

ANONYMOUS

Witness Name: GRO-B

Statement No: WITN5364001

Exhibits: WITN5364002

Dated: 14 April 2023

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 29 March 2021.

I, GRO-B will say as follows: -

Section 1. Introduction

1. My name is GRO-B. My date of birth is GRO-B 1976, I live in GRO-B, Hampshire and my full address is known to the Inquiry. I am single and I live alone. I used to GRO-B Treloar College, where I played GRO-B teacher and students. I also used to help in the GRO-B GRO-B tutor. I was previously a student at Treloar's school.
2. This statement relates to my severe haemophilia A and diagnosis with HIV, Hepatitis C ("HCV") and Hepatitis B ("HBV") due to treatment with infected blood products at Treloar's School and College. I intend to speak about my haemophilia, my infection with HIV, Hepatitis B and

ANONYMOUS

Hepatitis C, and the impact this had on me, my family and our lives together.

3. I confirm that I am not legally represented, and I am happy to give my statement to the Inquiry, but I wish to remain anonymous.
4. The Inquiry Investigator has explained to me the 'Right to Reply' procedure and I understand that if I am critical of a medical professional or organisation, they will have the right to reply to that criticism.

Section 2. How Infected

5. I was born with severe Haemophilia A which was diagnosed when I was two years old. I have a sister and I had an older brother called [GRO-B: B] [B] was born on [GRO-B] 1974 and was also a haemophiliac. Unfortunately, he passed away in 1999, a year after suffering from a stroke, which was likely to be related to his infection with HCV or HIV. Southampton Hospital never told [B] wife [GRO-B] what had caused the stroke. It is very unusual for a haemophiliac to suffer from a stroke, as far as I am aware without trauma [B] was lying in bed at the time as suffering a fit, and subsequent stroke.
6. My father was in the military, so we moved around a bit when I was a child. I was born in [GRO-B] in Northern Ireland, my sister was born in [GRO-B] Wiltshire, and my brother was born in Germany. I grew up in [GRO-B] Dorset near [GRO-B] for the most part until my brother and I went to Lord Mayor Treloar School Froyle near Alton when I was seven years old. I later attended Lord Mayor Treloar College.
7. My mum first suspected I had haemophilia due to her experience with [B] As a toddler, I used to have bleeds in my ankles and knees, which required overnight stays at the main hospital in [GRO-B] I was about five years old when it was realised that I had haemophilia.

8. We lived in Germany briefly before we moved to Dorset, where I went to kindergarten. My dad was in the Army at [GRO-B] and my brother went to [GRO-B] which was a disabled school facility nearby. When I was old enough, I joined my brother at [GRO-B] and went there until I was about seven years old.
9. [GRO-B] was a special needs school suggested by the local council at the time. It was a day school and felt like a stepping stone before Treloars.
10. When I was seven my brother began at Treloar School in Alton, Hampshire. That Easter, when I was about seven and half years old, I joined him there. I was allowed to start earlier than the beginning of the school year because I was so young, and they thought it would be best to help me get comfortable at the school. I was the youngest student to be admitted at the time. We were both full boarders due to the long distance from our home.
11. I liked going to school there for the most part, even though my brother used to pick on me. There were 60 haemophiliacs at the school, divided into Upper and Lower schools as it was called back then, and split into different houses by age group. I was in [GRO-B] House until I was ten years old, then I went to [GRO-B] House until the start of my GCSEs. By the time I was 16 there were other sites like the Evans and Gloucester sites at the school.
12. At Treloars it was easy to administer Factor VIII treatment for any bleeds we suffered. We did not have to spend long hours in hospitals which meant that we did not have to miss school. We had medical treatment available at all times, including night nurses. If we had any bleeds overnight, they could take us to the Upper school where the sick bay was and we would be back in school the next day in a wheelchair.

ANONYMOUS

13. I was behind in my reading when I first began at the school, but by the time I was 10, I was reading fast and had finished reading big books like the Lord of the Rings. I improved in other academic areas, so being at Treloar's was good for me from that perspective too.
14. We didn't think too much about having haemophilia. We were boys being boys. We played games like hide and seek and got up to mischief as children do. It was its own world like Narnia. It was also great for building friendships. It wasn't until we were older that we realised that maybe things were not as good as they could have been.
15. I was about 9 or 10 years old when I found out that I had contracted HIV. We were all taken into a room, five at a time. Dr Aronstam and Dr Wassef, along with some nurses, were present in the room, and they went around pointing to each boy in turn saying, "yes" or "no", and that was how we found out if we were infected or not. I am not sure how my parents were informed.
16. They provided us with support afterwards, but due to my age, I did not understand what the diagnosis meant or what was going on, but I know that my brother B was angry and upset about it.
17. Between the age of 14 and 16 I started feeling tired and ill. I was studying for my GCSEs and I would have to play Metallica to try and stay awake to study, but I would still sleep right through it.
18. I started receiving treatment for HIV at 18. I was prescribed Didanosine (DDI), one of the newer drugs, while B received Zidovudine (AZT). I used to have to dissolve the DDI overnight in a pint glass. It was not very nice and tasted like chalky refreshers. I know that I was very lucky that I never experienced side effects from my treatment at the time.

19. By this time, I understood what AIDS was, and it was awful. Many of the people we knew from Treloar's were dying from it. My best friend GRO-B passed away in 1999. B found AZT unhelpful and he suffered a stroke in 1998. He struggled for a year after that and passed away in 1999, just six months after my best friend GRO-B passing. B attended the funeral in a wheelchair, and I think GRO-B death had a detrimental effect on him.
20. Not long after my diagnosis with HIV, about two or three years later, I was informed that I had also contracted Hepatitis B ("HBV") and in 1991 I learned that I had contracted HCV, which I cleared naturally after having it for a few years.
21. Though Treloar's was good for us as children, my diagnoses have drastically changed my life. It has affected me physically and mentally, I have lost friends and family members, and it has impacted on many of my friendships and relationships.

Section 3. Other Infections

22. After I left Treloar's, I received a letter asking me to attend an appointment to be screened for vCJD. I think it was a blanket letter sent out to everyone. I may have been screened at GRO-B House, at Basingstoke General Hospital, although I cannot recall where precisely. However, I was never informed of the outcome of the screening.
23. I was diagnosed with HCV in 1991, but later found out I had cleared HCV naturally in 1998, perhaps because I was on HIV medication at the time, after having had HCV for several years. I was informed of my HCV diagnosis in person.
24. B was also diagnosed with HCV and HBV. He found out before me and warned me beforehand to know what to expect. Other than this, the

information I was provided was inadequate, and I was not offered any treatment.

Section 4. Consent

25. I was around ten years old when I was diagnosed with HIV. I do not know if my parents were informed beforehand or sent a letter afterwards. I guess my parents would have consented for us to be given Factor VIII for our haemophilia and any testing. I remember giving my parents a form seeking their consent for a change of Factor VIII product at one point, but it is difficult to know if they were always asked for consent. I guess that it would probably have to be ongoing consent since we were primarily boarding students.
26. We used to have regular blood tests as part of taking Factor VIII, but the number of tests increased after my diagnosis with HIV.
27. We were potentially experimented upon. I know there were whispers, especially among the older boys in upper school about that. There was no doubt that those higher up in government knew that the blood was contaminated and they had imported it from America, where prisoners, drug users, and anyone who could sell their blood were among the donors, with no screening.

Section 5. Impact

28. My parents sent us to Treloar's to make our life easier and so that we did not have to miss school because of frequent visits to the hospital. Before going to Treloar's, B and I were on cryoprecipitate for bleeds. Cryoprecipitate was stored in the freezer so every time we were suffering from a bleed we would have to go to the hospital, then wait a few hours for it to thaw before giving us the treatment in a drip.

29. At the school, we were given Factor VIII as a prophylactic treatment, so we used to take it every other day or so, to prevent us from getting bleeds. I still used to suffer from spontaneous bleeds, but they were not as frequent as before.
30. There was hardly ever a need for us to go to the hospital. We could go to the sick bay at the Upper School if we needed any treatments, unless it was severe and then we had a bus driver and nurses on call to take us to the hospital at the school's haemophilia centre at the Alton site.
31. B and I started as weekly boarders, going back home every weekend. However, we lived about 80 miles away so that reduced to a visit home after every three weeks, until eventually we were staying at school during the term time only returning home for the holidays such as half-terms, Easter, summer and Christmas breaks.
32. At first I was homesick, especially because I was so young. My sister also felt left out and hated that she could not join us there. I learned to inject myself from when I turned seven, so when we were at home during holidays, the school would send us home with plenty of Factor VIII to last through the period and we could self-administer the treatment. We never needed to go to a hospital.
33. I gained a lot of skills while at the school. They taught us sewing, needlepoint, textiles, music and photography. I learnt to type and I enjoyed photography and music. I was also good at science and I got decent grades without too much effort. Mostly, I was better at the practical side of things, but I did poorly at exams.
34. I was at Treloar's for a long time, up to my twenties. I moved out of the boarding school into sheltered accommodation at 18, but I was still attending Treloar's as a day student to retake my English and Maths GCSEs because I had missed a lot of school due to being ill.

ANONYMOUS

35. After I graduated, one of the tutors, GRO-B asked me to come back to help out with GRO-B at the college. I used to GRO-B GRO-B and I was happy to volunteer. I used to go in twice a week. I enjoyed GRO-B and it kept me busy. I also used to help out in the GRO-B GRO-B programme was cancelled about six years ago.
36. After graduating from Treloar's, I sent out hundreds of job applications, but I could not find work. Once they see you have a disability, they don't want to take you on. So I gave up on working in a traditional job after a while.
37. The stress of not finding a job was why I was happy to volunteer for a while in the GRO-B at Treloars. I enjoy GRO-B GRO-B with a few other haemophiliacs including GRO-B my best friend. This was when I was around 20 years old and volunteering at Treloar's.
38. Most of the medical staff at the school were nice. I still run into a couple of the nurses GRO-B and say hello to them now and then. Dr Wassef was good to us, he has passed away, but his wife still says hello to date. Nurse Yvonne was like a big mum to us and Nurse Jane Hurst was like a sister to us.
39. I was very young when I was first diagnosed with HCV so I did not understand the impact it would have on my life or my future. The main impact at that time was finding out on the grapevine that we had only three or five years to live. It became normal that people were dying all around me, but I thought that was a part of being a haemophiliac.
40. I remember being home during the holidays, I used to go around telling neighbourhood kids that I was haemophilia positive until B shouted

at me to stop doing that because he understood what the implication of the 'positive' meant.

41. It has had an impact on me maintaining relationships. I would usually tell people before things got too serious and they tend to run away. My longest relationship was with my ex-girlfriend of nine years, but we split up five years ago because she wanted children and did not think it was possible because of my HIV diagnosis.
42. I started dating another girl around three or four years ago. We had been seeing each other for about three months before she began to want to take things to the next level, but I was holding back. I live in a small town where everyone knows someone who knows someone.
43. She found out through her friend who knows another haemophiliac who I also knew, that I am a haemophiliac. She asked me over text whether I had HIV. She did not even give me the benefit of the doubt. She broke up with me and made a huge fuss, going around telling everyone that I had HIV and I could have infected her and her kids.
44. It caused a big stir, even after we stopped seeing each other. I started hanging out with my friend [GRO-B] whom I had known from back when I was in my long-term relationship. We used to drink together all the time. One day a girl came in and whispered in [GRO-B]'s ear, asking her if she knew that I had HIV. [GRO-B] did not make too much of a fuss about this and continued to be my friend after this incident.
45. One night after drinking too much, [GRO-B] and I slept together without using protection. We had both been very drunk, but a few days later, I woke up to banging on my front door from four police officers. They were alleging that I had raped [GRO-B]
46. They ransacked my house, went through the bins and stripped the bedsheets for evidence whilst I was on the way to the police station. They took me to Basingstoke police station and the female police officers

were pushing for me to be charged with Grievous Bodily Harm because of my HIV status.

47. **GRO-B** has bipolar disorder and had been going through a difficult time during this period. She later explained that her ex-boyfriend had pushed her into reporting it, but she did not want to take the matter further and refused to cooperate with the police. The police decided to drop the case due to lack of evidence and I eventually got my mobile phone back after three months.
48. I had to get legal representation because I am vulnerable and it was a challenging time for me. I had been drinking so much because my mother had recently passed away and it was around the same time, I lost my long-term girlfriend.
49. During this difficult period, I got a tattoo which the Haemophilia Centre were not happy about because of the risk of bleeding and bruising as a haemophilia sufferer. This was done professionally and I did not bleed much during the process.
50. **GRO-B** and I quit smoking and drinking because of this incident and we remain best friends. We encourage each other and text each other regularly. I only drink rarely now on birthdays and special occasions. Sometimes I have the alcohol-free drinks to feel like I'm drinking alcohol – placebo effect but without the annoying hangover. I also quit smoking and now I only vape.
51. While I was going through this legal process following the allegation, my doctors informed me that I could not have infected **GRO-B** because my viral loads for HIV and HBV were undetectable. My CD4 was also very good which corresponded to the fact that my viral loads were undetectable. They told me that I could have sex without protection and I could also have children safely without infecting anyone. This information would have been helpful to find out several years before

ANONYMOUS

when I was in my long-term relationship, as my girlfriend wanted children but no one told me.

52. After this episode with the police, I ended up telling a lot of the people in my life about my HIV infection. Some of them have known me for up to 20 years but they had no idea that I had HIV.
53. It was very tough to tell them but most of my good friends treated me the same after finding out. They had never believed I could have done anything to GRO-B, but I was surprised by how little my HIV diagnosis did not matter to the people who knew me. I still had to reassure a couple of my friends with children that my viral load was low and their kids could not be infected just from being around me.
54. I tend to have a positive attitude on life, but sometimes I am not in a good space. I was drinking heavily during those times, and it really affected my immune system.
55. I would probably have had a family by now if I had known it was possible much earlier. Dr GRO-D and Dr GRO-D, my doctors at the haemophilia centre, only informed me that I could have a family when I was going through the rape accusation process, and I was very annoyed and disappointed by that lack of information. They should have sent out letters to people, or at least told us, informing us that our counts are low and it was safe to have sex without protection and have children. Some friends tell me it is not too late to have children but now it is about finding the right person.
56. I don't think we were given any advice in regards to relationships or safety from Treloar's. They advised us to wear protection, which has impacted on me entering into relationships and telling people about my HIV status. In terms of general risk of transmission, we were told that even if you had bleeding gums the infection could be transmittable.

57. I think that may have also had something to do with rumours around the time and ensuring that people were not blurring the lines between relationships among staff members and students at Treloar's. There was a well-known case of a teacher who went to court after accusations of touching some students at Treloar's. On one occasion, when I was 17, I dropped off my television to one of the volunteer occupational therapists who was staying with another member of staff, and she was asked to leave because of that. I remember being called in by Dr Wassef to the haemophilia centre at Treloar's and asked if I had had sex with her which I had not. She was 20 or 21 at the time and not formally employed by the school, but it was frowned upon.
58. I have probably had about six significant relationships in my life but most men my age would have had a lot more without any consequences.
59. After all the things I have been through, I have learned to enjoy life and have travelled to see other parts of the world as a result. The view was that many of us would not make it to 18, but I am grateful to still be alive and I am in my mid-forties now. Back then when you see two out of three of your friends die, you learn to spend money quickly and appreciate life. I am more careful with my finances now.
60. Two weeks after my brother passed away in 1999, I travelled to Kos in Greece for a holiday with friends. I drank a lot during this period. On one of the final nights of the holiday I slipped on a wet floor and ended up with a spiral fracture in my femur which affected my knee. I had to wait a few days in a hospital in Greece but they flew me out on a private jet to have an operation at Basingstoke General Hospital. Luckily, I had travel insurance, so that covered all of the costs. The hotel argued that I had been drunk but the loud noise that neighbours had heard was due to my friends arguing next door.
61. I took a few cruises on the Princess Ruby and Royal Caribbean, which sailed across different islands of the Caribbean. I went to Goa in India

ANONYMOUS

and I enjoyed visiting Lapland. I've also been to Japan. I have never really had trouble obtaining travel insurance and I have always been upfront in declaring that I have HIV when completing the forms.

62. My parents split up when I was about nine or ten years old. My mum had always been our primary carer because our dad was away so frequently with the army. However, the change to our family dynamic following their breakup also impacted us. I started being a bit naughty for example, poking holes in walls with a cue stick at school and getting told off for those kinds of things. Later my mum had a difficult period with drinking. At that time, Treloar's was like another home and family for me.
63. It was difficult to know what the impact of having haemophilia and being infected with HIV, HCV and HBV had on my parents and sister because we spent most of our younger life at Treloar's. When we were home during the school holidays things were fine. My parents may have been trying to shelter us, but I know they were heartbroken when my brother passed away.
64. I have always been a bit more laid back, but my brother [B] was always angry up until he died. [B] used to vent to me all the time when we were younger. His mood gradually worsened in the last three or four years of his life and I could tell that this was the impact of the medication or the infections on him. I used to watch how angry [B] would get and I was determined never to be like that.
65. Despite that, [B] had some good things in his life. He married his childhood sweetheart [GRO-B] whom he had met at Treloar's. She had attended the school because she had juvenile arthritis.
66. They got married not long after [B] turned 18 when they had both left Treloar's. [B] diagnosis probably had an impact on their relationship. I later found out that they wanted to have children and had even considered the sperm washing procedure. They split up briefly, but they were back together by the time [B] passed away.

67. [B] was around 23 years old at the time of his stroke. It was odd for a haemophiliac to suffer from a stroke as mentioned earlier so I have always attributed his stroke as being related to [B] HIV and HCV diagnosis. After his stroke, which occurred around the summertime, he started to pick up around Christmas. However, he never recovered from that and spent the last few months of his life in palliative care in a hospice in [GRO-B]
68. My dad and [B] had not always had a good relationship, but my dad turned up the night before [B] died, to see him. At first, [B] did not want to see him, but he did, and they had a heart to heart. Not long after this, [B] passed away. The next day I received a call from his carer telling I asked what had happened and she told me that [B] had passed away that morning. I saw little point in rushing down at this point. We held [B] funeral on [GRO-B] 1999.
69. We did not make many friends where we lived when we were younger because we were not living at home. When we moved to [GRO-B] we used to spend the summer with one of my mum's friend's sons. For the most part though my siblings and I were close. My brother and I used to play PC games together and hang out as we grew older. So it was very hard for me when he passed away.
70. I don't think we faced any stigma growing up in [GRO-B] since we were only around there during the holidays. Some neighbours may have had some suspicion, but we were kept sheltered away from it, and while we were at Treloar's the school was like bubble wrap away from the real world.
71. [GRO-B] is a fairly small community, so gossip around here is terrible. When I had that situation with my friend [GRO-B] a few years ago, I knew that I had to tell people and set the record straight to avoid further gossip, but most people were kind.

72. I go to a regular dentist which is part of the NHS, and I have been using the same dentist for a few years now with no issues. When I changed dentists, I had to declare my HIV to them and state which tablets I am on and they were okay with that. There were times in the past when I felt like my appointment was pushed to just before lunchtime or late in the evening, but nowadays my appointments can happen anytime. My previous dentist was also aware and they never treated me any differently.
73. I have faced some stigma when it comes to travelling because I have to declare my HIV status. As a result, I usually have to pay extra for travel insurance but that has never stopped me from travelling. The last time I travelled out of the country was about four or five years ago and my insurance fee seemed normal, probably due to better societal awareness. I think that I may pay a slightly higher premium because of the medication which I have to carry and the fact that I have haemophilia.
74. Getting through airport security has been an issue in the past. I have to take my medication with me because I tended to need to take at least one dose of Factor VIII on the plane. Recent security clampdowns also makes carrying needles a problem. However, my Factor VIII has recently changed and it is much easier to administer and less frequent. My haemophilia team have advised me that I should continue to take my older medication with me on holiday in the event of a serious emergency.
75. One time when I was on a cruise when we stopped over at Cozumel, which is a dual nationality island between Mexico and the US, I was held up for a while for questioning by immigration officials. This was regarding my passport having a previous American visa stating HIV and there was a discrepancy, as the requirement to declare HIV had later been waived. My doctors have since told me to tick negative on these forms were I ever to return.

ANONYMOUS

76. I have been held by American Immigration security on two occasions which was also because of my HIV status. The first time they held me up for about an hour and my girlfriend had to wait for me on the other side of security. The second time it happened was when I was on holiday with a couple of friends who had been unaware of my diagnosis because they had only known me for about three years or so. I ended up having to tell them, but they were fine about it.
77. I have lived in the same council house for years, so I have never had to apply for a mortgage. I have lived in my current flat for so long so now I would like to buy it or buy a house. I would like something that is less financially burdensome in terms of my council tax and my benefits.
78. There have been times where I have struggled with my finances and not having any money. I am disabled and I get disability benefits of £80/90 weekly, paid every other week. I also have a mobility car.
79. My ex-girlfriend used to live in GRO-B so I moved down there to live with her. It is about 10 miles away from GRO- but I regularly drove down to see my friends and family in GRO-B. As a result, I ended up racking up around 60,000 miles on my mobility car in three years and was penalised for this.
80. The first 3000 miles was charged at 3 pence per mile. Then every 15 - 20 miles after that, was charged at 7 pence per mile. I had to pay an £800 penalty charge for being over my mileage at the end of the three years. However, the mileage allowance on my mobility car has been increased dramatically to around 20,000 miles a year, so very rarely will you reach the limit now.
81. I change my mobility car every three years. Previously, the process before was a hassle. I had to attend an interview in Portsmouth and fill out a form saying that my circumstances remained the same. The interviewer was really good, so that was fine.

82. Around the Christmas period about three years ago, I was going through the difficult time regarding the false allegation, so I forgot to fill out one of the forms and send it back on time. They told me that because the form was late, they would have to cancel my mobility car. I tried to phone them to rectify the issue, but the representative I spoke to on the phone hung up on me because I had given them my age incorrectly, even though I had said the correct date of birth.
83. I contacted them again and a different representative was helpful to me. She told me that I would have to wait until the following September, which was nine months away, until they could cover the cost of the new car. I spent six months waiting, not knowing what would happen and if they were going to come and take my car away.
84. It took two weeks to sort out the form issue just because I had missed the deadline by a couple of weeks, and this was after I had been going through a difficult and quite stressful situation. It was a very heavy-handed bureaucratic process.
85. I have made lifelong friends from Treloar's, and I am still in touch with one of my closest friends from the school. We were given a flat together for a year and we bonded from there. He lives in Bristol now, but we still meet up whenever he comes down to visit family in the area. I had not seen him for a couple of years because of Covid but I recently saw him.
86. Mine and my brother's diagnosis obviously affected my family in many ways. My dad, sister and brother-in-law, nieces and nephews are the only relatives I have alive now. My sister lives in GRO-B and my dad lives near her so I don't see them too often. I know that it affected my dad emotionally and my sister is always saying she wants me to live closer.

87. I don't think my sister is a carrier of the haemophilia gene because she has had three children, and none of my nephews have haemophilia.
88. I can imagine that there are families who have lost two or three brothers from Treloar's. I don't understand why anything wasn't done sooner if they had known or why it was allowed to happen in the first place.
89. Since my diagnosis with HIV I have to take tablets everyday which can sometimes be an issue. I have to take roughly three tablets a day; Nevirapine is my current HIV medication but it causes me stomach trouble so I have to take omeprazole to counteract that side effect. I also take iron tablets because I am anaemic. I don't go out much these days because I still get very tired. As mentioned, my Factor VIII medication has recently changed for the better and it is no longer administered intravenously.

Section 6. Treatment/Care/Support

90. As I mentioned, the school provided us with some support at the time of our diagnosis, but I was too young to understand the situation at the time.
91. We had social workers at the school, and when I turned 18 years of age, one of them helped me get my first flat and supported my move to GRO-B
92. I have never had any counselling or psychological support as an adult, although the Haemophilia centre has offered it in recent years.
93. At one point, I was taking Advate, which is a blood product for my haemophilia, and the haemophilia centre tried to change it to a different brand because it was cheaper. This caused me to take up to three times more Factor VIII than I would normally take because I was bleeding straight through it and getting bruises. It took a year or so before they

decided that it was not working and changed it back to the Advate. I know that it was definitely due to budgetary concerns.

94. I had HCV for several years so I was told to avoid alcohol. I had to get an ultrasound twice a year to check my liver but that was cut down to once a year after I cleared the HCV. However, previously I was not given the results or informed about the condition of my liver. Recently in September I attended a joint clinic at the haemophilia centre and I was given the results of my ultrasound and my hepatitis specialist told me she was happy with the condition of my liver. Additionally, they looked at my HIV and HBV treatment after Christmas when the tablets I was on were due to run out.
95. Presently, I am on Hemlibra, and I take medicine which acts as a prophylactic to prevent me from having bleeding episodes. Every two weeks, I inject it into my side rather than my veins like a person with diabetes. I am still classified as a severe haemophiliac but, my Factor VIII levels drop off slower than other severe haemophiliacs which afforded me the opportunity to be prescribed the new medicine. I understand this particular medication is still on trial in some areas and is not widely available.

Section 7. Financial Assistance

96. I was informed about the Macfarlane Trust by my brother B when I was still at Treloar's. I think he found out about the Trust through the Haemophilia Society.
97. I don't recall having any difficulties in applying. I think one of the nurses, Jane Hurst assisted a few of us with filling out the forms.
98. I received £23,000 from the Trust, but I was 16 or 17 years old at the time, so it was paid out to my mum. She said she would put it in a high-

ANONYMOUS

interest account for me until I turned 21, but I never received it in the end. I think my dad may have borrowed some money from it. I know that when I turned 21, I asked about it, but there was no money there for me.

99. Initially, my finances were limited. We were receiving £500 to £1000 a month back then, which did not go very far. However, the Macfarlane Trust allowed us to apply for extra money for things like Christmas and we also got a winter bonus to pay for fuel and heating.
100. I don't recall how I found out about the Skipton Fund, but I know I applied for stage one payment, but the Fund rejected my application on 25 January 2005 on the basis that I had cleared HCV naturally. This was despite a letter from one of my doctors at the time, Dr Mainwaring, challenging their decision and confirming that I had had HCV for several years before I cleared it. I provide this letter from Dr Mainwaring as exhibit **WITN5364002**.
101. My application to the Skipton Fund was eventually approved on 23 June 2011.
102. I did not apply for a stage two payment because, as far as I was aware, the condition of my liver did not qualify for it.
103. I was probably the angriest I have ever been about my diagnoses when I got that rejection from the Skipton Fund, especially because [B] had received his with ease, and I could not understand why I had not qualified for it.
104. I had an overdraft which I frequently used when I was younger to get by when the funds were so low and I didn't have enough money. I also had a credit card which I used frequently and part of the money I received from the Skipton Fund went towards paying it off.
105. The England Infected Blood Support Scheme (EIBSS) now handles all my payments which I receive monthly.

ANONYMOUS

106. I was receiving £1,800 a month up until four years ago when it doubled, possibly due to the Penrose Inquiry kicking off. I think I may have sent some documents and information off to the Penrose Inquiry but I wasn't directly involved.
107. Earlier last year I received two separate lump sum payments from the EIBSS which I was informed about over the phone on both occasions, which came out of the blue.
108. I got some money from a class-action lawsuit in the US against a drug pharma company based there. This was about six to ten years ago and before the Penrose Inquiry was set in motion. A few haemophiliacs in the UK were advised to join the lawsuit because nothing seemed to be happening in terms of financial assistance here in the UK. We had assistance from a liaison person at the haemophilia society. I had to obtain my records from archives to send copies over to the United States. I think the lawsuit went on for three or four years before it was settled, and I received £40,000 afterwards.
109. When the money arrived in the UK, I felt like I was forced to spend it because we were advised that any savings over £6,000 would affect my DWP benefits. I spent part of it on my 'Motability' car.

Section 8. Other Issues

110. I have seen my medical records when I requested them back in 2008, for the civil suit in the United States. Everything seemed fine with the documents as far as I am aware.
111. We have been waiting a long time for the government to admit what they have done. It is now left for them to take responsibility for what they have done to many families. I don't know if they can or how they will fund it, but the people infected in Scotland have had some big pay outs while we are

ANONYMOUS

the last to get any recognition that the government has done something wrong.

112. It is past time to deal with this. I felt for a long time that they were waiting for all of us to die so they could sweep it under the rug again. They have already had one inquiry and swept that under the table.

113. I think some of the haemophilia doctors higher up were willing to let us be guinea pigs and experimented upon. They were probably unsure about the safety of the Factor VIII and were happy to test it on us. I have heard a lot of talk from the older generation of haemophiliacs, those around a decade older than me who said that those in charge knew the blood was contaminated and should not have given it to us. They would have happily remained on Cryoprecipitate.

114. I am fine with my experience in giving my statement. Treloar's has received a lot of flak and has a bit of a bad reputation because of what happened, but I don't believe that it is their fault. It is the government and those higher up who knew.

115. I should have received a letter containing specific shielding instructions and advice regarding Covid 19, because I am obviously vulnerable but I received nothing. However, I received my vaccinations earlier than most people in my age group in this area.

Statement of Truth

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

Signed

GRO-B

Dated 14/4/23