

ANONYMOUS

Witness Name: GRO-B

Statement No: WITN5326001

Exhibits: Nil

Dated: 2ND MARCH 2022.

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 30 September 2021.

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 1967 and my address is known to the Inquiry. I am a GRO-C GRO-B although from 1 November, I will return to engineering. I have been married to my wife for ten years. I have one stepdaughter.
2. I intend to speak about my infection with HIV, Hepatitis C (HCV) and Hepatitis B (HBV) contracted from blood products used to treat my haemophilia. In particular, I intend to discuss the nature of my illnesses, how they have affected me, the treatments received and the impact this has had on the lives of myself and my family. I have an excellent

memory. Whilst I do not remember the names of brands of treatments, I can recall the timescales and chronology of events.

3. I can confirm that in the interests of both myself and my family, I would like to be anonymous.
4. I can also confirm that I am not legally represented.

Section 2. How Infected

5. When I was two years old, I was diagnosed with severe haemophilia A. I cut my finger and it wouldn't stop bleeding. Haemophilia is the chromosome passed from the female to the male. Because haemophilia was known in the family, I was checked for the condition. My mum had two cousins who inherited the disease from her mother's sister. My diagnosis came as a shock as they didn't think my mum was a carrier.
6. We are entering an era where the incidence of haemophilia is diminishing. In future, it will likely no longer exist. When my mother's cousins were alive, there was no treatment. I doubt I will see any more positives on the haemophilia side in my life span. At one point the possibility of pills to treat bleeds was discussed. However, I am highly doubtful that this will be introduced.
7. My sister always wanted a child. She was bitter about having the test which would identify her as a haemophilia carrier. It is based on DNA and gender testing. At 15 it wasn't something she wanted to interrogate. The technology was risky. Her decision to have a child will have been based on good judgment. I now have 15-year-old niece who will need to have the test although she is approaching a time where the risks of haemophilia are much diminished.

8. As a toddler, transfusions were the only effective treatment.
Subsequently, I was treated with cryoprecipitate at Booth Hall Hospital, a specialist Hospital in North Manchester. The product came in bags of plasma which were frozen, defrosted and then drawn out. The nurses would swill the bags out with water to get all the treatment. Cryoprecipitate was effective but inconvenient as I had to go to casualty to have it done, by which time the bleeding had already set in. It was no quick fix.
9. I was then treated with recombinant which came in a bottle of freeze-dried powder before being dissolved into water. As a result, I could respond to bleeds more quickly. My mother was taught how to administer intravenous injections. I was then able to rely on daily prophylaxis which I began to administer at 10 years old.
10. Heat-treated FVIII brought treatment into a new phase. It would take 10-15 minutes to make up. I could make it and have the needle in and out my arm in under five minutes. Treatment became very quick to deliver and the vials smaller. When I was a toddler, cryoprecipitate was administered in big syringes at 100 millilitres at a time. Conversely FVIII could be injected in five millilitre concentrates.
11. During my youth, even having been diagnosed with severe haemophilia, I was out and about and doing what young boys do. This led to a number of bleeds. As a result, I used product every day. It looked like I had two footballs on my leg. My knees have since been replaced. My ankles have also been fused. I am awaiting nerve surgery on my left elbow and two new elbow joints.
12. Booth Hall Hospital was great. The main centre was subsequently situated at Pendlebury Children's Hospital in Salford, Manchester. When I turned 18, my care was transferred to Manchester Royal Infirmary (MRI). The move had been delayed as my consultants pre-empted that the transition from child to adult care would not be easy.

13. In 1986, I was involved in a car accident on my way to college. A taxi was speeding and ran me over. He left me for dead in the middle of the road. I sued him privately and it transpired that he wasn't insured. The case was settled out of court, as it was argued that I could have dived out the way. My dad believed this result to be a travesty.
14. I was taken to Pendlebury Hospital. I suffered a compound fracture of the femur in my left leg. The bone had cracked almost in half. My skull was also cracked which meant that I couldn't see straight for three months. I also broke both wrists. They were reluctant to operate on me to fix the femur because they were nervous about potential excessive bleeding.
15. They had good cause to be concerned however, as it later transpired that at this point the doctors were aware of my infection with HIV which most likely also contributed to their aversion to treating me. Some years later I was also diagnosed with HBV whilst attending the Manchester Royal Infirmary. I suspect the doctors knew about this as well when I was hospitalised following the road accident.
16. Whilst I was convalescing and still very unwell, the head sister of the haemophilia unit, Sister Alex Shaw along with Dr Richard Stevens, informed me that I was HIV positive. My parents knew already but were preparing to tell me. They wanted to wait until I was a bit better. It wouldn't have made a difference to wait until I had recovered. The staff probably acted without my parent's permission as I was over 16.
17. My dad spoke with staff after this and complained about the tactless and insensitive manner in which I was informed of my diagnosis. I have always trusted my dad to speak on my behalf and defend my best interests. I have never had a solicitor but he has been the closest person to acting in this capacity. I was not provided with any information about the precautions to take or how to manage the

infection or what it meant for me going forward. I was left to mull on this life-changing news whilst still bruised, battered and incapacitated.

18. If I had been discharged, I would have required full time care. As such, I was put on bed rest in hospital to convalesce. A pin was inserted through the bone under my knee. I was also given a calliper. I am happy with the treatment I received following the road traffic accident. During this time, I kept up with my schooling. When I was discharged, my leg was still very weak. It took some time for my actual diagnosis with HIV to sink in as I had other obstacles to overcome.
19. I have never had a panic attack or broken down following my diagnosis with HIV. I have always been pragmatic. However, I have often felt disappointed that no one sat me down and explained the implications of my infection. I treated my diagnosis as something that was my responsibility to manage. I was never going to survive otherwise. I had already done my homework. Haemophiliacs were dropping like flies. I lost two close friends. I watched one in his bed before he died.
20. Some months after my diagnosis, I was told that that my viral load and CD4 count were under control. I only understood the latter to relate to the immune system. I knew I wasn't on death's door. What I had to do was concentrate on getting back on my feet and overcoming the physical injuries. The recovery from the car accident took around 12 months.
21. Shortly after my diagnosis, when I reached 18 years old, my care was transferred to the MRI. It was a drastic change from the children's Hospital. I started seeing the haemophilia specialist who was clued up about HIV.
22. My care was then overseen by Professor Charles Hay who has been a fantastic source of support and has grown to be a very good friend of mine. I don't know what I'll do the day he retires. As mentioned, I was diagnosed with HBV while under his care. It ordinarily clears

spontaneously without the need for treatment. However, an essential tablet I take for HIV also keeps the HBV under control.

23. In the 1990s', when I was undergoing various treatments for my HIV, I was diagnosed with HCV. I was having blood tests at the haemophilia centre every few months to monitor my haemophilia. I was told that treatment wasn't available at the time but that the virus would eventually damage my liver.
24. I was never given any indication by Pendlebury Hospital that there were any risks involved with the blood products I was given. Neither were my parents during treatments when I was younger. I never suspected something like this would happen to me. I have never been an intravenous drug user nor been medically treated overseas. I only got tattoos recently. Tattooing is done very safely these days. I treated myself before having them done. I didn't seek any permission beforehand.
25. Around two years ago, Professor Hay sought to reduce bleed counts in order to reduce patient attendance at hospital, which would in turn reduce costs. As a result, I volunteered for a new haemophilia treatment known as Hemlibra. The treatment doesn't involve injecting blood products but rather, fills the chromosome gap so that your body thinks it has the missing clotting agent. The product has a very long shelf-life. I was going from 500 units of FVIII a day to a small syringe of liquid a week.
26. For the future of haemophiliacs, Hemlibra is wonderful as there are no risks. Gene therapy is also underway, although it might not work for all haemophiliacs. The amount administered is matched to the patient's body weight. It takes two minutes to prepare and can barely be felt as it is injected. I merely feel a little bit of coldness once a week. Its effectiveness is based on dosage. I am still at risk of bleeding but it is basically prophylaxis in a one-shot treatment.

Section 3. Other Infections

27. Some years ago, I became concerned when I heard that a haemophiliac had become infected with vCJD. The incident was broadcast in the news. I received a letter from the head of department at the MRI alongside several additional communications. My dad and I brought it up at one of the clinics. I was told that I was at risk because of the blood products I had received. It was a big deal for a while and caused a wave of panic. Unnecessary really as there is nothing they can do for you if you are infected. For my dad, it as just another thing to worry about.
28. As far as I know, my parents have not been tested for HIV or Hepatitis viruses. My wife voluntarily tests for HIV and HCV.

Section 4. Consent

29. The use of American blood products was quite a defined era in the history of haemophilia treatment. I know when I would have received them at Pendlebury Hospital. I can remember being informed by letter that there was a shortage of British produced blood and therefore American blood was to be administered instead. Our consent to this was never sought.
30. I wasn't aware that I was being tested for HCV until my diagnosis in the early to mid 1990s. Dr Ed Wilkins from North Manchester General informed me that I was positive for the virus. I was given some information about precautions but it was the obvious stuff.
31. Professor Hay and I have had a fantastic relationship over the years. He helped me to get my knees done in 1998 which wasn't easy as a thirty old year-old patient. He also got me titanium parts – better quality. For someone to still have their knee replacements 20 years later is testament to the quality of the treatment.

32. Professor Hay understands quality of life. I have supported him on every initiative and trial treatment including Hemlibra two years ago. I have also cooperated with Dr Sukthankar at the MRI and his trial treatments for both HIV and haemophilia which are very much interlinked. I have always consented to these.

Section 5. Impact

33. I was 19 when I was diagnosed with HIV. Within next to no time, my world was turned upside down. I had to think about everything I said and did. I burdened myself with it being my problem and responsibility not to transmit the virus to others. People have said that I put too much pressure on myself to enforce this but I knew I wouldn't be able to sleep at night otherwise.

34. My last memory of Pendlebury Hospital was of a fellow patient GRO-B GRO-B on a drip. He was younger than me and a chronic haemophiliac. Back in the 1980s nobody knew what they were dealing with regarding HIV. I assumed he was just ill with haemophilia until we discovered that he had AIDS. He was one of the first publicised cases that came to my attention.

35. His parents were very vocal in their outrage about the circumstances surrounding their son's infection and death. The only blessing was that it took him very quickly. After GRO-B death, I realised that HIV was real and that my life was to change forever. I was diagnosed but assured that I was well. However, weeks later I saw friends dying and at the time the virus was elevated to being an epidemic and advertised as such on the news and across the media. I felt that I was being given conflicting information.

36. At some point in the late 1980s, I was told that my CD4 count was very low. The Concord trials were underway. I was offered a trial treatment of AZT, albeit I could have been given the placebo. However, having independently researched the drug, my father and I decided against treatment. Dr. [GRO-D] and Dr. [GRO-D] at the MRI were quite dogmatic in their approach to treatment. My father and I felt that we were shunned for making the choice that we did.
37. Opting not to go on AZT was one of the wisest decisions I ever made. Not only was it proven to be damaging in and of itself, but it could also impinge the effectiveness of future treatments. I am also sceptical about placebo treatments. However, at the same time, my CD4 count was rapidly diminishing. My viral load wasn't monitored until much later. Treatments were being discussed and developed. I was advised to moderate alcohol consumption, not that I drank a lot anyway, keep as well as possible and to be patient.
38. I found the early days at MRI challenging purely because of the regime enforced by the doctor at the time, Dr. [GRO-B]. He was very clued up about HIV but his bedside manner was appalling – and that's being kind! I was young and had only recently been diagnosed. It was the worst time to be around this type of attitude. My dad accompanied me to every appointment. I relied on his support. He was also unhappy with the treatment.
39. This doctor left and was replaced by three or four interim doctors. I embarked on a variety of treatment regimens which included DDI tablets which were chalky tablets dissolvable in water. Keeping this medication down was difficult. It was then discovered that I had a rare virus resistant to the HIV treatment. I was encouraged to keep going as best as I could as drug regimens were being formulated to combat the resistant virus.
40. I was very skinny and underweight. Around the time of my diagnosis, people told me I looked tired. I was 17, studying at college whilst

maintaining a part time job and social life, so part of looking run down may have been attributable to this. In the 1990s', I began taking a group of antiretrovirals which, though effective, caused lipodystrophy.

41. I took Indinavir for my HIV for 12 months, which caused the equivalent of kidney stones. Most passed naturally. Unfortunately, I wasn't advised that I should significantly increase my consumption of water to combat this outcome. One kidney stone had to be surgically removed, another battered out with an ultrasound. I took this medication for 12 months. I was often taking two or three tablets a day whereas now I only take one. There was never any discussion on whether the dosage should be relaxed.
42. Conversations with my consultants around HIV and HCV were always focused on the potential damage to my liver and immune system. I was warned about the possibility of opportunistic infections. The various medications had different effects on the virus. I began to see a specialist in communicable diseases at the North Manchester General Hospital, who was introduced on a temporary basis. His bedside manner was ok, albeit very matter-of-fact.
43. In the mid 1990s, I was diagnosed with a lung condition known as bronchiectasis. This was triggered by having such a low CD4 count. I thought my numbers were up. I was expecting to be told that I had AIDS. I also couldn't get rid of chest infections. I was very ill, suffering from night sweats and unable to eat. I was so unwell that antibiotics were obsolete. My work was also affected. After 12 months, the condition cleared.
44. Of all the effects of HIV and its related medications, lipodystrophy has caused me the most significant mental strain. I am not vain. However, the condition resulted in a shifting of body fats which was more than discernible to those around me. My dad certainly noticed the condition. I almost had a mental breakdown.

45. I decided to have cosmetic surgery on my face due to the affects. I refused the doctors permission to show the medical photos to their students as I looked so terrible; I had black eyes and a bruised face. When I returned to work, my colleagues asked if I had had cosmetic surgery. I had gone from looking skeletal to having a full face. I tried to explain that I had been unwell and had since recovered. After a few days, people lost interest.
46. In the early noughties, I continued to have trouble with the resistive virus. I had viral checks in which my blood was sent to America for sophisticated checks. I was told to wait for two new drugs. I began taking T-20 which was a very viscus liquid injected into stomach, leg or arm every day. It was brutal and caused bruising and nausea. It was different from interferon in that as it was viscous, it remained under the skin. I took T-20 for eight months.
47. The T-20 got everything under control. My CD4 count was brilliant and my viral load much diminished. The CD4 count was always the priority. It was a strange campaign as at each appointment the nurses would declare, 'I hope it's above 200!'. I know they meant well but I found the atmosphere quite intimidating and unnecessary.
48. My care was overseen by Professor Hay and Dr Ash. I was also seen at the clinic by HIV doctors, Dr Sukthankar or Dr Margaret Kingston. Once, they got the HIV under control, I started to feel a lot better. The fatigue, general malaise, and opportunistic infections including chest infections, all dissipated. It was like somebody was sucking the bad things away. My immune system became very resilient and I garnered strength.
49. I currently take five tablets every night, two of which are dissolved in water because they are a chalky consistency. I take three tablets for HIV, one of which as I've stated also keeps the Hepatitis B under

control. I also take two tablets of loperamide which contain Imodium to combat certain side effects of the medication.

50. The antiretrovirals are strong on your stomach although I've been taking them for so long that my body has more or less grown accustomed. They used to cause nausea and a heavy head. Other treatments would make my head feel like it was exploding. I now have a viral load of zero and a CD4 count higher than any normal person on street. The aim is to maintain the viral load at below 50 counts.

51. Between the late 1990s and early 2000s', Dr Ed Wilkins was concerned that the HIV could not be managed whilst I was still infected with HCV. Professor Hay came on board. They offered me treatment. I was told that it was relatively expensive and so the hospital would have to apply for funding.

52. The exact cost was not mentioned. I waited a couple of weeks. I was then invited for an appointment in which I was offered a three-month course of Interferon and Ribavirin. I was given four weeks' worth of treatment at a time. I was tested every week. The Interferon had to be kept out of the fridge for an hour and chilled to room temperature. This was administered in the stomach via injections. I took ribavirin tablets three times a day.

53. Within half an hour of starting treatment, I suffered severe flu like symptoms. I was sleeping beneath three quilts with the heating on full blast. This cleared after a couple of weeks. I also experienced night sweats and was very fatigued. Within one week, my viral load appeared to be diminishing. Over time, they then started to ween me off the treatment. It felt brilliant to clear the virus and I was elated.

54. The Hospital were good to me. I was progressing with my career and was very busy. Because of this, the Hospital would give me kits to take my own blood at home. My dad would take the packages up to the

university for me who would get in touch to assure me that I was doing well. I am screened for the virus each time I see the consultant. I remain PCR negative.

55. I have never been offered a biopsy to measure the damage to my liver. This is because of the risk of bleeding. Nevertheless, liver function tests have not revealed significant damage. It was explained to me that the biggest test would be after treatment was completed. I think I had a number of x-rays pumped full of dye to monitor the damage to my liver.

56. I never heard of it at the time but the main side effect was severe depression. To counter this, a month before starting treatment, Professor Hay pre-emptively prescribed me mild antidepressants. This was a wise tactic. However, I can be very straight-talking. For the three months in which I took antidepressants, I became quite numb. People around me thought I was more laid back. In retrospect, I may not have been the easiest to be around. I had to consciously reflect and force myself back into my former personality.

57. I was gradually weaned off the antidepressants but understood how easily one could grow dependent on them. Whilst the treatment regimen felt rigid, everything had been pre-empted and so I was somewhat prepared. I will never know if I would have been affected by depression because Professor Charles Hay eliminated the possibility.

58. Over the years, GPs and doctors have asked how I have survived without antidepressants. However, I believe in getting rid of the problem pragmatically and through environmental changes. I have always sought to persevere. There have been times when I've thought about taking medication but I don't want to become dependent.

59. A couple of years ago, Professor Hay noticed that I was very tired. I was getting up several times in the night to use the toilet. The urinary clinic couldn't identify a problem. He referred me for a sleep apnoea test. I was subsequently diagnosed at North Manchester General

Hospital. I can't confirm the origins of sleep apnoea but I can't rule out one or all of the viruses being responsible either.

60. I voluntarily relinquished my driving licence as a result. The DVLA must be satisfied that I am compliant. I've got to bring the sleep apnoea machine with me when I travel. I also think HCV in particular has exacerbated my joint problems, particularly my ankles Knees and wrists. Furthermore, I have elevated blood pressure which is possibly attributable to my various treatment regimes.
61. The only time I get upset and emotional is when I consider how my infections have impacted my personal life. I met my wife whilst undergoing treatment for HIV. She wondered what was going on. I vividly recall the process of preparing to tell her everything, which was nerve wracking. I knew I had to or I would have no hope of a future relationship and might lose her. I had track marks from administering the haemophilia and HIV treatment which I knew would be difficult to explain.
62. It was a struggle trying to juggle working life with my haemophilia and HIV. I became flustered with everything that I had to remember. I was working towards a degree which I completed in 1999. I was also undergoing sophisticated immune tests in relation to my HIV whilst suffering serious joint problems with my knees as a result of my haemophilia - and probably exacerbated by the HCV. I was living at home during this time. My father was a continued source of support.
63. My infections may also have affected my haemophilia. If I was worried or under extreme stress, the bleeds could be worse. During my diagnoses, I was working, whilst trying to attend frequent appointments. This was very stressful and coincided with the prescription of antidepressants. I don't know how I managed with everything coming at me all at once. My career has always been a

means or forging a semblance of normality; proof that I can rise above what has happened to me.

64. I have been forced to develop my career around the limitations of my conditions. In the mid 1990s', my employer offered to pay for me to relocate to San Francisco as an engineer. It would be all expenses paid including a visa. I was forced to turn down the opportunity. I would have gone in a heartbeat if it had not been for my diagnosis with HIV and the difficulties I encountered with lipodystrophy. Conversely, my haemophilia never held me back.
65. I got my degree in 1999. By this point, I had bilateral surgery in which both of my knees were replaced. In the picture that is still on my parent's wall, my face looks very drawn and gaunt because of the lipodystrophy. It shifted fat into my stomach area. I have already mentioned, I had pioneering fat replacement surgery at the Manchester Royal Maximo in which the fat was taken from my abdomen in four places and injected into strategic places in my face.
66. It has been distressing to reconcile with the reality that whilst I was always able to work around my haemophilia and live a normal life, HIV has held me back. Overnight, I had to change my story. When HIV began to cause me problems, I would have to attribute this to haemophilia. Fortunately, I had an answer for anything. I would tell people that I was lucky as I never received American products and was therefore unaffected by the AIDS epidemic.
67. Had I not received contaminated blood, without question I would be at a higher career level. At the same time, whilst I am not financially motivated, I have thrown myself into my career as a way of dealing with my circumstances. My wife has commented that I am too career focused. We are very different; she is cool, calm and collected. However, my outlook has been to maintain normality and persevere in spite of what has happened to me.

68. My infection with HIV has definitely held me back in romantic relationships. It is not something one can casually introduce in conversation. How do you trust somebody with this information? I have also never been promiscuous as I was concerned not to put others at risk. Back in the day, I didn't have my knees done and didn't have the highest self-esteem. I didn't even know if a girl was looking at me. If they did, I wondered if they were talking to me out of sympathy.
69. I have not experienced stigma as a result of my infections but I am very self-protective so I haven't exposed myself to this possibility. I have only told close friends where necessary. I have friends who don't know about my infections or even that I have haemophilia. I often dress things up as osteoarthritis. I don't believe in introducing something into a conversation unless it serves a purpose.
70. Finding a partner in this life is hard enough. I experienced the additional pressure of having to reveal my deepest darkest secrets and hope that my partner would accept this, knowing that she would be putting herself at risk. I met my wife later in life. She had a one-year-old daughter as her partner had walked out on her. I have one stepdaughter who I am happy to say sees me as a father.
71. She said that if I really wanted a child, she would be willing to try. However, I wasn't prepared to go down that road in our forties nor for **GRO-B** to have a child just for my benefit. I suspected that this was what she might have been doing. If we had met 10 years earlier, we could have had a child. Now, they let you carry on as normal. I was forced to accept that this ship has sailed.
72. Whilst I am not a bitter person, what will always haunt and upset me is that my infections have robbed me of the ability to have a child of my own. I will get around it but I don't think that I will ever get over it. I seized the opportunity to speak today because I want on the record that this was taken away from me. Although I love my step-daughter to bits, my wife knows that I really wanted a biological child too.

73. My parents have been very supportive. My mother initially gave me my haemophilia and HIV treatment injections. She would try to slow me down and keep me calm. She took me to my appointments and saw my HIV as something we could manage. She was very calm and strong. When I was suffering with lipodystrophy and bronchiectasis, she was fantastic and supportive.

74. My relationship with my father has also been affected by my infections. My dad has been my rock, both when I was diagnosed with haemophilia and subsequently when I was diagnosed with HIV. He refused to send me to a special school for bleeding disorders. My relationship with my dad was very good but it has also been very official, which took away some of the emphasis on simply being father and son.

75. I can look after myself these days but at the time, I needed somebody to help me with decision-making surrounding treatments. He was very strong in the early days of haemophilia. When he found out I had HIV, he was positive and pragmatic. He was adamant that I not embark on treatment with AZT. He remained with this decision even in the face of scorn and dismay at the hospital. We definitely fell into disfavour with the hospital doctors as a result.

76. My dad thrives on being combative. That is why his disposition had an effect on our personal relationship. He gains strength in situations of conflict. Conversely, I inherit my mother's calmer side. Nevertheless, I know where I inherit my career aspirations. When he retired at 52, he was pretty much top of the ladder as chief executive for GRO-B and GRO-B. He now has a small shop GRO-B which affords him a very comfortable life.

77. I have a sister with whom I have not properly spoken since I was 24. This is due to various personal differences. After my diagnosis with HIV, I would have appreciated her support. We experienced conflict

when I was diagnosed as she was forthright about me sharing my diagnosis with others. I tried to explain that this was easy to say from the outside. I didn't feel that she was empathising with my position.

78. I have never applied for private life insurance as it is expensive.

Companies also require a letter every year stating your condition. I was questioned heavily when I first applied for travel insurance. I was shut down by a health administrator on a health insurance company. I was warned to be very upfront and to disclose all conditions before taking out a policy. Travel insurance is very simple and private these days. Haemophilia is also not considered a problem.

79. In order to feel comfortable, my wife and I have a one-year gold cover policy. I do not have a mortgage now though they were never a problem when needed as I've always been in employment. My father was of the opinion that life insurance wasn't necessary as I would be covered by his will. He didn't see the need to complicate my life any further. He was quite circumspect in this way; he suspected that even with approved life insurance, the company might find a way to avoid paying out.

Section 6. Treatment/Care/Support

80. GRO-D was a big player in the Haemophilia Society, which I never joined. Dr Richard Stevens was an expert in haemophilia at the time. My dad was very angry with them for the way in which they informed me of my infection. I was only 17 years old and very unwell when I was diagnosed. They only provided very limited information on the precautions to take to protect others. I was really just told to wear a condom and see a doctor should I have a bleed.

81. My father was disgusted by their poor decision-making and voiced his dismay to the staff. Nevertheless, he was never rude and always

remained polite and professional. His support and astute judgment have been invaluable. Dr Stevens was later found deceased in the mountains in Wales having had a hiking accident. It provoked stirring thoughts for my father who felt very much betrayed by his manner.

82. I have found various doctors at the MRI to have a questionable bedside manner. This was at a time when patients such as myself really needed some empathy. As mentioned previously, they were not happy when I refused AZT treatment. I was made to feel as if I was breaking the law and letting the HIV community down. Two friends of mine were also very public about how badly they were treated at MRI. One died shortly after suffering a brain haemorrhage. His brother voices his criticisms on television.

83. I was offered counselling at Manchester Royal Infirmary. This was undertaken by an ex-nurse named Meg. We used to bounce off each other. She was very positive and friendly but I found that I didn't need psychological support. Professor Hay knows that I am independent. I have never been a malingerer or one to dwell on problems. I work and pay my own way in this life.

84. Moreover, whilst she was a listening ear, I wasn't entirely satisfied with the treatment. I found her support lacking in matters of practicality. I think more support should be given in financial and administrative matters relating to my treatments and the trusts and schemes. When she left with serious illness, she was never replaced. Now if I need advice at MRI, there is no one who can provide this. I'm probably going to the wrong department and should consult Dr Sukthankar's department.

85. I've got through dilemmas of my own steam and my father's. Professor Hay and I had a laugh a few years ago. I advised him to employ a counsellor who had been through what I have. It never came to fruition. I would find this deeply fulfilling but wouldn't wish to compromise my

anonymity which is precious to me and of which I have been very protective over the years. However, maybe once I am retired and am less at risk of compromising my career, I will take on a role of this kind.

86. I have never been refused dental treatment as a result of my infections.

If I ever need a tooth extraction, I may have to attend the haemophilia department at the Hospital. I have been looked after by the dental department at the hospital free of charge since I was a child. The dental support at MRI began to diminish. I would still get seen but it was becoming more difficult. They didn't have the facilities to provide the treatment that I needed. I was then advised that I should be paying my way at an NHS dentist practise. I am now seen by a local dentist and have had no problems.

Section 7. Financial Assistance

87. I was involved in the HIV litigation, after which I was awarded £25k. I am not aware of any waivers. I then registered with McFarlane. It was a simple process involving the completion of a couple of forms. I received a lumpsum payment followed by regular payments thereafter. The scheme is now run by the government. The payments have recently been restructured to bring England, Ireland, Scotland and Wales into unity.

88. Skipton and MacFarlane became one and were subsumed within the government. I was nervous about that but it seems quite transparent. The communications I received from the schemes was very good. I have not faced any difficulties with either scheme. I was never requested to provide medical evidence as they would go directly to hospitals.

89. In July 2004, I was paid around £10,000 from the Skipton Fund as a result of my HCV. I received a later payment in 2017. It was a simple process involving filling in an online form. They did not want to

discriminate against those who were cured and those who continued to have cirrhosis level 2. I contacted Skipton to divulge that I had the virus but was now clear. They confirmed that I was still eligible.

90. I receive quarterly payments of £9,734 from EIBSS. This helped with paying off the mortgage. Some have asked why we weren't paid £5 million instead, given the grave and far-reaching consequences of being given contaminated blood. If my father was sat here, he would also argue that those in my situation should have been compensated to a far greater degree. I have many mixed feelings about the financial schemes.

91. I received an extra payment when my daughter was at university. She didn't know where it had come from but amounted to around £100 a month. This was good for her. I had to fill in a survey every year and to honestly declare when she was out of the education system. I have also been told that if I was to lose my job, there would be extra monthly money. If I was very low earner, I would also receive more support.

Section 8. Other Issues

92. I believe that the work of the Inquiry signifies a positive movement. I wonder what the Inquiry seeks to achieve? Is this to allocate responsibility? Or to offer security to those infected and affected that they will be looked after for the rest of their days? Of those who have survived this, there will be different views; some will be satisfied with the apportionment of blame and accountability. Others will continue to feel swindled of an ordinary life.

GRO-B

93. I am not here to be a detective. All I can say is that somebody made a momentous decision many years ago with repercussions that continue to this day. I cannot blame the staff at Pendlebury Hospital. My reservations towards them are isolated to their bedside manner such as how they disclosed my HIV status. However, I cannot reproach anyone at a local NHS level regarding the choice and delivery of treatment. On a larger scale, decisions were made that proved to be reprehensible. Patients like myself were using American treatments that transpired to be infected with HIV and HCV. I saw people die within just a few weeks of using them.

94. I have been through a lot over the years. I will never get over not being able to have a child. I didn't know discussing this would make me this upset. I get emotional because this is the first occasion that I have sat in front of anyone like this and talked as deeply - and as personally as I have, about what I have been through.

Statement of Truth

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

Signed

GRO-B

Dated

2nd MARCH 2022