spoke up and said that was not the case, and I was referred to GRO-B Hospital, Glasgow, for tests.

8. I was diagnosed with Haemophilia A, with a factor rate of 0%. This meant I had severe haemophilia.

9. My younger brother, who is 4 and a half years younger than me, was also diagnosed with severe haemophilia. We have two older siblings who do not have haemophilia.

10. My treatment up until the age of 4 was whole plasma. When I was 4 and a half years old, I had an intracerebral brain haemorrhage. I was taken to GRO-B Hospital, however they didn't have any blood products which were effective enough to treat me.

11. They flew some cryoprecipitate (cryo) up from London in the hope that they could avoid surgical intervention. I had my head shaved and was mapped for my pre-op. The cryo arrived in time and proved effective at halting the bleed. I was still comatose for 2 more weeks, but I woke up and, fortunately, recovered rapidly.

12. I had various cognitive tests for the next 6-7 years to check for brain damage, but I was fine.

13. From this point until the age of 7, I spent half to three quarters of my time at GRO-B I experienced frequent muscle and joint bleeds over these few years and I was repeatedly admitted as an inpatient for hospital treatment and care.

14. In around 1977, when I was 7 years old, I was introduced to home treatment. My mother and father were trained to treat me with Factor VIII. I am aware that from then, I was regularly transfused with Factor VIII sourced from the USA, from its introduction to the UK until its eventual withdrawal.

15. As a result of the introduction of Factor VIII as an effective home treatment, my hospital admissions reduced dramatically. I was still bleeding; I was having around 5-6 bleeds per month, but my parents were able to treat me appropriately with Factor VIII much quicker, reducing the severity of any bleeds, without needing to go to hospital.

16. When I was 14 years old, I started to treat myself with Factor VIII, and also started to attend hospital appointments unaccompanied.

17. I can clearly remember my first solo visit to GRO-B Hospital as a 'semi-adult', i.e. alone without a parent. This was in 1985, (I would have been 14 or 15 years old). I was expecting this to be a routine appointment.

18. I saw Dr Anna Pettigrew. She took me to a small room and told me out of the blue that I had been infected with HTLV III, which later became known as HIV. She emphasised I shouldn't tell anyone. At the time, I took that quite literally, I didn't even tell my parents. I had never heard of HTLV III or had any idea of its implications. Dr Pettigrew didn't tell me what the disease was or provide me with any explanations.

19. I went home and went on with my life. I did not have any real understanding of what the diagnosis would mean for me, and did not mention it to anybody as I had been instructed not to.

20. A few months later, my parents were summoned to the hospital to be given the news that my younger brother had contacted HTLV III/HIV from the Factor VIII. During these few months I was watching TV and a programme that was on mentioned that HTLV was the same as HIV. This was a very difficult moment. Before that, I hadn't realised that HTLV and HIV were the same thing. The realisation that I had a serious condition suddenly hit me. I felt like I had been given a death sentence and everything changed. It was crushing.

21. My parents still didn't know about my status at this point. When they were discussing my brother, Dr Pettigrew said 'oh, don't you know about GRO-B?' Of course, they did not as I had been by myself when I was given the news and had been told not to tell anyone.

22. After this, the proverbial 'shit hit the fan'. My dad went to the papers. Our story was featured in the GRO-B newspaper. We were also in some national publications including The Sun. The BBC did interviews, and we featured in GRO-B My dad also made some television appearances. He ended up being quite vociferous in the press, and our story appeared in the media quite regularly from around 1985-1989.

23. When our story first hit the press, we were on the front page. There was no hope someone could flick through the newspaper and miss it. My brother and I were living in GRO-B a small village GRO-B at the time, with my parents and the rest of our family. The village only has around 5000 people, so most people know each other or are connected in some way. Fortunately, even during the days of sensationalist reporting in the 1980s, the overwhelming response from the community was very positive. This included neighbours, friends and classmates. I was, nonetheless, very uncomfortable with our private information being so public, especially as a 15 year old schoolboy. I just wanted to quietly get on with my life. I found it all very embarrassing.

24. Even prior to our diagnosis and the press coverage, we were already quite well-known in the local community as a result of the knock-on effects from our severe haemophilia. When we were young, my brother and I had to wear crash helmets to prevent injury and bleeds. The crash helmets would be the brightest colours like orange, pink and yellow. They really drew attention to us and everyone locally knew of us and realised something was wrong. We hated the crash helmets and would sometimes deliberately break or lose (bury) them, but we would only have to have another one made.

25. When we were later a regular feature in the press and our infections became common knowledge, we never had a negative response from our community. People were very supportive, and I consider myself very fortunate.

26. Towards the end of my schooling, I was suffering with a lot of bleeds, particularly abdominal bleeds. I sat my prelims (exams) fine and I did well, but I couldn't sit my final exams because of my health. I nearly didn't receive a grade at all, but I appealed and the grades from my prelims were downgraded by one grade which gave me my final grade. This was better than nothing, though by this time, I had grown somewhat disillusioned with school due to my HIV infection.

27. A year after receiving the devastating news of my HIV infection from Dr Pettigrew, my treatment was transferred from GRO-B to Glasgow Royal Infirmary. I subsequently found out from Professor Gordon Lowe that I was infected in the early 1980s via infected blood products administered at GRO-B Hospital.

28. Once my care was transferred, staff at the Glasgow Royal took great care to explain exactly what the virus was, the risks of transmission, likely progression and eventual expected outcome. Looking back, it is clear that the Haemophilia Unit at the Glasgow Royal implemented, for the first time, a solid system of support for those of us infected.

29. Physically, I remained symptom free from HIV until 1990. From 1990 onwards I experienced mild symptoms like sore throats and skin infections. These were early signs of my immune system being compromised and my CD4 count steadily declining.

30. Between 1994 and 1997, my immune system slowly collapsed. I became very unwell and knew my immune system was struggling under the weight of my HIV infection.

31. During this time, in 1994, I was told I also had HCV in addition to HIV. I was told by one of my doctors, Dr Williams, who thought I already knew. This news was very unwelcome and stressful, especially as I was aware my immune system was already struggling as a result of my HIV.

32. Although I was told about the HCV in 1994, I am aware that it was known that I had it in 1991. It is possible that my parents were told about it when they were informed about my brother's HCV, but they chose not to tell me as the HIV had already started to impact my immune system to such an extent that it seemed like I would die from an AIDS before any HCV related disease.

33. However, by the mid 1990s, it was decided to start tackling people's HCV status as the doctors realised that haemophiliacs who had been infected through blood products were dying of HCV rather than HIV. The doctors weren't even telling HIV positive haemophiliacs about HCV initially.

34. In terms of my HIV, by 1995, I was experiencing regular gastrointestinal upsets, chronic folliculitis, oesophageal ulcers, Gastrointestinal (GI) bleeding, bronchitis and 18.5 kg weight loss.

35. I continued to get more and more ill, until I was finally diagnosed with an infection called MAI, following some diligent investigatory work by Dr Williams. With treatment to supress this, which I will discuss further in Section 6, my CD4 count started increasing and my general health started to improve again.

36. By 1998, I felt well enough to return to work. I had been polishing my IT skills whilst recuperating, and I decided to start up my own IT company.

37. By 2001, Dr Alan Pithie, an Infectious Diseases Consultant at the Haemophilia Unit at the Glasgow Royal, was very keen that I start a course of Alpha Interferon to treat my HCV. I was reluctant to do this given at that time I felt in relative good health, and I knew it would severely impact my work opportunities.

38. I agreed to the treatment following a liver biopsy which showed the onset of fibrosis and cirrhosis. I will discuss this in more detail in Section 6. In 2001, in the around halfway through the Interferon treatment course, Dr Pithie mentioned very casually that I also had HBV.

39. I quickly asked what he meant, and, realising I was ignorant of that fact, he became very confused. I explained that I had previously categorically been told I did not have HBV and that I had been vaccinated against it, so it came as quite a shock to be told I did have it. Dr Pithie left the room, and when he returned he apologised that I had not been told previously.

40. My parents had been told that my younger brother had HBV, and I was then given a vaccine for HBV. But it turned out I must have already had both HBV and HCV at that point.

41. I could not believe that the news about the HCV and HBV was broken in the same way, i.e. with a doctor casually mentioning it in passing, thinking I was already aware.

Section 3. Other Infections

42. I was told I had HIV at a very young age, when I was just 14 or 15 years old. When I was 24, I found out I also had HCV. In 2001, I was told I also had HBV.

43. I became aware of the risk of vCJD. A letter was circulated to the unit's patients stating that a Haemophiliac had been treated with Factor VIII derived from a patient who later developed vCJD. We were asked if we wished to know if we had received Factor from this same batch. Of course, my brother and I wished to know and were later told by Prof. Gordon Lowe that we hadn't. He asked us if we wished to be informed if any other batches we may have been treated with were found to be at risk. We both said yes. This was one of the reasons why my brother and I petitioned to be put on recombinant factor VIII, and went on a treatment strike until this was agreed. We were very concerned about the risk of yet another infection.

Section 4. Consent

44. As a severe haemophiliac, when I was a child, my parents were aware I was being treated with blood products. These were required to save my life on a number of occasions. However I have no recollection during the multitude of visits and hospital admissions of any information about the risks of infection being given to my parents or I.

45. I was never aware of any tests until I was told I had HIV. I don't know if this was down to my age, but tests for diseases were never mentioned.

46. When I started being treated at the Glasgow Royal, they mentioned that they would be taking regular tests. I assumed this was to monitor the HIV. I didn't give it any thought about testing for hepatitis. It was not explained to me specifically what they meant.

47. When I was aged around 18-20, I provided blood samples for research which I was aware of and consented to. I don't have any recollection of what this was for, but it was at the Glasgow Royal.

Section 5. Impact

48. My Haemophilia, and subsequent HIV, HCV and HBV infections have dominated every aspect of my life until quite recently.

49. It is somewhat difficult to gauge the impact of the HIV, HBV and HCV as separate entities. The Haemophilia itself has also impacted my life from the very beginning, and had had an effect on my career choices. For example, it renders me not particularly employable due to the amount of time I need to take off work as a result of bleeds. This situation has of course been exacerbated by the infections which have also made holding down a job incredibly difficult.

50. The HIV and HCV have also undoubtedly impacted my opportunities for career choices, progression and development. For example, I couldn't pursue a role in health and safety which was a very good opportunity for me at the time, because of beginning treatment for HCV.

51. In terms of my education, my school were aware of my HIV status. Having HIV as a schoolboy undoubtedly had an impact on how I was able to study and apply myself academically. It was the mid 1980s, at the height of the negative publicity campaign regimes about HIV. I therefore thought it was only a matter of time before I would die a horrible death. It was all doom and gloom for a very long time. This had a big impact on me at a pivotal time in my life.

52. By the time I left school I knew my immune system was starting to respond to the HIV infection, but I generally felt quite well. I was keen to work, so upon leaving school, I tried to find a job. I was, however, still experiencing a lot of bleeds at that point which narrowed my choices.

53. I found work at a garden centre, which I was pleased about. However any repetitive action caused me bleeds, which often meant I ended up in hospital, requiring time off for treatment. It was therefore very hard to hold down a job. Furthermore, it started to be difficult to see work as a priority when I fully believed I was facing an imminent death sentence.

54. Throughout my working life, I have never been salaried. I have managed to work, in fact I had my own business, and money was good. I was able to set my own rates, and I was lucky to have access to commercial clients. I noticed a gap in the market and, as a result, managed to create a niche area of expertise. For a long time, I made good money from setting up IT systems for demolition companies, and then maintaining those IT systems.

55. In terms of my family life, when I married my second wife, for a period of time I was a house husband looking after our home and my two step children having wound down my IT business. Looking after the children was my favourite job of all. My wife and I wanted to have a third child; we would have loved to add to the family.

56. I asked my HIV consultant what to do to make it safe and he said to just go home and do it. My mindset from the age of 15 was to never put anybody at risk. To be able to conceive a child naturally seemed like anathema to me. To realise I was no longer a risk to others was a strangely liberating experience after all this time. We did try but we were not successful conceiving and stopped trying after a few months.

57. Physically, as a result of my HIV I have had to endure a wide range of symptoms and side effects of various treatments. In respect of the HCV and HBV, my liver deteriorated very quickly which I believe is indicative both viruses were active at the same time. I think my liver would have coped better for longer if I had only been infected with either HCV or HBV, and not both.

58. Mentally, learning I also had HCV during treatment for HIV, and then subsequently learning I also had HBV in a similar way, was challenging. I knew these other obstacles were looming on the horizon, and started wondering how they were going to affect me in the future. This was very stressful.

59. Ever since I was a young boy at the age of 7, I have suffered with my mental health, and the fact that I got infected via treatment that was supposed to be saving my life, exacerbated this. My mental health has fluctuated over the years and I have needed periods of treatment and support for my depression, some of which have in turn brought their own significant side effects. I will discuss I will discuss the physical impact of the infections and treatment as well as the mental health aspects in more detail in Section 6.

60. As I mentioned, I am very fortunate in that I did not experience any stigma really, even though when I was growing up, knowledge of my infections was very public as a result of the media attention. The only bad reaction was an initial one from my second wife, when after our first date she said my infections and health issues were all too much to cope with. Obviously, she later changed her mind and we embarked on a relationship together.

61. I feel that haemophiliacs in general tended to be portrayed as being innocent victims of the AIDS crisis whilst other groups were vilified in the press. We were seen as being innocent in it all, which meant, at least in my experience, people were understanding and not unkind. This made a big difference in terms of how I have been able to live with my infections. Although it has been extremely difficult living with HIV, HCV and HBV, life would have been a nightmare if I had also suffered socially as a result of my infections.

62. I chose not to tell my step children about my infections until after the episode at the transplant unit. We sat them down and told them my life story. Fortunately they took it well. My infections and treatment have undoubtedly had an impact on family life, in particular with my relationships with partners. For example, the breakdown of my first marriage was due to the stress caused by my first round of HCV treatment. I will discuss this further in Section 6.

Section 6. Treatment/Care/Support

63. When I was first told about my HIV, it was done in a very blasé way, during my first trip to the hospital alone as a 14 year old boy. No advice was given to me at all, it wasn't even explained to me what the virus was. There was some advice given later to my parents when they found out about it, and they then had to pass it on to me. However, my parents finding out about my HIV infection didn't really change my treatment thereafter.

64. When I was told I had HCV, I already knew a lot about it as my brother had already been diagnosed with it. The HBV seemed to be a total afterthought. Though, it obviously has similar advice and precautions for HIV and HCV, which I knew all about by that point.

65. I started treatment for HIV in 1990 at the Glasgow Royal. Ever since I was diagnosed, they had been monitoring my CD4 count on a regular basis. This meant they were checking my immune system was still functioning. By 1990, I reached a point where they wanted to start treatment. An effect of HIV is that you don't feel your CD4 count getting destroyed, it only becomes apparent once you start getting opportunistic infections. Initially, these are usually mild things, like a constant sore throat, or cough.

66. From 1990-1995 I tried a variety of early drugs, all of which I felt actually did more harm than good. I was first put on AZT, which caused nausea, gastrointestinal upsets and muscle wastage. The big concern at the time was 'AZT anorexia'. By this point my treatment had been transferred to Dr Williams. He was very open and honest and he said he didn't feel the drugs were helping. I agreed, and also felt I should stop, so I came off it.

67. My CD4 count gradually dropped and other drugs were tried, including DDI and DDC. However again, the side effects outweighed any perceived benefit. There was no rise in my CD4 count which actually continued to drop.

68. The doctors tried various cocktails of the drugs. In the end, I decided to come off all of them. I knew I might get to a point where my immune system couldn't protect me at all, but it was a risk I was willing to take as all the treatment options were making me so ill.

69. From 1991 I started to have PCP prophylaxis. I thought of this as going to hospital once a fortnight to get my lungs 'steam cleaned'. No one else could be in the room as it was so unpleasant to breath in.

70. I began to suffer from a series of opportunistic infections. These would include sores on my skin which would become infected to the bone, and throat ulcers. I got to a point where I couldn't eat solids, I could only drink Complan meal replacement shakes. I also developed bronchitis, regular gastrointestinal upsets and bleeding. I lost over 18kg in weight and my CD4 count dropped to 4. A normal CD4 count is from 500 to 1,400.

71. I was quickly admitted to GRO-B Hospital under Dr Williams. At this point things were looking very bleak as I was told my prognosis was only 2 weeks if they couldn't identify the underlying infection. I'm haunted to this day by the reflection of my skeletal frame in the mirror of my hospital room. This was the first true realisation that my death was imminent.

72. I came to learn that how a patient was infected with HIV could affect the manifestations of the HIV later on, and I became aware that haemophiliacs seemed to be more prone to bacterial infections. I was later diagnosed as having atypical mycobacterial infection (MAI), which is normally a type of lung infection, similar to TB.

73. After a long time of the doctors not being able to work out exactly what was causing the problems, extracts from my notes were taken by Dr Glynne Williams, to a conference in South America. Dr Williams asked colleagues at the conference for their opinion. One of the other doctors at the conference suggested testing me for MAI which later came back as positive. Although MAI normally presents in the lungs, I had developed Disseminated MAI. This effects the lymph nodes, liver, spleen, bone marrow and skin. My symptoms were quite severe, including fever, weight loss, fatigue and swollen lymph nodes. I have vivid memories of being drenched in sweat and a great deal of pain.

74. A combination of antibiotics quickly subdued the infection, and my symptoms began to ease, allowing me to take in more nourishment. My general health had improved somewhat but my immune system was still ravaged by HIV. Dr Williams explained that the life expectancy of someone diagnosed with MAI was only 3-4 months. While this was better than the original 2-week prognosis it brought very little encouragement, as it was only a matter of time till another serious opportunistic infection took hold.

75. A few weeks later the first Protease Inhibitor (Sequinavir) became available on a named patient basis. Combined with DDC this started to subdue the virus, resulting in an increase in my CD4 count. As more PI's became available, we settled on a combination of Sequinavir, Ritonavir and DDC, swapping out to newer drugs with a higher efficacy and improved side effect profiles as they became available. Various combinations of these drugs proved highly effective at preventing the virus from replicating, resulting in a rapid rise in my CD4 count to the range you'd expect in an uninfected person.

76. One major complication arose from taking a dual Protease Inhibitor combination though. I started to see a marked increase in the number of bleeding episodes. Although the Haemophilia Unit had no reports of increased bleeds on PI's, I had read reports from the US confirming a connection. The increased use of Factor 8 to treat these bleeds presented some difficulty as my veinous access had deteriorated markedly of the previous several years.

77. I approached the Haemophilia Unit with a view to getting a Portacath fitted but this was dismissed out of hand. Dr Williams however agreed that getting a PICC line inserted would help preserve the accessible veins I had remaining and made the arrangements. I had 2 PICC lines fitted over the following 12 months. I eventually switched to a non-PI regime and the bleeding episodes returned to a normal level.

78. I have suffered an encyclopaedia of side effects in relation to my HIV treatments. The nausea and loss of appetite have probably had the biggest impact on my general health, as they led me to stop eating, which caused me to lose weight and become weaker, which in turn impacts the other symptoms.

79. I was keen to get back to normal as much as possible and wanted to gain weight, so I withdrew some treatment including antibiotics, as the side effects from them had been quite severe. My general health gradually improved as newer more effective antivirals came out, and this continued until 2001. I continued to have regular appointments with Dr Pithie. He recommended I started interferon treatment for the HCV. By this time, haemophiliacs weren't dying of HIV anymore, but HCV.

80. My liver function tests had been elevated for quite some time but that's quite normal on HIV treatment, so I didn't think there was anything to be overly concerned about. However in around 2004, I underwent a liver biopsy in order to assess the damage. It is very unusual for a haemophiliac to have a biopsy due to the risk of bleeding but I wanted to know exactly what I was facing, and was reluctant to start interferon unless absolutely necessary, so I insisted. I was given a pre-op dose of Factor VIII and the biopsy was reluctantly carried out.

81. I was convinced it would come back normal and would show that treatment wouldn't be necessary at that stage, so it was a shock when it didn't. The results showed quite severe fibrosis and mid stage cirrhosis. I felt I had no choice but to start interferon treatment.

82. The interferon treatment lasted a year, and it can only be described as a year of hell. Interferon is a horrendous drug to have to take. I injected myself at home weekly, and I had and fortnightly visits to the treatment unit.

83. Initially I experienced flu-like symptoms such as fever, chills and aches, but it was nothing compared to the HIV treatment. About a quarter of the way into the interferon treatment I developed severe nausea. I couldn't eat, I couldn't even stand the smell of food. I then also started to experience muscle pain, weakness, hair loss and insomnia.

84. My white cell count plummeted, leaving me exposed to infections. I was given injections to boost my bone marrow production in order to compensate. This resulted in severe bone pain. I felt like my bones were being pushed apart from the inside. I was given various analgesia to help with this.

85. As well as the awful bone pain, I was also constantly tired, I had no option but to pass out asleep. I was sleeping a lot but didn't actually sleep well. I experienced night terrors and very vivid dreams and nightmares. I often woke up screaming. It was very distressing.

86. My mental health at that time was really suffering. I had known since I was very young that I was depressed, and I had had treatment for depression for a while. During the treatment for HCV, my mental health declined even further, and I was on a high dose of sertraline. This was taken in tablet form and it controlled my depression during the treatment well, but the high dose was quite toxic and also came with its own side effects.

87. Most significantly, I developed a severe Parkinsonian Tremor. It was a full body tremor, and I was regularly mistaken for someone who had Parkinson's. But it did work in regards to my mental health, so I continued with it despite the significant physical side effects.

88. I had injection site reactions, severe rashes and other skin issues caused by the injections. I had to rotate injection sites to allow them to heal. Towards the end of treatment, it was hard to find anywhere to inject as everywhere was so inflamed. I usually injected in my stomach, thighs, or upper arms, but all of those areas became very inflamed and sore. Sometimes, I accidentally injected too deep, causing a bleed. It would look like I had an egg underneath my skin.

89. Less than half way through the treatment course, it became apparent that I was unlikely to clear the virus. However I wanted to persevere as I was told it would be beneficial in delaying the onset of any HCC if I could get to the end of the course. So despite the many difficulties, I managed to complete a year on interferon. By the end of 52 weeks, however, I still had HCV. This was very deflating.

90. I couldn't press ahead with the career I was trying to advance in Health and Safety, as the treatment meant I had to stop the training as I was too ill. At the same time I had to wind down my computer business as I wasn't able to cope with it. Furthermore, a year after treatment, my marriage ended. It was quite amicable, but the stress of the treatment regime and its side effects had significantly affected our relationship, and it became clear things were irreparable.

91. This attempt at HCV treatment during what turned out to be the last year together with my wife, was a soul destroying process.

92. Around a year later, I met my second wife. At this point, I felt like I was in excellent health. My blood work was good, there were no major concerns, and my outlook was positive. Of course it was always in the back of my mind that my liver might fail, but I wanted to remain positive and get on with life. We got married in GRO-B and this was the happiest time in my life. My second wife had two young children when we met; one was 7 and one was 4 years old.

93. My first wife had already known about my haemophilia and HIV as we had been in the same year at school, so she was well aware of my history. When I met my second wife, I had to think about how and when to tell her. I decided to tell her about my health issues before our first date, before we actually met. I felt like I had to be upfront and lay it all on the table. She called after our first date and said she couldn't deal with all of it, and she had particular trouble getting her head around the HIV. I said okay and respected her decision, but we continued to message each other. I believe this decision caused her as much distress as it did me.

94. I was attending Gartnavel General Hospital at the time, and the support services on offer there were good. There was a counsellor who dealt with couples, and I asked her if she wanted to attend some sessions with me. She did and she started to feel a lot more comfortable about everything, and we were able to embark on our relationship.

95. We got married in GRO-B and the next GRO-B years things were great. I was on recombinant Factor VIII for my haemophilia, and this was very effective at treating bleeds. My treatment and infection didn't really have an impact on my marriage during this time.

96. Recombinant Factor VIII had been initially introduced for patients were not HIV or HCV positive, for cost reasons. My brother and I went on a treatment strike; we refused treatment for anything other than with recombinant factor products. They caved straight away, I think they probably feared a further public backlash like the one when we were younger. We were concerned about further infection and also about vCJD so were very keen to move on to the recombinant products.

97. Things were good until about 2014. Dr Sam Alan had taken over my care as Dr Williams had retired. A routine liver function test indicated my tumour markers were elevated. This could indicate the development of liver cancer. It was enough to start to imagine the worst. I had MRI & CT scans, and it was noted that my cirrhosis had progressed markedly, even though I felt fine. Some lesions had appeared on my liver, but they were reluctant to carry out a biopsy.

98. I was referred to the Transplant Unit at the Edinburgh Royal Infirmary in early 2015. The doctors there reviewed my liver. I underwent a series of scans including CT and MRI scans to highlight cirrhosis or potential hepatocellular carcinoma (HCC).

99. There is a long process you have to go through before you are able to be listed for a transplant. There is a point system called the UKELD score. I was told that I needed to score 49 as a minimum qualifying score in order to be put on the list. On my first visit, I scored 48, so I was one point short of the required score.

100. Over the next year, my markers continued rising. Each MRI/CT scan were showing new lesions or old ones expanding, though they were still small. I was told these were Dysplastic Nodules (pre-malignant lesions). Also, by this point I was a nice shade of yellow.

101. I continued having reviews at Edinburgh. These usually took place quarterly but after a few reviews, they decided to review me sooner due to the progression of the nodules.

102. At this review, my score had risen to 51-52 which should have qualified me to get on the list. A report was compiled and put in front of transplant committee. There were splits on the committee with oncologist believing one thing and the hepatologist believing another.

103. My older siblings had volunteered to donate a lobe of their liver so they were getting anxious as they might get called up, as for a while it was a bit 'up in the air' as to whether I was going to get listed or not. In the end they decided to list me. They repeated some blood work to get a good base line. By the time I got home I was informed my score had dropped back down to 48.

104. In between the 3rd and 4th reviews at the transplant unit, I had started another course of treatment for the HCV. This was a 12 week course of Ribavirin. It proved to be highly effective and I cleared the virus very quickly.

105. There had been no noticeable impact on my liver. However it was the effects of clearing the virus that had resulted in my score jumping back down to 48. My wife and I went to the review together as usual, it wasn't the usual consultant who I got on very well with. This was a professor, and he was very arrogant. Two students sat in without my consent and he barely even looked at us for the whole appointment.

106. Firstly, he didn't know I was a haemophiliac. This, in my mind, was not a good start, particularly as this was the origin of all of my subsequent infections and medical problems.

107. At the time I was on a combination of painkillers, namely fentanyl, codeine, Duloxetine and morphine to manage chronic liver capsule pain. Capsule pain felt like I was being stabbed in the stomach repeatedly. Though there were periods of reprieve from the stabbing pains, there was still a constant dull ache.

108. I was quite 'out of it' a lot of the time due to all the painkillers I was taking. My wife was there to help me communicate as I was having difficulty communicating due to the combination of the intense pain and strong painkillers I was on. I happened to have an abdominal bleed at the time and the professor prodded my stomach and I immediately winced in pain. He asked why I was wincing, and I replied, 'because I have a bleed'. He asked me why I had a bleed, so I told him 'because I am a haemophiliac'. He clearly didn't know. He hadn't read my notes and he hadn't bothered to ask us about my history.

109. Then he started talking to my wife and not me. My wife lost it, she was really angry at how the doctor was conducting the review. She ended up having to excuse herself and left the room.

110. The doctor phoned me later with a very different tone. He told me I had been listed and that I had to go back for another appointment in two weeks. I had further bloods taken, and again, my score had dropped below the threshold again. This was devastating.

111. A liver transplant would cure haemophilia as a new liver would produce Factor VIII at a near normal levels. So, at the time, a liver transplant was like a holy grail to me and my haemophiliac peers. As a result, knowing my liver would fail at some point, my end goal was a liver transplant. I was always focusing on this during the transplant process and was so looking forward to being able to lead a normal life.

112. It was therefore a crushing disappointment when I was told I couldn't have it, especially after so much back and forth about it, with positive followed by negative news. The stress of it all also caused a fracture to appear in our marriage.

113. After I cleared the virus, my liver started regenerating and my health was improving greatly, but mental health wasn't so good. I was still on a high dose of duloxetine and painkillers. I had gained weight. However, after a while of being on it, the duloxetine started to fail as an antidepressant.

114. Something broke in my psyche when I got the call saying I was suspended from the transplant list. The nurse who told me was really nice, but she said they had no choice but to take me off the list.

115. I tried various antidepressants, they would work for a few months but then they would stop working. I was becoming hopeless. I decided to try Electroconvulsive therapy (ECT). Because of my haemophilia, this came with a high risk of brain haemorrhage.

116. My psychiatrist, Dr Cameron, dealt with a large number of patients infected with HIV. He introduced various antidepressants. He was quite against ECT as I'm Haemophiliac.

117. Dr Julian, GRO-B was an ECT specialist and advocate of it. He felt that as long as I had pre-op Factor VIII, it should be safe for me. So I was scheduled for 8 treatments and monitoring, and I would have tests after every treatment.

118. For my first treatment batch, I was kept in as an inpatient for a fortnight, and had 2 per week. I found the effect amazing after the first 4 treatments.

119. The beneficial effects from the first course lasted around 6 months. I was monitoring my own HAD score at home; this is the scale on which depression and anxiety is measured. I had been in the habit of doing this as I had been having mental health care for such a long time.

120. After the effects wore off, I felt I needed another treatment course. I was booked in for a second course of treatment. This time I was only an inpatient for the first session, then I was sent home. After each treatment, I would wake up with a very sore head which would wear off after about 4 hours. I couldn't drive for 24 hours, so I would have to be picked up by my wife.

121. I later had a third course of ECT in combination with antidepressants and lithium. This was attempted in order to keep my mood higher for a longer period of time.

122. I managed to get to a good place with my mental health, then lockdown happened. All psychological services shut down and I was left without access to the mental health support I needed.

123. From the beginning of lockdown in March 2020, I strongly started to believe that I was causing too much stress and trauma to my family. I started weighing up how much stress there was in relation to me being alive against how much stress my death would cause, and I started to feel that my death would be less of a problem than my being alive.

124. By the time I needed a 4th course of treatment, my HAD score was the lowest it could go. I had entered a state of mind almost sociopathic in nature. Losing the ability to feel left only logic. I envisaged it as a scale; on one hand the benefits I brought to family versus the detriments on the other hand. I really started to feel like it would be better if I was no longer in the picture.

125. Being constantly in this state of mind led to suicidal ideation. I almost became preoccupied with how I could do it in the most efficient and effective manner. I felt that the logical way to reduce my preoccupation with suicide was to actually have a plan in place. I know this sounds crazy but this helped me to stop spending so much time thinking about it. Unfortunately, I was oblivious to the huge impact voicing these thoughts to my wife would have on her psyche.

126. Under this constant strain, and with no help on the horizon, our already fractured marriage crumbled. There were a couple of unpleasant incidents between us, and eventually, she asked me to leave. I had to find somewhere to go, so I went to my sister's. My wife and I formally split up in June 2020. I spent about 4 weeks bouncing between my sister's and mother's before finding a place of my own to rent.

127. At the time of our split I couldn't physically function enough to furnish a house etc. For the year prior to the split, I had been living on milk and Complan. I had extremely bad nausea, and I had been sleeping for 18 hours a day. I didn't feel hungry, I literally had to force myself to eat.

128. I think my nausea and fatigue was a combination of depression and the side effects of the medication. My sodium level was low due to my poor diet and the lithium was building up in my system because of this. This produces toxic effects, and it led to a vicious cycle of tiredness and nausea that I couldn't get out of. For a long time, I had no physical energy to get up and out of bed.

129. In the end, I stopped the drugs. As a result, my physical health improved and I could physically function again. Lithium is a mood stabiliser. If mood is low, it tends to keep it low. There are no highs and lows. After coming off lithium, I felt better.

130. I found a suitable house in August 2020. I had to start over from scratch, I took nothing from the home I had shared with my wife. With much help from my siblings and stepdaughter I managed to fully furnish the house by January 2021. It seemed a slow but positive process, providing much needed focus.

131. Before I left home my stepdaughter made me promise not to end my own life. This proved a pivotal moment as, for the first time in many months, I realised just how much my state of mind had negatively impacted those closest to me. For the next 6 months I managed to subdue any thoughts of suicide by recalling the promise I had made to her. I still have a very good relationship with her even after her mother and I split.

132. I am currently treated for my haemophilia with a relatively new treatment called HemLibra, after I successfully persuaded my doctors I could qualify for it. This treatment is in the form of subcutaneous injections once a fortnight. I started using it in October 2020, and I haven't bled since.

133. Knowing the benefits physical activity can have on your mind I started to exercise, something which before the advent of treatment was impossible, with the hope of controlling my depression. I gradually increased the amount and variety of exercise to test the limits and benefits of the drug and found that even with over 2 hours of exercise I remained bleed free. More importantly the biochemical benefits mean I can now fully control my depression without the need for medication.

134. Dr Julian advised in January that the ECT unit had started up again. Part of me wanted another dose of it to boost my mood, but I was concerned about the side effects. They thought my third course may have caused a bleed but the Factor VIII stopped it from becoming too serious.

135. My mental health was monitored by another psychiatrist from January till October via telephone consultations. At my last consultation it was agreed that, due to my high sustained mood, I could be safely discharged from the psychiatric service.

Section 7. Financial Assistance

136. I was one of the first applicants of the Macfarlane Trust. I received £25,000 as a lump sum and received a regular monthly payment thereafter. I still receive this via the SIBSS.

137. I heard about the Skipton Fund through the Macfarlane Trust. We were sent an application form automatically. Following my application, I received a Stage 2 payment from the Skipton fund. This was due to my diagnosis of liver cirrhosis which was confirmed by the consultant who signed off the form. I can't recall how much that was but I recall the process was very straightforward.

138. My overall impression of the two trusts is that they were well run. In my experience, the MacFarlane Trust was always helpful whenever we asked for their assistance.

139. I now have an open case with Scottish Support scheme (SIBSS). Annually I receive around £45,660.

Section 8. Other Issues

140. I have been part of some prior litigation as outlined earlier in my statement. The first started in around 1987 and was initiated by my father. He interacted with some legal representatives who were based in GRO-B and Edinburgh. Costs proved to be prohibitive and with no legal aid available for civil cases at the time, we were priced out and the case ended up being dropped. Little came out of it apart from the fact that our stored blood samples were tested, indicating HIV infection first occurred in 1982. At that time, the general consensus was that the infected blood was just a tragic, unforeseeable accident with no legal recourse.

141. In around 2014, I was also part of a group litigation GRO-B

GRO-B

GRO-B r an out of court settlement. This was a token payment, of which they took 65%. We each ended up taking £17,000 which was 35% of the total sum awarded.

142. During the last meeting with the GRO-B lawyers in Edinburgh, I spoke with one of them, fishing for information. He told me off the record that blood had been continued to be sold to UK on the basis of it only being used in primate studies into HIV transmission. However, it was decided primate testing was too expensive. I understand this was also echoed in evidence given in the Penrose Inquiry. I took this to mean that they then decided to test on people who had already been exposed to pooled blood products, so haemophiliacs. This all really stuck in my mind.

143. Just before my transfer from GRO-B to Glasgow Royal Infirmary, my parents were asked to return our treatment books for incineration. These were logs parents kept of treatment dates, bleed type and a record of batch numbers for each dose given. While most parents complied with the request my mum refused to hand them over.

144. During the GRO-B litigation I sent these books to the GRO-B so they could trace where our treatments originated. It was through this process that they managed to tell me our infection originated from blood harvested in Arkansas, USA. This applied to both my brother and I as our supply of Factor VIII was shared between us. I'm not sure where these treatment logs ended up or whether they were returned to me.

145. As I mentioned, my younger brother is also a severe haemophiliac. He was infected at around the same times as me, with the same infections. Our history is therefore very similar, the only difference is that I took my medication religiously while he secretly binned his. I don't believe he will be providing a statement to the Inquiry.

146. Lastly, I have seen lots of mistakes in my medical records. There are mistakes on dates, blood tests, results, mostly minor but obvious where secretary has been unable to read a doctor's writing, or just making simple mistakes. I find this quite concerning and I think this is something that should be improved as keeping thorough and legible medical records is very important.

Documentary Exhibits

147. I have sent 3 documents to the Investigators which I think are useful. These are:
1. Copies of communications between one of my psychiatrists, Dr Cameron. Before each visit I'd prepare a summary of events from my previous appointment, allowing him to get up to speed before we spoke and in case I forgot anything. These may be more accurate regarding dates and treatments than the information I prepared for our meeting. This is exhibited as **WITN6478002.**

2. A PowerPoint presentation made by Dr Cameron about my particular case for the GRO-B conference in 2018 relating to the use of ECT. I was present during this lecture, which is exhibited as **WITN6478003.**

3. I also spoke at this lecture and my notes are exhibited as **WITN6478004.**

148. These exhibits should provide an accurate picture of my mental state from 2016-2020.

Statement of Truth

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

Signed GRO-B

Dated 22/11/21