Witness Name: GRO-B
Statement No: WITN1489001
Exhibits: 0
Dated: December 2018

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF
GRO-B

I, GRO-B will say as follows:-

Section 1. Introduction

1. My name is GRO-B. My date of birth is the GRO-B 1966, and I live at GRO-B with my wife GRO-B, my 27-year-old daughter GRO-B and my 25-year-old son GRO-B. I have been a self-employed GRO-B for the past 8 ½ years.

2. This witness statement has been prepared without the benefit of access to my full medical records. If and in so far as I have been provided with limited records the relevant entries are set out in the medical chronology at the end of this statement.

Section 2. How infected

3. I was diagnosed at birth with severe Haemophilia A. My cousin, who was only GRO-B months older than me, had been diagnosed with the same condition, and as it is a genetic condition I was also tested.

4. I have been treated with blood products more or less since birth and I believe many different companies supplied the products.

5. I was treated at the haemophilia centre at the GRO-B GRO-B Dr GRO-B GRO-B was my consultant at the time.

6. The earliest blood product I recall receiving was when I was about 4 years old. A door slammed on my finger causing my finger nail to fall off, and my finger would not stop bleeding. I recall it was very painful. I was taken to hospital and given Cryoprecipitate to stop the bleeding. Thereafter, I was treated with Factor VIII throughout my life.

7. I never received Factor VIII prophylactically; I have only ever received on demand treatment.

8. As I have received Factor VIII more or less from birth, my parents would have been given any information or advice associated with any risks of receiving blood products. I do not think that my mother was ever told of any risks of being exposed to infection from blood products. She most certainly never mentioned it to me and we were always very close, so I would assume that if she had any such knowledge, she would have informed me. I have never been told of any risks.

9. As a result of receiving blood products, I have contracted the Human Immunodeficiency Virus (HIV) and Hepatitis C (HCV).

10. I found out about the infections in 1983, when I was about 17 years old. I was called in to see Dr GRO-B in his office. He was pretty blunt when he told me, though I believe it must have been quite hard for him as well as he had known me since I was a little boy.

11. I remember there was also a social worker, GRO-B present at the time to offer support and give advice; however she did not give me any advice. The general message that I received from her was that she was there in case I needed her, but I should just get on with my life. The only contribution the

social worker really made was to tell me that I was eligible for funding for this and that.

12. I do not consider I was given adequate information as to the management of my condition. I believe that this was because HIV and HCV were new conditions, so I am not sure how much information the doctors had at the time to reveal to me.

13. I might have received a leaflet on safe sex.

14. Following my diagnosis I received regular reviews at the Haematology Clinic.

15. Public awareness of HIV caused discrimination and stigmatisation against those with the condition. People associated HIV with being gay, which shows the ignorance at the time. Due to the public awareness I became afraid that people would become aware that I had the condition as well.

Section 3. Other Infections

16. It is noted in my medical records that I also have a trace of Creutzfeldt-Jakob Disease (CJD) in my blood .

Section 4. Consent

17. I have no idea if I have been treated or tested without my knowledge or without my consent or for the purposes of research. When I attended my bi-annual reviews I assumed that any blood tests were for my haemophilia condition. I was not told that I was being tested for any viruses and I don't think my mother was either.

18. I never questioned the need for the blood tests. I was also never told of any results, other than that one when Dr GRO-B told me about my HIV and HCV infections. I never knew what kind of tests were being undertaken.

19. I used to have blood tests whenever I went to the clinic, which seemed like a standard event. When my mother was alive, she never told me that I was tested for any viruses.

Section 5. Impact

20. The most severe physical effect of my HIV infection was that I had to have my spleen removed in 1988 at the London Hospital, as it had been damaged by my condition. The doctors tried to save it but the treatment was unsuccessful. The operation was the last resort as nothing else had worked, so it was removed.

21. After having it removed had to take penicillin twice a day as the spleen provides protection from pneumonia. However I have still contracted pneumonia a couple of times. I recall having a really severe bout of pneumonia in the 1990s, which caused me to be bed-ridden for three weeks. I am sure that would not have happened if it was not for my HIV infection.

22. My HCV infection has caused severe damage to my liver, which I am regularly reminded of by my doctors.

23. I have also developed jaundice eyes. I have had it for a long time, but GRO-B believes that it has become worse over the past 10 years, which would suggest that my liver has deteriorated.

24. In terms of the effect of the infections on my private life, I admit that it has been very difficult for me, I felt ashamed having HIV, particularly due to the stigma attached to it.

25. I was afraid that my condition would be revealed to my classmates or colleagues. This was particularly stressful when I entered sixth form. I would sometimes become so anxious that I would not be able to sleep. Therefore, I have never told anybody about it, other than GRO-B our closest friends and family. We told our children of my condition once they were older. We did not want to cause them any stress at school, and also we were afraid as to how

they would be treated at school if their peers found out about my condition. Also GRO-B's partner knows and GRO-B's parents

26. I recall that when I was at school I wanted to become a dentist and I never really thought anything of it when I first found out about my condition. However, after time I realised that becoming a dentist was not an option, so I did not try that career path.

27. I am also always anxious about my life expectancy. I feel I am a ticking bomb. Whenever I go to hospital I keep thinking: "Is this going to be it for me?" This was intensified when I lost my cousin to HIV, which he too contracted as a result of treatment for his Haemophilia from blood products.

28. My cousin died in 1988 and it really traumatised me. I never visited him in hospital, because I was too afraid that it could be me in the future.

29. When GRO-B and I started our relationship in 1987 we looked into practising safe sex. However the message was 'don't have babies' which was devastating. We purchased ovulation kits so as we could tell when GRO-B might conceive. GRO-B became pregnant and she decided that she would only terminate her pregnancy if she tested positive for HIV. GRO-B has been tested twice and both tests were negative, we have been together 32 years. Our children have been tested for HIV and fortunately the tests were negative.

30. I also have side-effects from the antiviral treatment that I currently receive, I get depressed and fatigued. I also lose my appetite significantly. I have also recently been told by my doctor that I might have to change the treatment I receive, as the current one is prone to give me kidney stones which I have had.

31. My depression is quite severe at times. I receive treatment for it which contributed to me to starting my own GRO-B business. I was at home all the time, which in itself made me feel very depressed and the side-effects of the medication made it worse. GRO-B GRO-B.

32. My business has proved to be very successful and I feel under pressure to continue it. I am not always well enough to see my clients and I do sometimes have to rely on help from GRO-B to cover for me. There is a lot of uncertainty for me, as notwithstanding the fact that I love my job and I would like to continue doing it for as long as possible, I am not sure how long I will be physically able to work, as my health is deteriorating.

33. I have been admitted to the hospital twice this year and I feel my health is becoming worse. The deterioration is due to the damage to my liver and I have also been diagnosed with kidney stones. Doctors have told me that my kidney will continue to flare up, which means that I might have to make more visits to the hospital which will effect my ability to work.

34. I am also afraid of my HIV status being revealed to my clients which would make them uninterested in my services anymore. I certainly think that they would feel uncomfortable being with me.

35. I find it very frustrating as I have finally found something that I truly enjoy, that I am good at and that I am able to do, but I am not sure how long I will be able to continue doing it due to the deterioration in my health.

36. The fact that I have not always been able to work, because of the symptoms caused by my condition or the side-effects of the medications which I have been taking, has had an effect on our finances. I am paid when I work and as I am not always able to work, I lose pay.

37. It has been extremely stressful lately because of my deteriorating health, not only from the infections and my Haemophilia, but also because of the pressure caused by running my own business. The reason I decided to become a self-employed GRO-B in the first place was because of the flexibility offered by the job and the fact that I could rearrange my days if I was unwell.

38. As a result of the pain I suffer I was unable to sleep for a few days and I became so low that there was a point when I considered ending my own life. I felt nobody could help me. This happened around September this year.

39. My condition has effected my ability to gain promotion and earn a higher income. For example, I used to be a GRO-B in the 1990s and I applied for promotion, however the promotion meant that I would have direct contact with food. Once my manager realised my HIV status, I was told I could not work in the position, therefore I lost out on promotion. As there were no job prospects, I resigned.

40. The poor state of my liver is also a problem as the doctors have trouble finding the right treatment for it. One of the options is an operation, but the doctors describe me as their 'worst nightmare', because not only is my liver severely damaged, I am also a high risk of excessive bleeding, which is obviously very dangerous. Another option is to remove my gallbladder, which is also dangerous for me, due to my haemophilia.

41. My conditions, particularly HIV, have also affected my wife. We felt she was treated poorly by the medical staff at the hospital when she gave birth to our daughter. She had a large tear as a result of giving birth and she was bleeding severely. The nurse took our new-born daughter away and left her in the corridor of the hospital. The nurses were more concerned about isolating my wife as they believed that as I am HIV positive, my wife and potentially my daughter would also be HIV, therefore they were discriminating due to my HIV status. What I also find upsetting is the fact that they assumed that GRO-B was infected, rather than checking her medical notes.

42. My wife has also not always been able to work, because I have needed care and as she used to work in care homes, she is the most suitable person to look after me.

43. This has also affected our family life, as we have always wanted to take our children on a holiday to America; however, we have not able to travel there due to the travel restrictions placed on those with HIV by the American government.

44. My financial situation has also caused difficulties. We do not feel comfortable telling our more some friends and our neighbours about my medical condition.

I have had long periods of time when I have been unemployed, as my health did not allow me to work. This raised questions amongst our neighbours as to how we have been able to afford items such as a car.

45. As a result we were contacted by the DHSS office when my daughter was around 6 months old, with regards to living beyond our means. They questioned how we were able to afford a new car (Mobility) and have Sky fitted whilst I was not working and my wife was at home to taking care of me. I did not feel comfortable telling my neighbours about my infections and the financial help I receive, and I do not believe that I should have to justify our life style. That added to my desire to fine employment so as others would stop looking down on our family. I find this additional pressure very stressful.

Section 6. Treatment/Care/Support

46. I have not had any problem accessing treatment. I have been quite lucky, as I have been under the GRO-B, specifically the GRO-B, which is a sexual health clinic. I was under GRO-B who was the expert undertaking research to find an antivirus for HIV. Whenever a new drug was available he would work out the best 'cocktail' for me. Thanks to this I have managed to be treated for HCV and HIV with the same drug.

47. However, I did have to wait a long time before I was treated following my diagnosis, as there was no actual treatment. The treatment appeared quite suddenly, I believe in the 90s, around 24/25 years ago.

48. The only aspect, which has been disappointing, is the lack of counselling. Other than the social worker being present when I was told about my infections, and a nurse working at the Haemophilia centre, who I could talk to whenever I needed to, I have never been offered counselling.

Section 7. Financial Assistance

49. I have been receiving monthly payments from the MacFarlane Trust (now the England Infected Blood Support Scheme or EIBSS), plus winter fuel payments.

50. I also received a lump sum of about £23,000 from the US litigation and about £20,000 relating my HCV and £23,000 for my HCV and HIV from the Skipton Fund.

51. The specific requirement that I recall is that I had to sign a waiver in relation to the American litigation, in order for myself and the other parties to be able to receive our payments.

52. I believe that the funding arrangements are not fair as they are not equal.

53. The grants from the MacFarlane Trust are disappointing, for example I received a letter from them stating if there was anything we needed I should make an application. I applied for a new roof to our house and we provided two quotes from two different companies. The quotes showed the roof would cost about £8,000. However, the application was rejected. We appealed the decision and as a result we were given an offer stating that due to my earnings I was not entitled to the full amount, but they could contribute around £4,000 to the new roof. I would have to pay the balance.

54. I do not think that this is fair due to the inequality.

55. I am unaware of any pre-conditions attached to the applications for grants, but the applications have to be supported by reputable quotes, photos and other evidence to support the claim.

56. What I have observed about the Skipton Fund is that I have received two payments: the first one was £20,000 for HCV; and the second one for £23,000 was for being co-infected with HVC and HIV.

57. I understand t can obtain another payment for any other infection. I have been told that another type of Hepatitis has been discovered in my body but in order for the condition to be confirmed I have to have a liver biopsy, which is

very dangerous for me, as I am a Haemophiliac. I have therefore been denied a further payment from the Fund, notwithstanding the fact that that they were informed by my consultant at the GRO-B about the further condition.

58. I am also aware that due to my deteriorating health and not being able to sleep at night, we might need an extra room downstairs to accommodate a bed for me so as I can sleep downstairs and not disturb anybody at home. However, we are very reluctant to apply for any financial help to assist with this as we are aware that it might be extremely difficult to get it.

Anonymity, disclosure and redaction

59. NOT RELEVANT I understand this statement will be published and disclosed as part of the Inquiry.

60. I do wish to be called to give oral evidence.

Statement of Truth

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

Signed...

GRO-B

Dated December 2018

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Dated ~~November 2018~~

18-12-18