Witness Name: GRO-B
Statement No: WITN1491001
Exhibits: 0
Dated: July 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF GRO-B

I, 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. I am unemployed due to my health problems.

2. I make this statement concerning the impact of my infection with HIV and Hepatitis C as a result of receiving contaminated blood products.

3. This witness statement has been prepared without the benefit of access to my full medical records.

Section 2. How infected

4. I was diagnosed with severe Haemophilia A at 15 months old, and I was found to have no clotting factor. At the beginning I was treated with Cryoprecipitate (Cryo) whenever I had a bleed. I used to live in GRO-B GRO-B at the time, so my parents used to drive me to GRO-B in

GRO-B for my treatment. I recall knowing that Cryo was expensive and that it had to be used within a short period of time from it thawing. I often had to wait in agony for a couple of hours, waiting for it to thaw. I recall that the nurses often had difficulty administering my treatment, as my veins were very thin. Cryo was the regular treatment that I had in the early 1970s.

5. I used to receive my treatment fairly regularly; on average once a week. However, there were periods of time when I would go two to three times per week and periods when I would go a whole week without needing treatment.

6. In or about GRO-B, I was first put on Factor VIII concentrate at GRO-B GRO-B. At the time I thought that it was wonderful, as the whole treatment process was a lot faster.

7. I was never informed about the potential risks associated with being treated with blood products, neither were my parents. At the time, we had no reason to believe we were being treated with anything but British blood products. I now know this is unlikely to have been the case.

8. I had a very difficult time at school. I attended the GRO-B GRO-B, where I was sexually molested by a teacher. I never told anybody about it, as she told me that if I did, I would be taken away from my parents. In order not to have to go to school I deliberately bashed myself into the walls to cause bleeds, which resulted me in needing to have time away from school. Eventually, the local authority got involved because of the amount of time I have taken off school.

9. I recall that while I was still at GRO-B, Acquired Immuno-deficiency Syndrome (AIDS) started to show up in the media. I recall being invited to a conference ran by Armour Pharmaceutical at around that time. It took place in around 1985 and it was in a conference room of a hotel in Oxford, and I recall it being rather lavish. It was a large event attended by many haemophiliacs from all over the country. It was to eradicate any fears and suspicions about safety of their products. The conference consisted of a lunch, slide shows, a presenter and representatives of Armours. I cannot remember much from that

conference. I recall chatting to a boy from GRO-B who was in a very similar situation to mine. That boy later died of HIV in about 1990.

10. We eventually moved to the North and I was treated at GRO-B. I was there from around the age of about 8 to 10 years old. I was treated at the pathology department, where I was under the care of Dr Wiley.

11. I attended the GRO-B, where I was assaulted by one of the orderlies who was responsible for pushing students around in wheelchairs. I was teasing him and he hit me on my back with his fist. I was around 8 at the time, and I had a massive bleed on my left shoulder. I did not say anything until it became very bad. I was then hospitalised. My parents were advised to prosecute him, but they did not want to cause any trouble which could potentially lead me to have to leave the school.

12. These two experiences of being abused in the two separate schools, left me extremely traumatised. However, notwithstanding these experiences, I was a very bright child and after I finished my education at the special school I wanted to return to my mainstream school. I had learned that the teacher who had abused me and the headmaster, who did not want me there because of my haemophilia, had both left. Therefore, I returned to GRO-B where I enjoyed my last year of primary school. I was still treated at the GRO-B GRO-B at the time.

13. Around GRO-B I went to GRO-B to attend an appointment with Dr Wiley. I went to the hospital with my mum, but I went in to the consulting room on my own. Dr Wiley said to me that I was exposed to Hepatitis B. I did not understand what he meant by that. I also distinctly remember him telling me that I was dirty.

14. Around this time I had a lot of bleeds. Dr Wiley and other medical staff at the hospital thought that I was being abused by my parents. It was arranged for me to be seen by a psychiatrist. During my visit it became apparent that I was not abused by my parents. This was in GRO-B when I was around GRO-B

and this was also around the time when I started being trained at the GRO-B GRO-B how to self-administer Factor VIII so that I could do it at home.

15. Eventually, my mum was struck off by Dr Wiley, who refused to treat me, so we had to go back to GRO-B I was there under GRO-B This is where I found out that I was not receiving enough Factor VIII under the care of Dr Wiley, which eventually resulted in damage caused by consequent bleeds. At the time, I had a lot of bleeds, particularly in my left ankle and right elbow, because they became the target joints prone to bleeds. GRO-B put me on three or four times the dose of Factor VIII that I was originally given by Dr Wiley.

16. I subsequently found out that Dr Wiley only used the British Factor VIII products. I am not sure as to the reasons why; I can only speculate that he might have known something about the potential risks that the American products posed. I also believe that this was partially the reason why he was rather stringent with how much treatment he was giving out, as I presume that he did not have a lot of the British Factor VIII.

17. For Secondary School, I went to GRO-B During this time I continued to be treated at GRO-B I had a lot of health problems at the time because of my haemophilia. I had a lot of bleeds, so I often had to use a sling or a wheelchair. I got bullied at the new school, so I would often refuse to go in.

18. My family and I ended up moving houses, and I moved school when I was around GRO-B The reason for this because people started to associate haemophilia with AIDS.

19. Very shortly after I moved schools, when I was about GRO-B I went to one of my regular hospital check-ups. I was called in with my mum and I was told in a very matter of fact way that I had the AIDS virus. I was told that did not have long to live. The term was not used at the time, but I now know that I was "HIV positive".

20. I am not certain when exactly I was infected; however, I believe that it was a long time before I was told. I believe heat-treated Factor VIII came out in around 1985 or 1986 and that I must have been given an infected batch of Factor VIII before this time. I also believe that I was infected whilst being at GRO-B GRO-B

21. I was told I was infected with Hepatitis C in or about 1992. I had had a blood test in about November 1991 was showed that I was free from Hepatitis C. About 3-6 months later, I went back to GRO-B for one of my routine check-ups, where I was told by a doctor that they were "sorry" but there had been a mix-up with my results and I did, in fact, have Hepatitis C. It was a traumatic experience to be potentially at risk of an illness, to be told that I did not have it, to be then told without any warning that I did in fact have it.

Section 3. Other Infections

22. I do not believe that I was infected with anything else, as a result of my treatments with blood products.

Section 4. Consent

23. I was tested without my consent. I used to give blood samples, but neither I nor my parents were ever made aware as to their purpose. I did that as long as I could remember. The only tests, which we were aware of were to do with my clotting factor levels.

Section 5. Impact of the Infection

24. When I was told about my infection with the "AIDS virus" (later known as HIV), I was terrified and in a state of disbelief. Nothing had been said before that appointment to prepare my mum or I for this news. My mum was shocked and

asked how it happened. The doctor responded that "they" (i.e. all haemophiliacs) had it. I do not think that I took in the information straight away.

25. I was given some advice about the things that I should not do. I was told that I could not have a girlfriend, that I could not share toothbrushes and razorblades, and that I should be careful with my blood when having a bleed. A senior nurse took me to a room aside and said that I "must not go near girls". Whilst I do understand that the intentions behind her giving me this advice were good, and that this was an attempt to prevent other people being infected, I did not appreciate the way it was given. It certainly had a negative impact on my ability to form relationships; ultimately I see it as one of the reasons why I am still single until this day.

26. After I was diagnosed with HIV, I had to be treated with the non-heat-treated blood products; they only gave the heat-treated products to those who were not infected. Looking back at it I do find it worrying, as I might have had one infection to begin with and I might have been co-infected at a later date.

27. At about the age of 16, as a result of HIV, I lost a lot of weight. My doctors were worried as I went from 13 stone to 9.5 stone in a short period of time. I was still eating but kept on losing weight.

28. Since HIV suppressed my immune system, I also suffered from gastrointestinal problems; this included diarrhoea, stomach ulcers and thrush in the throat, mouth and stomach.

29. The knowledge of my infections also affected my parents. It was very hard for them to cope with and a lot of the time I felt like I was the one helping them, rather than them helping me. None of us had any support from the outside; my parents felt as though their son had been given a death sentence. I could never talk to them openly about it which eventually took its toll on me emotionally.

30. At about the age of around 15 or 16 I started to have horrendous nose bleeds. I found out that this was as a result of HIV reducing my platelet count. I often had to stand over a sink with blood dripping from my nose for ages. With my conditions, it was very worrying as there was blood everywhere and Factor VIII injections did not help. I was given Epsikapron and Tranexamic acid to increase my platelet level. I suffered from the heavy nose bleeds until I was about 18 or 19 years old. They then suddenly stopped.

31. Knowledge of my infections, particularly HIV, also affected my mental health. My attitude to life was profoundly affected and meant that I became increasingly reckless; I thought I was already dead and so had nothing to lose. I bought a motorcycle and eventually crashed it; I ended up in a ditch with it on top of me. I had a lot of health problems as a result of this crash. The exhaust ended up right by my ankle and it burned through to my bone. I was due to go on a holiday the next week and I was told by a doctor that I could not go anymore; however, I went anyway.

32. I also started to drink a lot of alcohol (at the time I did not know I had any liver condition). I drank as much as I could, mainly cheap beer and cider. On one instance I almost killed myself. I was 16, everyone was out of the house, I drank everything out of the alcohol cupboard and passed out in my own vomit. I was fine in the end, as my mum came home and slept next to me to make sure that it did not choke.

33. Despite being happy to put myself at risk, I would never risk passing on my infection to anyone else; I had a lot of attention from girls, but I did nothing about it, as I did not want to risk passing on my infection.

34. I was very concerned about the stigma associated with my infections, particularly the HIV. I became very selective about who I told about my haemophilia, as people learned to associate haemophilia with HIV and AIDS. I had heard horror stories about people's windows being smashed because they were suspected of having AIDS and I did not want to risk the same happening to me. As a teenager, I would even tell my best friends about my haemophilia. Whenever I had a bleed, I hid from them. When they would

come to see me, my parents would say that I was out. For a long time, the only people who knew about my HIV infection were my parents and my younger sister.

35. After I had finished sixth form, I decided that I did not want to go to university straight away; instead I wanted to work and earn some money. I got a job as a GRO-B which was very good considering that I was only 18 at the time. It was a great scheme for me as I got to learn about cars, bikes and retail management, and I really enjoyed it. Unfortunately, the work took a huge toll on me and I quickly started to feel exhausted. The job itself was very demanding, it had a 7-day working structure and as a manager I had to work from 7:45am until 8:00pm. I quickly realised that I had a lot less energy than other people my age.

36. Eventually I was unable to continue working there and I had to look for another job. I started working for GRO-B and initially this went well. However, once again I started to become fatigued and began suffering from stomach problems and diarrhoea. I lived in GRO-B at the time and my job was in GRO-B which was a long commute. Eventually my stomach problems became so bad that I had to pull over every 15 minutes during the drive to work to go to the toilet. This meant I had to take lengthy periods off work which eventually led me to lose my job.

37. I was very sick when I was around 19 or 20 years old; however, after the worst period passed, I started to feel better and I wanted to start a new job. I got a job in the Civil Service, working in GRO-B. I told my employer about my health problem and they proved to be very understanding. I wanted to live as normal life as possible, but this was difficult. My ill health continued whilst working for the Civil Service. At the time my Haemophilia was manageable, however, the symptoms of my infections were not. I still suffered from severe gastrointestinal problems, and eventually I lost my Civil Service job as well.

38. I am not sure whether the above health issues were due to HIV or my Hepatitis C infection. It could have been connected to both. However, as a result of them I have lost three jobs and a chance to build a successful career.

39. I also was not doing very well mentally. I sought medical treatment for depression, but instead of being offered counselling or medication, I was told something along the lines of "this is what whiskey is for". They did not know about my Hepatitis C infection at the time. I was eventually given antidepressants (tricylic), which made me feel even worse, so I stopped taking it.

40. I then joined my sister and GRO-B on a road trip around Europe. I had a terrible breakdown in France near the beginning of our trip and I could not stop crying. I could not sleep or eat, I was sweating, could not concentrate and my heart was racing. I thought that I was going to die. We had to drive all the way back from France. Everybody, including my sister, were very upset with me over this, because they did not understand what was happening.

41. In or about September 1991, I was admitted to the GRO-B suffering from severe panic attacks and heart palpitations. It turned out that someone gave me acid and when I went to the doctor I had a full breakdown. I felt like all the mental walls that I had put up until then were blown away in one night. It was an absolute turmoil. The effects of acid wore off, but the feeling of panic did not go away. I was given antipsychotics after which I slept for 2 days. This was as a result of being so mentally exhausted. I was then referred to a retreat, where I was treated with beta blockers and chlorpromasine. In the letters from doctors it was stated that this was all a reaction to the physical illnesses I had (i.e. my HIV).

42. I had managed to stop drinking for quite a while before this incident; however the stress of this situation caused me to start drinking quite heavily all over again. I also began smoking marijuana; I think this was all because I had given up on life.

43. I was 21 years old before I told my best friend of 3 years about my infections for the first time. I was scared, as I believed that he might reject me. However, he broke down crying and he stuck by me. It really affected him, as he cried for many days after that. I did eventually tell all of my close friends, but it took me a long time to do it. I built up the courage and told a few people in 1998 and then a few since then. I am still weary of telling people about it as I never know how they will react, so I do not tell people about my illnesses unless I absolutely have to.

44. After the mental breakdown I started to attend church, which I found to be a great help. I attended services every Sunday and became a very devout Christian. I bought a camper van with the money I had received from the Skipton Fund and I took part in a charity organised by the church. We drove to Ukraine via Poland, Belarus and I also went to Russia. The purpose of this trip was to distribute medicine, bibles and toys to orphanages. When I went to Ukraine, I went just outside the Chernobyl exclusion zone. When I visited the hospitals there, I found many skinny, bald children on drips, which clearly indicated that they had cancer. It was an eye-opening experience.

45. Around that time, I met a girl called GRO-B who was a member of the congregation. We eventually became a couple. I told her that I was HIV-positive and she stood by me.

46. Later on, I found out about being Hepatitis C-positive, which I also informed her about. She was able to deal with one infection, but not two. Our relationship was very serious at that stage and we even spoke about marriage. It turned out that her parents were very unhappy about her being with me, given my infections. This was revealed when one day her dad took me aside and accused me of trying to kill his daughter. He said that and that somebody in my situation should not have a relationship and should not even want one. I tried to argue with him, but nothing helped. Given the environment around us the relationship eventually crumbled.

47. GRO-D

GRO-D

GRO-D Knowing that GRO-B family were prepared to accept GRO-D into their family on the one hand but, on the other, were not prepared to accept me because of my infections made the experience all the more hurtful.

48. At the time I was leading a confirmation group at the church; this fell apart when GRO-B family told others in the congregation about my condition. As a result, nobody wanted to have anything to do with me. This rejection by members of the church affected my faith and was a further blow to my mental health; I have been on antidepressants ever since this time.

49. I had a few other relationships; however, I did find it extremely hard to disclose my status to people. I was always afraid of rejection. It was as if I had grasped happiness with GRO-B and then had it yanked from me. Apart from one other relationship at university, I have never had another romantic relationship.

50. In GRO-B I moved to GRO-B to attend the University there. I had also switched to the GRO-B My illnesses also affected my further education. I studied GRO-B at the university, but I had to drop out because of my depression. It was a very deep-thinking course, so I found it very difficult to deal with, particularly in relation to what happened at the church and the fact that my course was so closely related to it. This was all after my relationship with GRO-B broke down. It took me a very long time to get over this relationship.

51. I had gone through many different stages of depression throughout my life: from binge drinking, to periods when I did not go out, I did not wash and layed in bed for the whole day. I also had suicidal tendencies; I often thought of overdosing and driving off a cliff; at one point I found myself with a gun in my mouth. My housemates were very worried so they finally went to speak to a

doctor about it. I then had some counselling with a community psychiatric nurse who visited me at home. I have been on antidepressants ever since the breakup. I am pretty certain that I am addicted to them by now, as every time I tried to come off of them, I relapsed. None of this would have happened if it was not for my infections. I am currently on the maximum dose of Duloxetine.

52. I did well in the first year of university, despite the fact that I had gastroscopy, in which I was diagnosed with a stomach ulcer, and I had also developed arthritis in my elbow. However, everything went downhill in the second year of university, so I dropped out in GRO-B

53. For a number of years I have been hoping to go back to the university. If I was to go back I would do a different course, because of the emotional difficulties that my original course had caused me. A degree also costs great amounts, so I would probably never go back, as I am aware that I would probably never be able to work. I do often feel guilty and put extra pressure on myself by thinking that I could make more of my life, but at the same time I am aware that I physically cannot.

54. I first started hearing about azidothymidine (AZT) around 1991. I believe that this was around the time when it came out, but it was first given to people with full-blown AIDS, not people who were HIV positive. I believe that this was because the treatment was very expensive. I was first put on AZT treatment, in about 1993. It was the first treatment I had but I was not able to tolerate it for a long time. They kept on changing the drugs that I was on until they could find something that I would tolerate. A lot of the drugs caused me terrible aches, headaches and nausea.

55. I do not recall the name of the next drug that I was given in 1998, but I do recall that it caused me severe gastrointestinal problems, so I had to be put on something else again. One drug that they put me on was working well for me for a long time, but after a while it caused me awful ingrown toenails which eventually got infected. A doctor did tell me that it was a direct side-effect of the drug that I was given, so my treatment had to be changed again. It was all done on trial and error basis.

56. The doctors did eventually find the right combination of drugs that worked for me. They were Abacavir, Lamivudine and Raltegravir. I am still taking them now to manage HIV. New improved drugs did come out since I was put on this combination, however, the doctors did not want to put me on them, in case if they were unsuccessful, and since I do not experience any major side-effects from the current combination, we decided to just continue it.

57. I first received antiviral treatment for Hepatitis C in 2002 and was given Interferon and Ribavirin. I believe that I had to be taken off this treatment, as my liver began to fail, as a result of which I became jaundiced. I also lost a lot of weight. I did have some liver damage, but at that point I was not getting further damage.

58. A coupe of years later a trial of Pegylated Interferon came out and I was put on it. The side-effects of it were horrible; it was as if I had a constant flu. Besides the flu I was constantly exhausted, I had temperature, I was feverish and I slept all the time. I believe the treatment lasted for around a year and a half in total. Fortunately, the treatment managed to clear Hepatitis C.

59. I was happy to have cleared Hepatitis, but the damage to my liver was already significant. I have to have regular liver function tests to this day. I have been told that at the age of 49 my liver function is equivalent to a person in their 60s.

60. More recently, I have also developed fibromyalgia (FMS), which causes me great pain all over my body and exhaustion, as well as brain fog. It became worse after an operation on my ankle for haemarthropathy and bone growth, which I believe was contributed to the lack of sufficient Factor VIII treatment over the years.

Section 6. Treatment/care/support

61. I was not offered counselling after my HIV or Hepatitis diagnoses. I ended up bottling it up and ignoring the issues, this was partially because my family did not want to speak about it. I would have taken it if I had been offered it. I was offered to see somebody in 1993, but it was a long time after I found out about my illnesses, so I did not think that it would be of much use.

Section 7. Financial Assistance

62. I received the initial payment of £20,000 from the MacFarlane Trust.

63. I have been also receiving monthly payments. At the beginning they were very low and it was hard for me to survive on them. I used to live in a very small one bedroom flat and I was always in debt. In around 2000 things started to become easier, as the payments began to increase.

64. The application process was pretty straightforward; I recall having to fill in a form and sign something, so that the Trust could then contact me.

65. I had also applied to the Skipton Fund. I received the stage 1 payment of £20,000. I did not get the stage 2 payment.

66. The application process for that was not as straightforward. It was based on signing authority forms for them to see if I was a genuine case.

67. I did find the MacFarlane Trust to be quite restrictive. The grants were restricted to people with houses and mortgages, which I believe was quite biased towards people who were adults when infected. When I spoke to someone from the Trust I was told that those were an extension to the benefit, and that people applying needed to meet certain criteria. I was a child when I got infected so I did not have my own house and a mortgage. They would also not give me any money towards a deposit.

68. I had heard that someone was given £100,000 for a house extension which I found appalling when I was not being permitted to get on the housing ladder. I complained about this to GRO-B, my local MP. It was found that the MacFarlane Trust had around £3,5 million of unspent money that they had to get rid of, so they had decided to spend it on house improvements. It made me furious all over again. I felt like this was what the MacFarlane Trust was focused on; helping the home owners. On the other hand, I did not receive a penny.

69. I believe that when the Trust was originally set up in the 90s, they made provisions for people with mortgages and families but they did not take into account that the children and teenagers that were infected would grow up. This demonstrated how badly this was organised and planned out.

70. Eventually, I managed to save up some money and pay for the deposit for my house.

71. I do get financial assistance from the England Infected Blood Support Scheme (EIBSS); however, what worries me is that there is no guarantee that I will continue receiving the payments until I die.

72. I recall that I had to sign a waiver for the Macfarlane Special Payments Trust (MSPT). I was advised by my solicitors at the time (I do not remember the name of the firm) to sign it in order to receive £20,000, as otherwise none of the other haemophiliacs involved would receive anything. None of us expected to live for very long at the time, and I thought that it was best to sign it for the good of the rest of the group. I do find the waivers disgusting. I do not think it was right for us to have to sign the waiver, under the threat that other people would not receive any money.

Section 8. Other Issues

73. We have not had any closure or justice from this tragedy. There is a constant feeling of helplessness, frustration and anger, and there is nowhere to direct it to. Which we need to squash down our frustration, as otherwise it would lead to further frustration and anger.

74. I hope that the Inquiry will find who is responsible for what happened and will discover who is responsible for the cover-up, as I am convinced that there was one. I also hope that the Inquiry will eventually lead to prosecution.

Anonymity, disclosure and redaction

75. I confirm that I do wish to apply for anonymity and that I understand this statement will be published and disclosed as part of the Inquiry.

76. I would be prepared to give oral evidence, if my health allowed me to.

Statement of Truth

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

Signed GRO-B 18.7.19

GRO-B