Witness Name: GRO-B
Statement No: WITN1245001
Exhibits: 4
Dated: September 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. My date of birth is GRO-B. I am currently married and have two grown up children.

2. As a result of receiving contaminated blood products, I was infected with Hepatitis C.

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

Section 2. How infected

4. I suffer from severe haemophilia A and have a clotting factor of 0%.

5. According to my memory and the records in my possession, I have received the following products during my lifetime: whole blood, Cryoprecipitate, EHF, FFP (fresh frozen plasma,) Lister, Factor VIII concentrate, BPL Factor VIII

Travenol/Hyland/Hemofil, Factor VIII Factorate, BPL Factor VIII 8Y, Helixate Nexgen, Kogenate, Advate and Novoeight. As per exhibit **WITN1245002**, this medical record lists the year I was treated, the centre, the specific product and number of units issued.

6. I do not know for certain when I was infected, but it is highly likely to have been during my years at Treloar College in Hampshire. I attended between GRO-B. Most, (maybe all) of my treatment was given at Treloar Hospital, Alton. I am unsure of whether I was given Factor VIII concentrate products at the college itself. There could have been an odd follow up occasion, but I cannot recall a specific time.

7. I did not receive treatment very often, in comparison to many other haemophiliacs at the college. The only advice I was given, was that I should report any bleeds to sick-bay without delay so that they could be treated promptly. On some occasions, I ignored that advice, especially if I thought the bleed was not very serious and I could get away with not having treatment. Being driven to the hospital in the minibus and enduring a dose of treatment was not very pleasant. The only risk I was ever told about and was fully aware of, was that I could react to the treatment. I was routinely given Piriton midway through the treatment to minimise or remove that risk. I'm not exactly sure what kind of "reaction" might have occurred, but I have a vague recollection of feeling trembly on at least one occasion.

8. Having requested medical records, it may be significant that my treatment records for the years 1972 and 1973 are missing. It was during the years of 1972 and 1973, that I was receiving the new pooled plasma concentrate at Treloar Hospital. However, I do not know for sure and don't think there is any way I could possibly know exactly when I was infected.

9. I would very much like to know exactly where and when I was infected. Was it just one rogue dose or, as is more likely, was it a number of different doses over a period of time? As well as the treatment received at Treloar Hospital, my records show that I also received treatment at Oxford Haemophilia Centre, (my local centre when not at boarding school) and one dose at Bristol

Haemophilia Centre, (during a family holiday in the west country.) In 1976, I moved to GRO-B and my GRO-B treatment centre was Addenbrooke's Hospital, until 1984.

10. I don't recall ever being told that there was a risk of infection from receiving treatment for my haemophilia. My parents have confirmed that they were also unaware of any infection risk.

11. I was infected with Hepatitis C as a result of being given blood products.

12. I vividly remember being told about AIDS and HIV by the consultant at Oxford Haemophilia Centre during the early to mid 1980s. I was told I had escaped the virus. He told me that only about 10% of people infected with HIV would go on to develop AIDS. I remember thinking that he was wrong and that everyone infected would progress and develop AIDS. It was not until afterwards that I reflected on how my life could have changed in that moment. I was very lucky.

13. However, I was not so lucky with the Hepatitis C virus. Unfortunately, neither my wife nor I, can recall when I was told about my Hepatitis C infection. It was definitely during a routine appointment at Addenbrooke's Hospital in Cambridge and was probably in the late 1980s. My medical history concerning my infection has been exhibited as per **WITN1245003** and confirms the infection to have been diagnosed in 1980 at the earliest. Although it would have been called Non A Non B Hepatitis at the time.

14. I was told that Hepatitis C was a virus that could affect the liver. The consultant at the time was Dr GRO-D and either he or one of his team members gave me the news that I had been infected.

15. I was advised not to drink alcohol and to eat a healthy diet. They wanted to carry out a liver biopsy to assess how damaged my liver was.

16. I do not believe that adequate information was provided to help me understand and manage the infection, as I did not realise at that time how potentially serious the infection could be.

17. I do not have a view about how the results of the tests had been communicated to me, but I certainly have a view about how the biopsy was carried out. I am naturally nervous of most hospital procedures, but the thought of having a liver biopsy was truly terrifying. I was physically shaking with fear. I was told they would give me a sedative to calm my nerves and they pretended to do so. My wife was with me throughout and told me afterwards that the "sedative" was actually just saline.

18. Both my wife and I are medically qualified and she knew they were deceiving me, but was too afraid to speak out. To this day, that procedure still haunts me. I cannot talk about it or write about it without being reduced to tears. I cried as I was writing about it within this statement.

19. In terms of the information I was given about the risks of others being infected as a result of the infection, I was told there was a small risk of infecting my wife during sex and that I should always wear a condom as a precaution. Obviously adhering to this advice would mean no more children. I ignored it.

20. This was in addition to the strong advice to avoid alcohol. For many young people that could have proved very difficult and affected their lifestyle enormously, but for me it was not a great problem. I rarely touched alcohol anyway, which is probably a key reason as to why I am still alive today.

Section 3. Other Infections

21. I was advised (I believe by a letter) that I was officially "at risk" of vCJD because of the blood products I had received between 1980 and 2001. My records (as exhibited under **WITN1245004**) show three tests / assessments, as follows:

- 24/9/2004 at Oxford by Dr D M Keeling.

- 8/12/2004 at Norwich by GRO-D.
- 18/5/2005 at Cambridge by E Hayman.

22. The test at Norwich was a dreadful ordeal and made me feel very uncomfortable. My appointment was at 1.30pm and I sat in the waiting area for my blood to be taken. I was still waiting at 5pm, watching as everyone else was attended to. Finally, when there were no other people waiting, they called me. It was about 5.30pm by the time I laid on the couch in readiness for my blood sample to be taken.

23. What happened next was extraordinary! A medical professional appeared dressed from head to toe in protective garments. Think of a beekeeper and you will get the idea. It was as if I'd got the plague or Ebola. It was quite shocking.

Section 4. Consent

24. I believe that I have been treated and tested without my knowledge, consent and without being given adequate or full information.

25. I do believe that I have been treated and tested for the purposes of research.

26. My records show I was given a dose of treatment as part of "Dr Craske's research work" in 1974.

27. I have no idea who Dr Craske is/was or what that research work was for. I would be interested to know. It coincided with being given Travenol/Hyland/Hemofil FVIII, so he may well have been testing these commercial products on me. Please see exhibit, **WITN1245005.**

28. I also believe that the liver biopsy I endured to assess how the hepatitis virus may have affected my liver, was probably more for research and data purposes than for my immediate benefit.

Section 5. Impact of the Infection

29. When my Hepatitis C infection was first diagnosed I was not overly concerned. I did not see it as adversely affecting my life to any great extent.

30. Then people started dying.

31. As the years progressed, I became much more aware of its implications, although I have not suffered some of the serious effects that others have. About five or six years ago, as more and more haemophiliacs became ill and died, I grew increasingly concerned, aware that I had most likely been infected for forty years. If I too was going to become ill, then it was probably going to happen soon.

32. I started to fear having the virus flowing around my bloodstream and the implications of dreadfully unpleasant Interferon treatment, to try to remove it. I was also aware that the Interferon treatment was not overly successful. For someone who is irrationally scared of most medical procedures, I felt like I was in a 'Catch 22' situation. I avidly followed the latest research into new treatments, but was advised that there was no government funding for people like me who were symptom-free.

33. One day, whilst my wife was at work, I received a letter from my haemophilia hospital requesting me to attend for an endoscopy. I knew the procedure was very unpleasant and potentially quite dangerous for someone with haemophilia. I also knew the reasons behind the request and what they would be looking for. I also knew what they would want to do if they found anything abnormal. Once again I was terrified, but this time I was acutely aware that the virus might be catching up with me. I felt completely trapped in the awful reality that there was no easy solution to my situation. I sat and stared at the letter and cried for hours. In the end, I refused the endoscopy.

34. A Fibroscan in 2016 showed my liver was cirrhotic. I still felt okay, but soon afterwards, I was fortunate enough to be offered a course of treatment to try to rid myself of the Hepatitis C virus. I began the course in January 2017 and completed it three months later. All of my subsequent blood tests have been

negative and the virus has been cleared. I am advised that I remain at risk of further complications, including liver cancer and have to undergo six-monthly blood tests, but I feel okay.

35. The treatment involved a three-month course of Zepatier, which has only recently been introduced. I think I may have been one of the first people to use it. The liver nursing team at Bournemouth Hospital oversaw the treatment and it was wonderfully successful. My first blood test was done just two weeks after starting the course of treatment and already there was no sign of the virus. I had no side effects at all. It was like a miracle.

36. Initially, there was insufficient funding for treatment. However, this may have been to my advantage because when I was eventually offered a course of treatment it was the very latest drug and it cured me without any side effects or other issues.

37. It is possible that there were treatments which ought to have been (but were not) made available to me, but funds were limited and there were others in greater need of treatment. I am just enormously grateful that I was eventually offered the chance of a cure and it worked.

38. Despite the lack of physical side effects, mentally I was adversely affected by the treatment. I experience a whole gamut of emotions; from the trauma of the liver biopsy and the prospect of dying while my children were still young, to the elation of negative blood tests after ridding myself of the virus. I hate having blood taken (my veins are poor after decades of injections) and I still worry about possible future complications from having been infected.

39. My entire life has been fraught with difficulties caused by haemophilia and being infected with Hepatitis C, has added to those difficulties by causing me considerable stress, especially during the last decade. Despite everything, I regard myself as incredibly lucky. There is no doubt in my mind that avoiding alcohol, eating healthily, having a supportive wife and family, having relatively few financial problems, adopting a positive attitude, and the chance to cure the virus just in time, have all contributed to my survival.

40. My dentist always took sensible precautions to combat the fact that I had Hepatitis C, but overall my dental care and other treatments have been fine.

41. Socially, I sometimes felt uneasy about not drinking alcohol when my friends were enjoying a pint or three or at family events where others would be drinking wine or whatever. I remember feeling annoyed at my daughter's wedding because everyone else could toast the happy couple with champagne, but I had to resist.

42. From a family perspective, being newly married and then being told to always wear a condom for fear of infecting my wife was upsetting. It immediately put us into the dreadful situation whereby every time we made love we had to think … should we or shouldn't we?

43. The other impact that the virus has had is the regular need for blood tests and hospital appointments. I live a long way from the liver nursing team at Bournemouth and even further from the liver consultant based at Southampton that I've had to visit on several occasions. It is a two-hour drive away.

44. Luckily, my family have all been very supportive of my infections so I have not faced any stigma.

45. Financially, I have had to incur the additional costs of travelling to and from hospital and the car park fees.

Section 6. Treatment/care/support

46. I have never been offered counselling or psychological support, nor have I ever requested it.

Section 7. Financial Assistance

47. I believe it was in or around 2003, that the Haemophilia Society made me aware that financial assistance was available via the Skipton Fund.

48. Soon after I received a lump sum of £20,000 that was paid to everyone who was known to be infected by contaminated blood. I also received the lower rate of assistance. I'm not sure how much that was, but it was minimal.

49. In 2016, after my diagnosis of cirrhosis, I applied for the higher rate from the Skipton Fund. The application was refused. I was sure a diagnosis of cirrhosis by Fibroscan fulfilled their criteria, so I appealed the decision. With supportive written evidence from my consultant and a strongly worded explanation from me, their decision was reversed and I was awarded the higher rate. In addition, I received a further lump sum payment of £50,000.

Section 8. Other Issues

50. I'd like those responsible for delaying heat treatment to be held accountable. These are people such as old fashioned doctors and MPs, all of whom knew what was going on and deliberately authorised such an operation to commence in the UK. There is evidence by way of letters and documentation, to support my allegations and to suggest just how scandalous this was.
51. I would also expect there to be some form of financial recompense for the victims of contaminated blood.

Anonymity

52. I would like to apply for anonymity.

53. I do not wish to provide oral evidence to the Inquiry.

Statement of Truth

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

Signed. GRO-B ....

GRO-B

Dated.....24 September 2019..