Witness Name: GRO-B
Statement No.: WITN0022001
Exhibits: NIL
Dated: 02/05/2019

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 14 February 2019.

I, GRO-B will say as follows: -

Section 1. Introduction

1. My name is GRO-B and I am 60 years of age having been born GRO-B 1958. My address is known to the Inquiry. I have been married to my wife GRO-B for 10 years and we have twin boys named GRO-B

2. I hold a Bachelor of Science and a PhD in Biochemistry and Chemistry and have extensive career experience and expertise in drug discovery and development, and of finance and commerce in biotechnology and pharma. In my line of work, I have been involved with the application and development of drugs to HIV targets and as a patient received experimental drugs of multiple classes and combinations, from early failures and modest improvements through to the remarkable success of current therapies. I also worked on HCV drugs, although as a patient 15 years ago I received interferon/ribavirin which cleared my infection albeit not before sustaining ongoing (but stable) liver injury. I am currently the head of research and development of a biopharmaceutical group having been CEO and

founder of drug discovery and modelling company acquired by our current owners. I have previously worked as a lab protein biochemist and biophysicist.

3. I have severe haemophilia A and was infected with hepatitis C and HIV as a result of receiving infected blood products which were inappropriately heat-treated. As a member of the scientific and haemophilia communities, I believe I have a unique perspective on the infected blood scandal.

Section 2. How Infected

4. I was diagnosed with severe haemophilia A as an infant. At the time, I was under the care of the Lewisham Hospital in South-East London. When I was first diagnosed, my haemophilia was treated periodically on demand with Fresh Frozen Plasma (FFP). In the early 1970's, my treatment switched to cryoprecipitate which was initially used on demand and then subsequently prophylactically. The treatment was self-administered at home.

5. In the 1980s, treatment of haemophilia patients began to move away from cryoprecipitate and patients began receiving Factor VIII blood products in their place. Around this time, the risks of contracting hepatitis from blood and blood products were well known although perhaps not widely appreciated. I was studying biochemistry at University at the time and I was acutely aware that the risks associated with Factor VIII, made from pooled blood, would be higher than cryoprecipitate. In the early 1980s, the HIV virus was discovered and AIDS emerged as a serious public health priority.

6. I was not comfortable changing my treatment from cryoprecipitate to Factor VIII and sat down with my doctors at Northwick Park Hospital in Harrow and told them that I did not want to be treated with Factor VIII. I felt relatively safe using cryoprecipitate and, unusually, the doctors agreed to allow me to continue with the treatment despite the fact it was uncommon for haemophilia patients to be allowed to elect their treatment. They were very helpful and like all of us uncertain of the nature and scale of the threat posed by HIV.

7. My doctors provided me with a steady supply of circa 20 units of cryoprecipitate to keep in the freezer to treat bleeds on demand. While at university, the warden

at my hall of residence kindly kept the cryoprecipitate in his freezer so that I could access it whenever I needed.

8. By the mid-1980s, most if not all haemophiliac's treatment moved onto freeze-dried Factor VIII products (concentrate), being far more convenient and not dependent on local supplies of blood. Around the same time, my haemophilia treatment moved to the GRO-B Hospital where I was under the care of a consultant haematologist named Jill. I understood American blood products were being sourced from at-risk groups of donors, and Jill and I came to an agreement that I would only be treated with UK sourced, NHS heat-treated blood products which were known to be safer.

9. The UK products came from a 'cleaner' donor pool and it was known Elstree products were adequately heat-treated. Conversely, the American company responsible for the bad batch that infected me cheated and did not properly heat-treat their products – using "dry heating" instead of the validated "wet heating" method.

10. When I began using the UK heat-treated Factor VIII I had quarterly blood tests to check for HIV and, at that stage, the results showed that I was HIV negative.

11. In 1984 I attended the GRO-B Hospital with an elbow bleed that required urgent attention. I was in a lot of pain and it was quite late in the night and a doctor, who wasn't aware of my agreement with Jill, treated me. I told the doctor I wanted UK sourced blood-products. The doctor removed blood products from the freezer and told me it wasn't UK sourced but it would be fine. It was late in the night and I needed treatment so I let the doctor give me the product. I just wanted the treatment so I could go home, treat and be out of pain.

12. Three months later after my elbow treatment, I underwent a routine HIV test and the preliminary results indicated it required further testing. The final results confirmed I was HIV positive. I was told I was infected when treated with inadequately heat-treated Factor VIII blood product produced by GRO-D [Note I signed a CDA GRO-D as I recall this indemnified them against further compensation – I received £100K as I recall].

13. I don't blame the doctor who treated my elbow for my infection. The doctor was not aware of my agreement with Jill and was simply trying to treat me as best she could. I was in agony and she simply gave me treatment to stop the pain. Neither do I in any way hold Jill responsible, she was already bending the rules to help me. We were all cheated by GRO-D

14. I do not blame any of the doctors for what has happened to me as I always received adequate care from medical professionals. I see what has happened as an institutional failure of will. However, I do believe the Department of Health failed to revert patients, particularly children, to treatment with cryoprecipitate once they were aware of the risks of hepatitis and HIV from imported blood/blood products and for this they were culpable.

Section 3. Other Infections

15. As well as HIV, I was also contracted Hepatitis C and B via blood products.

Section 4. Consent

16. As far as I am aware I was never tested without my prior consent.

Section 5. Impact

Mental Impact:

17. Growing up and living with haemophilia made my acutely aware of my own mortality. Contracting HIV and hepatitis's B and C strongly strengthened this awareness. I recognised that there were aspects of my life which were out of my control and I realised I need to make the most of my life and the opportunities afforded to me.

18. I live with the knowledge that I may have avoided contracting HIV (definitely) if I had never been treated with GRO-D products for my elbow bleed. Likewise that more thought and priority given to the broader issue of viral

contamination of pooled blood products should have been given and earlier action taken would have reduced the impact on patients.

Physical Impact:

19. My HIV and hepatitis infections mean that I am a more susceptible to illness. The hepatitis C has caused me to suffer 'grade 1' cirrhosis of the liver. My liver damage is currently well managed and thankfully the hepatitis C virus was cleared in the 1980's with Interferon and Ribavirin combination treatment.

20. Hepatitis C also led to portal hypertension, which at one stage caused an almost fatal bleed. I sometimes have gastrointestinal bleeding which has resulted in iron deficiency anaemia. Generally, my energy levels are mostly good except during periods when I am anaemic.

21. I'm fortunate in that I have not presented with other symptoms commonly associated with hepatitis C such as brain fog.

Impact on Social Life:

22. I lost confidence for a while after receiving my HIV diagnosis. I split up with my girlfriend at the time and I was quite adrift. In a way I felt it was better being on my own. It was hard being in a relationship as the initial flush of joy at the beginning wore off and relationships quickly became daunting for me and partners. My diagnosis made me a bit clingy in my relationships, which doesn't tend to play out well in most cases. I found that I didn't know how to broach the subject with girls so it really did affect my overall confidence. However with time and experience and good fortune I recovered and this all seems a distant memory now.

23. Thankfully I had my work and studies to lean on which was a great help to me. At the time of my HIV diagnosis, I was working on a large project which I was fully absorbed in so it was a welcome distraction. I told my parents, a handful of friends and some other immediate family about the HIV and they were very supportive. I think having haemophilia made me cope well with the HIV as it instilled me with resilience. Although, at times there is a tendency to

feel doubly 'picked on' having both haemophilia and HIV but this is of course irrational, it is a matter of chance. Fortunately, the support I received from the hospital was great, it was like a home from home.

Impact on Education/Work:

24. I missed a lot of school due to my haemophilia condition and I was a bit slow in maturing. I then went on to college and I had a girlfriend and everything was going well as I was just starting to grow and take things in my stride.

25. Haempohilia did have an impact on my schooling but it wasn't a severe impact. Even though it had an impact on social interaction it meant that I could get my work done and do my best academically without being distracted by friends. I was able to focus and work hard on school work and as a result I got into a very good university and everything took off from there.

26. The diagnosis did affect my work, and it did have an impact on my finances, as I felt unable to change jobs at the point of my diagnosis due to the stigma. My HIV status meant that it was very difficult to travel to the United States ("America") for work given the America government policy on HIV positive visitors at the time. The visa process was arduous and required regular attendance at American embassy here in the UK. In order to receive a visa, I needed a pretext for visiting. It was a tiresome process. However, I do recall there was a kind woman who worked at the embassy and she would always facilitate my visa. She must have been an angel as she was so lovely to me. I was fortunate to receive good support from work throughout it all.

27. I do feel that but for my HIV status I could have 'flown freer' both in relationships and in my career. Career-wise, having HIV meant that I was least likely to take a risk in the job market so it made me risk adverse.

28. When the *Disability Act 1995* was enacted it made me feel bolder to assert my rights and make a move in the job market. In 2000 I was managing 300 members of staff and my job became more of an employee management job, which I didn't really like so I decided to venture into a start-up company. It was very rocky in the first 5 years but I learnt a lot and I was able to use what I learnt to set up my own company.

Impact on Family:

29. For my parents, my HIV diagnosis was another big worry especially as my brother, GRO-B:B who was also a haemophiliac, had died from AIDS after contracting HIV from infected blood products. B dealt with the whole thing with great fortitude.

30. My father, who passed away last year, had helped my mother not to fuss over me too much in the early days of my diagnosis. He encouraged her to leave us be, as he knew how we wanted to deal with things.

31. My father was not a cynical man. He didn't want my brother and I to bear a grudge or to have anger towards anyone for what we had happened to us. My dad was more stoic in the sense that he didn't want us to concentrate on things that we couldn't change but to focus on things that could be changed. My brother lived in his own world and died in his own world.

32. My mother would say "don't let it be a blight or cover your life". The words "let it" stayed with me and that is why I decided to come forward and speak out as I don't like the whole 'victimhood' thing. The world isn't meant to be fair sometimes and we need to be positive and make the most of what is in front of us.

33. My first wife and I never had unprotected sex due to the HIV and it was more of an issue with me as I was extremely careful and I was absolutely terrified of transferring it to anyone. She was a virologist so she was knowledgeable and well informed about it.

34. My current wife isn't a technical expert in this field but we have had tests and they have been fine. She has taken it all on board and dealt with the problem very well. My children know about my haemophilia but they are only 5 years old so they are not completely aware of the implications or my infections. I inject myself in front of them sometimes and one of them wanders off and the other comes close and watches.

Stigma

35. Stigma wasn't a big issue for me because I kept my HIV diagnosis quiet as it wasn't anyone else's business.

36. One interesting thing about having HIV is that it often doesn't show on the outside. People presume I haven't got it, as there is an assumption that there should be something sprouting from your head. There is an unconscious bias in favour of non-infected persons.

37. During the mid-1980's I would hear different things on this topic from educated people that were often quite inappropriate. They made 'off the cuff' comments about people being dead soon and how HIV had stemmed from the gay community. After that I remember feeling a (purely platonic!) affinity to the gay community because they were suffering from the same problem through no fault of their own and I went a few times to do volunteer with the Terrence Higgins Trust. Although I was aware there was a distinct attitude from some of the women at the Trust that they didn't want heterosexual men working there. I found the reaction to the whole thing, especially from educated people, so surprising.

38. I informed 2 or 3 people of my HIV status. They were scientists themselves so they could weigh up the data and there was no ignorance on their part. On the other hand, I remember an occasion in the 1980's, before I knew my HIV status, whilst in Cambridge at a work conference, I told a fellow scientist from California that I had haemophilia and he just walked away from me.

Section 6. Treatment/Care/Support

39. When I received my HIV diagnosis in 1984 I read everything that there was to know on the subject and the correlation between haemophiliacs and the use of blood products. I think most people in the medical world were also trying to find out more about it at the time.

40. In 1985 the doctors couldn't even test for viral load and it was reasonably clear at the time that there was nothing that could be done in terms of treatment.

Counselling/Support

41. When I was first diagnosed, my doctors told me that I could come and speak to them anytime I wanted. They offered me formal counselling but I declined and chose to face up to the situation myself, although I did receive a reasonable degree of ad-hoc counselling from the hospital and medical staff. It was mostly informal but it was enough for me.

42. At the time of my diagnosis the doctors did not have all the related information and brochures like they do now. They did, however, have staff at the haemophilia centre that would offer help and their support. The doctors didn't take a negative view on the situation and I think the information and support given was delivered perfectly well.

43. I had supporting literature on HIV and I had the opportunity to talk to a doctor who was a Consultant and a scientific researcher at GRO-B He was marvellous in his approach and he was so lucid and easy to talk to. We talked about the problem all round and discussed what we thought needed to change for the future.

44. When I was diagnosed with HIV I was told about the risks of infection via sexual contact. The hospital was very good about it all and they made me feel like they were on my side. They were balanced and thoughtful in making me aware of the risks.

45. I remember receiving counselling from a lady called Riva Miller at the Royal Free Hospital, who has since passed away. I found her to be brilliant, informative and matter-of-fact in her approach which I liked.

46. I did try and speak to another counsellor but it didn't work out in the long term as she had a different approach to things and it didn't feel like it was organic relationship. She came across like a social worker who had a certain set of ideas which she projected on me and my situation.

47. I don't think I have faced any difficulties obtaining support from any hospital at all.

HIV Treatment:

48. In the late 1980's I began treatment for HIV and I was given the opportunity to try an experimental drug called azidothymidine (AZT) which was the first drug that was used to treat HIV. AZT was first introduced as a trial drug and I contacted Mike Adler, a consultant at Middlesex Hospital where they were running a set of trials, and he told me I would be given a chance to take it.

49. I voluntarily joined various other HIV drug trials in order to find a drug that could successfully suppress the virus. When joining the trials, I was always advised of the risks and possible side effects involved.

50. One of the drugs I used was called Ritonavir, which came in tablet form, made me faint and feel dreadfully sick but it worked well in lowering my viral load. However the side effects were so bad that the treatment became unbearable and I could not continue with the course.

51. Thereafter, I trialled other anti-viral drugs such as Didanosine (DDI) which gave me tingling sensations in my body, Kaletra and Indinavir which I carried on taking for a number of years and which successfully supressed the virus quite well.

52. I was aware that the virus could mutate against drugs used to treat it so I tried different anti-viral combinations, which I knew to be an effective method of treating HIV. Each drug used various different techniques to treat the virus.

53. I currently take anti-viral drugs for my HIV called Rezolsta and Truvada, which I take once a day. They have worked tremendously well for me. Currently, my HIV is successfully managed and I currently have no detectable virus in my blood stream. I will have to continue to take the medicines every day, which thankfully I can manage as I do not experience any side effects.

Hepatitis C Treatment:

54. Since 1990 I have been under the care of the Royal Free Hospital in Hampstead, London. In 2003 I started a course of Interferon injections and Ribavirin in tablet form to treat my hepatitis C. The treatment went 48 weeks

in total. Thankfully the treatment was successful and I am cleared of the virus, and my liver cirrhosis has stabilised.

Side Effects and Impact of Hepatitis C Treatment:

55. The side effects of Interferon and Ribavirin were flu-like symptoms, which made me constantly exhausted so I took paracetamol solidly for the whole year whilst I was on the treatment. I would have the shot of Interferon each Saturday and the symptoms would slowly start to lift during the week but then it would be Saturday again and I would have another shot and the flu-like symptoms would re-surface so it was a repetitive cycle of constantly feeling unwell.

56. The combination of Interferon and Ribavirin made me feel listless and lethargic. Throughout this period, I continued to work as I loved my job and didn't want to give up working. Luckily my colleagues and the investors on my work projects at the time were very supportive. However the symptoms were obvious and eventually my colleagues wanted to know what was wrong with me and I had to hand over the project to someone else.

57. During the Interferon treatment I noticed that I stopped salivating properly and my hair became thinner and thinner. I realise, on reflection, the Interferon gave me depression and I found myself not wanting to engage with others around me. It was what I call the 'flattened affect' as I just wanted to be on my own most of the time.

58. Although I am not a depressive type, I became quite down whilst on Interferon and my former wife was not able to cope with it. She became increasingly distant with me and subsequently left me just before the end of the treatment.

59. The only criticism I have against the doctors is that it would have helped to have some advice beforehand about the possibility of depression whilst taking Interferon. However the doctors were very clear and informative on making me aware of the other side effects. I don't attach any blame to the doctors for not informing me of the possibility of depression. They knew I would die if I did not take it and did not want to put me off. I think that in general, people including medical professionals, are much better informed nowadays.

60. I had excellent clinical care, which I received and continue to receive, from the Royal Free and GRO-B Hospital.

61. Shortly after my diagnosis, I had some bad experiences with GP's, whose names I don't recall, where I got the sense that they didn't know what to do with HIV or hepatitis c positive patients. I think seeing people moaning about things day in day out perhaps made them cynical but I think things have certainly changed now.

62. I was a trustee of the Haemophilia Society during the late 1980's or early 1990's but I left as I started to become impatient with them. Although David Waters and Alan Tanner were exceptional. They were a great help during that period though I no longer have much to do with them. It was a terribly tough job but I think they ran it very well.

63. I had a bulletin sent to me every month from the Haemophilia Society, which also kept me informed. Initially, my parents took part in the fundraising efforts for the Blackheath and the Lewisham groups.

64. My dad was a science teacher and he was very involved with the haemophilia centres. He would help squeeze the cryoprecipitate into bags. Back then there was a great community spirit however I feel that everything is budgeted quite strictly and scientifically now.

Section 7. Financial Assistance

65. I received assistance from the Skipton Fund, Macfarlane and Caxton and I was initially made aware of these by the Haemophilia society.

66. I had a one off payment from the Macfarlane of £20,000 and a one off from Skipton £20,000 as soon as they became available and I received both within a matter of months). I don't remember facing any difficulties or obstacles accessing the payments and from memory the process for applying for funds was easy and straightforward and simply involved completing numerous

forms. You could only access certain levels of funding depending how advanced your illnesses was.

67. Currently, I receive total payments of around £3,000 a month. The figure is an amalgamation of payments I receive separately for my hepatitis C and HIV budgets. I have also have mobility allowance and a blue badge.

68. I also received £100,000 from GRO-D litigation processing which took place from 1986 to 1987. I must have been part of the 'class-action' and I think I signed some paperwork to that effect. It wasn't a positive experience. I received great help from Mark Mildred the lawyer at Pannone Napier.

Section 8. Other Issues

69. I do not believe that this situation could have been avoided but I do feel the outcome could have been lessened. The important thing for me here is that there are lessons that need to be learnt so that in the future better decisions are made. Authorities should face up to issues and take pre-emptive action not 'wish situations away' or, even worse, consider they are too late to make any difference.

70. However I do think people need to understand that this was an unfortunate mistake and no one was plotting or conniving to infect people with this blood.

71. When news of the scandal first came out, I could see how some NHS staff were suffering to learn that their patients, many of whom they had treated since they were children, were infected and dying. It was a soul-destroying experience for these medical professionals, many of whom felt like we were their children. I'm certain it was hard on them knowing that this happened on their watch.

72. When a situation like this happens it should be brought up for debate by the Department of Health and there should be a robust weighing up of risks. Medical professionals need to have a safe place to be able to discuss things and have a robust debate on what is the best decision for the patient.

Decisions should be discussed and peer-reviewed. Thereafter the government need to take responsibility so that things don't go awry.

73. If doctors had pushed for patients to be put back on cryoprecipitate or if there was a better alternative I think things would have been different. I don't think there was any communication or transparency at all. Doctors didn't want to go back to using cryoprecipitate but I think they should have treated the situation with the same severity as they do in a situation of war. If they assessed the gravity of the situation with the same outlook then they wouldn't have continued to allow the use of Factor 8.

74. I don't believe that they could quantify the risk of the situation. I don't think it was based on negligence but I feel that the approach and judgement behind it all could have been handled differently. The government should have announced that they were aware of these issues in the first place.

75. I understand that in the 1970's David Owen did try and move to UK self-sufficiency in blood products but it never occurred due to cost reasons or just bureaucratic inertia. There should have been rapid action as oppose to slow reaction, which governments are famous for. Some might say that they cover up things to defend themselves. I was told by lawyers on the case that it was very difficult to extract information from hospitals, records disappeared, photocopies were illegible etc. Fortunately I kept my own records and could challenge concisely.

76. I think this Inquiry should lead to constructive outputs and recommendations rather than vilification of those that are involved. I think there should be guidelines put in place to deal with situations like this in the future.

77. I strongly believe that the government should provide better care and support for haemophiliacs that have been affected by this whole situation. As a 60-year-old haemophiliac I feel that I should have a ticket that says I have the option to have any approved treatment available to me that will help my health regardless of the financial cost to the government. If there are better treatments coming in then, and it is a matter of priority, that those affected and infected by the blood scandal should have priority. If such treatment

happens to be expensive then the government should cover the cost of this. It shouldn't be our responsibility.

78. I think it adds insult to injury that we should have to argue about budgets and costs associated with treatments as it is incumbent on NHS England to provide this treatment to us.

79. Back in the 1980's I was aware that Margaret Thatcher didn't like 'sob stories' and she didn't have strong empathy buttons. Thus I am pretty sure that she put the boot into any compensation for infected or affected persons. It may be worth asking Kenneth Clarke about this. I suspect this is why we didn't receive anything until she left government in 1990 and John Major came in. I think he was a much kinder man.

80. I believe there should be an understanding or guideline to say that if you have haemophilia and you were infected with HIV or hepatitis C, you may not receive any more lump sum payments but you will receive direct and uncomplicated access to any treatments for those infections and for your haemophilia and its consequences.

81. I also want some sort of security for my dependants and it is important to me that there will be something left to them if anything should happen to me as a result of my HIV/hepatitis C. I still cannot get approval for life insurance and although I have benefits from work it is very limited. I have never been able to get travel insurance to cover health issues should I wish to go abroad.

82. I think people shouldn't have to fight for things like money or adequate healthcare or indeed compensation. In this country everything is slowed down and drawn out over long periods of time and there is a sort of meanness to it.

83. However I do not agree with the view that we should see what happened as murder. Also a lot of things have changed since then and hospitals are a hundred times better than before.

84. What bothers me most is the how the outcome of this Inquiry affects future decisions. There is no point in dwelling on the past or looking for people to blame. We are not "victims" because nobody has done this to us by an act of will.

Statement of Truth

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

Signed GRO-B

Dated 02/05/2019