GRO-B

Statement No: WITN1091001

Exhibits:WITN1091002-5

Dated: March 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF GRO-B

GRO-B will say as follows:-

Section 1. Introduction

1. My name is GRO-B My date of birth is GRO-B and I live at GRO-B

2. I was infected with HIV, Hepatitis C and Hepatitis B as the result of being given contaminated blood products.

3. This witness statement has been prepared without the benefit of access to my full medical records. If and in so far as I have been provided with limited records, the relevant entries are set out in the medical chronology at the end of this statement.

Section 2. How infected

4. I was diagnosed with severe Haemophilia A (0% clotting factor) in March 1977, a few months after my birth. There was history of this in my family so the diagnosis didn't come as a surprise.

5. My treatment records for 1978 to 1985 and exhibited to this statement at **WITN1091002**. These are not complete.

6. I was treated at the GRO-B GRO-B GRO-B

7. I was treated regularly with cryoprecipitate from 1977 to 1979 and in 1981. I was given platelets in November 1986 and August 1987.

8. According to my records I was first given Factor VIII concentrate on 23 January 1979.

9. According to my Mum there was no discussion regarding any risks associated with Factor VIII. It was described as a new wonder-drug and there was no discussion of any side effects or negative aspects to the drug.

10. I went onto home treatment with Factor VIII in August 1979. I was given 6-10 bottles a month on average. This was on demand treatment. We lived about an hour away from the hospital and my Mum didn't drive, so treatment at home was extremely useful.

11. I was trained how to infuse and administer the treatment myself around the age of 4.

12. Prior to attending my local primary school there were discussions and questioning by the school as to how I should be treated and managed because of my haemophilia and the possible dangers of bleeding or sustaining an injury while at school GRO-B the head nurse from the hospital's haemophilia centre, visited the school and reassured them that I would be okay there. When I started to attend the school I wasn't allowed to use scissors, run and jump, or fully join in with P.E. I often used to be separated from my class during P.E. to draw or do some other non

physical activity GRO-B

GRO-B

13. During the period 1979 to 1985 (when I was diagnosed with HIV) I was given Factor VIII from the following manufacturers: Armour factorate, NHS, Alpha Profilate. I also had tooth extractions in November 1983 and March 1984 for which I was given Factor VIII concentrate.

14. According to my records I was first given heat treated Factor VIII on 9 December 1984 (X5507-H) and was not given any non heated treatment after that date.

15. Between starting Factor treatment and the link coming out in the press in or around 1984, my mother had not heard anything regarding a potential risk or infection from my haemophilia centre or any doctors. She only became aware of the risk through the press.

16. In or around 1984 my mother received a letter confirming that I had been diagnosed with HTLV-III. She was invited to one of several conferences with other parents of infected boys, in which they said we had been infected but they had little information about the disease itself. I have been unable to locate a copy of this letter in my medical records.

17. These meetings were run by the consultant GRO-B and GRO-B At one such meeting I believe they had to throw out a member of the press who had sneaked in.

18. There was no individual meeting or consultation, only information provided to the group. This was at a time where doctors weren't really questioned and what they said was accepted.

19. The first blood test in my records which tested for HTLV III antibodies is dated 1983. However there is no report date and I believe that this test may have been done retrospectively after I tested positive for HIV following a sample taken on 12 May 1986 and reported on 20 May 1986. The 1983 result is filed between results from April and August 1985. It is therefore clear that my sero-conversion occurred at some stage before 1983.

20. There is a letter in my medical records dated 18 October 1985 which states that all haemophiliacs treated by GRO-B were being tested for the antibody to the HTLV III virus. The letter confirms that GRO-B had arranged for a stored sample of my blood to be tested and that I had antibodies from 1983. The letter also confirms that they did not know whether the result meant I was immune or had the virus and would develop symptoms. It confirms that the only advice my mother was given was to wear rubber gloves when administering my treatment. A copy of this letter is now shown to me marked **WITN1091003.**

21. There is also a letter in my records from GRO-B dated 23 September 1986 which appears to be to my GP. It was written after GRO-B was contacted direct by my school. This confirms that it was not policy to discuss the antibody status of any of his haemophiliac patients with anyone apart from their GPs because it was not a notifiable disease and not infectious unless one received a blood transfusion or had sexual intercourse with someone carrying the virus. The letter also confirms that it was known boys could develop Hepatitis B at any point during their treatment and that advice therefore had needed to be given to schools in order to minimise the risks to staff.

22. My parents told me that GRO-B said that it was Blood Products from the United States that caused my HIV infection. He

did not tell them the brand, although the attached batch numbers indicate that it was ARMOUR concentrate that caused my infection **WITN1091004.**

23. I was not informed of my diagnosis until January 1989. An opportunity arose for my Mum to inform me of my diagnosis when a boy at school asked if I had AIDS. When I went home and told my Mum what the boy had said she told me that actually I did have AIDS. I was 12 years old.

24. The next day my Mum took me to see **GRO-B** who reassured me and told me I had nothing to worry about and it wasn't 'curtains'. I recall the meeting was brief, only a few minutes.

25. I received no information from the doctors regarding routes of transmission or prognosis, nor did my parents ever really talk about it. They were as much victims as I was; what were they supposed to say? Everything I knew I found out for myself or absorbed gradually from what was said on TV or in the papers.

26. HIV was never mentioned at this hospital again as a child. They would tell me to take certain pills but they would never talk about the virus again or why I was taking these pills.

27. From 1985 onwards it felt like I was spending a lot more time in hospital than I previously had. In hindsight, this seems strange as I was being kept in hospital to rest bleeds I could rest and treat with Factor VIII at home. It seemed an opportunity to take a blood sample was rarely missed.

28. I would occasionally do cognitive tests, answer questions and complete puzzles as requested by the hospital. I am aware there was always concern about the amount of time we missed from school due to bleeds and I understand that perhaps this was done to monitor this, but I believe they were also running these tests to track the effects of HIV and gather more information for it. I recall being called into hospital to do these tests on at least

2 occasions but do not recall ever being given a reason why I was being tested.

29. This was also at the stage when the atmosphere surrounding HIV was extremely oppressive. The government were running adverts on TV and there were storylines depicting AIDS on Eastenders.

30. I have never been told by doctors that I have Hepatitis C. All I know for a fact is that I am Hepatitis C antibody positive but PCR negative. I only know this because I asked about it outright in or around 2000. No information regarding Hepatitis C, its effects, transmission routes or treatments has ever been offered to me from a doctor. All I was told in 2000 was that I had cleared it and had nothing to worry about. I do not believe I have ever been treated for Hepatitis.

31. GRO-B told me in the summer of 2015 that when I transferred to the GRO-B GRO-B they treated me as if I had Hepatitis.

32. According to my medical records I first tested positive for Hepatitis C antibodies by EIA on 22 February 1994. I have had numerous other tests for Hepatitis C antibodies; none of which were ever discussed with me.

33. With regards to Hepatitis B; my surface antibodies were positive in February 1981 and core antibodies intermittently positive since February 1981. Like Hepatitis C, I have never received any information from doctors about Hepatitis B. While I always assumed I probably been exposed to Hepatitis B, it should be noted that my solicitor's examination of my records for this statement, and subsequent reporting to me, is how I received confirmation of this.

34. There obviously must have been some strain on my body of having and clearing the Hepatitis virus, but doctors always attributed everything that was

wrong with me to HIV. I believe incidents of low platelet counts in 1986 and 1987 could have been due to Hepatitis.

Section 3. Other Infections

35. I received a letter out of the blue in 2001 from GRO-B informing me that I had been treated with a batch of Factor VIII concentrate that had been contaminated by vCJD and I should therefore not donate my brain and other body parts. I was also told that I had the responsibility to inform surgeons if I required invasive surgical treatments. There has been no further information or support in regard to vCJD from any hospital or doctor since that letter.

36. I believe I was given treatment for Tuberculosis (TB) in 1982-3 however I do not know whether I actually had TB or whether I was treated purely because there was a risk that I might have developed it due to the proximity of an infected person during a stay in hospital. The doctors were vague and never gave a definite answer on this.

Section 4. Consent

37. It was routine for doctors to take copious amounts of blood from me to monitor my haemophilia. My Mum never consented to them taking blood for any other reason or to run tests. Any tests for HIV or Hepatitis were therefore done without her knowledge or consent.

38. I also never consented or was informed about my tests for Hepatitis, and would not have found out I had tested positive for Hepatitis C antibodies if I had not specifically asked.

Section 5. Impact of the Infection

Physical

39. According to my medical records I had cervical nodes from October 1986 with axillary nodes from April 1985. I had spontaneous bruising due to thrombocytopenia from March 1986 which was considered related to my HIV infection but I believe could also be attributed to Hepatitis. This was treated with steroids from December 1987 to February 1988 and June to July 1988. I was started on AZT in May 1989.

40. Due to HIV related illnesses I have suffered loss of appetite at times and struggled to keep weight on. However, I have also at times suffered rapid weight gain as a result of steroid treatment that I was prescribed. This has left stretch marks on my skin. The side effects of my anti retroviral treatment mean that I regularly have stomach upsets so take anti-diarrhoea tablets. This is often severe enough to make me not want to socialise or be 'away' from a toilet. I have struggled to maintain a healthy weight for much of my adult life and during a severe bout of illness in the late 1990s my weight fell to just 7 stone, which is not a lot for someone like me who is quite tall. I also suffer from lipodystrophy, caused by HIV and its medications, which has greatly affected my body image and self confidence.

41. I have suffered from many additional illnesses since being diagnosed with HIV. Some are chronic and ongoing like warts and fungal nail infections. Others are acute and unexplained such as rashes and itching. I have also had several bouts of chickenpox/shingles and cataracts which I understand were caused as a side effect of some of my medication.

42. Although I have never been told I have AIDS I have had multiple AIDS defining illnesses and a CD4 count below 200 with a very high viral load on numerous and prolonged periods.

43. I have experienced fatigue, depression, nausea, vomiting, joint aches, headaches, muscle aches, fever, insomnia, anaemia, rash/itching, loss of appetite, loss of platelets, peripheral neuropathy, hair loss, chills and diarrhoea. I have also suffered with low bone density which resulted in a hip fracture. This required surgery to implant steel pins to repair the joint and

nearly 10 months of rehab and the use of crutches and wheel chairs. Low bone density was attributed to my then HIV medication. My doctors usually put my symptoms down to HIV or medication side effects but I am aware that a number of my symptoms are also symptoms of Hepatitis C.

44. My neuropathy tends to be worse on the right side of my body and I have progressive hearing loss in my right ear, to the extent I am now nearly completely deaf in that ear. [redacted] There is no apparent physical damage to my ear, and while there is no conclusive evidence, I believe it is reasonable to assume there is some link between my hearing loss and the neuropathy.

45. Despite having relatively stable health now and being virally suppressed, much of my time is still spent managing my health and illness. It simply is not a matter of popping a couple of pills as the news would suggest. Most weeks I have an appointment related to my health or managing my HIV and haemophilia. Be it a hospital appointment, scan, blood test, physiotherapy, holistic therapy, or just having to have bed rest. It is all necessary and takes time. It's usually an hour or more each way in travelling to a major hospital. I still take over a dozen tablets a day, require pain management, and suffer with bleeding and joint damage from haemophilia which requires injecting myself 4 times a week with Factor concentrate. It can be a near full time job managing and living with all this and you almost have to treat it as such. This aspect gets forgotten and is not appreciated by anyone outside our community.

Education and Career

46. My education undoubtedly suffered as a result of my infection. I was a bright kid, I did well in school, but I stopped caring during my A-levels because I thought I was going to be dead soon; I had a very fatalistic attitude.

47. I had always wanted to study Art but I wasn't allowed to pursue this at A Level. I had spent a lot of time in hospital before my Art GCSE and as a result didn't perform well in the exam and didn't obtain the required grade.

48. I somehow managed to get into GRO-B to study engineering; however I had to drop out due to several instances of pneumonia in 1996 and it was apparent that 'full-blown AIDS' had now taken hold. I had to move back home and live with my Mum and step-Dad.

49. In the next few years I was always ill. I spent most of my time in bed and had absolutely no energy. During this period I developed cataracts as well as having both of my lungs collapse, I had an operation on my sinuses and got infected mouth ulcers.

50. When my health improved I was able to return to university. However, I did so in a far less demanding subject where my time and workload could be better managed in light of my HIV infection. I also did this, not to progress a career, but more to show willing and 'keep going' for my family. I still had AIDS, I was still considered terminally ill. I graduated from GRO-B with an Art degree in 2003.

51. I moved back home in 2003 and optimistically thought about training as a chef as I had always enjoyed cooking. But I was too anxious about preparing food, contamination and disclosure to my employer, not to mention I'd be on my feet all day and due to my infection I knew I'd be too tired and fatigued to maintain it.

52. GRO-B

53. Starting a business has ultimately proved great for my personal well-being, as it has helped me to establish an identity again. By normal measures of turnover or profit the company is not successful, but this is not why I do it. I do it to feel and appear normal and so that I can manage my health without fear or necessary disclosure to HR departments. And most importantly work is good for the soul. I don't make lots of money but I work as much as I can and what I do helps other companies and individuals. This I am proud of. I do feel very frustrated that I have missed out on the opportunity of having the time and good health needed to build a successful career. When I see my friends working well paid, interesting jobs, and I think that these are the same friends who copied my homework and I competed academically with in school, it is a constant reminder of what this infection took away from me.

Financial

54. The financial impact of HIV infection is massive. Quite simply, if you cannot work you cannot provide for yourself, build wealth or have financial independence. You can't save, you can't pay into a pension, you can't get life insurance, and you can't get mortgages. You are therefore forced to rely on state benefits. Not from my own life choices or any perceived lack of work ethic, but because I developed AIDS from infected blood products and simply couldn't provide for myself.

55. While I have managed to buy a home it was because of the intervention of the Macfarlane Trust or a family member. And while I currently do work as best I can it is not sufficient to provide financial security.

56. This financial impact is also not just on me, it's been on my family too. My mother who had to work around my hospital visits, at the expense of her career and earning power. My brother who risked his financial security to ensure I was in a decent home that met my needs. The £2.50 for parking every hospital visit really adds up over 40 years, and let's not think about fuel costs for the hours spent back and forth to visit me in hospital so I wasn't alone.

57. While financial support is now much better it should not be forgotten that this has only recently been the case and for all the 1980s, 90s, it was practically non existent except for the lump sum payments that had to be fought for and came with conditions attached. Support only reached meaningful levels in the 2010s and then only for some people in our community.

Relationships

58. The prospect of dating as someone who is HIV positive is extremely daunting, and there are so many questions that fly through your head; how many dates should I go on before I tell this woman I'm HIV positive? If I tell her, how will she react? What will her family say? I feel like if I see someone too much without telling her then I am deceiving her, but if you tell them too soon you don't get the chance to bond and see if there really is a potential relationship there.

59. I have been in one serious relationship in my life. However, despite the fact I had been declared virally suppressed (and therefore not infectious according to my doctor), and we received reassurance and advice from the hospital, we struggled with sexual intimacy as we were both too afraid of my HIV. Attempts at intimacy were clinical, checking for bleeding gums before kissing or keeping a mental check of who had touched what and when. Not romantic, not sexy, not the sort of intimacy that builds a relationship or brings you closer together.

60. We disagreed over informing her family, I wanted her to tell her parents about my condition because I didn't want to lie to them and knew they would be crucial in supporting her if times got tough. But she didn't want them to know, for reasons I still don't understand. HIV/AIDS just got in the way of being together.

61. I'm at the stage now where I don't even want to try dating because I can't face telling another woman that I'm HIV positive and to have to look at her while

her face turns to that all to familiar expression of 'you poor thing'. In that instant your are no longer a potential partner, lover or father to children, your an AIDS victim.

62. There was no support or advice about sex, or transmission of HIV from anywhere when I was a teenager or young adult. I had the same school lesson about puberty as my class mates, but there was no support provided from doctors or relationship counsellors on how to cope with HIV in relationships. The only advice I ever received regarding this was a pamphlet given to me while at the children's hospital. It was a comic strip of a haemophiliac lad telling his girlfriend he had HIV. They both agreed they should not have sex, but it was okay to kiss. That pamphlet and John Hurt's voice over on the TV ads 'don't die of ignorance' was the extent of the advice or support I received until I was well into my 20s.

63. I must have taken that pamphlet to heart because as of writing I have yet to have sexual intercourse. I feel like I am no longer deserving of a relationship, it just doesn't seem right to ask someone to risk their health to be with me. I get extremely lonely and it is incredibly difficult seeing my friends get married and have children.

Family

64. My illness has not only impacted my life, but it has had a huge impact on my family. My Mum had to carry the weight of knowing about my infection on her own as my Dad left us a few months before my Mum told me about my diagnosis. It completely changed my Mum's life as she was only able to have jobs with very understanding bosses who would let her leave with no notice to care for me. She had no other support. She didn't feel able to tell her parents, her sister or any friends. She was completely alone until she met my step Dad several years later.

65. My Mum only told her own sister about my infection after she worked it out for herself following my pneumonia while at GRO-B My grandfather and auntie would also have to structure their work patterns to enable them to take me to hospital.

66. My brother suffered as he was not given the attention he needed and deserved as a child. My Mum was brilliant at trying to treat us equally, but it is with doubt that I was the focus of attention. I only told my brother about my infection after dropping out of University. He tells me that he now divides his life into the time before he knew I had HIV and the time after. My brother is awesome.

67. It must have been so difficult for all of them, especially my Mum, living with someone with HIV in the 1980's and 90s, a time which coincided with the media campaign and HIV adverts. There were stories about people vandalising the property of people with HIV and stories from America of people's homes being burnt down. I cannot begin to imagine what they went through.

Psychological

68. This is probably the hardest thing to talk about or put into words. This section of my statement has been re written so many times.

69. I feel guilty. That I have put my Mum and family through so much. That I want a relationship but know it will asking so much of a partner. That I can't work or provide for myself like a grown adult should. That every time a have surgery or have blood taken there is a risk to the medical team.

70. I feel jealous. Of my friends who did finish university, are married and have children and successful careers.

71. I feel stigmatised. Not just by having AIDS and having to hide it, but for being in a position where I had no choice but to claim benefits and receive charity.

72. I feel anger. Not really at being infected but that no one owned up and took responsibility. At having to endlessly reapply for support. At having to fight for inquiries that should have been volunteered years before. At politicians who talk endlessly but say nothing. I could go on.

73. I am lonely. Despite having an amazing family and friends I still feel isolated. My HIV wasn't something I felt I could really talk to my family about, it would have been to load even more on to them. I wasn't able to tell any of my friends whilst at school and I only told my best friend during A-levels about it because I just needed to tell someone. Although he was okay with it and we remain friends to this day, it is something we struggle to talk about and it is generally avoided in conversation.

74. I am cynical, jaded and judgemental. I tend to have a pretty low opinion of people before I meet them to guard against disappointment later and this has made me a generally cynical and distrusting person, especially regarding doctors and politicians who I feel have repeatedly let us down. It has also left me with a very short fuse for people who complain about what I see as trivial matters.

75. These are not feelings or aspects of my character and personality that I am proud of. But it is truthfully how I feel.

76. I believe I have suffered a degree of institutionalisation. It is hard to be a normal person when you are used to being unwell or viewed by those around you as 'poorly'. I will admit to there being a rather twisted sense of comfort at having a bout of pneumonia. It's familiar, you know what to do, what to expect and what is expected of you. Being ill all the time, going to the same hospital all the time, seeing the same staff, taking the same drugs. How is that different than having the same job all the time, going to the same place of work all the time, working with the same people all the time? The hardest part about AIDS now is having to live with it, its so unfamiliar from when you knew you would die from it and this I have really struggled with in recent years.

77. I am fearful for the future. Having no family of my own I worry about who might look after me when I get old. I worry about needing nursing care and getting into care homes because my health is needs are likely to be quite complicated. I worry about being able to afford this care.

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Section 6. Treatment/care/support

84. In 1996 I was put on DDI. This treatment made me physically retch. You would drink it and have to spend the next hour trying not to throw up, and if I didn't throw up I would have diarrhoea instead. The doctors have put in my medical notes that I simply didn't 'like the taste'. A classic example of doctors under reporting what we went through.

85. I have also been treated with AZT, which I started when I was still at GRO-B

86. From late 1995 to Easter 1996 I was treated at the GRO-B GRO-B near the university I was attending. I believe this was the first time I was seen by a HIV specialist and had access to the latest medications.

87. When I was at the GRO-B in the later half of the 1990s I was in a very bad way and was back under the care of Dr Wilde, the haemophilia consultant. Dr Wilde told my mother that he didn't think there was anything else that could be done for me. When my Mum asked if we could get a second opinion, she was simply told by Dr Wilde that they would say the same thing. My Mum broke down and had to be comforted by the doctors secretary GRO-B

88. Not long after, a social worker at the hospital (who worked a lot with the gay community) told my Mum about a doctor at another hospital who she should talk to. I was referred to a GRO-B When we visited him I was so out of it that I needed a wheelchair to get from the car to the building and I have little recollection of the day.

89. GRO-B reeled off the name of some drugs to my Mum assuming that I would have already tried them, but she had never heard of any of them. Within a few weeks I was put on new medication.

90. I am not sure why Dr Wilde was not aware that there were other drugs available or why he felt a second opinion would result in the same response as his. Maybe he saw it as a kindness because he felt my time had come, or had some misplaced sense of patriarchal responsibility that stopped them seeking outside help from other doctors. Was he just overwhelmed by the whole sorry mess to the point of not being able to act? I don't know. But if it hadn't been for the intervention of the social worker and GRO-B I would have died.

91. I have also been treated for HIV by GRO-B GRO-B from late 2001 to Summer 2003 and GRO-B GRO-B from 2002 to date. GRO-B was quick to refer me to GRO-B GRO-B as he realised I was again becoming quite ill and that I needed access to new drugs only available on trials being held at certain hospitals.

92. I had never been offered counseling until I met GRO-B GRO-B around 1999. He was very easy to talk to and let me know there were people I could talk to if I wanted to.

93. I did not have therapy until I had told one of the nurses that I had thought about how I would kill myself. Even after that I never received any structured therapy, I talked as and when I felt I needed, but this was not always possible as a therapist was not always available or their was a significant wait to see them at the hospitals I went to.

94. I tried anti-depressants just before I went to university in GRO-B however they just made me feel nothing, no highs or lows, so I stopped taking them. I do still suffer from bouts of depression but just try to ride it out.

Section 7. Financial Assistance

State Benefits

95. I first claimed DLA when I was 16 and got a 'for life' award as I had severe haemophilia and HIV. The 'for life' award is no longer recognised by the DWP and I have to reclaim when the DWP requires. I have yet be reassessed for the new PIP system.

96. I also claimed what was then known as Income Support once I was over 18. This mainly went to my Mum to help her with the costs of looking after me while I lived at home and then it helped me to attend university.

97. In my view my support needs haven't changed, and my mobility is worse now than when I was younger due to damage to my joints from haemophilia, but the criteria I have to meet keeps changing so you never know whether you will qualify or not. The damage to our life is done, so it is frustrating and stressful that I keep having to be reassessed.

98. I have had to attend 3 appeal tribunals in my life to contest awards made by the DWP. I have successfully overturned all three, often with the apologies of the panel that I had had to get to this stage. It should be noted that the DWP never send anyone to these hearings to explain why they made the decision they did and that these hearings often take place in a court, where you have to sit in the dock like a criminal. The stigmatisation is endless.

Macfarlane Trust and other support schemes

99. I received an original payment of £22,000 and a later payment of £20,000 from the MacFarlane Trust, which was on the condition of signing a waiver that my mother had to sign. My mother has told me that she felt intimidated when signing the document. She had gone up to the solicitors in GRO-B a grand authoritative office, on her own, and was basically told that it was this or nothing. There was no discussion about other options and she was made

to feel like she had no other choice. There was no one else to talk to or seek advice from.

100. This money was put in a trust for me and was not touched by me or my mother for years. It was used occasionally to fund a holiday or for driving lessons and such, but the bulk wasn't used until I purchased my first home.

101. I had no involvement or awareness of assistance from the Trusts until the late 1990s as neither my Mum or I were made aware of this possibility. Nothing was really explained to us.

102. This all changed around 1999 when I met GRO-B without whom I probably wouldn't be aware of the Trusts. He helped me to get a setting up home grant of £2,000 which helped me with moving my stuff down to GRO-B also helped me to get a laptop and funds for an online course from the Trust. In these days it was relatively easy and they were quite clear with what you could or couldn't apply for. At this time I don't think the Trusts refused me anything and I was never required to prove my income or 'charitable need', despite widely acknowledged underfunding.

103. I managed to buy a house during my second attempt at university with money I had saved from the initial MacFarlane Trust payments. The mortgage had to be specially arranged by a financial expert who worked with the Macfarlane Trust.

104. For my current house I again paid the deposit but my brother had to sort out the mortgage for me as I was unable to get one. He is therefore the legal owner of my property as I wouldn't have been able to get it without him.

105. In the last few years the Macfarlane Trust changed. GRO-D GRO-D it became very financially focused and everything was means-tested. You had to prove that you were in charitable need to receive anything and they defined charitable need solely by your income, or lack of. Anyone who was fairly well off or who managed their

money well was excluded from payments. GRO-D

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106. There are various anecdotes of questionable judgements and behavior from the Trust over the years. There is one well known instance of a person applying for double glazing in a house suffering with mould and damp, but when he was asked to supply pictures they saw a PlayStation in the background of the picture so he was refused funding on the basis of he could afford a games console he could afford double glazing.

107. In 2013 I applied to the Trust for a downstairs wet room, as advised by my social workers, doctors and occupational therapist assessment. After having to obtain quotes for prices and submit evidence as to the necessity of the wet room, they finally told me that they could not offer me the grant but they could loan me the money instead. To put this in context, at this time I believe the Trust had several million pounds in its reserves. The then Chief Executive had to threaten to resign before they finally, after many months, agreed to award a grant instead of a loan.

108. They appointed and entrusted trustees with far too much personal bias and no understanding of the different social and economic positions of those that were infected. There was no training or written criteria for making decisions on grants or assistance. There was little to no record keeping of what requests had been approved and why and what had been refused. In the later years I feel like they were trying to make things as difficult as possible and felt that protecting the bank balance was more important than distributing it to those it was intended for.

109. Technically the Macfarlane Trust was a charity, but all of their characteristics show them to be a QUANGO. They have received special powers and funding from the Government to benefit a certain group of people,

that makes them an emanation of the state and as such the Trusts failings and underfunding are the responsibility of Government.

110. I find that the new EIBSS is heading in a similar direction. They are still very focused on assessing household income. For example people who have adult children living with them receive less because they count the income of the adult child as part of the household income. This places the burden of costs of living with contaminated blood onto a blameless family member, which I don't believe is fair.

111. You also need to have a strong doctor or social worker who is willing to fight for you to receive anything from the schemes. There appears to be a policy of refuse in the first instance or try other avenues of funding first.

112. Despite its flaws, I do not have a problem with the levels of support I currently receive from EIBSS. If this has been in place from the start I doubt I or anyone else in my situation would have campaigned for all these years.

113. I also received the Skipton Stage 1 payment of £20,000. Dr Wilde had told me I wouldn't receive it so not to bother applying, so didn't for years. But I eventually insisted and applied. During my application the panel asked if there was some other way I could have positive Hepatitis C antibodies, despite the fact records showed I was only around 6 years old when infected, so it clearly wouldn't have been through sex or drugs which are the only other likely ways of getting it.

114. I used to be the GRO-B GRO-B and am willing to provide further evidence on this if required.

115. Pursuant to paragraph 2.9 of the Notice of Determination in the Award made to my Solicitors preparation of this statement does not cover all the issues on which I wish to give evidence. I would like to give evidence on the matters set out at Paragraph 113 above and I am unable to do so in this statement.

Section 8. Other Issues

116. I worry that those suffering with HIV are being forgotten. Due to the improvements in medicine we are expected to live into our 80s and people assume everything is fine for us now, forgetting the 30 years of hell we have already lived through and irreparable damage done to us both physically and mentally. This is something that even people infected with HIV in the last 10-15 years often do no understand, as it is seen as a manageable disease now.

117. I am worried about the long term provisions in place for us and the problems we will face later in life, such as difficulties getting put into care homes; none of them want to take people with complex health needs and if they will the fees are extortionately expensive.

118. The MacFarlane Trust was conceptually wrong and it needs looking at from the beginning to end.

119. The Inquiry needs to look into the loans offered by the Trust on a seemingly ad-hoc basis. That they took charges out on property belonging to people who would clearly have been in a vulnerable position, with no other avenue of financial support available to them, is at best poor judgement.

120. The Inquiry also needs to investigate how the Trust has been able to now pass these charges onto the Terrence Higgins Trust.

121. Lastly, I would also like there to be special recognition for those who went above and beyond to help the people infected and affected. The likes of **GRO-B** They were there for us. Every step of the way. They have suffered and endured too having to witness what people in their care went through and that should not be forgotten. I personally wouldn't have made it without their care and support, and I am certainly not the only one to feel this way.

122 GRO-B

Anonymity

123. I want to be anonymous.

124. I do not wish to be called to give oral evidence at the inquiry.

Statement of Truth

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

Signed GRO-B

Dated 30/4/19