Witness Name: GRO-B
Statement No:WITN1774001
Exhibits:WITN1774002
Dated: July 2019

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. I live at GRO-B GRO-B I am divorced; my youngest son GRO-B lives with me. I was born on GRO-B GRO-B I am a solicitor by profession but I am not working at the present time.

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

Section 2. How Infected

3. I have Christmas disease which is a type of Haemophilia caused by a deficiency of Factor IX. I was diagnosed from a very early age; my father asked for me to be tested for Haemophilia as there was a family history of it.

4. My father wanted me to be circumcised, but as a result of my diagnosis I was not.

5. My first memory of being treated for bleeds was when I was about 5 or 6 when I had a very bad nose bleed. It would not stop and I was taken to GRO-B

GRO-B. By the time I arrived I was very anaemic and I was treated with whole blood. I remember counting the drips of blood as I was being infused.

6. I was quite a resilient child and was not wrapped in cotton wool by my parents. I was able to take care of myself and I remember frequently fighting with other children when I was younger.

7. I remember going to GRO-B School in GRO-B This was a school for the physically and mentally handicapped. We played marbles all day and got involved in fights with not too many adverse affects. However, one day I recall that I was kicked on my right knee by a child called James. There was no treatment for haemophilia at the time and I was in GRO-B for three weeks. They attempted to deal with it by traction; it was a very painful experience.

8. After three weeks in GRO-B I was sent to their country convalescent hospital in GRO-B. There were concerns that I would not walk again but I had a very good physiotherapist who treated me and got me walking.

9. I bruise very easily due to my haemophilia and during my younger years my bleeds were treated with bed rest, splints and ice.

10. Whilst I was at GRO-B I received a good education with one to one tuition. My reading skills improved dramatically and my family were advised that if they could find a school that were prepared to take me with my condition then I could enter mainstream schooling.

11. I went to GRO-B Primary School and after an initial encounter when a boy came up to me and hit me and I thumped him back I never had any further problems at school.

12. To the best of my knowledge I was 9 years old when I first started treatment with fresh frozen plasma. This was at GRO-B. They administered the plasma very slowly and I would be hooked up for days at a time. I didn't really like this as I hated using a bed pan during the process and so I preferred to sit my bleeds out at home with bed rest.

13. When I was 11 my treatment care was transferred from GRO-B to the Haemophilia Centre at GRO-B Initially I hated this hospital; it was antiquated and I remember thinking that it was like a place straight out of a Charles Dickens novel. The hospital was vast and spread out. I remember that when you walked along the

corridors steam and fumes would come out of the pipes. I was scared stiff when I went there.

14. However, when I was about 12 or 13 I went to the GRO-B with a severe bleed in my left knee which had swelled into a balloon from measuring 14.5 inches to measuring 17 inches. They aspirated the joint and the pain relief was enormous. They gave me 3 pints of plasma in 20 minutes and the whole experience was so good. Whilst the building was a scary place; the treatment was first class.

15. My best recollection is that I was switched from fresh frozen plasma to Factor IX concentrate in or about 1973.

16. I remember clearly the first time I treated myself almost like it was yesterday. I had been envious of my friends being able to take themselves away on holiday whilst I was restricted and had to be close to a haemophilia centre. As I had learnt to home administer I was able to go away and my friends and I went on a road trip. We went for a week in Scotland and a week in Blackpool. I was the only driver and I recall having a bleed in my left elbow. I was able to drive off the road onto a track, administer the concentrate and carry on.

17. I had no problem with home treatment and for very many years never missed a vein.

18. In or around 1990 I was called to the GRO-B one day and I was told that there was good news and bad; the good news that I did not have HIV but the bad news that I was infected with non A non B Hepatitis. I remember at the time that the staff at the hospital appeared to be in a state of panic and high anxiety. I cannot remember who told me. I did not have a clue what they meant and they didn't expand any further. I was given no advice at this point.

19. I was not told which blood products I was contaminated with nor have I been told when I was contaminated.

20. Some two years later I was told that like others I had been infected with Hepatitis C (HCV). This was a longer meeting than the first and I was given some more information. I was told that if I had a sexual partner that we should practice safe sex. I was not told anything about the symptoms I may suffer or about treatment.

Section 3. Other Infections

21. I am not aware of any other infection nor have I been told that I have any other infection.

Section 4. Consent

22. I was not aware that my blood was being tested however I might have been told but did not appreciate at the time the significance of such information. If I was so informed I was never aware of whether they told me about testing for HIV.

Section 5. Impact

23. I studied law at GRO-B and after I graduated I started working in a Solicitor's office. I became a partner in the practice of GRO-B which was based in GRO-B in 1979 and was a very successful solicitor.

24. I was married on GRO-B and we had two sons. GRO-B was born on GRO-B GRO-B and GRO-B was born on GRO-B.

25. During the 1980's things were going very well both in my private and my working life. Through my mid 20's to 1990 I was at my peak.

26. My recollection over the years is hazy and I remember certain incidents well but other matters I cannot recall. From the beginning of 1989 to June 1989 I was working extremely long hours approximately 80 hours a week and then my wife had an ectopic pregnancy so I took time off to care for her.

27. The effects of HCV can creep up on you; it is like a ticking time bomb. One of the problems I have faced is distinguishing between the symptoms manifesting from HCV and those manifesting from the Haemophilia. When I was told that I had HCV I was not suffering at the time. I would say however that I am by my very nature an optimistic person.

28. We went on holiday in 1991 and 1992 to the USA. I remember saying to my wife that that was what I wanted to do whilst I had the chance. By this time I was extremely arthritic and already on Naproxen. When we went to the Epcott centre I had a buggy to get around.

29. From about 1994 my health deteriorated. I had surgery in the summer of 1994 when I had an arthroscopy on my right knee and I had my left ankle fused. I was not fit for work for a long period after this surgery and from then until 1997 I could only manage working 15 hours per week. I was in so much pain and I had gone downhill during the early 1990s.

30. The practice in which I was a partner was dissolved in GRO-B

31. I was never able to go back to work full-time and if I were to accurately say what I did do during this time is that I worked full time managing my pain. I could not find the right words for things and I had no drive.

32. In or about 1996 I started smoking cannabis to deal with the incredible pain that I was in. I found that this helped.

33. I had been offered counselling when I was told that I had HCV in or about 1992. I remember going home and reporting to my wife. We decided at that time that we were not going to change our sexual habits and by agreement we did not use condoms. I think we took a "glass half full" attitude that everything was going to be alright and we did not see HCV in such grave terms. I am pretty sure that my wife has been tested but I cannot say definitely.

34. I recall that I was asked to take part in a study in 1999. I cannot remember what it was for but I attach as Exhibit WITN1774002 a copy of the questionnaire and my responses which accurately reflects how I was feeling at the time.

35. In or about 2002 I went to see GRO-B at the GRO-B He was the director of medical health at the GRO-B and I had said to my wife that if I could find a better medication other than cannabis that I would do so. He told me that I was clinically depressed. I was prescribed Oxycodone Hydrochloride. I had thought that I was meant to take this medication like you do with ordinary painkillers but you were meant to take it whether or not you were in pain to prevent the pain coming. I remember that I was in excruciating pain at

that time; it was like a constant severe migraine in my bottom and pain everywhere in my body.

36. He asked me what I thought was causing the pain. I said that I thought it was as a result of my Haemophilia and bleeding in joints. GRO-B said "Is it? Are you certain it is from the haemophilia", and of course that got me thinking. Without actually saying it he was inferring that some if not all the pain was caused by the HCV.

37. My wife and I split up in 2006; we had disagreements about my cannabis habits and undoubtedly my health had an impact on our relationship. It is difficult to see things from another person's standpoint particularly when dealing with frequent and chronic pain. It makes someone self-centred. Instead of getting a successful solicitor as a life partner she got someone suffering from pain and unlikely to work again.

38. In or about 2012 when I was at the Haemophilia Centre one day I was approached by GRO-B known to me as GRO-B. He asked me whether I would like to be part of the trial that he was doing with regard to gene replacement therapy in respect of the haemophilia gene. I said yes to this; that I would like to be part of the trial.

39. In order to become a trialist however, I had to be cleared of the Hepatitis C virus. They started treating me with a combination of Ribavirin and Interferon. After 3 weeks of being on this medication I felt utterly wretched. I was sick and it was just awful and ghastly. I told the nurses that I was going to stop the treatment which I did for a few days but then felt that I was not going to give up and gave the drugs another go.

40. Within three weeks of restarting the drug I became anaemic and required at least one if not more blood transfusions. GRO-B told me at that time that I had had one of the worse reactions to the drugs that he had ever seen.

41. As a result of this I developed psoriasis which has become increasingly worse. I find it disgusting and I battle constantly with the itchiness it creates on my body. I find this disgusting.

42. I also developed psoriatic arthritis in my hands and I find that at some times I cannot shake hands with people because of the pain. I cannot shuffle a pack of cards and I find fine hand motions difficult.

43. Unfortunately, the HCV was not cleared by this drug and therefore the gene replacement was put on hold because of it.

44. A couple of years later I was put on a biological drug which I think was called Humera but I am not sure. This did not have the same dramatic side-effects but it did not work.

45. I was later treated with one dose of Harvoni which did work and has cleared the HCV. I receive regular liver function tests and I am told that my liver is not in a terrible condition.

46. When I was told about the HCV I was told that if I did not indulge in alcohol already that I would be well advised not to as my liver needed to be looked after. I used to enjoy wine with my food but I hardly drink anymore because of this. I felt that this was odd in terms of advice being given.

47. Despite clearing HCV the gene replacement therapy has not taken place. I have not pushed for it.

48. Currently, I am very poorly and it is a combination of being constantly in pain, lacking energy or drive, and I also suffer from panic attacks. Those things combined are lethal. It makes it very hard for me to get anything done, as on the infrequent occasions when I eventually feel better I need to spend some time on resting before I get anything done. I have been feeling very withdrawn. I find myself living from an hour to an hour, not even from a day to a day, as my wellbeing keeps on going up and down so frequently. It gets to the point, whereby I have left things for so long that everything needs catching up and things need to be rushed.

49. I am also no longer able to enjoy the things I love, such as watching sports. I love cricket and football, but I found myself unable to watch cricket and football matches, as I have suffered from panic attacks on multiple occasions. The first time I had a panic attack, I was afraid that I was going to die.

Section 6. Treatment/Care/Support

50. The psoriasis has given me a low self body image. I was offered treatment with a drug Apremilasd but my treating doctors said that as this was expensive I would have to wait for it. I find this ironic because the psoriasis constantly itches. When I scratch it I bleed and as a consequence of the bleeding I require concentrate treatment which I believe costs in the region of £3,500. By the time they decided that they would pay for it, it had already cost the NHS a fortune.

51. The Apremilasd has kept the psoriasis in check. However, one of the side-effects of it is that it made me feel nauseous. I stopped it for a while and then retook it. For at least two years prior to Christmas 2018 I had needed one or two crutches at all times to get about but after starting to retake the Apremilasd I have been able to walk much better and without a crutch. For some inexplicable reason my ankles are much improved but my hands are worse.

52. I had been asked by GRO-B in the Haemophilia Centre at the GRO-B whether I wanted to have treatment of interferon from the early 2000's. As a result of a consultation with her I did not have the treatment because she considered that it would be bad for me. The evidence at the time was that it caused depression and the chances of success were not outweighed by the side-effects. She thought that the treatments for HCV would improve with time and she was right.

53. I cannot say that I have been denied any other treatment. I received dental treatment at the GRO-B until the department closed and then the haemophiliacs were moved to the GRO-B GRO-B but they did not want all these difficult patients. Eventually I was treated there but I have lost almost all of my teeth. I am not so sure it was because of the infections but more the Haemophilia that was the problem with this clinic taking us on as patients.

Section 7. Financial Assistance

54. In the early 2000's I received the Stage 1 payment of £20,000 from the Skipton Fund. I did not have any difficulties with this application and receipt of the funds.

Section 8. Other Issues

55. I recall one of the nurses or one of the medical staff at GRO-B saying that in the late 1970's they were holding back batches of Factor VIII concentrate specifically for those aged under 16 and that those patients did not get any virus. I believe therefore that there was an ability to protect patients if the doctors had made this specific decision. I am unable to neither give any specific date when I heard this nor give details of the person that told me.

56. I also heard that when you went to haemophilia centres for treatment you would be asked if you were in any pain and if so were asked if you would like anything for it. Patients in pain were regularly given IV painkillers such as Fortral and I believe a number of these patients have been treated for drug addiction. I am unable to give anymore detail in this regard.

57. I was never made fully aware of any risk associated with blood products.

58. I think the scale of this is huge and despite living in a country where we are supposed to behave ourselves I am not certain this has happened. 96 people died at Hillsborough and the fall out from that is considerable. From what I hear for example from Lord Owen about shredded papers makes me think that the Government may well have done the same thing in our particular case. However, it was not 96 people in this case it is in excess of 2,000.

59. Another important point is that for every Haemophilia B patient, there are 6 times as many Haemophilia A patients. Whilst it is best if all haemophiliacs appear to be as one, it is important to point out that at all material times the Blood Transfusion Service could have been and should have been self-sufficient in Concentrate Factor 9, without the need for any imports.

60. I would like to give oral evidence before the Chair, but I do not think that I would be physically able to do so. I have no energy or drive, and I suffer from panic attacks. I am afraid of suffering from a panic attack at the Inquiry, so I am discouraged from doing so.

61. In order for the outcome of the Inquiry to be deemed successful, I believe that the government should be found culpable of the scandal. Their public policy is not adequate, as nobody is admitting to their faults. Secondly, I would like for the people that were affected by this to be appropriately compensated.

Anonymity, disclosure and redaction

62. I wish to apply for anonymity. I understand that this statement will be disclosed and published as part of the Inquiry. I do not wish to give evidence.

Statement of Truth

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

Signed GRO-B

GRO-B

Dated 26th June 2019