Witness Name: GRO-B

Statement No: WITN1310001

Exhibits: WITN1310002 - 11

Dated: November 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 GRO-B and I live at GRO-B GRO-B I have been married to my wife GRO-B for 26 years.

2. This witness statement has been prepared without access to my full medical records.

Section 2. How infected

3. I have severe Haemophilia A with a clotting factor of less than 1%. **Exhibit WITN1310002** is my National Haemophilia Database record which confirms which products and over which time periods I received blood products.

4. When lived in GRO-B I was under the care of Dr Paul Hayes at my local hospital, GRO-B. As a child I was under the care of GRO-B GRO-B. I was also treated at St Thomas's Hospital where I alternated between two consultants Dr Hayes and GRO-B. Currently I am still monitored and treated at St. Thomas's Hospital.

5. I was not provided with any information or advice regarding the risks associated with blood products. My mother also advised me that she was not provided with any advice pertaining to the risks of receiving blood products. GRO-B had expertise in Haemophilia but my mother had researched Factor VIII and she took this information to GRO-B Factor VIII was considered to be a "*wonder drug*" because it allowed us to go out and play and "*be boys again*". Prior to the advent of Factor VIII I recall that GRO-B advised my mother to place me in a padded suit. However, the use of Factor VIII meant that this was no longer necessary.

6. I was infected with HIV, Hepatitis B and Hepatitis C as a result of being given blood products. **Exhibit WITN1310003** is a letter dated 10th March 2013 to GRO-B from Dr GRO-B which stated "*During his treatment for his haemophilia, he has contracted HIV*".

7. **Exhibit WITN1310004** is a letter dated 25th November 1982 from Dr Hayes to GRO-B which stated "*we have a degree of low grade liver damage, possibly resulting from non-A and non-B hepatitis acquired from Factor VIII medication*".

8. **Exhibit WITN1310005** is a letter from Dr Hayes to GRO-B dated 26th February 1987. This stated *"I have his permission to let you know that he was found to have antibodies against Hepatitis B surface and core antibodies in October of last year and is also HIV Positive. We have had a short discussion about the significance of the latter and I have told him that I shall be ready to answer further questions he may ask me about it."*

9. This account of the discussion is definitely not correct. What actually happened was that I saw Dr Hayes for a general appointment and at the end of this appointment he just mentioned, in a very matter of fact way, that I was HIV positive. I was totally stunned. Dr Hayes then told me that I had only two or three years to live. He did not give me any information other than this; no advice, empathy or sympathy. I walked out of this appointment a very different man. The information imparted to me was definitely insufficient. I headed to work in London the next day but instead of turning right to go to my office, I turned left and sat in a pub all day and got drunk.

10. As can be seen from **Exhibit WITN1310004** above, the medical profession was aware that I had non-A non-B Hepatitis as early as 1982 but this information as not imparted to me until 2001 when my community nurse advised me. Despite the fact that it was 2001 this information was also imparted to me in a very matter of fact way.

11. **Exhibit WITN1310006** is a letter dated 13th June 1989 from GRO-B to GRO-B which stated *"He has been Hepatitis antibody positive since 1979"*. To this day no-one in the medical profession has ever advised me that I am Hepatitis B positive.

12. I believe that I should have been told about my infections much earlier. Furthermore, and rather worryingly, I was not told about the risks of infecting others. When I was told that I had HIV in 1987, I had a girlfriend but thankfully I had not infected her and we split up in 1988. However, to put her and others at risk of infection was entirely unacceptable and morally wrong.

Section 3- Other Infections

13. There was a risk that I had received blood products from a donor who had been exposed to or had vCJD. However, I received a letter to confirm that, as far as the medical professionals were aware, I had not actually received blood products from a donor who had been exposed to or had vCJD.

Section 4. Consent

14. **Exhibit WITN1310007** is a letter dated 21st March 1985 from Dr Hayes to GRO-B GRO-B which stated "*I am now doing HTLV III screening on all haemophilacs and have arranged for* GRO-B *to take 10mls of clotted blood next time he has to give himself an injection of Factor VIII*". I had no knowledge of this and therefore by default this was without my consent.

15. I confirm that I have been tested without my knowledge and therefore without my consent on a number of occasions.

Section 5- Impact

16. My life has been very difficult as a result of being infected with HIV, Hepatitis B and Hepatitis C. I am and have been on anti-depressants for a very long time and they do work well for me. For a long time after I found out that I was HIV positive I was on a downward spiral.

17. I was put on a medical trial in GRO-B in relation to my HIV. I was not advised whether I was going to be given AZT or the placebo drug. For the entire two years I was wondering which treatment regime I had been placed on. Upon conclusion of the trial, I found out that I was on AZT. During the two years I was very sick but I did not know whether this was down to my HIV or the side effects of AZT; if indeed I had been placed on this regime. However, AZT was the only drug on offer at the time and I jumped at the chance of this trial but I did feel very poorly for the entire two years.

18. The mental impact of being infected meant that I was worrying all the time and I have now been diagnosed with severe clinical depression. I have tried a number of different anti-depressants and eventually I was put on Escitalopram which worked and still works for me. I have now accepted the fact that I will be on this medication for the rest of my life.

19. I did not tell anyone at work and I did not tell my parents for about a year; in fact initially I told no-one and dealt with the diagnosis of HIV on my own.

20. In GRO-B I managed to tell some friends and it reduced me to floods of tears. They appeared to be understanding but we ended up losing touch. To this day I do not know if that was because of my HIV or if it was just a product of them having busy lives and moving on.

21. I also managed to tell a couple of friends in GRO-B and they were okay about it. I have now grown into myself over the years and I don't really care anymore. However, as a family we never talk about my HIV. It is only very recently that I have started to discuss my infections with my sisters. I have now slowly started posting about things related to my infections on social media.

22. Physically it has been a real struggle. I still suffer with fatigue on a daily basis. Looking back historically I remember as a child I used to go upstairs to lie on my bed on a Saturday. People would tell me not to be lazy. I have struggled with extreme fatigue and exhaustion throughout my life and my community nurse advised me that this was as a result of my Hepatitis C infection. Currently my daily routine is to wake up, have breakfast and then curled up on the sofa for a sleep. GRO-B has now given up work to be my carer.

23. Physically I suffer from osteoporosis and I have severe arthritis in both ankles and my elbows. I had a left knee replacement in October 1998 and a right elbow silastic implant in October 2002. I also have enhanced liver fibrosis and have six monthly checks in this regard. I also take an awful lot of medication on a daily basis.

24. I have been on numerous antiretroviral agents for my HIV. The side effects of these included diarrhoea, depression, fatigue, anxiety and panic attacks. In fact I had to discontinue taking HAART on 6th December 2007 due to constant tiredness, anxiety, panic attacks and depression. **Exhibit WITN1310008** is a letter dated 8th January 2008 which confirmed this.

25. In GRO-B I underwent a 48 week treatment for my Hepatitis C comprising Interferon and Ribavirin. When I started the treatment I was stick thin; I weighed only 8 stones. During the treatment I lost a considerable amount of weight and some of my hair fell out. The treatment ruined my metabolism and I now need to be very careful with what I eat whereas in the past I have always been fortunate enough to eat whatever I wanted without putting on weight. The treatment has caused me to gain a considerable amount of weight since finishing, mostly around my tummy area. As a result of this treatment I have managed to clear the Hepatitis C virus.

26. I was very poorly when I was on the treatment and I was very depressed. I ached all over and had flu like symptoms. I also felt sick all the time and had to curl up and sleep. I could not interact with people as I was so irritated which meant that I avoided most interactions because I could not trust myself. I am still suffering to this day despite the fact that the treatment concluded in GRO-B

27. I take my HIV medication at night because I prefer to sleep through any side effects but unfortunately this does not combat the severe nausea and diarrhoea. I switched to Descovy in GRO-B which I hoped would limit the severity of the diarrhoea. However, I still need to make sure that I know exactly where the toilet is when I am out but it is better than it was last year. The drug regime, in general, is now better than it was a few years ago. I now only take two tablets a day. I still have to go down to St Thomas's Hospital for my appointments though; I go down about twice a year.

28. Before I had to give up work I was a GRO-B I dealt with people's GRO-B at the same time as dealing with my own death sentence and wondering when I was going to die. I really struggled with this. **Exhibit WITN1310009** is a letter dated 15th October 1997 which confirmed this. This exhibit also described my depressive symptoms to include loss of enjoyment, neglected hobbies, low mood, irrational idea of guilt and self approach about not working, lacked energy, motivation and that my concentration was markedly impaired.

29. The infection has had a very large impact on my family life. I did not tell my mother and father for about a year after my HIV diagnosis. It was in or around GRO-B when I took my mother shopping to GRO-B that we had our first conversation about my status, if you could call it a conversation. My mother asked me if I was infected and I replied that I was. That was that and we carried on shopping.

30. I did not really talk to my dad about my viruses and he passed away in GRO-B He was paralysed down his left side so he had to stop working but I never spoke to him about it.

31. I think that my mother must have told my sisters and my father. My two sisters were really supportive. It has been difficult at times but really I have kept it all to myself and that has its own consequences.

32. The HIV caused an issue between my mother and I in 1991. **Exhibit WITN1310010** is a letter dated 21st January 1991 from Dr Hayes to me which stated "*Since you are the only surviving haemophiliac relative, it is rather important that we should test some of your blood so as to find out which of her chromosomes may be carrying the haemophilia gene*".

33. I was not aware that my haemophiliac GRO-B had died and it was not until this time that my mother actually told me that he had died 5 years ago. The reason that she did not tell me was because he died of AIDS and she wanted to protect me.

34. The first time GRO-B and I went for a drink I talked to her about my health and infections; which was so strange because I was not prepared to risk telling most people but it just felt like the most natural thing in the world. The next day GRO-B passed me a lovely letter which she had written the night before. The letter said that she could not care less about my infections and she would look after and support me. It felt so comfortable and right being with her. It was the

best thing I ever did. However even with GRO-B being so understanding there have been some ups and downs in our relationship.

35. GRO-B used to be GRO-B and that is how we met. However, she left a lucrative job in GRO-B to become my full time registered carer and now receives a carer's allowance for this. I needed a full time carer because I was having difficulty concentrating and was not even able to deal with my medication. She also assists me with my 3ml Elocta injections which are required every 3 days.

36. I have had some particularly difficult times with the various treatment regimes over the years. I used to get angry and violent and would tell the doctors that everything was fine and it was only when GRO-B attended appointments with me that the doctors realised that I was anything but fine.

37. When GRO-B and I were still living in GRO-B I watched GRO-B leave for work every day and I would be in floods of tears thinking to myself that I am supposed to be the man of the house and that I can't possibly retire at the tender age of 44.

38. The major impact of my viruses on GRO-B and I was that we were unable to have children and we have therefore lost out on a full family life; there is a real void here. As a result of my infections I have felt suicidal at times because I did not have a purpose in life.

39. In order to distract myself I took up stained glass work and then I did a glass fusing course. I still do stained glass work today but it is just for fun.

40. I tried not to let the infection totally stop me in my tracks. I still met up with old school friends for drinks. I count every day I have as a bonus. It seems odd but when you are told that you only have two or three years to live, when you get to year four you just keep going and forget what you were told. I have had friends though who made jokes saying "*I bet that bloke over there probably has AIDS*" and I thought "*if you only knew the truth of who was sitting next to*

you". It was frightening really that my friends had that attitude but I felt relieved that I had not imparted news of my infected status to them.

41. Financially, GRO-B and I have been okay and have managed to make good decisions together. This has enabled us to purchase our dream home in GRO-B. Furthermore, I have been on an income protection scheme since GRO-B so I do get a modest salary each month which I am forever grateful for. However, I would prefer to be out there working for a living.

42. The infections did affect my employment. After my HIV diagnosis I commenced a professional course in GRO-B, which I completed. I went on to AZT treatment in GRO-B and was taking tablets at work and they did not have a clue. I kept working and I was reasonably lucky that between 1985 and 1987 I did not have any real physical problems. Following this, I was going to train as a driving instructor but I dropped out because you had to take the exam in a set period of time.

43. I could not tell anyone for a very long time that I was infected; that is where the mental struggle has occurred. I think that GRO-B found it difficult to talk about it as well. Although she totally accepts me for who I am she did not really talk about it much. However, today that has changed and we do discuss my infections and the past with regard to the contaminated blood scandal.

44. I have never really gone public about my infections and I have not sought press coverage. I moved to GRO-B for a new life and I do not want whispers to spread around the GRO-B or to be treated differently. This is one reason why I have never gone public with press or anything like that. I have got into a couple of heated arguments with other haemophiliacs in the Tainted Blood Campaign Group because they want me to go public. However, as previously stated I have recently started posting a few things on social media about my infections.

45. HIV and Hepatitis C have made me who I am today as I have had the opportunity to save and end up where I am today; in a beautiful house in GRO-B

GRO-B However, I often wonder what life would have been like if I had been "*normal*". If it were not for my infections I wanted to be a fireman or a policeman. However, my Haemophilia diagnosis would have posed a problem in this regard. I did not want to do an office job because I had problems concentrating after I was infected with HIV and Hepatitis C.

Section 6.Treatment/Care/Support

46. I have not had any difficulty accessing medical or dental care. Dr Hayes put me in touch with a local dentist who was happy to treat patients with HIV and when I moved to GRO-B my new dentist did not bat an eyelid at my HIV status and treated me like a normal person.

47. When I had a nervous breakdown in GRO-B I found out that my local haemophilia centre had an agreement with GRO-B to provide counselling. This service was aimed at homosexuals who were dealing with the effects of HIV but they agreed to see me. I saw GRO-B, Consultant Clinical Psychologist, for at least four years; he was fantastic and seeing him really helped my mental health. **Exhibit WITN1310011** is a letter dated 10th May 2001 which confirmed my treatment with GRO-B in which I am described as "*an extraordinarily courageous and stoical person. At times he becomes clinically depressed. You will see in the records that we have tried a variety of anti-depressants, but on balance when* GRO-B *is severely depressed, he does seem to benefit, at least in the short term. He will go on seeing* GRO-B, *from whom he gets a great deal of support*".

Section 7. Financial Assistance

48. The first time that I found out about The Macfarlane Trust was in or around 1990.

49. The first payment that I received from The MacFarlane Trust was £10,000.00. I then ascertained that if you were married you could receive a top up payment GRO-B and I therefore went down the route of proving that we were living together as man and wife and engaged to be married and received the uplift to £32,000.00. This was in or around 1991.

50. I became a GRO-B of The Macfarlane Trust in GRO-B but I GRO-B GRO-B my severe clinical depression.

51. I also received about £200.00 per month until about 2010. This then increased to £10,500 per annum and gradually increased beyond this figure. I think I now receive about £18,000.00 per annum from The Macfarlane Trust.

52. With regard to The Skipton Trust I received the Stage 1 £20,000.00 lump sum. My consultant applied for the Stage 2 payment but this was turned down because I did not have cirrhosis.

53. I now receive the Special Categories Mechanism (SCM) payments and these have really helped my financial situation.

54. I was aware that both Trusts provided grants and I have had small ones for washing machines and bedding because one of the problems I endured was savage night sweats which meant that I was going through my bedding very quickly.

55. When I applied for the Stage 1 Skipton payment there were few obstacles and the procedure was relatively easy because I just had to prove that I had Hepatitis C. However, with the SCM payments there were numerous hoops to jump through. I had to write everything down and pass it to my consultant for him to put the procedure in place. Then there was a somewhat protracted waiting period which was stressful as I wondered whether I had been successful or not. Eventually I was told that I had been successful. However, I would say that the procedure was somewhat arduous and not ideal for someone who is suffering with viruses.

56. Nowadays both Trusts always ask for copious amounts of information including bank statements often spanning three months if you wanted to apply for a grant. I did not even bother as by this time GRO-B and I were in a more comfortable financial position. I did not want to beg either and, for example, if you needed a new boiler they would ask you for three quotes; in GRO-B GRO-B this was not possible as it was hard enough to get even one plumber out to quote without paying them.

57. There was one very sad situation I heard about was that someone asked for and obtained a new boiler only to be evicted by his landlord because the landlord knew that he could now demand a much higher rent following the installation of the new boiler.

58. Unfortunately when Jan Barlow was in charge of The Macfarlane Trust she just wanted to line her own pocket and this was disappointing; the Trust was not fit for purpose.

59. Furthermore, the amounts of grants and payments were dependent upon what partners earned which I did not think was right. My monthly payments were reduced because of what GRO-B earned; GRO-B cared for me, put up with me and because she had worked and saved hard, we were penalised financially by the Trusts.

Section 8. Other issues.

60. Unfortunately I had to drop out of the earlier litigation because I could not afford the contribution of £150.00 per month at that time.

61. I also took part in the USA litigation which took about seven years to complete. We were all told that if one person did not sign a waiver or agree to the payment sum then no one would get anything. It was a brutal bullying tactic.

62. I have been quietly campaigning for the last ten years. I have supported The Tainted Blood Campaign and if they said I needed to do anything to assist I would do it. I wrote copious amounts of emails. However, I would not go public which infuriated some members at times. However, The Tainted Blood Campaign Group have provided me with invaluable support and I don't know where I or the infected haemophiliacs would be without them.

Conclusion

63. I want to find out what happened and why. I want to know why I was not told about my infections until much later on. This is unforgivable. Financially I think victims need adequately compensating.

64. This tragedy has been simmering for thirty or so years. The Government has relied on the victims not going public due to the stigma surrounding HIV and Hepatitis C.

Anonymity, disclosure and redaction

67. I confirm that I want to apply for anonymity and that I do not want to give oral evidence to the inquiry.

Statement of Truth

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

Signed........ GRO-B ......(Electronically signed)............................

Dated......29th November 2018..