Witness Name: David Eric Bell
Statement No.: WITN0375001
Exhibits: WITN0375002–8
Dated: 27 February 2020

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF DAVID ERIC BELL

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 5 November 2019.

I, David Eric Bell, will say as follows: -

Section 1: Introduction

1. My name is David Eric Bell. I was born on GRO-C 1961 My address is known to the Inquiry.

2. I am a haemophiliac. I intend to write about my infections with HIV and hepatitis C (HCV), which I have contracted through infected blood and blood products to treat my haemophilia.

3. I am deaf and I am not able to read very well. I can read words, but I have difficulty reading and writing sentences. My vocabulary is simple. For example. I generally express my opinion on matters as "*good*", "*bad*", "*very good*" or "*very bad*". I have limited education and no qualifications.

4. I have been assisted in providing this statement by a sign language interpreter provided by the Infected blood Inquiry. I am not the best at sign language, but I can also lip read well. The sign language interpreters have explained things to me in simple terms and I feel that I am able to understand them. This witness statement has also been read back to me with the assistance of sign language interpreter and a deaf relay.

5. There are some limitations on what can be explained through sign language, particularly with medical words. Generally, where I have used medical words in this witness statement, I have described the treatment that I have received to the sign language interpreter and Inquiry investigator. They have then attributed the medical words to my description. For example, I explain having a blood transfusion as, "*Red blood in a bag with pipe going into my arm*". I know the name "*Factor VIII*", which a treatment that I have received for my haemophilia that comes in a little bottle.

6. I have also been helped with this witness statement by Steve Earle, who is my support worker and advocate from Sahir House, an HIV charity in Liverpool. He has been my support worker for 22 years. Whilst he does not speak sign language, we can communicate fairly well through lip reading. He has helped me with communicating with the sign language interpreter.

7. My first interview took place over five days. On each of the first four days, I spent three hours with the investigator, paralegal, sign language interpreter and Steve. On the final day, we had a short meeting to clarify any points that were raised. My statement was read back to me and amendments were made with the above assistance and a deaf relay, which took three days of three-hour sessions.

8. This statement was read back to me and signed with the assistance of Andrew Jackson P.G Dip MRSLIA/ VLP, British Sign Language Interpreter and Bryan David Fowler, Deaf Relay and Level 6 British Sign Language.

9. I am not legally represented for the purpose of this Inquiry.

10. I do not want to be anonymous. I want my name to be known and for people to read and understand my story.

11. The Inquiry Investigator has explained to me the "*Right to Reply*". I understand that any doctor, nurse or medical professional that is the subject of a significant criticism raised in this statement may be asked to provide a response.

12. Many of the events I refer to in this happened a long time ago. As a result, my memory has faded over time and I have difficulty recalling specific dates. The dates mentioned in this statement should therefore be treated as an approximation.

About me

13. I was born Eric Bell on GRO-C 1961 at the Broad Green hospital in Liverpool. Soon after, I became known as Eric Brabbins, the name of my foster parents. I changed my name to David Eric Bell on 8 April 1992. I explain why I changed my name later in this section of my witness statement.

14. My birth mother was from Scotland. She travelled to Liverpool to give birth to me so I could be put into children's home. There were severe complications with my birth, during which, I almost died. As a result of these complications, I lost my hearing and also suffered brain damage. I speak about these complications in more detail later in my statement.

15. I was referred to a children's home in Heswall, on the Wirral. I stayed there for the best part of a year, whilst they found a family to foster me. My early days are best documented in a letter dated 19 October 1961 from the Almoner of the Royal Children's Hospital, Heswall to the Secretary of the National Deaf Children's Society [Exhibit WITN0375002]. I have included an extract from this letter:

> "*Eric is the only child of an unmarried mother, whose home is in Scotland. Miss Bell's family do not know of Eric's existence, as originally his mother had come to the Liverpool area for the sole purpose of having her confinement there and arranging for the baby to be legally adopted. Of course, the baby's severe illness so soon after birth prevented further action along these lines and when Eric had sufficiently recovered, he was transferred here, purely in order that his progress might be watched and any signs of kernicterus duly noted. A copy of Dr Harvey's medical summary of the case is also attached for your information. Whilst we are all convinced that Eric's mother is very fond of him, she insists that she cannot keep him and now that she realises that legal adoption is probably impossible, she is willing to consider him being placed with foster-parents and she would contribute towards his maintenance.*"

16. In January 1962, when I was nine months old, I was fostered by the Brabbins family. Until I was 30, I believed that they were my real family. They were a bad family. All of them. They never stopped fighting. My foster mother and father drank and smoked heavily. I wanted nothing to do with them. Throughout their lives, they all took advantage of me, robbed me and abused me because I am deaf and ill.

17. My foster father was called Ronald Brabbins, and my foster mother, Audrey Brabbins. They had four children other than myself: Paul, who is 14 years older than me; Lyn who is 12 years older than me; John, who is 6 years older than me; and Moira, who is

3 years older than me. GRO-C is deaf; I understand that this is why the Brabbins family took me under their care.

18. On 13 October 1984, my foster mother died of cancer. In January 1985, my foster father was admitted to hospital for a heart murmur and remained there for the rest of his life. I stayed living in the house. My foster brothers and sisters had left the family home, so I lived there alone. My foster father died in hospital in on 4 December 1986. I continued to live in the family home.

19. After my father died, my foster siblings left the family home. My two brothers left after my father died and I did not speak to them again. My sisters also left, but I would speak to them from time to time. I would sometimes see GRO-C at the Liverpool Deaf Club, which we both attended.

20. In May 1991, I discovered that I was not a Brabbins. I found this out when my friend explained to me that everyone has a birth certificate. At the time, I did not know what a birth certificate was. So, I asked him. He took me to the office of registrations and births in Liverpool. I told the man at the office that my name was Eric Brabbins. He had a look through the big book for my name but he could not find it. He phoned the Royal Liverpool Hospital ("the Royal"). When he got off the phone, he told me to go to the hospital.

21. I went to the Royal to see my haemophilia nurse, Alison Jones. She phoned my foster sister, Moira, and told me that Moira would visit me at my home. When Moira came to visit, she gave me my birth certificate, with other papers from my childhood, such as school reports. The birth certificate had the name "Eric Bell". Moira explained to me that my real mother lives in Scotland, and she left. I was in total shock.

22. GRO-C

23. In 2003, I asked a solicitor to obtain a copy of my father's Will, dated 17 June 1985 [Exhibit WITN0375003]. It states,

GRO-C

24. A Codicil dated 11 July 1986 [Exhibit WITN0375004] also states,

GRO-C

25. GRO-C

26. I never spoke to my foster siblings after I was forced to leave the family home. I do not know if they are still alive. The only contact I have had with them since then is a letter that Moira sent me in 2011, which I exhibit at [Exhibit WITN0375005].

27. When I was forced out of the family home, I wanted to forget my foster family. I had enough and wanted rid of them. They were too much trouble and had told too many lies. They did not bother with me because I was ill. I decided that I wanted to be called Bell, the name of my real mother and the name listed on my birth certificate. So, I asked Alison Jones, my haemophilia nurse at the time, for help. She told me that if I wanted to change my name, I could choose any name. She asked what name I would I like. I chose the first name David. On 8 April 1992 I changed my name by deed poll to David Eric Bell, and that is how I am known today [Exhibit WITN0375006]. I go by my first name, David.

28. I lead a lonely and restricted life. I have two friends, Graham and GRO-C Graham is hearing and GRO-C is deaf. A lot of my friends have died already; they were mostly haemophiliacs.

29. I see Steve and his colleagues at Sahir House. I now come to Sahir House, which is a charity that provides advice and support for HIV sufferers once a week. They are teaching me how to use a computer. Steve and Kellie at Sahir House help me with reading. If I get a letter I do not understand, they help me to read it. I see Steve as an advocate for me.

30. I have bought a house, which I have paid for using the financial assistance I have received, mostly from the various trusts for infected blood victims, which I describe later in this statement. I am house-proud and work hard to keep a clean home. My legs are painful, especially in my foot, so spend a lot of time lying down watching TV.

31. I am not well enough to work. Throughout my life, I have been back and forwards to the hospital because of my haemophilia and admitted for treatment and operations on several occasions. I have never had a job. I used to entertain myself with art and activities at a disabled centre. But, I have not gone for a long time. I went there when I was 17. I left when I was 29. I would describe myself as small in stature. I am disabled and have difficulty walking.

32. I have applied for my medical records. I have received some of them, but not all. I have received medical records which date back to 1998 from the Royal. The only records I have before this are documents that Moira, my foster sister, provided to me with the letter she wrote which I have exhibited above [Exhibit WITN0375005]. I have provided them to the Infected Blood Inquiry to assist them in taking my statement.

Section 2: How Infected

Haemophilia treatment

33. I suffer from severe haemophilia A. This means that I bleed a lot. I have internal bleeds mostly in my knee, foot and my arm. When I was very small, right through my youth, I was in and out of the hospital constantly.

34. As mentioned above, I was severely ill when I was born. A document from the Royal Liverpool Children's Hospital titled "Summary of Case History", details the complications with my birth [Exhibit WITN0375007]. It states that within 2-4 days after my birth, I was given three blood transfusions and was admitted into the Neo-Natal Unit at Alder Hay Children's Hospital as an emergency. I had a history of haematesis (vomiting blood) and melaena (blood in stool as a result of internal bleeding or swallowing blood). I was jaundiced. When I was examined, I was found have a

perforated gastric ulcer. I had a bleed in my brain which may have also caused brain damage.

35. The document titled "Summary of Case History" describes my birth as follows.

> *"The above-named infant was born at Broadgreen Hospital Maternity Unit on 19th April, 1961, and admitted to the Neo-Natal Unit at Alder Hey four days later, as an emergency. There was a history of haematemesis and melaena for the previous 48 hours and he had been given three blood transfusions.*
>
> *Laparatomy was performed on the day of admission and the infant was found to have a perforated gastric ulcer. This was associated with a large sub-serosal haematoma which extended along the greater curvature of the stomach. The area containing the ulcer was removed. The infant tolerated the procedure quite well but he had developed jaundice prior to the operation and this increased in the post-operative period. On 25.4.611. he developed signs of kernicterus and in view of this, an exchange transfusion was performed. The signs of cerebral irritation subsided within 24 hours. The jaundice cleared satisfactorily and the baby's subsequent progress was uneventful."*

36. I do not understand much about my birth. The Inquiry Investigator has brought to my attention to the contents of the documents (specifically, the 19 October Letter and Summary of Case History) and has tried to explain them to me.

37. At some stage, but I do not know when, I was diagnosed with haemophilia. Throughout my childhood, I was back and forth to the Alder Hay Children's Hospital in Liverpool. I suffered severe internal bleeds which resulted in swelling and joint pain. Before I was 12 years old, I had an operation on my knee. This was to relieve the swelling and joint

pain by draining the blood out with a big needle. Between ages 8–12, I was in a wheelchair because my leg and knee were so painful and swollen that I could not walk.

38. My earliest memories of being treated for haemophilia was that I was often attached to a drip. It had an old-fashioned pack, which put a yellowy-orange liquid into my arm. That helped build me up and made me better.

39. The hospital gave my foster father a yellow pack to give to me when I was bleeding. My foster father would hold it in the air, stick a tube in it which had a needle attached. He would put the needle in my arm and inject the yellowy-orange liquid. My foster father was given six bags in total. They were thin and there was not much liquid in them. He would use all six bags to stop one bleed. When one was empty, he brought another one. This process would take 20 to 30 minutes in total.

40. I was only young, so what was in these bags was not explained to me. I know it was for the bleeding, the swelling and the pain. I do not know the name of the treatment. The Inquiry Investigator has asked me if I recognise the word "*cryoprecipitate*", but I do not.

41. **GRO-C**

42. **GRO-C**

GRO-C

43. GRO-C

44. GRO-C

45. Around 1977, I stopped being treated with the yellow bags. My treatment was changed to a little bottle called Factor VIII. My foster father would give me the injections at home. If I had a bad bleed, I would go to the hospital. The hospital would give me injections to stop the pain in the arm and painkillers, when I was in a lot of pain. They would also give me Factor VIII. I would stay there and recover for a week.

46. Until I was about 20, I would stay in hospital whenever I got a bad bleed. This was every month or two. I would stay in the hospital for two to two and a half weeks before I was sent home. As a result, I spent half of my childhood in hospital, which affected my level of education.

47. I also had hospital checks every six months. Until I was 16, I was seen at Alder Hay Children's Hospital. I then went to the Royal Hospital. I started to receive Factor VIII treatment there. They would do an examination on my legs, knees and arms. They would take bloods. They would weigh and measure me. The nurse would ask me if I was all right. I could understand her to this extent but I did not have an interpreter.

48. On my hospital visits, if my blood levels went too low, I would be given blood transfusions. Between 16 and 19 I had blood transfusions four times. When I was 16 and 18, and I went to the toilet, blood came out of my urine. I told my foster father and they took me straight to hospital to have blood transfusions. I had two further transfusions when I was 17 and 19. I had these because my blood levels were down. I would have, maybe, two units of blood on each transfusion.

49. In 1985, when I was 24 and after my foster father went to hospital for his heart murmur, I learned to inject myself with Factor VIII. I would do this at home.

50. At some stage I became infected with HIV and hepatitis C. I do not know when this happened. I think this was because I received treatment with infected blood products.

51. I do not know precisely when I was diagnosed with HIV or hepatitis C but understand that I was diagnosed with HIV around 1985 and 1995 around for hepatitis C.

The information I received about my haemophilia treatment

52. In 1981, when I was 20, I used to see Dr McVerry at the Royal Liverpool Hospital. Every six months, Dr McVerry, my foster father and I would be in a consultation. Dr McVerry would talk to my foster father, who would ask me to leave the room. A nurse would take me by the hand and placed me in another room. I was always sent out. I wanted to stay. It seemed to me that Dr McVerry told my foster father that I had to leave. He kept the nature of my illness between him and my foster father.

53. After these appointments, I spoke to my father in the hospital café. I asked him what he was talking to Dr McVerry about when I was not in the room. He would not say. He always said it was about my leg and about my foot. He would not tell me any detail,

although I would always ask him. I wanted to know. At the time, I did not know what they were discussing.

54. In 1985, my Dad went into hospital so could no longer attend my appointments. After that, I would go with Lyn or Moira to my hospital appointments. I would stay in the room at this point. Dr McVerry would talk to whichever foster sister attended with me, but not for long. I would have blood tests and go home. Lyn or Moira would never tell me what Dr McVerry said.

55. In March 1987 Dr McVerry left the hospital's employment. He just walked out. We did not know why. I would ask about him. The hospital said they were waiting for a new doctor. I had to wait until 1988 for the new doctor to arrive. His name was Dr Hay. In 1989, I was assigned a new haemophilia nurse called Alison Jones.

How I found out about my HIV diagnosis

56. I did not learn that I had HIV until October 1991. This was after I found out that I had been fostered and forced out of my home. I do not know why nobody ever told me that I had HIV before that. I should have been told about my diagnosis much sooner — at an earlier age, from when I between 20 to 24. All my haemophiliac friends said Dr McVerry was bad for not telling me.

57. In October 1991, Dr Hay phoned the deaf centre on Queens Drive. He asked me to attend an appointment with my social worker, Andy Corean. Alison was also at this appointment. Dr Hay explained to me that I had a disease called HIV. I wanted to know what that meant. Dr Hay said that HIV was from the Factor VIII injections in the little bottle. I was shocked. I did not realise that Factor VIII would make me ill. They

explained that HIV was inside me and it was hard to take out. Factor VIII had infected all of my blood.

58. I understand that, when Dr Hay looked through my medical records, he found out the foster family knew I had HIV. The records said that Dr McVerry had told my foster father but my foster father did not tell me that I had HIV. The records said that the hospital knew that I did not know that I had HIV. I was angry and very upset, especially with my foster family. Dr Hay was also angry with the Brabbins family for not telling me about my HIV diagnosis.

59. I think I was given adequate information to understand and manage the infection. I know it is something to do with my health. Dr Hay asked me if I ever had sex and I said no. He was relieved. My understanding of what Dr Hay said is that, if I had sex with another person, I could give them cancer. But, I have never had sex with another person. Dr Hay also explained about condoms. They explained I should go to the gym to keep fit three times a week and build up my muscle, but stop if I am ill, and to eat well. It was such a long time ago, I do not really remember all of it. They offered me information to take home and read — the "rules" — I could not read them. I am not very good at reading and I was even worse back then, so it was pointless.

60. I now know what HIV is, but back in that meeting, I did not understand what it was. I now understand that HIV is a virus that negatively affects my health. It is inside me and it will carry on. I think the "*H*" means "*Health*", "*I*" is the "*Infection*" called AIDS and "*V*" stands for "*Virus*".

61. When Dr Hay and Andy had finished explaining HIV to me, I was very upset. Alison asked me if I would like them to visit my house every two weeks to help me manage my HIV. I said, "*Yes*". Alison Jones visited my house every two weeks for six years.

62. About two weeks later, Alison and Andy visited me at my home and explained HIV a little bit more. I asked to the nurse, "*Why did I get HIV*"? She gave me an explanation, and I understood the following from it:

> *There were two people in America, who were gay. They kept it quiet. In America, people go to the blood bank and gave their blood. They keep the blood in the blood bank. Lots of people do this. These two men kept the fact that they were gay and gave them their blood. The nurse at the blood bank took their blood. The nurse did not know that those two men had HIV. All the blood that was there was mixed together in a big pot. This is what factor VIII was made from. This was put into the little bottle. These bottles were shipped over to Britain. They gave them out to the different hospitals. The hospitals did not check the bottles to see if it had anything in it. They just gave them to people. They gave them to me. They gave me HIV and I did not know I had HIV.*

63. My understanding of HIV and how I contracted this disease has since improved, and I recognise that the above description is a crude over-simplification. But I believe that any information I received about HIV should have been given to me sooner, at the time I was diagnosed in 1985.

64. In May 1989, I started to see a GP at the Garston Surgery, Dr Cookie. Moira would go with me to see him. I suspect Dr Cookie told Moira that I had HIV. I could lip read and noticed that Moira was holding information from me and would not tell me. For example, at one of these appointments, Dr Cookie gave Moira a yellow box. I did not know what it was for. Dr Cookie told Moira what it was and she did not explain to me what it was. I had the box at home. Moira told me to throw the box in the bin. I did not use it. I now understand that the yellow box was to put needles in.

Further information about HIV

65. I have also received information about HIV from support groups. I cannot remember exactly when, but around 1991 – 1994 I was also taken into a big room at the Royal Liverpool Hospital with lots of haemophiliacs who had been infected with HIV. All the patients were the same as me. I believe it was organised by the Haemophilia Society. Andy, a doctor and a nurse were there.

Hepatitis C diagnosis

66. I learned that I had hepatitis C in 1995. I was in a consultation at the Royal with Dr Toh, who was my haemophilia doctor at the time. I was accompanied by my social worker, Andy. He is the same social worker who was with me when I was diagnosed with HIV. There was also a nurse present called Cathy Marsh. I cannot remember what they told me about hepatitis C at this point.

67. Around 1996–1997, a new nurse called Jayne Kearney gave me a little bit of an explanation about hepatitis C. She explained to me that it was from Factor VIII and it affected my liver. I do not remember much about it because it was a long time ago. I now know that it is serious and that I could have died from it.

68. I had HIV and HCV but for me, I could not care less. I have come accept that these things can just happen.

Risks of other infections

69. Dr Toh told me that eating beef is bad for my blood because of mad cow disease. He said some haemophiliacs had died from it. Initially, they did tests on our blood and they

were shocked that we were getting the disease. The doctors then realised that it was because haemophiliacs were eating beef, so I stopped eating it. I am not aware of any other way that you can contract this disease.

Section 3: Other Infections

70. As far as I am aware, the only viruses I have contrived from infected blood or blood products are HIV and HCV. The side effects from my treatment for these viruses are also linked to the infected blood products I have received. I describe these in "*Section 5: Impact*" of this witness statement.

Section 4: Consent

71. Out of everything that has happened to me, my main complaint is that the medical professionals did not tell me that I have HIV. They told my family, but they did not explain anything to me. It was only in 1991, when I was 30 that I discovered my infection.

72. I have been treated without my consent. My foster parents signed everything for me until my foster father died in 1986, when I was 25 years old. I do not know whether they had the legal right to give consent on my behalf. I started to sign documents for myself when I was 31 years old. To the best of my knowledge, I did not undergo any treatment which required my signed consent between the age of 25 and 31.

73. The letters for my hospital appointments were always addressed to my foster father, not to me. For two years after my foster father died, the Royal continued send them to him. I did not know they were for me, so I threw them in the bin. As a result, I missed

many hospital appointments. This was not fixed until I opened a letter, discovered it was for me and showed it to Dr Hay. He fixed it immediately.

74. Every time I went for an operation, there has been an interpreter there. The interpreter would sign the documents as well as me. Some I just signed myself. When I go to the hospital without an appointment, I do not have an interpreter. When I have an appointment at Broad Green, I have an interpreter. At the Royal, Dr Khoo, who can speak sign language, signs for me. Occasionally I have an interpreter there.

75. From 1985, when I was 25, I went to the hospital by myself for my haemophilia. I was given blood tests. I should have been told I had HIV. No one explained what the blood tests were for. Between 1985 and 1991, I did not see the results for any of the blood tests. The first time I heard of HIV was in 1991 when I was informed about diagnosis.

76. Over the years, I have taken lots of new medication for my HIV infection, which I refer to in paragraph [83] of this statement. I may have been given these drugs for the purpose of research, but I am not sure.

Section 5: Impact

Physical effects of HIV

77. When I go to bed, I get a lot of pain and I feel stressed. It also affects my blood pressure, which causes pain, so I take painkillers. When I go to bed, I wake up and I am drenched in sweat. I asked the doctor what caused this, who explained that it is because of my HIV.

Mental effects of HIV

78. In the past, in 1991, I was very sad and upset. I was upset and worried because I do not want to die. I was diagnosed with depression. I have come to accept that my infection with HIV was an accident and it happened.

Physical effects of HCV

79. I find it difficult to talk about the physical symptoms of my HCV infection as I have difficulty understanding the symptoms and distinguishing them from my other conditions.

Mental effects of HCV

80. I have struggled with depression because I was afraid that I was going to die.

Further medical complications

81. Because of my blood pressure, I have to have a strict diet. I cannot eat sugar, cheese or chocolate.

82. I was prescribed painkillers that were too strong, which caused me to have kidney stones in 2000. These were the painkillers I took to treat my blood pressure, which is a direct result of my HIV medication. The HIV medications I was taking at the time were stopped because of these kidney stones.

83. On 2 March 2016 I had a stroke. There was a bleed at the back of my brain. From 2016 to this year, I have had pain in my left leg and my foot due to the stroke. I went

straight to hospital and I stayed for two weeks. The pain has carried on for 3 ½ years. It has improved now, but there is some pain. I do not know whether this is a result of HIV, hepatitis C or the treatments that I have received for these diseases.

Impact of treatment

84. I have been on HIV medication for a very long time. I understand, since the early years of medication being made available. I take a combination of Kivexa and Raltegravia. I have taken other drugs previously: Kaletra and Niverapine. I also take medication to control the fluctuation of my blood levels, which is a side effect of my HIV medication.

85. The HIV medication has caused me to have night-sweats; pain in my arms, chest and legs; headaches and diarrhoea. I use medication to counter-act these side effects. The HIV treatment also causes me to have nightmares.

86. The HIV medication that I have been has also caused me to have lipodystrophy. This is a condition which redistributes the fat in my body. This has sucked all of the fat out of my face and has made me look like a skeleton. It is irreversible. This has been the most debilitating effect of any treatment I have had. I describe the impact that this has had on my social life at paragraphs [96] – [99] of this statement. I now have regular appointments for fillers in my face which is paid for by the NHS. This has helped me and I feel less self-conscious as I did when my lipodystrophy was at its worse.

87. I started treatment for hepatitis C in 2005, when I was 34. I was treated with Pegylated Interferon and Ribavirin. I do not remember this period very well, so I refer to my medical records. They list the following aspects of my hepatitis C treatment [Exhibit WITN0375008]:

Date	Comment
31 May 2005	HCV treatment week 1 commences
7 June 2005	David has experienced some flu like symptoms. His appetite is reduced, his mood is low. His sleep pattern, he is not sleeping at all.
14 June 2005	Headaches, general aches and pains, shivering.
December 2005	Hair falling out and sleepy
23 October 2006	Hep C cleared

88. In addition to the above, I remember feeling very itchy on my hands and arms.

89. As a deaf person, I feel that I face obstacles in accessing treatment. Because I am deaf, I do not feel like treatments have been explained to me, because it is too difficult for doctors to explain them properly to me. I think this is bad, but it happens.

90. My dental treatment has been good. I bleed a lot so I go to a dental hospital at the Royal Hospital. They give me factor VIII injections, before I have a procedure, and they are experienced with dealing with patients who have HIV.

91. HIV has affected my social life. I live on my own. I am indifferent about this. I stay at home most of the time. I do not leave the house because people do not like my face and laugh at me, which makes me depressed.

92. I do not go on holiday anymore. I used to go on holiday before I knew that I had HIV. I do not go on holiday anymore because of my face. I am not allowed in the sun, either, because the sun will damage my face and make it thinner again. I also do not go because of my stroke and the pains I get in my leg. From 2016 I have not been able to go on holiday.

93. I used to enjoy going to the pub, or at least went to pass the time. I have lived a lonely life, especially between ages 20-48. I would go to the pub, just on my own to quietly have a drink, or with my friend, Graham. I now cannot drink beer because of my painkillers. My GP, Dr Naviad Alam, told me to stop drinking because it will interfere with my HIV medication. I have also stopped going to the pub because of my lipodystrophy.

Stigma

94. I struggle badly with stigma.

95. GRO-C

96. GRO-C

97. I suffer a lot of stigma because of my face. This happens wherever I go. On the bus, in the pubs, in the shops. I mind my own business, walking in the street, and people will laugh at me. A lot of people laugh at my face, especially young people. It makes

me very sad and depressed. People look at me, and I see them, and they follow me. I look behind, they are still there, looking at me.

98. On one occasion, I was sitting behind a young woman with a pram on the bus. She took out her camera, tried to hide it, and was secretly taking photos of me. Some of the nurses at GRO-D hospital laugh and sometimes nudge each other, the nurse will look behind and laugh at me. Some people follow me, touch my shoulder to make me look around and they stare at me. It happens all the time and everywhere, because they want to see my face. I will ask, "*What?*", and they will walk away. I feel very sad. It is too much trouble and I feel depressed, so I go home.

99. In the Wirral, I was at the bus stop. Two men were coming towards me. One man came in front of me and called me a "*Horrible faced bastard*". Even in the newsagents, the staff looked at me and make comments, like "*Are you alright? Look at your face!*" So, I do not go to that newsagent anymore. It is only across the road but I have been driven away, I now have to go further.

100. Before, all these experiences made me feel very depressed. But now, I go for the fillers so I feel better than I did. Now, it has calmed down.

Section 6: Treatment, Care and Support

101. I understand that I have had "counselling" but I struggle to recognise the term. Lynne Evans, my social worker, and Donna, from Sahir House, spoke to me about the problems I have had. I was helped by a support worker called Jenny, who used to work at Sahir House, who explained HIV to me. Steve from Sahir House has also helped me.

102. I started going to Sahir House around Christmas in 1996. The haemophilia nurse, Alison Jones, directed me here. I come here once a week. That was the first time I met Steve. Everyone was sitting in a circle and talking about HIV. There was an interpreter there too.

103. I would like to talk to someone about how I feel about the HIV and the blood.

104. The Inquiry Investigator has told me about the Hepatitis C Trust and that they have a website. I will consider visiting their website to understand more about my history with this disease.

Section 7: Financial Assistance

105. I receive money from a number of different trusts. I do not really understand them or what they are.

106. The Macfarlane Trust sent me lots of money. They posted lots of letters to me about claiming money because of my HIV infection.

107. In 1989, Alison gave me forms that the Macfarlane Trust sent to her. I did not know what it was for. I took it home and I gave it to Moira. She read it and did not tell me what it said. She ripped it up and threw it in the bin. She said nothing, so I left it.

108. Later, Alison was waiting for my form. Alison phoned Moira and asked me and Moira to visit her. We went to visit her. Alison had another form like I had been sent before. I told Alison I had seen it before. Alison knew that Moira was bad because she ripped it up and threw it in the bin. Alison told Moira to fill it in. I could see that Moira was getting angry. I needed to sign the form. Moira would not explain what it meant or what it was for. I thought it was to do with haemophilia. This was 1989. I signed the form and Alison posted it to the Macfarlane Trust. In 1989, the Macfarlane Trust sent me a cheque.

109. In 1991 I found out that I had HIV. I thought I was receiving the money for haemophilia, for my leg. I showed Alison the cheque (I did not show Moira). Alison told me to go to the bank. The cheque was for £23,000. In 1991, I got a second cheque for £25,000.

110. I received a monthly amount of £2085 under the Macfarlane Trust. I also received money from the Skipton fund. I only received about three payments, which was not a lot and I do not remember when this was. I think it was around £9000. I now receive £3066 every three months under the EIBSS. I get winter fuel allowance in November for £519 every year. I also receive welfare payments from the DHSS. I get money every two weeks (£395). I get another one, every month (£595) Disability Living Allowance.

111. I bought my house with this money. The first house I bought was in the GRO-C region of Liverpool. I bought that house and made everything new: a new carpet, everything. I used the Macfarlane Trust money for that. Later, the Macfarlane Trust gave me money for furniture and decorating. I then sold the house and I moved to a house in the Wirral, where I live now. I had a snooker table, a gym, a running machine. I paid for that myself.

112. The Inquiry have explained to me that the payments I receive from the trusts are *ex gratia*. I understand that to mean that they pay me money for my infections but they do not accept that it is their fault. I think that is bad because the family and the hospital made me ill. They made me ill with HIV. The government in Britain paid America and brought the boxes of factor VIII and gave them to people here. The British Government did not check what was inside the Factor VIII. Britain was to blame for this. They are therefore wrong.

Section 8: Other Issues

113. I want to be safe from HIV and hepatitis C. I am worried, because I do not want to die. I asked a nurse from the Royal Liverpool Hospital how many people like me had HIV. She replied that around 86 people were haemophiliacs like me. But, now, I asked the nurse how many people today. She said that 76 have died. Now there are 10 that are left, haemophiliacs with HIV, left. My friends like me have all died. The haemophilia nurse Jane Kearney at the Royal Liverpool hospital told me that they are now trying to help these people carry on living. She told me that there will not be any more who will die from HIV.

114. I want to know why the government sourced the Factor VIII from America. I thought they made it here, that it was from Britain. It is the government's fault. They should not have brought it here. If they did, the first thing they should have done is open the damned thing up and checked it. They did not, so it is their fault.

115. I do not think that the government has learnt from this. The Factor VIII should be checked first, under a microscope, and people told not to use it. The government should have given it back or thrown it away. Instead, they told us to use it. It is now too late to do anything.

Statement of Truth

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

Signed GRO-C

Dated 27.02-2020

Declaration of Interpreters

I declare that the facts stated in this written statement as interpreted by me are a faithful and true explanation according to the best of my skill and understanding.

Signed GRO-C BRYAN DAVID FOWLER (LEVEL 6 BRITISH SIGN LANGUAGE – DEAF RELAY INTERPRETER)

Dated 27/02/2020

Signed GRO-C ANDREW JACKSON (BRITISH SIGN LANGUAGE INTERPRETER)

Dated 27.02.2020