ANONYMOUS

Witness Name: GRO-B
Statement No.: WITN2117001
Exhibits: **WITN2117002-008**
Dated: 13th January 2020

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 November 2018.

I, GRO-B will say as follows: -

Section 1. Introduction

1. My name is GRO-B My date of birth is GRO-B 1956. My address is known to the Inquiry. I intend to speak about my infection with HIV and Hepatitis C, through infected blood products. In particular, the nature of my illness, how the illness affected me, the treatment received and the impact it had on me.

2. I am living in my own home jointly owned with my partner. My immediate family are all deceased. I had one brother GRO-B GRO-B He was 16 months my senior. Prior to my retirement, I worked as a GRO-B

Section 2. How Infected

3. I have severe Haemophilia A.

4. Treatment for haemophilia has included whole blood, plasma, cryoprecipitate, human derived Factor VIII and synthetic Factor VIII. I cannot name the brand names of all the products, as these have changed over the years depending on the contract arrangements made by the NHS. I have located a limited number of records that list some of the products I have received, which I exhibit as **WITN2117002.** These form a small proportion of the treatment I have received. I self-administered my treatment, on demand, from my twenties. I switched to extended life Factor VIII treatment on a prophylactic basis from October 2016.

5. I was born in England and until 1989 lived in Manchester. So long as I can remember, I attended Manchester Royal Infirmary Haematology Department, until I moved to Scotland in GRO-B I initially (possibly for about six months) attended Edinburgh Royal Infirmary, but then I transferred to the Haemophilia Centre at Glasgow Royal Infirmary. I have attended there ever since. Initially the Royal covered Haemophilia and HIV, but as treatments for HIV started to develop, a separate clinic for HIV and later HCV was established at the Brownlee Centre (Infectious Diseases) at Gartnavel General Hospital which I attended. Since I cleared the HCV infection in February 2015 on the second attempt, I have been monitored by the gastroenterology department at Gartnavel General Hospital for my existing cirrhosis of the liver and the ongoing increased possibility of liver related disease.

6. I can only say when I was advised that I had been given infected blood products. I do not know which batch or which product infected me. I was advised at the end of June 1985 via a consultant at Manchester Royal Infirmary Department of Clinical Haematology that I had been infected with HIV. I exhibit a letter between Dr Wensley and my GP, Dr GRO-B as **WITN2117003**. I was advised in early 1994 by the Consultant at Glasgow Royal Infirmary that I had been infected with the HCV virus. I also received a letter in February 2009 from Glasgow Royal Infirmary of a theoretical risk that I may have been exposed to vCJD. I exhibit this as **WITN2117004**. That letter gave me the option of a discussion with the Consultant in Charge about the implications of this. I had read about vCJD and decided not to have a face to face discussion.

7. I have no recollection of any advice being given of risks associated with treatment with blood or blood products. The switch from cryoprecipitate to human derived factor VIII would have been in the 80's, if not before and any conversation would have been with me directly. As I recall comments were more about how the Factor VIII replacement would offer more effective response to a bleeding episode. The dangers of injecting a product from pooled plasma donations never came into the equation.

8. I will describe the situation over how I became aware of HIV and HCV infection and the treatment regimes that followed separately. I have not been infected with HBV and was provided with a vaccine against HBV.

9. On HIV, my recollection was that I attended a routine clinic appointment with Dr Wensley at Manchester Royal Infirmary (who was a Consultant Haematologist). During the consultation he referred to the publicity about HIV and AIDs (as it was more often referred to then) and advised me that I had been tested for the virus and was found to be positive.. I was not prepared to be told about this at the time and whilst I knew from media reports and government advertising that people were being infected, I would say that I was simply stunned and unprepared to have any sort of discussion about this. I have established from my medical records that this test was done in June 1985, when I would have been GRO-B The rest of the consultation is not that clear. It sticks in my mind that I was told that there was no cure at present, but that the most serious threat to my wellbeing was haemophilia. That sounds such a strange thing to hear now. I don't recall much else of what was said. It was a short consultation. I do recall thinking how could he just tell me like that with no advance notice or offer of support. I think he warned me about cross infection, but from the media and official sources it was well known that the virus passed through blood and sexual activity or illicit drug use. I did not start any form of treatment for HIV until well after I had moved to Glasgow.

10. On HCV, this was discussed with me by Professor Lowe at Glasgow Royal. Initial discussion was about testing for HCV becoming available and whether I would wish to be tested. He recommended testing. I can't recall the timeframe between that conversation and the results being available. It was not until early 1994 that I was

advised that I was positive for HCV. Professor Lowe discussed the implications of this with me and basically said that I would need to be monitored to see the impact on my liver.

11. I am sorry that I cannot be more precise over dates, but there is an element in living with these infections of trying to put them to the back of one's mind and to get on with one's life.

12. At my request, I have recently discovered through the current consultant haematologist that I was tested negative for HCV in 1991. It has been explained to me that some of the early antibody tests were unreliable or could be influenced by the presence of HIV. It is difficult to say if I should have been told of that first negative response. Thinking about it I don't have an issue with that as it would have been more devastating to be told I was negative and then a few years later to be told that I was positive where the only possible source of infection was blood products.. I exhibit a letter referring to my HCV infection as **WITN2117005** This was notified to me by the previous consultant in Glasgow in early 1994.

Section 3. Other Infections

13. I have been infected with Hepatitis C and HIV. I did receive a letter at one stage that said I was under a theoretical risk of contracting CJV. This is documented in my medical records and is already exhibited.

Section 4. Consent

14. I believe that the testing for HIV was without consent. Apart from that I feel that consent has been obtained appropriately. There was not full disclosure of the potential risk of taking human derived Factor VIII. I have knowingly participated in research, sometimes related to HIV and HCV, and as far as I can tell appropriate consent was sought and given. I chose not to participate in any drug trials.

Section 5. Impact

15. HIV was something akin to be sent to death row. You know that you are going to die, but you don't know when. We all die at some stage, but reports in the 1980s suggested that it would be soon, but not pleasant or quick. Medicines then started to become available and the prognosis from the medical profession was that things would get better. The early medicines like AZT were vicious and at times made it that one could not function properly due to headaches, tiredness and blurred thought processes. I recall that the dose of AZT was frequently changed to account for blood results (low Haemoglobin) and how it affected me in daily living. I had a secure job, but more than once the medicines nearly got the better of me and I was close to giving up. I had a couple of incidents where my performance in work was put into question. I think the hospital told me to have a break from AZT a few times, or to change the dosage as I was not coping with it.

16. I have had so many cocktails of HIV drugs over the years that I have lost count how many I have taken. Current medication is working, but emotionally one worries about what might happen in the future and the occasional abnormal blood results show increase in the level of detectable virus remain a worry. These blips are sufficient for the doctors to ask for bloods to be repeated, but they tend to say it is nothing to worry about.

17. I have only recently realised from reading my health records that a GRO-B I required in 1994 as a result of Thrombocytopenia (a condition where the body stops or reduces its production of platelets) was attributed by the medical profession to my HIV infection. I exhibit this as **WITN2117006.** No one told me of this at the time. I was simply told that my GRO-B was killing my platelets causing anaemia and an impact on the bloods already compromised clotting abilities through haemophilia and that removal of the spleen was the best way to address this.

18. It took a long time for me to be convinced to take treatment for HCV. Initially none was available, but by early 2000 medication to clear the hepatitis virus became available. It did not clear the damage already suffered. HCV has been called the silent illness and for many there are no obvious signs until long after the infection. It does leave one exposed to significant problems over time i.e. fatigue, varices in

the gullet, cirrhosis of the liver, other liver disease including cancer. Unfortunately the early treatments were also quite debilitating.

19. I was treated with Interferon and Ribavirin from October 2001 until the following November. There is a letter in my medical notes dated the 30th December, 2001 relating to my commencement of the treatment, I exhibit this as **WITN2117007**. This treatment was not successful. I had genotype 1B which was known to be difficult to eradicate. The symptoms of this treatment included general tiredness and fatigue. I was depressed during the treatment and saw a psychiatrist who prescribed medication. These were not as bad as the symptoms I went on to face during my next treatment. There was a gap of thirteen years before I was persuaded by the clinical team to have further treatment aimed at eradicating the HCV infection. By this stage I developed cirrhosis of the liver and I think they were quite concerned about the general deterioration

20. In 2013 I had discussions with the clinical team about trying again to clear the infection. Second time round it was supposed to be more reliable in getting a good outcome. The course of treatment commenced in September 2013 and included Telaprevir for three months alongside Ribavirin and Pegylated Interferon. The first was to be taken for three months and the latter two for 12 months. I completely lost my appetite during the treatment, but it required me to take high levels of fat in the first three months to allow the Telaprevir to be absorbed. My body reacted badly to the treatment. It wrecked my haemoglobin levels and affected my blood platelets. I became severely anaemic and had to have blood transfusions and regular injections of Darbepoetin to keep my blood stable. For a period, I was attending the clinic for weekly blood tests. One can imagine that the prospect of having transfusions of whole blood was not something I welcomed. I suffered very badly from lethargy and one or two people commented that I looked like a ghost. During the treatment I developed a skin irritation that I assumed would go away, but I have had ongoing problems with dry and flaky skin since my treatment. I was off work for five months during the treatment.

21. The outcome was a success thanks very much to the skill, perseverance and persuasive skills of the treating Consultant. She was able to confirm that I had achieved a sustained clearance of the virus in January 2015.

22. I am not out of the woods with HCV. I am monitored on a six monthly basis with ultrasound and blood tests. Cirrhosis of the liver will not go away, it is just less. There remains the higher than normal risk of liver cancer and varices of the oesophagus. My skin remains quite dry and prone to outbreaks of irritation. There is a letter in my medical notes dated 9th February, 2011 referring to my cirrhosis. I produce this letter in evidence and refer to it as **WITN2117008.**

23. One does not really know if things like hypertension and diabetes are influenced by the medication taken.

24. HIV is under control, but not cured. As described above my body remains exposed to future medical conditions arising from HCV.

25. I have not experienced any issues with accessing treatment. I would also wish to say that the doctors and clinical staff who have treated me for HIV and HCV have all been very approachable, knowledgeable and caring. The same applies to the Haemophilia team that provides on-going care.

26. There are no treatments I am aware of that should have been made available to me.

27. In the early days, there was probably some overreaction to my infection e.g. member of staff in A&E wearing full protective clothing to attend to a blister on my hand. Other than that, I have had dental treatment from a GDP without problem where I declared my medical conditions. I have had three major operations which have been planned and delivered without any obvious hesitation.

28. The infections have had a significant effect on my relations with family and the wider community, simply because one wants to protect family from the anguish of it all and one is not sure how friends and colleagues will react. Imagine sitting watching the television with your family when an advert comes on warning about the dangers of the infection you have. You haven't told your family because you

don't want them to worry or get upset. It makes one feel very isolated from family. The same with friends. There was so much stigma associated with HIV in the 1980s and later that I did not feel comfortable telling people. Then they can't understand why you are being miserable, when it is because of the medication you are taking. I have not had many intimate relationships. The one that has lasted for over 30 years nearly didn't happen because I could not face the prospect of them becoming infected by accident. Thankfully they talked me round and have been a great support in all that I have been through.

29. The impact in terms of stigma was simply not talking about it and keeping that secret for so long. Whether I succeeded I will now never know. I know that my brother was infected with HIV, but we never talked about it.

30. I do not believe that my condition had any educational impact.

31. In terms of work, beyond what I have already described, I struggled to keep going at times. I retired early due to increasing tiredness, GRO-B GRO-B

32. My condition has had an impact financially. For the most part I held jobs which I enjoyed and could cope with. GRO-B GRO-B I was reluctant to look for better more well paid jobs, in case my medical condition became worse or an issue with a new employer. I did have problems with mortgages. I recall that one bank decided that they could not give me a repayment mortgage because they felt that the financial obligations would place too much stress on my health. There was never the possibility of an endowment mortgage.

33. I have described my conscious decision not to share my condition with family. This inevitably led to the potential for discovery and a feeling of a lack of trust by family members. I have no children. I have almost certainly been a worry to my partner on a number of occasions, but he is unfailing in his support to me.

Section 6. Treatment/Care/Support

34. I did not face any difficulties in accessing treatment, care and support as a consequence of being infected.

35. I was offered counselling with a Psychiatrist, who I respect as a professional in his field, and accepted the offer of anti-depressants during the first course of HCV treatment, but politely declined the offer of medication during the second round of treatment.

Section 7. Financial Assistance

36. I first became aware of the financial assistance available when they were publically announced.

37. I have received from the Macfarlane Trust lump sum and regular payments which have varied over the years. From the Skipton Trust I have received two lump sums and regular payments which have varied over the years. These funds were applied for through forms which was countersigned by my doctor. I did not face any difficulties or obstacles accessing financial assistance. Since these trusts ceased, I have received equivalent payment from the English Support Scheme as they determined that I had been infected in England. How they did this when the HCV positive result was not recorded until after I had been living in Scotland for three years, I am not sure.

38. I have heard and read comments from others about inconsistency of treatment by the trusts referred to above, but I think this was over discretionary payments. My own experience was straightforward.

39. On the financial assistance received, this has never been described as compensation. Indeed, as I recall one had to sign an undertaking not to sue the UK government before one could obtain assistance. This is in my opinion unethical. The government should have not put people in that position.

40. There is disparity between the value of assistance received between England, Wales, Northern Ireland and Scotland. As everyone was infected when we had a

UK wide health service, such variation is inequitable. There should be a common system across the UK. The system should recognise that those infected have a right to be compensated for something which has caused a tremendous impact on their lives. There is the secondary element of providing on-going support to those who are still alive and their dependants so that they can live without reliance on state benefits. I do not believe that any payment should be means tested.

Section 8. Other Issues

41. I have read and heard throughout the inquiry and separately about issues over the loss or destruction of records. Amongst the millions of records held, I can understand that some go missing, but not on the scale that we have heard.

42. I sought to access my health records and these were provided, but there are noticeable gaps. My GP records have been the major source of historical information going back to just before I moved to Scotland. There are no hospital records for Manchester, and Glasgow records provided appear incomplete. Those records that do exist are very jumbled in a way that makes it difficult to follow. Where individuals have long term chronic illness, one would hope that a system can be put in place that ensures the transfer of NHS records to follow them and for those records to be retained at least during the life of that patient.

43. I wish for my statement to be made anonymously.

Statement of Truth

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

Signed GRO-B

Dated 13th January 2020