Witness Name: GRO-B
Statement No: WITN5542001
Exhibits: **Nil**
Dated: 27 April 2022

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF GRO-B

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 18 October 2021.

I, GRO-B will say as follows: -

Section 1. Introduction

1. My name is GRO-B. My date of birth is GRO-B 1966. My address is GRO-B. I am 55 years old. I own and run a beautiful pub in GRO-B Prior to that, I have worked in various jobs, primarily as a Potter. I have been with my current partner for nearly two years. She has two lovely daughters who are six and twelve. I am currently fit and well.

2. I intend to speak about my infection with HIV and Hepatitis C (HCV) following receipt of contaminated blood product during the course of my treatment for Haemophilia. In particular, I intend to discuss the nature of my illness, how the illness affected me, the treatment received and the impact it had on my life.

3. I can confirm that I have chosen not to have legal representation and that the Inquiry Investigator has explained the anonymity process to me. I would like to remain anonymous, the reasons of which I will explain in more detail within the **Section 8.** on 'Other Issues'.

4. I can also confirm that the Inquiry Investigator has explained to me the 'Right to Reply' procedure, and that if I am critical of a medical professional or organisation, they will have the right to reply to that criticism.

5. I wish to acknowledge that naturally as time passes, memories can fade. I have been able to provide approximate timeframes to matters based on life events. However, these timeframes should be accepted as 'near to' rather than precise dates.

Section 2. How Infected

6. I grew up in the countryside with my parents and younger sister. At 18 months old, I was coming out in a lot of bruises. My dad had a bit of a reputation for angry outbursts (albeit never of a physical nature), and so I have vague recollections that there were initial suspicions of domestic abuse. These were quickly dispelled when my mother took me to the doctor.

7. I was diagnosed with severe Haemophilia A, with less than one percent clotting factor. I was the first known case in the family. After my diagnosis, it transpired that my maternal grandmother was the first carrier. I also have a nephew and cousin who both have haemophilia.

8. In some ways, I had a lovely childhood. I grew up in the country, enjoying a very free and active life. However, because our lives were very physical, my haemophilia had a very significant impact on my childhood. I think there was a great deal of fear surrounding my condition. I experienced fairly frequent episodes of bleeding, which

resulted in hospitalisations at GRO-B. My mother was torn between maintaining family life and looking after me. At the same time, I was a child and didn't know any different, and so I didn't think about it too much.

9. I have many memories of being left in the hospital. On other occasions, I was physically forced to lie on the sofa in our house and not allowed to move. The sun was shining and my sister was running outside as a child should be able to do. As a result, I was highly motivated to hide any bleed. Bleeds caused my family a great deal of trouble and often resulted in hospital admissions. I wouldn't wish it on anybody.

10. At times, I experienced bleeds following accidents, one of which followed a fall from a cliff in which I broke my arm. However, most often my bleeds were spontaneous. This was a source of conflict in my family as my dad thought that if I was more careful, I could avoid bleeds. Nevertheless, I suspected from a young age, that I would experience them regardless of any boisterous activity.

11. I think I was one of the 'first group' for whom there was any real effective treatment. Initially I was treated with cryoprecipitate. However, in the mid to late 1970s, when I was 10, I have a deeply traumatic memory of experiencing a massive anaphylactic shock following receipt of cryoprecipitate when I was in GRO-B

12. There was something in that batch that my body rejected. I can remember being scooped up and whisked to the operating theatre. I remember the fear on the surgeons' faces. They thought I was dying and I believed them. I passed out, but they kept me going. It was only many decades later that I processed this incident. A part of me was worried about being fully lucid, in case I had died.

13. This incident upped the ante of my treatment. Doctors were worried about killing me with cryoprecipitate. This ensued a nasty regime where they tried to only give me cryoprecipitate from people of my

blood group. I'm AB negative, so this must have been a nightmare. Various prick tests preceded treatment, which was pretty unpleasant.

14. When I was 11 or 12, Factor VIII came along, which was revolutionary, although, compared to today's treatment, it's still pretty crude. I remember the freedom of being taught to self-inject at home. I was always given treatment on demand. There was a period in my teenage years when prophylaxis was attempted before quickly being discovered to be ineffective. A while later I came to understand that the prophylaxis I received was so low, that it stood no real chance.

15. When I was due to start secondary school, the school that I should have attended, took one look at me and told my mother that they could not accept me. My mum, being the entitled parent that she was, wrote to the council to remind them of their duty to educate. I was enrolled at a private boarding school, GRO-B, near GRO-B in GRO-B. I was one of the small percentages of 'day boys'.

16. In hindsight, the school was a horrible place but the education was a great deal better than I would have otherwise received. I do not harbour fond memories from this time. The few friends and acquaintances with whom I have kept in touch share similarly unpleasant memories. It was a fairly middle to the bottom rank public school for army, farmers and the rich. The culture was very brutal and sports orientated and of course I was disqualified. I likened it to a place you survived but did not enjoy.

17. I kept myself busy in the art and pottery rooms. I also loved English. That's what I'm best at. At the same time, the experience was pretty toughening. My nickname at school was GRO-B GRO-B. Being a haemophiliac with regular stays in hospital, I learnt to be a fighter. I did my 'O' levels at that school, walking away shaking the dust from my feet. I then achieved two pretty poor 'A' levels at the local comprehensive school. But life nevertheless started to

improve. I passed my driving test at 17 and my social life started opening up.

18. Then, in my 18th year, I got a phone call asking me to come into the Bristol Royal Infirmary (BRI). I was taken into a room where a rather confused and worried doctor told me that I had contracted some sort of infection from FVIII but that they didn't know exactly what it was. I was merely told not to have unprotected sex with anybody and that they would get back to me. I was provided with very little information and left feeling confused.

19. I don't remember my health being monitored during this time. The medical practitioners overseeing my care may have done so but I do not remember. I was also not aware that I was being tested for HIV before my diagnosis.

20. A few weeks later, in late 1983 or 1984, headlines about HIV and AIDS were strewn across 'The Sun' newspaper. I found out from the newspapers that I had two or three years left to live. The hospital didn't tell me, and so I was left to educate myself through the media.

21. Nevertheless, it transpires that the media were wrong about my life expectancy and that they vastly exaggerated the dangers of the virus. At that point, the probability of me infecting someone else was effectively zero. The chances of me dying immediately, were also fairly low.

Section 3. Other Infections

22. From a relatively young age, I was aware that I had immunity to Hepatitis B. I can only presume that this means that I was exposed to the virus at some point.

Section 4. Consent

23. I was aware that I was being monitored for my haemophilia but I wasn't aware that I was being tested for HIV. Since then, every treatment I've had, I've consented to. I am aware that St Thomas' have examined my blood. But, as far as I am aware, they have always been clear and transparent with me. I've also not been experimented on to the best of my knowledge.

24. I was never aware of the risks associated with Factor VIII. However, had I known of the risks, I would still have taken it. I didn't have a choice; I needed treatment.

Section 5. Impact

25. This may sound odd, but I would say that the most significant impact of being infected with HIV has been positive. I believe I've led a better and more fulfilling life because I thought I'd lost it at 17. My diagnosis redefined my life. Since then, I've pretty much spent every day doing what I want to do with my life; not what someone else wants or what I think I'm supposed to be doing. My life has been difficult but it has also been brilliant, interesting and varied. Every day since my diagnosis has been a win.

26. I haven't got my own children, but to a degree, this is also because of my haemophilia. It may be that HIV and Hepatitis C have taken this from me but I've had the opportunity to be a father to my partner's children, which has been very rewarding. I love my partner's two girls. I'm going to have ball for the next twenty years.

27. At the time of my diagnosis, my parents' relationship, which had been getting progressively worse for several years, finally collapsed. I'd fallen out with my father in a big way and was living in my

grandmother's house. My grandfather was dying after a series of strokes left him wheelchair bound. My sister remained at home.

28. Not only did I not have a relationship with my parents in which I could seek support, everybody around me was also in turmoil. As a result, I internalised my diagnosis. I was depressed for about three months, which was the first and only time I have been depressed in my life. I was coming to terms with the fact that my life was a mess anyway, and then I was led to believe I had finally lost it.

29. I was intelligent enough to realise that it would be unwise to share my diagnosis with anybody. I didn't speak to my parents about it and merely kept it to myself. Only years later, did I realise that I grew up into a fairly dysfunctional family. With my dad being an engineer, whilst I got an education in practical matters, we didn't really communicate about the big stuff. Most of my education in being human, I have garnished over the years, from friends and partners.

30. Looking back, there is no denying that, although my diagnosis with HIV was extremely horrible, feeling that I had lost my life at 17 or 18, enabled me to strip away all the aspects of my life that I didn't consider important. I was at a point where I was potentially considering University. I asked myself what I truly and earnestly wanted to do with my life.

31. I moved in with friends in a shared house. We all rode and tinkered with motorbikes and drank cider. I'd also grown up in a farming world, earning my money shooting wild rabbits with an air rifle. So, my friends and I were also familiar with guns. They did drugs, but I did not. We hung out and just passed the time for a couple of years. It was a nice break from the reality of the world; from the struggle of my schooldays to the turmoil of my parent's divorce and subsequently, my diagnosis.

32. This experience came to a fairly natural end. My friends and I weren't getting along anymore and realised that it was time to move on. Someone offered me a room for a fortnight in GRO-B I went to a pub called the GRO-B it was great. I was exposed to a room full of people who were very different to those I'd known in the rural world. I met people from all over the world, people with new ideas; who discussed books, art, music, intelligent men and women.

33. I remained in GRO-B doing various part time jobs, until I grew restless and wanted to do something different. I bought a ticket to go to Jamaica for three months, naively thinking that I could sleep on the beach with the little money I had. I very quickly lost half my money on the bus. I didn't know how I was going to live and sought advice from the High Commission, who advised me to get a job on the other side of the island.

34. I got a job on a big beautiful Dutch schooner. I started to have some fun. I got into my first serious relationship with an older Jamaican woman. She was 36 and I was 22. She was from a very wealthy mixed family. We lived in a house with servants, which was a novel experience. When she fell out with her mother, we got a flat in the UK. We both got jobs. It was all very good.

35. I told her about my infection, which to large extent I put to the back of my mind. Because so much time had passed and I remained in good health, I was in a degree of denial. I told her but in a way that played down the seriousness. She didn't seem that bothered. It was kind of a non-issue. We were generally having protected sex.

36. Between 1989 and1990, her 13-year-old daughter joined us. I was contacted by the Macfarlane Trust who provided me with a payment of around £20,000, which contributed to the deposit of my house. I received an additional payment because I was living with my then partner's daughter. The relationship soon fell apart and they returned to Jamaica.

37. I met my next partner with whom I was in a relationship for 14 years. She had a couple of young boys. She was more worried about my infection than my previous partner. I started to become aware of the need to be more careful. We had protected sex. I helped raise her boys. I did various kinds of jobs. That relationship came to an end when I was in my mid-thirties.

38. At this time, I mainly worked as a potter. My first love is ceramics. However, my income was not high and I grew fed up of being cold, tired and poor. I did an aptitude test to become a computer programmer. I enrolled myself on a couple of training courses in London which enabled me to secure various jobs in this field. I went on to enjoy a decent income.

39. Three or four years later, as my then partner's boys were teenagers, the relationship became strained GRO-B was not very happy. She'd always wanted a pub so we bought a pub together. At that point our relationship immediately fell apart. But professionally it improved because we were no longer trying to be a couple and focused solely on maintaining the pub management, which we did for the next 10 years until she retired.

40. After a couple of years of being single, I met a lovely woman called GRO-B who I was with for 10 years. She is a lovely, intelligent and vibrant woman. However, various traumatic experiences in her past left her with a number of mental health issues. We spent half our income trying to help her.

41. Essentially, whilst her mental health improved, mine plummeted. She was incapable of living in the present and making decisions, whereas I have to be doing things. The stasis of life got to me and the relationship collapsed. I dated a doctor for a while. I've been with my current partner for nearly two years. I've owned the GRO-B since 2004.

42. In the late 1990's, I sought to familiarise myself with the AIDS community. One of the doctors was very keen that I start taking AZT. I'm delighted that I refused. I witnessed people dying having taken the drug. I watched a couple of people die. I made myself go to the Lighthouse in London. I remember seeing what looked like corpses, only barely breathing.

43. I had transferred to St Thomas' in 1997, where I was under the care of Professor Jeff Savage. My blood work was initially good. Then in around 2000 or 2001, I felt that I was not healing properly. My blood work showed that my T cells were dropping. My consultant, Dr Babu urged me to take my infection more seriously. He initiated me onto an anti-HIV medication known as Abacavir. It was alarming embarking on this road as once you start, you don't stop. However, I knew I didn't have any choice.

44. Unfortunately, I was one of the few who had a nasty reaction. After a few weeks, I felt that I was going to die. I phone Dr Babu who advised me to stop taking the medication immediately. He said never to take it again or it could kill me on the spot. Although I didn't manifest any outward physical symptoms, it felt like my system was shutting down. I was lying in bed and it was like the force was leaving me.

45. My medication was changed to Kaletra It changed my body shape and I experienced bouts of nausea, but nothing serious. Over the years, my medications were tweaked. I'm now on Odefsy. Fairly soon, I was on treatment which entailed no noticeable side effects. I'd made a decision to be 100% compliant with treatment.

46. For several decades, I have been undetectable and in excellent health. I can still have unprotected sex without endangering anybody. I continue to consult with Dr Babu. My infection with HIV is not a burden to me. I don't think about it from one month to the next or even from six months to the next.

47. Around 2003, during one of my regular check-ups, I was diagnosed with HCV. Up until then, I did not experience any symptoms. It wasn't presented to me as a big deal. I was merely told not to drink too much, which wasn't a problem as I didn't drink much anyway. One of the lovely doctors at St Thomas' offered me treatment. Work at the pub had settled down and so I felt it was a good year to embark on treatment.

48. I took weekly injections of Interferon, which I administered into my stomach, together with a daily oral dose of Ribavirin. It was very unpleasant but it cleared the virus. People thought I was becoming an alcoholic, although ironically, I was sober. I lost my appetite and forced myself to eat, though I still lost a lot of weight. My skin cracked, for which I self-treated with E45.

49. In 2004 or 2005, the treatment was completed. I remember the day when I realised that I would never have to take the medication again. I was very relieved. After a couple of months, I felt completely normal. I do not have any liver damage or cirrhosis. A doctor who was 10 years younger than me said my liver was in better shape than his.

50. I only disclosed my infected status to my parents' years after I was diagnosed. They reacted badly. They didn't have the expected emotional response of empathy or sympathy. It made me grateful that I made the decision to abstain from telling them when I was first informed. As a result, I can't say my infections had any impact on their lives.

51. My sister's son GRO-B is also a haemophiliac. But treatment is very different these days. Fortunately, he has not been directly affected by contaminated blood. He is very fit and healthy. He used to work as a basketball coach.

52. Apart from a year of feeling pretty ill from treatment, HCV has not had any significant impact on my life. I am the kind of person whereby, however awful something is, when it has passed, I do not dwell on it. I move on with my life.

53. I have experienced stigma in the banking world as a result of my infection with HIV. When myself and my Jamaican ex-girlfriend were looking to buy a house in the UK, we sought to open a bank account at NatWest. By this point, I had received money from MacFarlane. We answered a question truthfully about where our money came from. We were told that we couldn't have a bank account. I have a feeling that this record was lost as we have not had problems since with other banks.

54. I long ago learnt that the best way is keep your mouth shut and get on with your life. I learnt that if you need to lie to bureaucracy then so be it. I wasn't expecting the world to be fair so I wasn't surprised at NatWest's behaviour, but I was nevertheless angry. I never felt that I owed anybody the truth because not everyone is fair or reasonable.

Section 6. Treatment/Care/Support

55. I have not experienced any problems in obtaining medical treatments including for dental care as a result of my infected status. Nevertheless, I haven't really needed it. I am fit and healthy and have good teeth.

56. As far as I am aware, I was offered counselling 20 years after I needed it. Nevertheless, I think that at the point I would have benefited from counselling, it would not necessarily have been effective because of the unknowns surrounding HIV at the time. I don't blame them for not doing better, because I'm not sure what 'better' would have looked like.

57. Indeed, apart from being led to believe that I had lost my life at 17 or 18, in a way, all these medical matters have merely featured in my life,

but without having a huge impact. My haemophilia trained me early on in life to fight and to be self-determining. I was never one to dwell on my issues.

58. My medical care from the BRI, was very poor. In hindsight, my impression is that when they diagnosed me with HIV, they were genuinely a bit unsure about the nature of my infection. Nevertheless, I still believe that they were trying to save money at the expense of my health. St Thomas', conversely, have been fantastic.

59. When I was under the care of the BRI, the problems with my joints were left to creep up on me. In primary school I remember being in a wheelchair quite frequently. Even from a fairly young age, the damage in my joints was manifesting, particularly in my knees.

60. By the time I was 32 or 33, I was walking like a cripple. My cousin GRO-B who was under the care St Thomas', advised me to transfer over there. I got my GP to refer me. My care was overseen by Professor Jeff Savage, who saved my life. He took one look at me and initiated me onto serious prophylaxis. My knees were gone. I was having a bleed a week regardless of the FVIII.

61. Mike Smith then rebuilt my knees. I had an osteotomy and he cleaned up the joints before giving me two knee replacements. That got me through a few more years. I've also had one ankle frozen. I felt that life started again; that I was given a new lease of life.

Section 7. Financial Assistance

62. Some years ago, I was contacted by Macfarlane. I was told that I was eligible for a payment due to my infection with HIV. I can't recall whether I filled out a formal application. I was young and needed money. I believe I was given £20K. I signed a disclaimer, agreeing that I would not sue the government in the future which was fine as I hadn't planned to in the first place. I used the money to contribute to the

purchase of my house. Years later, they started giving me money regularly.

63. Sometime in the 2000s', I was contacted by Skipton. I don't remember having to apply for financial support. In 2017, I signed up to EIBSS. I receive a quarterly figure of £10,000 for which I am extremely grateful. I also receive a winter fuel allowance.

64. I got a vague impression that someone felt guilty in some way and provided me with the money with very little hassle. I had no difficulties in accessing these payments. It seems that I'm a known entity.

Section 8. Other Issues

65. In the introduction of my statement, I confirmed my wishes to remain anonymous. I've lived my whole life without inhabiting the identity of someone infected with HIV and Hepatitis C. Apart from my close friends and family, no one knows about my infections. As a result, I would like to remain anonymous.

66. Another reason for my wishes for anonymity, is that I was in the public domain when GRO-B

GRO-B

67. I've got mixed feelings about the Infected Blood Inquiry I am certain that it should be done and that it's a brilliant thing. However, I have observed people who have the same medical condition as me and many others who live their lives as professional patients. I've travelled enough to know that if, for example, If I had happened to be born in a

different country, I could have died as a young boy from complications resulting from haemophilia.

68. It may be that there was a monumental disaster and that that certain individuals and organisations are accountable. Nevertheless, I don't consider myself a victim. It's not like I had a choice in taking treatment or not. Even if someone had informed me of the risks of contracting HIV and/or Hepatitis C, I would have taken it regardless.

69. It would be nice if the inquiry achieved something in the way of a lesson but I think it would be naïve to expect that. In light of everything going on in the last few years with Covid; of what this has illuminated about the relationships between pharma, government and compliance, I don't have much faith that any lessons will be learnt. I know enough doctors to have somewhat of an inside view into the complexity of those relationships. At the same time, I am aware that for some people, this situation is very much unresolved. I think if the inquiry helps to provide some sort of resolution or closure for those individuals, I would be happy.

Statement of Truth

I believ ment are true.

Signed GRO-B

Dated 27/04/2022