Witness Name: GRO-B
Statement No.: WITN5534001
Exhibits: **Nil**
Dated: 14 October 2021

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF GRO-B
ANONYMOUS

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 24 September 2021.

I, GRO-B will say as follows: -

Section 1. Introduction

1. My name is GRO-B My date of birth is GRO-B 1969 and my address is GRO-B

2. I have severe haemophilia A, with less than 1% clotting factor.

3. I work as an accountant on a contractual basis. I am single and I live alone GRO-B I have never married and have no children.

4. I intend to speak about my infection with HIV and hepatitis C ("HCV"). In particular, the nature of my illness, how the illness affected me, the treatment received and the impact it had on me, my family and our lives together.

5. I wish to remain anonymous for reasons that will become clear within this statement.

6. I should explain that I have no memory around dates and even years are extremely vague. Obviously when I was very young I have relied on what I had been told by my parents as I grew up. I have no records to refer to apart from some for the Skipton Fund/ the Macfarlane Trust/ EIBSS letters.

Section 2. How Infected

7. I grew up in the GRO-B area and have lived around there and close to it for all of my life. I am the youngest of three brothers. My eldest brother is four years older than I and my middle brother is two years older .

8. As a young child I had a lot of bleeds and bruised easily. My mother's cousin had haemophilia so my parents were aware of the possibility that I could also be a haemophiliac. However, my two brothers had shown no signs of haemophilia, so my doctor thought that it was very unlikely.

9. My parents had to fight to get me tested. I struggled to walk sometimes and used to have to hold onto things. I was eventually tested and diagnosed with severe haemophilia A when I was four years old. I have had regular bleeds in my knees and elbows, which has caused me problems to this day.

10. I used to go to hospital once or twice a month to receive frozen factor. This was a yellowish looking liquid that was administered using multiple large syringes. I remember arriving at the hospital and waiting to be diagnosed with a bleed before the nurses defrosted a bag of frozen

plasma. The Inquiry investigator has explained to me that this was most likely cryoprecipitate but previously I had thought that it was all factor VIII.

11. I remember the change to what I now know would have been factor VIII products, which came in the form of a small vial that was mixed with water before injecting. This started when I was around 11 or 12, around 1980. I remember it was a much quicker process and I was given batches of factor VIII for my father to administer to me at home.

12. After this, if I had a bleed at school, my father used to pick me up and inject the factor VIII into me. This continued until I was around 18 when I started to self-inject the factor product. I continued to receive factor VIII around once or twice a month at this time.

13. I was originally treated at GRO-B (no longer there). I then began receiving what I now believed to have been cryoprecipitate at Hammersmith Hospital before being transferred to St George's Hospital, Tooting, which was where I was first administered factor VIII product.

14. I remember on one occasion when I was still very young, perhaps aged 6 or 7, that Treloar's College was discussed with my parents by the doctors at GRO-B I cannot remember the name of the doctor, they changed regularly and it was basically whoever was on duty at the children's ward on that particular day.

15. The doctor at GRO-B talked about the possibility of me attending Treloar's College. My parents had heard of Treloar's and had seen pictures of children in wheelchairs at the school. Neither of them wanted me to go to Treloar's anyway but my father tells the story that when we got into the car after this appointment I burst into tears. I didn't want to be sent away to boarding school, but of most concern was that I didn't want to be seen to be being treated differently to other children. My

parents would never have sent me after this and as far as I can remember this was the only time it was discussed.

16. I can remember another boy in my year at senior school who also had haemophilia. I didn't want to be labelled with 'haemophilia' so I often avoided him so as to prevent being seen as the haemophiliac kid at school. I just wanted to be seen as 'normal' and would do anything not to be singled out.

17. I remember around 1984 or early 1985 that the haemophilia centre at St George's Hospital began testing us for HIV. I was told that I was being tested for HIV and I believe that my parents must have consented to it. We all knew about HIV by that time as it was all over the news and in the papers. I knew that haemophiliacs could be vulnerable to getting HIV and we were aware that there was concern that blood products were infected.

18. After being tested I waited six months and still hadn't received the results. It was at my regular six monthly clinic and saw Dr Bevan at St George's. During this consultation my parents asked Dr Bevan if he had my HIV test results, to which he seemed surprised that I had not received my results.

19. Dr Bevan took us told us that I had tested positive for HIV. Both my parents and I were in complete shock. No explanation was given as to how I had been infected; it was just assumed that I had been infected through contaminated blood products. I was diagnosed on GRO-B 1985, exactly a week before my 16th birthday. I know this date because it is on a Macfarlane Trust document that I still have.

20. I was not given any form of advice or information about HIV. I was given no leaflets or consultation about infection control. I just went home and had to get on with it. It felt like a death sentence. I felt that I had been sent home to die.

21. When we got home my father's anger increased. He had held this in during the appointment and on the drive home, but when he got home he started blaming everyone.

22. I felt completely neglected after my diagnosis. There was no treatment available and I just had to learn to live with the burden of knowing that I would be dead before I was 30. It was not until I was aged 22, after graduating from polytechnic, that I first received any form of treatment.

23. My father took me to St George's and we came out with a big pot of pills, which was AZT. I remember becoming very emotional; it had all suddenly become real and it hit me hard.

24. I viewed the AZT treatment as just delaying the inevitable outcome that I was going to die. I did not experience any side-effects from the AZT treatment, nor did I have any obvious symptoms or illnesses related to my HIV infection. I remember one particular treatment caused me to suffer from eczema and diarrhoea. Another change in my meds caused me to have an allergic reaction whereby my face puffed up. When they changed my medication the side-effects stopped. I have had many different types of treatment for my HIV, the names of which I cannot recall. Apart from from the side effects I have explained, I have experienced very few difficulties with my HIV treatments over the years.

25. During the six year gap between my diagnosis and first receiving treatment I stopped attending the haemophilia centre at St George's for about a 2 year period. I didn't see the point in attending as I thought I was going to die anyway. The centre phoned me up and threatened to stop giving me factor VIII unless I attended my appointments, which were every 6 months. After this I started to attend my appointments again.

26. As a result of my HIV infection, it seemed like a lot of hassle to try and apply for a job. Instead I started working for GRO-B mechanical engineering company. I initially worked on the machinery until I began working on the books and accounts after my mother's death.

27. I worked for GRO-B for 13 years until I decided to study to qualify as an accountant. After completing my exams, I began working as an accountant.

28. At some point after my HIV diagnosis, certainly within the following 10 years, I was diagnosed with HCV. This diagnosis almost went over my head. It didn't seem very relevant compared to my HIV and I didn't see it as a big deal. I can't remember how I was tested or diagnosed. I can recall very little about any of the HCV stuff simply because it seemed insignificant compared to HIV, which as far as I could tell then, was going to bring my early death.

29. I received no treatment for HCV until the early to mid 2000s. I received a twelve month course of interferon and ribavirin combination treatment. I injected interferon once weekly and took ribavirin tablets daily. This was under the care of the clinical infection unit at St George's Hospital.

30. I thought I was anaemic during the course of treatment, but after testing this was found not to be the case. I felt tired and a bit fatigued but in general the side-effects were not too debilitating. I was still able to work for GRO-B during this period.

31. Throughout the course of treatment, I was tested every 3 months or so, though I cannot remember the outcome of these tests. After completing the course of treatment, I was told that it had been successful and the HCV was undetectable. My liver function has been tested and is normal and I have had a liver ultrasound which also appears to be fine. The hospital discussed the possibility of a liver biopsy but decided against this because of my haemophilia and also because my liver function tests showed no abnormalities.

32. My HIV today is undetectable owing to my current treatment. I now take one tablet daily and this has no side-effects whatsoever. I also continue to take factor VIII every 48 hours as a prophylaxis.

Section 3. Other Infections

33. At some stage I believe I tested positive for hepatitis A, but I cannot be certain. I was regularly tested for hepatitis B but do not believe I ever tested positive.

Section 4. Consent

34. As far as I am aware I or my parents when I was too young, have consented to all tests and treatments that I have received. Though I cannot be certain.

35. My father once told me that prior to any diagnosis, he had asked whether there were any dangers with the factor VIII blood products and was told that they were negligible in comparison to the risks of not taking it i.e the good outweighed the bad. This suggests to me that the clinicians knew that there was a risk of blood products being infected.

Section 5. Impact

36. I was effectively given a death sentence just before my 16th birthday. This caused me to ignore all important life choices and instead focus on the short-term. I didn't think it was worth planning ahead as I was convinced I was going to die. If someone said to me that I was going to live past 30 I wouldn't have believed them.

37. I kept my HIV infection to myself and my parents. I did not even tell my brothers until after my mother died. It deeply saddens me to think that my mother died in the belief that I didn't have long left to live. After telling my brothers they have both been extremely supportive and have not treated me any differently.

38. I can remember my brother, who works for HSBC, nagging me about putting money into my pension. He didn't know about my diagnosis at

the time. I obviously didn't see the point as I thought I would be dead before long, though I eventually put some money in just to shut him up.

39. I started studying at a polytechnic because I didn't want to start working. I wanted to delay going into the real world. I soon neglected my studies and instead began drinking regularly. I have long since reigned this in as I knew it was getting out of hand.

40. At the time of my diagnosis, HIV was all over the news. It was horrible seeing the well known "don't die of ignorance", tombstone HIV adverts everywhere and I began to feel desensitised to it. I hid away from society and, although I was always fairly shy, I withdrew from people and social interactions.

41. I am wary, even now, of people asking me questions. I have always been open about my haemophilia but I am very protective with regards HIV being known amongst my friends. Lots of people draw a link between haemophilia and HIV. A handful of people have asked me, after learning about my haemophilia, if I have HIV. I have always responded "no" to this question; I would be glib and just laugh it off.

42. In retrospect, these questions used to get me down. I became increasingly self-conscious and even now I often assume that my close friends have worked out that I have HIV, without actually knowing if they have.

43. Over time I believe all of this has caused me to suffer with depression on occasions. I have lived a secret life to a large extent, even hiding it from my brothers for so many years, including when living under the same roof. All of this has taken a toll. Going for treatments and appointments would drag me down and I used to think about HIV constantly.

44. I have felt more self-conscious and anxious since the Inquiry was established. I feel that it has brought it all back into people's

consciousness once again, and people are being reminded of the connection between haemophilia and HIV.

45. A significant consequence of my HIV infection has been my inability to form and maintain a close personal and physical relationship. I had a relationship whilst at college but this did not develop into anything sexual, principally because of my HIV. I didn't want to discuss the subject or risk infecting anyone. I have never had the opportunity to have children, both because I thought I was going to die and because HIV deterred me from having sexual relationships. One of my close friends has recently re-married. He pesters me about going on dating sites and trying to meet someone but I don't because of my HIV and the years of living with it.

46. I don't have any other form of insurance apart from for travel, which I got through a specialist HIV travel insurance company. I have never even tried to get a mortgage because of my HIV. I don't want to answer the question about HIV so I have avoided the insurance applications altogether. GRO-B

47. I hardly ever go on holiday as a result. Whenever I have gone away I take a letter covering my haemophilia treatment. I also keep my HIV medication in the same bag but thus far it has never been looked at. The risk of this happening means going on holiday with my mates is a complete non-starter as I don't want them to know about my HIV.

48. My knees have suffered for over 20 years owing to persistent bleeds in my joints. I had my left knee replaced four years ago. Due to my hip over compensating for my damaged knee, I had had my left hip replaced seven years ago and now my other hip is causing me pain. I have chronic arthritis in both elbows.

49. My treatment for HIV now is very manageable and effective, so much so that my HIV is technically 'undetectable'. I take one tablet daily, though at one time I was taking 21 tablets a day. I can't remember the name of

the medication I take now, let alone all the medications I have taken in the past. I am able to live life pretty much as normal as a result of this medication.

50. I have been careful throughout the Covid-19 pandemic because my perceived weak immune system may make me vulnerable to infections. In the long-term, I don't see my HIV as a threat to my lifespan or longevity. Rather, I see the problems associated with my haemophilia as more of an inhibitor on my life and long-term prospects. I should've done more physiotherapy and I am now paying the price for failing to do so, though at the time I thought I only had a few years left to live. Another effect of living with HIV.

51. My family and I didn't discuss HIV after my diagnosis. We are not a very talkative and open family and my parents didn't discuss it with me. I am not sure how it affected them as a result.

52. GRO-B who was also a haemophiliac, died suddenly around the time I was diagnosed with HIV, around 1985. He was around 30 years older than me, which would make him roughly 46 when he died. I believe now that his death may well have been caused by HIV as a consequence of receiving infected blood products for his haemophilia.

53. I haven't seen a dentist for years. I haven't registered at a dentist because this would require me to disclose my HIV status. My teeth used to be a problem when I was young and my dental treatment was restricted by my haemophilia. I was occasionally treated by the specialist dentist at St George's Hospital. My teeth now are a mess but I still refuse to register with a dentist because I don't want to tick a box that says I am HIV positive or to face awkward questions and have my condition exposed to people within the community in which I live, after years of protecting my status.

Section 6. Treatment/Care/Support

54. I have faced no difficulties in obtaining treatment, care or support in consequence of my HIV and HCV infections. This was not an issue when I had my knee and hip replacements, though obviously I required a significant amount of factor VIII as a prophylactic prior to the procedures.

55. After my diagnosis with HIV aged just 15, I received no advice or counselling from St George's Hospital. I felt completely isolated and abandoned, and it was as if I had been sent home to die. I believe that this was a systematic failure and do not wish to personally criticise Dr Bevan as for over twenty years, he was of great assistance to me and we had a very good relationship.

56. I believe at a later stage I was offered counselling for my HIV but I turned this down. As a result, I have not received any other form of counselling or psychological support.

Section 7. Financial Assistance

57. My father asked me if I wanted to apply to the Macfarlane Trust when I was around 20-22 years old. I remember exactly where I was when he asked me GRO-B He approached me and asked if I wanted to apply. I simply replied that I thought it was blood money and was effectively the government paying people off for their mistakes. I thought it would not affect my life, which I thought had a limited span, or give me back my health so I refused point blank, at that time.

58. I was informed about the Skipton Fund by someone at St George's Hospital, probably by the haematology department or the HIV clinic. I didn't apply immediately. I decided to apply in the mid 2000s and my application was supported by Dr Bevan.

59. I was awarded a first stage payment of £20,000 from the Skipton Fund. I barely remember applying and cannot recall any difficulties with the

application. Until the English Infected Blood Support Scheme ("EIBSS") was established, I used to receive monthly payments of £341.33 a month from the Skipton Fund.

60. I decided to apply to the Macfarlane Trust in 2016. I received a payment of £43,500 in December 2016 as a lump sum and also received monthly payments of £1536 a month from the Macfarlane Trust prior to the founding of the EIBSS.

61. After the EIBSS consolidated the various funds, I received annual payments of £18,432 for HIV payments and £4,096 for HCV payments. I also received a winter fuel allowance of £531.

62. I recently received a levelling-up payment of £67,000 which brought my payments in line with those paid to infected persons in Scotland. This was followed by an uplift in my monthly payments to £3244 per month or £38,928 annually. I will also receive a winter fuel allowance in December 2021 of £544.

Section 8. Other Issues

63. There are thousands of people who can't be here to tell their story. I initially didn't want to engage with the Inquiry but on reflection I have decided that I must do so because I am one of the lucky few to have the chance. This is why I want to tell my story.

64. The way this was all treated was as if it was ignored. I was not given my diagnosis when I should have been and I was given next to no support after being handed what at the time seemed like a certain death sentence, now more like a life sentence. It is devastating to think that this could have been avoided if the government had invested in our facilities to become self-sufficient. Instead, they failed to do so and imported blood from prisoners and anyone else who was desperate for money in the USA. They failed us.

65. It has taken too many decades for this Inquiry to be launched. Successive governments have pushed the matter into the long grass probably in the hope that we would all be dead by the time this came to a head.

Statement of Truth

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

Signed GRO-B

Dated 14/10/2021