Witness Name: GRO-B
Statement No.: WITN0869
Exhibits: **WITN0869002-25**
Dated: 2nd August 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF GRO-B

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

I, GRO-B will say as follows: -

Section 1. Introduction

1. My name is GRO-B. My date of birth is GRO-B and my address is known to the Inquiry.

2. I intend to speak about my infection with the Hepatitis B Virus ("HBV"), the Hepatitis C Virus ("HCV"), the Human Immunodeficiency Virus ("HIV") and exposure to Variant Creutzfeldt-Jakob Disease ("vCJD"), which I contracted as a result of being given contaminated blood products to the treat my haemophilia A.

3. In particular, I intend to discuss the nature of my illness, how the illness affected me, the treatment that I received and the devastating impact it has had on my life and the rest of my family.

Section 2. How Infected

4. I am a forty-four year-old Haemophiliac. Following treatment with contaminated Factor VIII, I contracted HBV, HCV and HIV. I was also exposed to a batch of Factor VIII, which was produced from a blood donor who had vCJD.

5. I was born with a severe version of Haemophilia A. I received most of my care from the Haemophilia Centre at St James Hospital in Leeds. In the mid 1980s, I also had a spell of care at the Infectious Diseases department at GRO-B which was also situated in Leeds.

6. I received many NHS blood products, including the following: Cryoprecipitate (1976-1978); Factorate (1980); Lister (1981); Factorate (1982); High Purity and High Potency Factorate (1983); High Purity Factorate (1984); High Purity Factorate and HT Profilate (1985); HT Profilate (1986). Since 1986, I have received many other blood products.

7. I was infected with HIV, HBV and HCV as a result of using these contaminated blood products. These products were administered on visits to the St James's University Hospital and the GRO-B or administered as prescribed at home. My clinicians at the time were Dr L Swinburne, Dr Bailey, Dr Clifford Howarth and later, from 1986 to 2012, Dr Brian McVerry.

8. My medical records demonstrate that I was diagnosed with HBV on 11th November 1981 at the latest (WITN0869002). My records also show I was tested for HBV on at least two other occasions, once on 5th May 1982 (WITN0869003) and again on 9th June 1983 (WITN0869004). My records also include a hepatitis survey completed on 11th November 1981 by Dr Swinburne, which includes the batch

numbers, and blood products I was given in the six months prior to my diagnosis (WITN0869005).

9. My records show that, on 28th February 1985, my consultant, Dr Bailey, was concerned that my brother and I were "high-risk" and asked Dr Swinburne to assess whether we had already been exposed to HIV (WITN0869006). Dr Swinburne provided my results in response to this request on 6th March 1985, these results show that I tested positive for HIV (WITN0869007). This information was communicated to my G.P. Dr GRO-B by Dr Swinburne on 7th March 1985 (WITN0869008). I also have a record of another occasion when I was tested positive for HIV, at the Public Health Laboratory Service on 11th March 1987 (WITN0869009). Additionally, since obtaining my records, I have identified a further document, which shows that on 10th December 1984, I tested positive for HIV (WITN0869010). It is unclear when this test took place and why this result was not communicated to my parents or my haematology consultant.

10. From my medical records, it is not possible to establish when I was first diagnosed with HCV or when this diagnosis was first communicated to my parents. I would like to know where my medical records relating to my diagnosis of HCV are and why they are not with the rest of my records. My mother told me that I had contracted HIV in 1992. I later learned that I had also contracted HBV and HCV. I am not sure of what my parents were told about my infections, as I was only a child at the time.

11. I received very little information or support regarding my infections, which was hard, as I had nobody to talk to. My Haematology Consultant was not a good communicator, and his appointments were always brief. It wasn't as if I could go online to join a forum or download information. The Internet was in its infancy in the 1990s. The first time I received information and support was in 2000, aged twenty-six, when my GP arranged for me to see a counsellor.

12. I also received no information about the risks of transferring the diseases to other people. This wasn't really an issue though, as I felt I should not pursue a relationship, as due to the stigma surrounding HIV and HCV; I did not think anybody would want to be in a relationship with me.

Section 3. Other Infections

13. I received a batch of Factor VIII, which was produced from a blood donor who had vCJD. I was first alerted to the possibility that I had been given blood products produced from a blood donor diagnosed with vCJD on 22nd January 2001 in a letter from Dr McVerry (WITN0869011). I was invited to submit a reply sheet if I wished to know whether I had received blood products from the infected donor. On 5th February, Dr McVerry confirmed that I had received factor concentrate product, which contained a donation from the donor who was diagnosed with vCJD (WITN0869012).

14. On 20th September 2004, I was sent further information on vCJD and Plasma Products and was again invited to fill out a reply slip (WITN0869013). I was sent the same information a third time on 17th November 2004 (WITN0869014). Since receiving my medical records, I have found a document entitled 'Patient vCJD Exposure Assessment Form', which shows that I am at risk of vCJD and lists the batch of infected blood that I was given (WITN0869015).

15. I also remember being told that I had received blood products from a donor diagnosed with vCJD by my Haemophilia nurse over the phone in 2006. I remember this phone call clearly as I was at work when I received the call. She told me that it was unlikely that I would contract the virus at a future date. Fortunately, I have not shown any symptoms yet.

16. Obviously, HIV has weakened my immune system and I have experienced some very lengthy periods of flu. I have often exceeded the sickness limits at work and have received warnings in the past as a result. Because of this, I have been forced to go to work when feeling ill. Had I not gone to work, it is likely that I would have been dismissed.

17. Since receiving my medical records, I found a document dated 23rd March 1976, which shows I was admitted to hospital with a viral infection and severe symptoms (WITN0869016). I now wonder whether I was that ill because I was already suffering from the effects of the HBV. I also find it difficult to understand why I was under the care of a paediatric oncologist.

Section 4. Consent

18. On 28th September 1983, I suffered a broken finger when playing with my friends. My friend was swinging on his outside gate and I don't know how, but I managed to trap my finger in the gate. The pain was unbearable and my Dad had to take me to St James's University Hospital straight away (WITN0869017). Although I was only nine at the time, I do remember that I was allowed to go home the same night after I had received treatment.

19. For the same injury, I was admitted to GRO-B on 10th October 1983 (WITN0869018). I spent nearly a month in isolation as an inpatient at GRO-B because of my HBV status (WITN0869019). I cannot believe that I needed to be in hospital for such a long time for a finger injury. I do hope that I was not part of any research without my consent. I used to plead with my family, nurses, and doctors to let me go home. I would ask anybody who would listen, as I was very, very scared and I felt really vulnerable. It was hard to deal with being in isolation for such a long time and at such a young age. They kept on doing lots and lots of blood tests and infusions. I

couldn't understand why I needed so many and why I could not go home.

20. During 1986, I was an inpatient again. This time it was for an operation on my ankle to try to minimise the bleeds. Again, I could not understand why I was in a room on my own and why the porters and surgeons looked like space astronauts when going into theatre. The surgery took place at GRO-B and then my aftercare was at St James's University Hospital. Again, I was in hospital for a long period of time, I think it was for three weeks.

21. At the start of the next decade, in 1990, I had another operation. This time it was on my shoulder, but I was once again placed in isolation. I was fifteen and I still didn't understand why I was always placed in a separate room. This time I was there for around two weeks. I had another operation in 1995, when finally, I wasn't considered a risk and I was allowed to be in a bay with other patients.

Section 5. Impact

22. I was only a child in the 1980s, so unfortunately I was not aware of everything that was happening. I have asked my parents over the years about what occurred during the key times, but they could never really accept what had happened to me and so would choose not to talk about the subject whenever possible. The majority of my family and friends do not know about my infections.

23. In 1992, my mother told me about my infections. I had just started college and by that time, I had already suffered a lifetime of bullying at school for being ill and regularly absent. When I was first told, I was just stunned and I obviously knew that what life I had left would never be the same. I just didn't know what to do, I just could not believe how and why this had happened to me. I strongly considered leaving college, as I just thought I would probably be dead in a couple of years.

That was the perception from the media and it was my only source of information at the time. Fortunately, I didn't leave the course, as I thought that I would at least try and achieve something whilst I was still alive, even though my mental state was rapidly deteriorating.

24. I found college life just as difficult as school, but for different reasons. I had a small group of friends and I did socialise, but I often found this difficult. I made every attempt to not get involved with girls, as I just thought nobody would want to be with me. This led to my friends thinking I was gay and that was really hard to deal with. However, against the odds, I did graduate at the end of college, but my mental and emotional state continued to suffer.

25. The support and guidance I received from my Haemophilia Consultant was poor. I just wish he had said: "You could have a future, your T cells and viral load are really good." I might have had a better outlook on life. I wish he had advised me about my lifestyle at the time. I remember him saying once: "Do you drink?" I answered; "Yes, socially, with friends." His response was simply "Ok." If he had said it is not advisable for someone with HCV to be drinking, I would have considered stopping or reducing my intake. I did stop drinking in 2001 after finding out more information about the risks.

26. By the time I graduated, I had known about my status for around five years, but my outlook was still the same - time was not on my side - I wasn't going to be around. But I had to do something in the meantime. The pitiful £20,000 ex-gratia payment I received from the government for having been infected with HIV wasn't a sum of money that I could base my future on. Therefore, I had to work, even though this was very daunting. Working was inexplicably hard, especially with the fatigue and my bleeds from the Haemophilia. I also seemed to regularly pick up infections. Furthermore, I was worried about my employers finding out about my medical history. My worst nightmare was confirmed at one job and consequently, work life became very hard, as I was treated

'differently'. One example of this was, whenever it was my turn to make the drinks, I think only one or two of the fifteen people in the office accepted a drink from me. This discrimination lasted about a year until I found another job.

27. With the advancement in medicine and also to some extent the Internet, I learnt that perhaps I could have a future. I had not been on antiviral drugs yet as my t cell and viral load levels were good. I decided to see if I could possibly have a relationship. I didn't know if this was practical, as I still thought it would be hard for anybody to accept me with the stigma surrounding HIV as strong as ever. Furthermore, as I had avoided being with girls, I had not even had a kiss and I was twenty-four years of age!

28. From 1999 to 2004, I had three relationships, two of which ended directly because of my HIV, HBV and HCV status. A previous partner said the following to me after I disclosed my status: "I am sorry, but I am just not attracted to you anymore because of the virus." The result was that I felt dirty, akin to a germ and my confidence and self-worth were at rock bottom.

29. Another partner who I informed reacted similarly, but on this occasion her family made violent threats against me, telling me to stay away from them and their daughter. This was such a contrast to my first meeting with them, when they viewed me as a future son-in-law, but just the virus alone was enough to radically change their view.

30. The pain and hurt never ceased with these experiences. There have been lots of other cases of rejection that I have experienced, all of which have negatively affected my mental health. This was the early 2000s and the level of education, ignorance and stigma was no different to 1984.

31. Over the last twenty years or so, I have experienced mild to severe depression, which has required medical intervention on some occasions. During the real low points of rejection and isolation, I have contemplated suicide. I have often sat alone with a knife next to my wrists or a bottle of paracetamol.

32. The infections have resulted in me becoming introverted and isolated. Avoiding social situations where possible has become the norm for me. I am often asked: "Why don't you drink alcohol?" "Why are you always tired?" "Why are you not enjoying yourself?" This is just a small selection of the questions, which I get asked, all of which increase my mental burden. I am tired of making excuses and I simply do not have the energy or mental capacity to do it anymore, so being on my own seems the easier and safer option.

33. My view of the world has been tainted as a result of receiving contaminated blood. It affects so much of who I am. Of the friends I do have, the majority of them are in the same situation as myself, but a lot of them have now died. Sadly, funerals are a regular occurrence in the contaminated blood community. Furthermore, I do not have the physical, mental or emotional capability to socialise or attend events, as I also suffer from chronic fatigue. This has further exacerbated my depression.

34. My most recent medical intervention for depression commenced in September 2016, when my GP prescribed me Fluoxetine, with a view to long-term treatment. At present, I am still taking this drug.

35. The viruses affect every aspect of my life. A good example of this was when I was injured in a car accident. I was not the negligent driver and was encouraged to seek damages from my insurer for my injury. I decided to pursue legal action, but then decided to refrain from this, as I had to disclose my medical history to pursue a claim. I just didn't have

the mental strength and capacity to explain my medical status and was also worried about confidentiality.

36. If I go on holiday I have to secure expensive travel insurance. Arranging travel insurance is not a pleasant experience. I have to inform them of my latest blood results and they always probe into how I acquired the viruses. I am always worried when I go through customs that they will search my bag containing the considerable amount of medication I have to take with me. I have a letter from my physician authorising the medication, but it still could be an unpleasant situation if I have to tell them what the medication is for.

37. On one occasion when I had a short break in England, I forgot to take my medication with me. I was only going away for four days, so I phoned my consultant and asked if it was ok if I had a break from the antiviral medication. The end result was that I had to drive 100 miles back to my house to get the medication and then drive another 100 miles back to my destination. Like I say, my infections have affected my life so much.

38. When I finally met a special person who accepted me for who I was and didn't just see the infections, it was a wonderful experience and all the rejection and pain seemed worth it. However, having a relationship with infections is hard. On one intimate occasion, the contraception didn't work and my partner had to have a course of PEP (Post Exposure Prophylaxis). This was extremely stressful, as we had to go to the A&E department in the middle of the night. Seeing my partner suffer with the same side effects from medication that I have experienced was really difficult and I said to her that I would understand if she wanted to end the relationship.

Section 6. Treatment/Care/Support

39. The Hepatitis infections have scarred my liver. This was confirmed by a liver biopsy at St James's Hospital in 1996. This is a very uncomfortable procedure and requires a hospital stay afterwards. Shortly after the biopsy, I received Interferon treatment to try and eradicate the HCV, which unfortunately failed. I experienced some bad side effects with this drug. It made me extremely tired. Nevertheless, I tried it again in 2002, when an improved version of the drug was introduced. Again the treatment failed and again the side effects were terrible. Extreme fatigue and anaemia were hard to deal with, especially as I was working full-time.

40. I was told new treatments were on the horizon, but I had a vision that at some point I would need a liver transplant, that's if I had not died first, either through HIV, or had a bleed on my brain through haemophilia, or if vCJD decided to make an appearance. Thankfully, a new treatment was introduced in 2014, but it was expensive and not everybody could have it. Although my liver was scarred and my liver function tests were irregular, and despite not having had a drink of alcohol for sixteen years, I was still not able to access this treatment until 2017. Thankfully, the treatment proved to be a success and I have been told that I have eradicated the virus. Unfortunately, I still suffer from fatigue and I worry about the long-term damage to my liver, as I do know people who have been cleared of the virus and subsequently still died from liver cancer.

41. This was not the first time I had problems accessing treatment. I have never ever seen a private dentist. As a child, I had to go to the dental school in Leeds. For reasons that I am not aware of, I stopped going there sometime in the mid to late 1980s. The next dental examination I had was in 2004 (WITN0869020). Haemophiliacs are not a sought after client group by dentists.

42. In terms of HIV treatment, my T cells and viral load were fairly good following the initial infection. However, they started to decline around

2005 and I was advised to start antiviral treatment. I was worried about the side effects, but I was assured that the newer drugs were much safer. I started treatment in 2010 and suffered immediate side effects, the most serious being my liver function test, which went through the roof so I had to change treatment. I had diarrhoea for a long time, until I started to tolerate the drugs, although it is still present at a lower level nearly ten years later.

43. I received no counselling, nor was information on accessing psychological services offered until 2000, when my GP arranged for me to see a counsellor. Looking back it certainly would have helped me to cope and understand what my body was going through.

Section 7. Financial Assistance

44. I found out that there was some financial assistance available when I was first told that I had been infected. I expected a substantial sum, given the way in which I was infected. To be told I would receive an ex gratia payment of £20,000 for major life threatening diseases was very hard to deal with and made me so angry. I did find out nearly twenty-five years later that I had actually received another £20,000, but this was kept from me. My parents rightly or wrongly let me have bits of this money over the years, but I was unaware that it came from an ex gratia payment. A lot of key emotional moments in my life changed as a result of finding out. I always thought that I was really lucky. I used to think that my parents really took care of me; they have helped me put a deposit on my first apartment and things like that. My parent's intentions were undoubtedly good, but it took me a while to come to terms with this.

45. In the early 1990s, I applied for started to receive small monthly payments from the Macfarlane Trust. These regularly varied in value. When I was first employed, I think I received something like £140 a month, which was very hard to live off. I did work, but I have never

been a huge earner, especially in my first job. I think I was on around £11,500 a year in 1998. Although I graduated with a degree, I did not have the energy or confidence to try and go up the promotional ladder. I was constantly fatigued, so my career has been in low to medium paid administrative work. In order to give me the best chance of survival, I try to eat healthily as much as I can, but healthy food is expensive and it is not always possible to purchase it, as I simply do not have the financial resources.

46. Work stability has not been good due to my ill health with the infections. I have received warnings because of the high number of sick days I accumulate. As previously mentioned, on one occasion I was ostracised and bullied when my health status was revealed, without my consent, to my work colleagues. My social skills and confidence were massively affected, reducing my ability to cope with difficult situations. I am constantly depressed and have become a very introverted person. All of the above has massively reduced my earning potential. I can now only work two days a week as I just feel exhausted all of the time with the infections. This is on top of the bleeds and arthritis I experience on a daily basis. I know that I will have to quit work soon and then I will face a very uncertain future, as I will have to try and survive on benefits.

47. I have often been in debt and have had to re-mortgage my home on two occasions. When I found out in around 2012 that the Macfarlane Trust had been sitting on reserves of £1 - £2 million, I was very angry. If I had had a little bit extra when I first started work, it would have made such a difference to my wellbeing. Furthermore, when the Macfarlane Trust ceased, they handed over a large portion of the reserves to the Terrence Higgins Trust. I did not agree with this, as this money was meant to be for Macfarlane Trust beneficiaries.

48. I did not find out that grants were available from the Macfarlane Trust for sometime. I did receive some grants for a couple of Personal

Computers over the years. I did not like applying for grants as the process was exhausting and it felt very demeaning, almost like begging. The amount of paperwork you had to complete or supporting evidence you had to provide was overwhelming. For example, if you needed assistance for anything household related, you would have to provide work quotes from numerous builders and statements from your doctor, nurse or physiotherapist on why you need that particular form of assistance. You could go through all of the effort of providing all the information and then have your claim rejected, so it tended to put you off from applying.

49. When the Macfarlane Trust monthly payments started to increase in around 2009, the level of paperwork also increased as well. Every beneficiary had to complete an income questionnaire, and we received a discretionary top-up to our monthly payment, relative to our income. The questionnaire was lengthy and intrusive. I had to provide bank statements, wage slips, council tax bills, utility bills and more as part of my income evidence. I know it is important to have an audit trail, but it just seemed like overkill. If every beneficiary received the same payment, it would have been a much fairer system, as some beneficiaries never applied for grants.

50. In my opinion, it is unfair for the Trust to calculate the amount paid to infected people by using their household income rather than their individual income. I used to live on my own, but when I got a house with my partner, I ended up being about £2,000 worse off in my payments from the Macfarlane Trust. Furthermore, my partner also has to provide evidence of her income, so she has to provide all the above evidence in addition to me otherwise my discretionary payment wouldn't be processed. I think it is very unfair that my partner's income is taken into account. Unfortunately, the same income questionnaire and rules are still in place with the successor to the Macfarlane Trust – the England Infected Blood Support Scheme.

51. Another unfair aspect of the discretionary payment scheme, in my opinion, is that it is related to income of the household, not the infected beneficiary. I used to live on my own, but when I got a house with my partner, I ended up being about £2,000 worse off in my payments from the Macfarlane Trust. Furthermore, my partner also has to provide evidence of her income, so she has to provide all the above evidence in addition to me otherwise my discretionary payment wouldn't be processed. I think it is very unfair that my partner's income is taken into account. Unfortunately, the same income questionnaire and rules are still in place with the successor to the Macfarlane Trust – the England Infected Blood Support Scheme.

52. I have also received a Stage 1 payment for the HCV infection. In total, I received £20,000 in 2004 via the Skipton Fund.

53. In conclusion, I believe the financial assistance has not been sufficient. As previously mentioned, every aspect of my life has been affected by the infections. In other countries, beneficiaries have been rewarded handsomely. In Ireland in particular, I believe the average payment was around £300,000. Such a large disparity is hard to take, as I have received nowhere near this figure. Even more recently, with the introduction of the new support schemes, beneficiaries who reside in Scotland receive more financial support than those in England. That is just ludicrous. I cannot accept how such a rich and prosperous country as England can provide so little to people who have suffered so much.

Section 8. Other Issues

54. In 2004, I was made aware of possible action against the American drug companies. An associate from Lieff, Cabraser, Heimann & Bernstein of San Francisco came to a weekend meeting organised by the Macfarlane Trust and explained the case to us and what they hoped to achieve.

55. I was eager to be involved as I thought I could finally get justice for the emotional and physical damage I have suffered. It also represented a possible escape route from the job I was in, as I was currently working at the employer who found out about my medical status. Lieff, Cabraser, Heimann & Bernstein agreed to represent me on a no win, no fee basis. I provided them with my medical records and they created a 'Preliminary Patient Profile Form', which sets out which blood products I was given (WITN0869021). I exhibit the plaintiff's trial bundle as WITN0869022 and a client letter that was sent to me as WITN0869023.

56. The Judge seemed to be on the defendant's side from the outset and this did not change as the case progressed. I remember he said something along the lines of "a class action could result in the defendants having to declare bankruptcy!". I don't know if this was due to their vast financial resources, but the judge dismissed a class action, so my attorney had to file individual cases, which took an immense amount of time and resources. The drugs companies attacked my case word for word and purposefully requested documents which they knew I would not be able to access. I exhibit WITN0869024, which contains my responses and objections to the drugs companies requests for production.

57. The next unfair incident was that, nearly four years after the case was commenced, the Judge agreed with the defendants that individual cases should not be heard in the United States, and instead should be heard in the UK. My attorney appealed, but it took nearly 18 months before a decision was made. The appeal failed, so my attorney established links with two British based solicitors – Irwin Mitchell and Michelmores. I decided to be represented by Michelmores, but the case slowly started to die.

58. I didn't understand all the legal terminology, but I think they struggled to get the case insured and I couldn't get legal aid, so at that point, the

initiative swung with the defendants lawyers. They made a take it or leave it settlement offer of around £20,000. I and everybody else had to agree before they would pay. I remember my solicitor saying something like "they want global peace" so they don't have to fight any other action at a later date. The case finally ended in 2010, which I was really pleased about. I wasn't pleased with the outcome, far from it, but it was eight years of stress I could do without. I had countless early morning conversations with my attorney but it was at this point that I thought I would never be able to get any justice.

59. In my current job, I have had to liaise with one of the drug companies who were involved in the contaminated blood scandal - Baxter. This is really hard to deal with. I try and stay professional, but this is difficult knowing the damage that they caused to my life and so many others.

60. I have not been involved in any campaign groups. I would like to be involved, but I am scared of my status becoming public knowledge for obvious reasons.

61. I had a new degree of hope when the Archer Inquiry was announced, but the Government did not really get on board with it from the start. They issued the same tired statements, such as "we sympathise with the Haemophiliac community, but the decisions were made in good faith".

62. The next glimmer of hope was when former Prime Minister David Cameron started to take an interest in our plight. I really started to feel we might be on the verge of something, especially when he apologised in the House of Commons amid the impending publication of the Penrose Inquiry. However, my hope yet again turned to anger and then consequently depression. I resigned myself to never getting justice, and this sent me into a deep depression.

63. I exhibit WITN0869025. Letter such as this one from Dr Bailey to my GP demonstrate that the doctors at the time were aware that there was high risk of HIV in American Factor VIII. I would like to know why the NHS was purchasing such high risk blood products, why NHS doctors continued to use high risk blood products and why I was never informed of the risk.

64. I need those responsible like former Secretary of State for Health Kenneth Clarke and former Prime Minister John Major to be held to account. They need to explain why they did this to my family and me. They need to explain why they allowed contaminated blood to be used. I need justice and to have some peace.

Statement of Truth

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

Signed GRO-B

Dated 2/8/2019