

ANONYMOUS

Witness Name: **GRO-B**

Statement No: WITN1297001

Exhibits: WITN1297002 -012

Dated:

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF **GRO-B**

I, **GRO-B** will say as follows:-

Section 1. Introduction

1. I am **GRO-B**, of **GRO-B** West Midlands, **GRO-B** My date of birth is **GRO-B** 1974. I live at the above address with my partner and my 7-year old son, **GRO-B**

Section 2. How infected

2. I have Haemophilia A. The severity of my original condition was classed as mild. I was diagnosed with this in December 1975.
3. As treatment for my Haemophilia, I was given cryoprecipitate between 1977 – 1980. However, my treatment was changed to Factor VIII in 1980 and I was first given Factor VIII concentrate on 24th October 1980, which was a product manufactured by Armour. A chronology of products I received, which are detailed in my medical records, is annexed to this witness statement.

ANONYMOUS

4. As a child, I received my haemophilia care from the Birmingham Children's Hospital. When I was 19, my care transferred to the Queen Elizabeth Hospital in Birmingham. At the children's Hospital my treatment was overseen by a Mr Hill, Consultant Haematologist. I was also treated by a nurse. Sister Marion was in charge of administering the blood products. I did not attend the hospital very often for treatment, perhaps once or twice a year. I attended the centre mostly for internal bleeding and also for some minor external cuts/injuries.
5. On the 27th January 1986, I attended the hospital with a sore knee. I did not have a bleed, but I received Factor VIII. I was given a batch of Armour heat-treated products, batch number Y83006C, "batch J". This was part of a batch of heat-treated Armour products that was supposed to have been withdrawn following evidence of contamination. However, the batch I received was not returned to Armour by the blood laboratory technician and was given to me.
6. The Lindsay report established that I was given "batch J" in January 1986 and that somebody else was given "batch A" in February 1986. The report established that the same blood was used to make the blood product for both "J" and "A" batches. It is from this batch "J" that I was thought to have acquired HIV. I exhibit a relevant extract from the Lindsay report at **WITN1297002**.
7. As I only had mild haemophilia, my parents were told that I would only be given British blood products, but this didn't happen and I was given American products for some reason.
8. When I was a child it felt like I was at the hospital all the time and receiving treatment due to my haemophilia, but from my records, it looks like I attended my centre 2 or 3 times a year. I'm not sure if this is because my records are incomplete.
9. My parents have told me that they were not given any information before I received Factor VIII about any risks of being exposed to infection from blood

ANONYMOUS

products. My parents should have been made aware of the risks of infection from the blood products before I was given them. I believe that the doctors should have assessed whether the risks justified the treatment for my minor injuries.

10. Further to this, my parents were not consulted about my treatment being changed from cryoprecipitate to Factor VIII. They were just informed that I was allergic to cryoprecipitate and was being moved to something else. I understand that this was a reason given for many people being moved to Factor VIII. I believe they wanted to move everybody over to Factor VIII.
11. After a while, we saw stories on the news linking HIV to blood products given to haemophiliacs. Naturally, we were concerned and asked at the Haemophilia Centre if there would be any problems for me. We were told not to worry and that everything was okay.
12. As a result of being given blood products, I was infected with a combination of HIV, Hepatitis C and B.
13. In around 1985, when I was about 11, my parents were informed by letter that I had contracted Hepatitis B. The letter was brief, just a couple of paragraphs and didn't contain much in the way of advice on how to manage the infection. It advised them that care needed to be taken within the family in that we shouldn't do things such as sharing toothbrushes. My parents were not called in for a meeting about my Hepatitis B infection as far as I know. I don't believe it was classed as anything serious.
14. A letter to my Haematology department from a **GRO-D** Senior Registrar in Haematology confirming my Hepatitis B diagnosis is annexed at exhibit **WITN11297003**.
15. I also discovered from my medical records that the Hospital wrote to the local Health Authority, who could have told my school. My parents were not aware of this.

ANONYMOUS

16. I never had my Hepatitis B infection discussed with me by any doctor.
17. When I was in the second year of infant school, I suffered from my first dose of ill health at around the age of 6 or 7. My mum told me that I had jaundice and was off school for around 6 weeks. It is believed that this is when the Hepatitis C virus took residence in my body. There is an entry on the Haemophilia database which records me as being jaundiced due to Hepatitis C on 15.11.1980, which ties up with my period of ill health then. I annex this exhibit at **WITN1297004**. I also annex at **WITN11297005** an extract from my hospital records which relates to this and refers to my jaundice being of the non A non B variety.
18. I don't think my parents were told that I had Hepatitis C. For years I thought Hepatitis B was my first infection, but when I saw my haemophilia database records I discovered that the Hepatitis C came first.
19. In around 1995, at a routine clinic appointment, I was told that I had tested PCR positive and that I had Hepatitis C. I would have been about 21 and had just moved over to the Queen Elizabeth Hospital.
20. I was told not to worry about the Hepatitis C diagnosis and that it wouldn't be a problem. I felt that the doctor glossed over it. Maybe, because I had the HIV side of things to deal with, they didn't want to add to my stress.
21. I believe I must have had chronic Hepatitis C for around 20 years, because when the Hepatitis C test came out, I was PCR positive and then when I was retested 6 months later, the virus had cleared. I must have had it much longer than 6 months.
22. Fortunately, over time as the Hepatitis C virus has cleared I didn't require treatment. I believe I cleared the virus in around 1995. I still attend the clinic every year for a test to ensure I am not PCR positive, as there is a risk that the Hepatitis C could return.

ANONYMOUS

23. In April 1986, I was given a blood test for HIV, without my parent's knowledge or consent.
24. I annex at exhibit **WITN1297006** the first HIV positive test result in my medical records. I also annex at exhibit **WITN1297007** a letter from my Consultant Haematologist Dr Hill to Dr **GRO-D** dated 26.09.86 referring to my HIV test results and the fact that my parents had not yet been informed.
25. I annex at **WITN1297008** a letter from Dr Hill, Consultant Haematologist to a Dr **GRO-D** at the Central Public Health Laboratory dated 3rd October 1986 detailing the history of my treatment and HIV infection.
26. In September/October 1986 my parents were called to a meeting at the children's Hospital with other parents whose children had been infected. They were informed at the same time that their children had been infected with HIV.
27. At the meeting, I understand my parents were informed to be careful with open wounds and when dressing wounds, and not to share the same toothbrush or suck the same sweets as me.
28. On 2nd December 1988 my parents attended the Birmingham Children's hospital again to discuss with Dr Hill how to inform me of my infection. I annex at **WITN1297009** a letter to my GP detailing this meeting dated 21.12.88.
29. On 30th December 1988, when I was 14 years old, I attended the hospital with my parents, where I was informed by Dr Hill of my HIV status.
30. When I was called to the meeting with Dr Hill, I suspected what was going on as it was all over the news, the link between HIV and haemophiliacs. At that time, HIV was seen as a big killer.
31. Dr Hill informed me that I was HIV positive and asked if I knew what this meant. I said that I did. Dr Hill did not provide me with any further information about HIV, he just said that I had HIV and would have it for the rest of my life.

ANONYMOUS

He told me that I would never be able to have sex or have a girlfriend. The emphasis was placed on my responsibility not to infect other people and there wasn't any acknowledgment that I had been infected due to products given to me by the NHS.

32. It was explained that I could only give HIV to someone else via intercourse and that there were drugs available to treat those who become unwell and that I had a 3% chance of becoming unwell in any year. I was told that I could return to the clinic if I wished to talk further.
33. When we left the appointment, my parents asked me if I wanted to talk about it, but I just said that I wanted to forget about it and not talk about it.
34. I was subsequently seen again on 13th January 1989, 21st April 1989 and 23rd October 1989, to discuss my HIV infection.
35. I annex at exhibit **WITN12970010** a letter from Dr Hill to my GP detailing some of the history of these meetings.
36. I was not offered any counselling, nor was the delivery softened in any way. I was not provided with any information on how to understand or manage the infection. I felt that the whole process was very clinical and harsh.
37. Following this, in every appointment I had at the hospital, I was asked about whether I had a girlfriend. I didn't tell Dr Hill about any of my girlfriends. I got fed up with being asked about my personal life and I didn't want to attend the appointments any more. I also didn't want my Mum to come in to the appointments with me, as I was embarrassed about what I was being asked.
38. Dr Hill also regularly checked how my body was developing during puberty, by examining my genitals and pubic hair. This was extremely difficult and unpleasant for me as a teenage boy.
39. I annex at **WITN1297011** a record of the Factor VIII I was given from my hospital records.

ANONYMOUS

Section 3. Other infections

40. In addition to HIV, HBV and HCV, I believe that I have contracted a number of other infections.
41. I have reason to believe that I have been infected with vCJD. I have friends that have passed away who have tested positive for vCJD following their deaths. In January 2004 I received a letter stating that I was not at risk of vCJD, as the implicated batch that I had received was no longer considered 'at risk'. However, my Haemophilia database record still shows me as being at risk, which is something I need to follow up with my centre. I annex at exhibit **WITN1297012** letter I have received about me being at risk of being infected with vCJD.

Section 4. Consent

42. I was tested without my or my parents' knowledge or consent. Routine blood tests were carried out on those receiving blood products and we were not informed what they were for or what the results were.

Section 5. Impact

43. Being infected with HIV has had a significant impact on my physical health. I have always struggled to maintain weight, which started when I was about 11. This was exacerbated by my loss of appetite. I just didn't feel hungry and I wasn't on medication at the time. In particular, this would show as fat loss on my face. This made me paranoid and I was very concerned that people would be able to tell that I had HIV, as it was a sign. If anyone looked at me, I would be worried that they would notice changes in me.
44. I have also struggled with muscle building. I lack energy and get really bad lethargy. The infections give rise to pretty similar symptoms and make me feel dreadful.

ANONYMOUS

45. When I first became infected, I regularly suffered with oral thrush and fungal infections, particularly under my arms and in my groin.
46. I am more susceptible to infections due to my weakened immune system caused by the HIV. In 2012, I got an infection in my face. In 2015, I had a toothache, which developed in to an infection and required me to be hospitalised for a week. I also developed pneumonia in 2017. If I get a cold, I have to get antibiotics immediately, so it doesn't turn into something else.
47. I am sick of taking medication and feeling really unwell. I am fed up of having to attend hospitals. I have a lot of pent up anger regarding what has happened to me. I feel as though everyone else is moving on with their lives and I am being held back by my infections. As a result of this, I am quite aggressive and argumentative. Having dealt with these issues from such a young age, I find this has had an impact on my personality.
48. I try not to think about my future a lot. I try to maintain a positive outlook on life and I believe it is better to be grateful that I am still here, rather than thinking about when I am not going to be here anymore. I believe that this positivity is what keeps me alive. I can sometimes not think about my infections for weeks, then there will be something on TV which reminds me.
49. If anyone asked me how my life has been I would say it has been miserable.
50. As a result of my infections I have suffered from other medical complications. In particular I have suffered from jaundice on a number of occasions and my spleen has become enlarged.
51. My liver results and renal function are erratic, even though my infections are now under control. My base line is what you would expect from an alcoholic. This poses a huge risk of complications, such as liver cancer, if they rise any further.
52. Further to this, I have had to have both of my knees replaced, due to the bones and cartilage crumbling. This caused me a great deal of pain and I was

ANONYMOUS

unable to walk far prior to my replacements in February 2015 and March 2016. It has been suggested by my rheumatologist that this was due to me having viral infections in my body for prolonged periods of time.

53. I take medication daily to control my Hepatitis B in conjunction with my HIV medication. As some anti-virals can make Hepatitis B worse, my HIV medication is tailored to ensure this does not happen. I began this treatment in 2005, when it first became available to me.
54. There was no adequate treatment for HIV for 10 years after I was informed of my infection. I started taking AZT to start with, when I was about 15 in 1989. I wasn't taking this medication properly and was very blasé about it. The AZT caused bad side effects of diarrhoea, sweats and lethargy. As a result of the AZT, I have osteoporosis and this puts me at high risks of heart and kidney disease.
55. In 1997, I started taking anti-viral medication. As I have haemophilia, this complicated my treatment and I didn't respond well to some of the medication I was given. I must have been given 5 to 6 different types of medication over a period of a few months. In addition to this, new medication was constantly being introduced and the community nurse would give us new drugs to try. I was given different medication until I found one that my body would tolerate.
56. The anti-viral medication caused me to have a range of side-effects, including blood in my urine due to my kidneys bleeding, and a bad rash on my face and body.
57. Some of the early medication I was given have caused ongoing side effects that still affect me today, such as the drastic fat loss on my face that I have still not been able to put back on.
58. Even though the medication caused terrible side-effects, I would continue with any advice they gave me, as I was told that these were drugs that could save my life.

ANONYMOUS

59. In 2005, I was informed that my HIV was no longer detectable. I was considered at zero risk of transmission a couple of years ago.
60. I have had low neutrophils since June 1987 and low platelets since March 1980. The low platelets are considered to be due to my HIV infection and were the reason I started AZT treatment on 17th November 1989. Following my treatment with AZT my platelets improved, but I suffered from the side effects as a result of the treatment.
61. I had difficulties accessing medication when I was younger, as a Dr [GRO-D] Consultant Haematologist continued to look after those of us who had been infected as children, even though he was not a GUM doctor. Dr [GRO-D] was able to access some medication and he received advice from other doctors in the field. However, after trying all of the medication that he was able to access, I ran out of options. There was other medication that was available to GUM doctors, that Dr [GRO-D] was unable to access.
62. My health started to decline a few times and I recall reading in my records that my HIV had progressed to full-blown AIDS.
63. In May 2004 I was hospitalised due to my ill health. The doctors believed that I had Tuberculosis. I was severely unwell for two and a half years, 6-months of which were spent in bed. I was advised to stay in hospital but I refused as I was sick of hospitals, and in any event I needed to be at home to care for my dog. Cultures were taken and I underwent a test for Tuberculosis, but the doctors didn't even monitor the cultures. Initially I took a 6 month course of antibiotic treatment for Tuberculosis. I went through 18 months of hell, when I could have been better treated if my cultures had been properly monitored.
64. Finally a Professor Ross, the head of the GU clinic came to see me and told me that there was a new injectable drug that I could trial called T20. I tried this and it saved my life. T20 was an entry inhibitor which I injected into my stomach. It caused terrible side effects of painful lumps around the injection

ANONYMOUS

sites, which were worse for me as I'm a haemophiliac. However, I used this twice a day for 18-months. After this period, my HIV was undetectable.

65. For me, fear of people finding out about my HIV has been one of the worst aspects of my infections. Even my best friend of 38 years does not know about my HIV.
66. My wider family also do not know about my infections. Telling people has always been on a need to know basis.
67. Due to my HIV status I find it very difficult to open up to people and I do not trust any partners with this information, unless I believe they are 'the one'.
68. I have always been careful and used protection. This has restricted the amount of girlfriends and serious relationships I have had.
69. I have often felt like I live an unfortunate life. This has been exacerbated by personal circumstances that have occurred.
70. In 2001, I was 26 years old and in a serious relationship with my partner at the time **GRO-B: P** whom I had told about my infections. Once we had been together for 5 years, we sought advice and began trying for a baby.
71. I had also started to set up a courier and haulage business and we had bought a house together. **GRO-B**
P **GRO-B** died very suddenly. I was absolutely devastated by this.
72. My life started to spiral out of control. I became very depressed. I took **GRO-C** **GRO-C** drank to excess to keep myself distracted. I worked excessively, which resulted in me earning a substantial income. This downward spiral lasted for about a year.

ANONYMOUS

73. After **P** died, I was single for a long time. I tried casual dating, but I didn't want to be with anyone. I met someone I liked in around 2004, but I got ill and it fizzled out. I didn't know her well enough to tell her about my infections. I still see her around now.
74. I have been with my partner, **GRO-B** for around 9 years. I told her about my infections a few months into our relationship and she was fine with it. As I have been clear of infection since 2005, there is zero risk of transmission.
75. The stigma associated with HIV has always been a concern for me. I had heard frightening stories of people having their houses burnt down and suffering other abuse, due to their HIV status. I was therefore always very concerned that people would discover my status. This made me increasingly paranoid. Keeping my infection a secret was the most important thing to me, which was very stressful.
76. I do not even tend to tell people that I have haemophilia, because of the connection to HIV.
77. I have become very good at hiding things and I feel as though I have been living a double-life. All medical letters and medication are hidden in my house. I have become an expert at hiding things, as I cannot risk leaving something lying around. I always have to be on guard and monitor what I say and where I leave things in my house.
78. In terms of stigma for my family, they kept my infections quiet like I did, to avoid any trouble. It was just not spoken about. My mum didn't even tell her own Mum. The only people who knew in my family were my parents and my brother and it has stayed like that now.
79. I loved school and really enjoyed attending. I had a good group of friends and enjoyed the camaraderie.

ANONYMOUS

80. However, due to my infections, my schooling proved futile and I didn't even consider college or University as an option, as I didn't think I would be around long enough to complete a course.
81. I thought that exams were a waste of time as I would not be around for very long. I attended a few of my "O" level exams, but did not turn up for many of them. My parents received a letter about my exam truancy. They didn't mind, given the circumstances. I got a B, 3 C's and 2 F's in my "O" levels. I didn't bother with maths.
82. When I had career's counselling, I deliberately said that I wanted to be a lorry driver, as you couldn't do it until you were 21 and I said I was going to do nothing until then. I thought it was all a big joke and I didn't care.
83. I have always been mad about cars and I just wanted to get to 17 and pass my driving test. I took a week long intensive driving course and I passed my test first time around.
84. Throughout my life I have enjoyed manual work. I initially worked as a mechanic on a Youth Training Scheme for several months in 1991. I then worked for a builder's merchants driving a van and moving slabs from 1994 – 1998. I had to sneak off every few weeks to go to the hospital. The job used to wear me out, but I think I was quite fit considering my condition.
85. Following this, I obtained my HGV licence and worked as a driver for a courier service for several years, where I earned around £800/a week.
86. I bought a house in **GRO-B** which I moved into in mid 1995, which needed renovating. I therefore stopped work to do this. I worked for **GRO-B** on and off as a lorry driver. He suggested to me that I buy my own lorry and become a self employed contractor, which I was looking into when **P** died.
87. Around a year after **P** died, I set up business as a haulage contractor with a business partner. We had a few lorries and did motorway maintenance and site clearing, such as clearing soil from housing estates.

ANONYMOUS

88. I enjoyed being self-employed and the work was very lucrative. However, when I became ill in 2004 with TB, we shut down the business quickly. I was scared of my business partner asking questions and noticing that I wasn't well.
89. The whole thing about living with the infections is the constant need to make excuses for when you are ill.
90. At this point in my life I got in to a lot of debt and was unable to access benefits. There was a delay with my benefits due to the DWP wanting to see paperwork in relation to my business. My financial circumstances were dire. I had gone from having a lot of money to nothing at all.
91. When I finally received benefits they were 14 months late and I received back pay of around £9,000.
92. By the time I got better, things were dire financially. I owed about £60,000 on my overdraft, credit cards and loans.
93. When the financial crash happened, the bank pulled the plug on me and I had to enter an IVA (Individual Voluntary Arrangement), which I got out of in 2016. On one hand, this was stressful, but on the other hand, I didn't really care.
94. However, I was still in debt and had no choice but to return to work when my health improved.
95. I worked for a few years from around 2007. I returned to GRO-B to undertake general distance courier work. Whilst working, I found it difficult to collect medication and I often missed appointments due to being unable to tell anyone at work where I was going and why I had a bag of medication.
96. Eventually due to my ill health and treatment, I was unable to continue working. At one point, I had 30-40 hospital appointments a year, something which would have caused significant difficulty if I were employed.
97. My treatment causes me to become fatigued and I wouldn't be able to manage work now with my fatigue.

ANONYMOUS

98. Since stopping work, I have survived on benefits (Employment Support Allowance, Personal Independence payments and Disability Living Allowance, which I have had since I was 17). My partner is a teaching assistant and is on a relatively low salary. Until recently, we have always just had enough money to live on.
99. My infections have had a significant impact on my loved ones.
100. I have had to stay in hospital due to ill health 3 times over the last 5 years for various reasons. This is very stressful for my partner and she worries as she does not know what is going to happen next. For the 9 month period that she was pregnant with our son, I was very nervous that something would be wrong with her or the baby. Fortunately, neither of them have become infected.
101. I never thought I would have a child, especially after P was killed. Having a child makes my infections even more of a concern, but I cannot control them, I just have to try and stay well.
102. Although we do not really discuss it within our family, I know my parents must have struggled and been very upset at my diagnoses. My mum used to take me to the hospital for my appointments and now that I am a parent, I can understand that this must have caused them a lot of hurt and upset. I believe that the only reason my parents were able to continue being so strong, is due to me wanting to get on with life and not talk about it.
103. My only friends who are aware of my infections are those that are in the same position as me. I have around 10 friends who are also infected. I met them through McFarlane Trust meetings. My best friend of 30 years is not infected and I have not told him about my infections. I don't think he would treat me any differently, but I know that he would worry about my health and I do not want to worry anyone else.

ANONYMOUS

Section 6. Treatment/ Care/Support

104. I was previously treated at the Queen Elizabeth Hospital in Birmingham, but I moved to the Heartlands Hospital to receive better options for treatment. Under the Queen Elizabeth Hospital I was taking 9 tablets twice a day and I was frequently waking up feeling intoxicated. After conducting my own research, I suggested to my treating Consultant at the Queen Elizabeth Hospital that I was taking too much medication. My doctor refused to reduce the amount of medication I was on, as he did not want to take any risks and he said that it would kill me.
105. After posting a question about this online, I was put in contact with a Dr Steve Taylor at the Heartlands Hospital, who now treats me and who has reduced my medication from 9 (3000mg) to 3 tablets (1275mg) a day. I also now have less medical appointments.
106. When I was about 16, I started self harming due to everything I had to deal with. I wanted to hurt myself more. I would use knives to cut my arms, legs, and stomach. This went on for about 7 years.
107. The social worker who was available in my earlier years wasn't very nice and I didn't feel I wanted her involved in my care.
108. In 1998, when I was a bit older, I had a better social worker, Mark Simmons, who referred me to a psychotherapist for support, as I was feeling very down. I attended 5 or 6 sessions, which were enough at that time. Around 10 years later I had a further few sessions. I need to have trust to feel comfortable with counsellor.
109. A lot of people, even people in the medical profession, don't know about the contaminated blood scandal and I have been shocked at the amount of doctors I have seen, particularly in A and E, who are unaware of it. I have

ANONYMOUS

sometimes found their questions and attitude towards me obnoxious. I often have to go through things from scratch with them if going to A and E.

Section 7. Financial assistance

110. The first payment I received due to being infected by contaminated blood products was £20,000, which was an ex-gratia compassionate payment from the Government. My Dad received this money for me when I was about 14.
111. I then received an out of Court settlement of £23,500 from the 1991 litigation.
112. In 1991, I had only been given 18 - 24 months to live. There was significant pressure to accept the settlement that was being offered. We were led to believe that we could either accept the money or try to sue the government, but legal aid was not available, so we were told that we would have to pay our own costs and potentially lose our homes if we lost our claims. As such, my parents felt forced to accept the out of court settlement on my behalf, as I was a minor.
113. These settlements were on a tiered basis and the amount I received was for a child under 18. The settlement was held by the MacFarlane Trust until I was 18.
114. If we needed any of this money, my Dad had to write to the Trust to ask, outlining the reasons it was needed and what it would be used for.
115. In 2004, I received a lump sum payment of £20,000 from the Skipton fund, which was the Hepatitis C stage 1 payment.
116. Over the years I have received £19,000 in health related means tested grants from the MacFarlane Trust.
117. These grants would be for things such as domestic items or for holidays.
118. I found the way the MacFarlane Trust operated to be really unhelpful. The Trust was set up to help people infected with HIV, but to receive grants you

ANONYMOUS

would have to prove you were sick enough to justify the grant being made to you.

119. The system required you to provide a supporting letter from your social worker and doctor in support of your grant application.
120. We all needed the grants as we were skint.
121. It felt like they were dangling a carrot and controlling your life.
122. It would take weeks for applications to be processed. The more money you asked for, the longer an application would take. The quickest application could be dealt with in 2 to 3 weeks. If they deemed an application "complicated", it would have to be dealt with at a board meeting, which only took place once every few months.
123. This added to people's daily stresses. We were in poor financial situations, not due to any fault of our own, and the people responsible for our situations tortured us more. It felt like we were made to beg for money.
124. In 1989, I started to receive monthly payments from the MacFarlane Trust. Initially the payments were £89 a month. This slowly rose over the next 14 years to around £550 in 2004. This was when payments became means tested based on household income.
125. This seemed unfair, as if your partner earned a good wage, you may not be eligible for anything. We weren't or shouldn't have been our partner's dependants.
126. Following the Archer Inquiry in 2010, the payments I received from the MacFarlane Trust increased to annual income of £12,500, which were index-linked. I don't understand how this figure was arrived at, as it was meant to be based on an average wage, but it wasn't.
127. The annual income rose slowly under CPI increases until the latest changes to the support schemes in general.

ANONYMOUS

128. I now receive financial support under the EIBSS scheme, which took over from the MacFarlane Trust. I receive around £15,500 per annum under this scheme.
129. I have not had enough experience with this scheme to comment on their application process or efficiency.
130. I now receive a total of £53,000 due to increased rates and the Special Category Mechanism. I receive a double payment due to my HIV and HCV infections.
131. When I went through a drastic change in financial circumstances, I did not receive extra payments and they would only really give people a small amount of help if they were losing their house.
132. Although the MacFarlane Trust was supposed to be a charity, it felt as though we were asking the Department of Health for money and it was a constant battle for everything.
133. The MacFarlane Trust had a lot of money to give; we knew this because we saw their accounts every year. However, they were very reluctant to help when you needed money just to get by.
134. I used to wake up every day and worry about money. Now, I live a much more comfortable life. We were living on scraps for years.
135. It feels as if the Government is throwing money at us now. The increase in financial support has transformed my life and alleviated a lot of stress for me.
136. People want money whilst they are still alive and can enjoy it.

ANONYMOUS

137. I confirm that I wish to apply for anonymity. I also confirm that I would be prepared to give oral evidence to the Inquiry, provided my anonymity is *preserved*.

Statement of Truth

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

GRO-B

Date

30.11.2018

GRO-B

ANONYMOUS

CHRONOLOGY

(This summary is not intended to be exhaustive but summarises the key points in the medical records relevant to the Statement.)

Treatment record – Factor VIII concentrate

Batch numbers by month and year

1980

24.10	U70902
25.10- 31.10	U83304

1981

15.06	U99108
26.06	U99108
13.08	U15409
31.12	U11708

1982

18.01	U11708
21.01	U11708/
22.01	U20610
26.01	U11708
29.01	U11708
30.01	U11708
01.02-03.02	U11708
04.02-05.02	U83904
14.06-17.06	V48508
18.06	V60311
19.07-26.07	V59811
30.08	V45107
13.09, 14.09,15.09,	
16.09,17.09, 24.09	V45107
25.10	W67502
26.10	W67502/V60812
27.10-29.10	W67502

1983

31.01	V55010
-------	--------

ANONYMOUS

01.02-04.02	V55010
29.04	W95009
08.08	X29504
11.08-26.08	X24302
12.09-13.09	X29504
22.12-23.12	X32504

1984

02.07,10.07,23.07	X61611
15.10	X61611
19.11	X60311

1985

11.02-13.02	Y57310
09.04-11.04	Y94110
20.05	Y88908
23.08	A24704 (Tetanus)

1986

27.01	Y33006C (600 units)
-------	---------------------

1987

09.01	AW6044A
16.07	AW7015A
12.10	AW7046A

1988

08.08-09.08	AW8026A+ AW8012A
23.08	AW8012A
09.09-12.08	AW8033A

1989

10.05	FH20079
09.07-12.07	FHC0112
01.09	FHC0124
30.09	FHC0124
02.10	FHC0124

1990

05.04	FHC0189
-------	---------

1991

ANONYMOUS

01.02
02.03

8Y2316
FHC0295

Virology results

09.12.1975	Haemophilia A diagnosed.
12.1980	Non A Non B Hepatities diagnosed.
00.02.1985	Hepatitis B carrier (positive?)
00.04.1985	HIV antibody negative
09.07.1985	HIV antibody negative
29.04.1986	HIV antibody negative
08.05.1986	HIV antibody negative
12.05.1986	Hepatitis B positive
16.06.1986	HIV positive sampled
01.07.1986	Hepatitis B positive reported
11.07.1986	HIV positive (developed antibodies)
29.07.1986	HIV positive
08.08.1986	HIV positive/ Hepatitis B positive
26.09.1986	HIV positive
23.12.1990	Hepatitis C
05.10.1992	Hepatitis B Positive HIV Positive
15.11.1993	Hepatitis B Positive HIV antibody 1&2 Positive Hepatitis A Negative
17.02.1994	Hepatitis B Positive HIV antibody 1 & 2 Positive Hepatitis A Negative
08.03.1994	Hepatitis B Positive HIV Positive

ANONYMOUS

30.12.1994 Hepatitis B Positive
 Hepatitis C Positive
 HIV antibody 1&2 Positive
 Hepatitis A Negative

Significant correspondence/medical records entries

- 07.02.1985 Letter from [GRO-D] to Dr [GRO-D] confirming that [GRO-B] tested hepatitis B surface antigen positive. "His parents are aware of this".
- 18.02.1985 Letter to [GRO-B] parents confirming the Hepatitis B diagnosis from Mr Hill.
- 09.09.1985 Note on [GRO-B] blood test results "this patient was on your original list of HTLV3+ patients! 2 previous specimens also negative by Colindale".
- 24.09.1985 Letter from F Hill, Consultant Haematologist to Dr [GRO-D] confirming that there are to [GRO-B] with different spelling and only one developed HIV antibodies. Clarifying that [GRO-D]'s report confused the two [GRO-B]
- 27.01.1986 Nursing record " Pain ? (illegible) left knee 2/7 stiffness on walking. O/E some bruising. Nil else. Keep off school today. Full ?(illegible) see tomorrow if no better. FVIII x 3. (Dose of Factor VIII which infected [GRO-B] with HIV).
- Left leg. Total FVIII Armour = 600 units. Y83006C.
- 26.09.1986 Letter to Dr [GRO-D] from Mr Hill, Consultant Haematologist "We are looking into this matter at the moment to be sure it is a true finding, as false positives are not uncommon with some tests. As yet I have not mentioned this to [GRO-B] parents, but if it proves that he is HTLV-III antibody positive, I will be seeing them to explain the situation to them".
- 03.10.1986 Letter from F Hill, Consultant Haematologist to Dr [GRO-D] [GRO-D] at Central Public Laboratory advising that [GRO-B] is HIV positive and that three other boys given the same batch as [GRO-B] were identified. The letter goes on "we have tested these boys in the past week and all three are currently seronegative... we are intending to follow these boys to see whether or not they remain seronegative".
- 21.12.1986 [GRO-B] parents attended a meeting with Mr Hill to discuss how to tell [GRO-B] about his HIV status.

ANONYMOUS

- 08.04.1988 Examination note headaches and poor appetite, but normal for him, tiredness, lacking in energy, backache, low back.
- 29.07.1988 Examination noted no further headaches on holiday. Noted testes and penis changing some early pubic hair. See parents in autumn to discuss sexual counselling of GRO-B
- 28.10.1988 Examination of GRO-B Noted that his pubic hair was growing.
- 02.12.1988 Parents seen in parents clinic. Long discussion about how we should tell GRO-B about his HIV status. Both parents wish to be present in interview.
- 30.12.1988 GRO-B told of his diagnosis in Mr Hill's clinic at The Children's Hospital in Birmingham and counselled.
- Examination: Testes have changed and grown and penis enlarged.
- GRO-B seen with both parents as arranged with parents. Told of HIV seropositivity.
- a) Carries virus for life.
 - b) Cant give it to anyone else except during sexual intercourse.
 - c) Some drugs becoming available for those that seem unwell.
- 13.01.1989 GRO-B and his parents attended a further appointment with Mr Hill for further counselling re diagnosis – dealing with blood spillages/sexual relationships.
- 21.04.1989 Examination noted testes enlarging some pubic hair.
- 24.07.1989 GRO-B seen at the Haemophilia Unit having developed haematuria which lasted for at least 2 days and followed bilateral renal pain.
- 23.04.1990 On Zidovudine because of his thrombocytopenia believed to be linked with his HIV infection.
- 25.11.1991 Letter to Dr GRO-D GP from Mr Hill, Consultant Haematologist dated 25.11.91 GRO-B came to the clinic on his own and this gave me the opportunity of talking to him about his HIV status. He does have a current girlfriend but he tells me that they are not having sexual relationships. I have informed him of the importance of informing the

ANONYMOUS

girlfriend if the relationship develops further and they decide to have sex and have offered to see her to counsel her before such events should take place. I have also discussed safe sex with him and he understands the need for wearing a condom and also that he must make sure that he uses one with a kite mark on the packet as these are the safer ones to use".

- 10.06.1993 Worry that AZT does not prolong life, only improves quality of life and that GRO-B HIV will become resistant to AZT. Discussed the new drug with GRO-B and his mother. Arrangements made to obtain DDI from the supplier, GRO-B is aware that this is a new drug and we cannot guarantee anything".
- 25.06.1993 Started on DDI treatment.
- 03.08.1993 Placed on combination chemotherapy with DDI and AZT.
- 18.03.1994 Episode of oral candida.
- 14.06.1994 Letter to GRO-B from Dr Hill's secretary rearranging 2 failed appointments.
- 29.04.1994 "Unfortunately he became infected with HIV when he was being treated with heat treated concentrate at a time when we hoped that concentrates were safe" letter to Dr GRO-D GP from Mr Hill, Consultant Haematologist.
- 22.08.1994 Letter to Dr GRO-D (GP) from Mr Hill, Consultant Haematologist "I have stressed to him that it is important that he takes his DDI regularly not intermittently, as this is what he has been doing."
- September 94 Episode of oral candida.
- 04.01.1995 "I have now discussed with him the fact that we have recently tested him and found that he is hepatitis C seropositive. He understands that there is a possibility that hepatitis C could become more active and cause him to have progressive hepatitis.
- 28.08.2007 VCJD exposure assessment form
- Undated Letter to Dr GRO-D at the Queen Elizabeth Hospital, upon GRO-B transfer from the Children's Hospital, copied to the client's GP and Haemophilia Unit nurses "clearly GRO-B has been informed about his HIV infection and has been counselled about the consequences and has received sexual counselling. He has been told that if he is

ANONYMOUS

contemplating having sexual intercourse with anyone, that he must inform them of his HIV status and then he must clearly adopt safe sexual practices and use a condom. Whenever I have asked him about girlfriends, he has denied that there are any and says he is more interested in his car."