Witness Name: GRO-B
Statement No: WITN1532001
Exhibits: WITN1532002
Dated: June 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF GRO-B

I, GRO-B, will say as follows:-

1.Introduction

1. My name is GRO-B and I live at GRO-B, GRO-B. My date of birth is GRO-B. I am married to GRO-B and we have no children. I worked as a design engineer and I have now retired on medical grounds.

2. I have been infected with Hepatitis B and Hepatitis C (Non-A Non-B as it was then known) as a result of receiving contaminated blood products.

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

2.How infected

4. I was diagnosed with severe Haemophilia B when I was 18 months old. I had a large bruise at the time which led to the diagnosis. The only treatment available was transfusion of plasma on a drip when I was around 5 or 6 years old.

5. The nearest hospitals to me were the Churchill Hospital and Nuffield Hospital in Oxford. It was quite traumatic lying on a bed having a transfusion. I had to stay in hospital for 2 to 3 weeks for every single bleed. I spent as much time in hospital as I did outside of hospital.

6. My treatment did not change until I was approximately 17 years old. I was then given Factor IX concentrate which was administered by my local GP. I went to the GP at least once or twice a week. Factor IX was a dry solution which had to be mixed with saline. I had to wait for it to dissolve until it got to the right body temperature and then it was injected. When I was aged 18 I started administering it myself because the doctors could never find the vein. I kept the concentrate in the fridge at home.

7. I refer to **Exhibit WITN1532002** which is an extract from the National Haemophilia Database which confirms that I was given several different blood products including FFP, FIX (BPL), FIX (PFC), French FIX, Replenine (BPL) and Alphanine and BeneFIX.

8. I was under the care of Dr Matthews between the ages of 2 to my mid 30s.

9. I was also under the care of Dr Rizza for some time.

10. I believe I was infected between 1978 and 1985. When I was first infected with Hepatitis Non-A Non-B (now known as Hepatitis C) the doctors appeared to be very unfamiliar with it. I had symptoms of jaundice, I was very lethargic and my eyes started to go yellow.

11. I tested positive for Hepatitis B in or around 1978 to 1979.

12. I was tested at the Oxford Haemophilia Centre at the Churchill Hospital.

13. I was not provided any advice in relation to risks of infection from blood products.

14. In or around 1982 to 1983 Dr Rizza and Dr Matthews told me in a matter-of-fact way that I had been infected with Hepatitis. They were both vague and not forthcoming with adequate information which signaled to me that they did not know what the infection really was. They told me that it was an infection which they had observed through testing other patient's blood samples and that there was a chance that all of the haemophiliacs could have been infected.

15. I had such a good relationship with Dr Mathews that I thought he would have told me everything he knew. I therefore believe that he did not know much at the time. I would have been backwards and forwards every 2 to 3 weeks to pick up treatment so I would have seen the doctors on a regular basis.

16. I do not know if I felt particularly shocked or was not more concerned because I did not really know what Hepatitis C was or the damage it could cause, such as cirrhosis of the liver. I did have some concerns but I just moved on. It was a long time ago and it is difficult to recall in detail.

17. They seemed to lump AIDS with Hepatitis C and fortunately I didn't come in to contact with HIV. I was not provided with adequate information in relation to how to treat or manage my infection. I think that more information should have been provided to me at the time.

18. It was only after the diagnosis of Hepatitis C was confirmed that I was told that I could infect my wife. The main thing that came up was contraception and that we had to use it.

3.Other Infections

19. Approximately 15 years ago vCJD raised its ugly head. Haemophiliacs were found to have vCJD only after they had died and it was found in their brains.

20. I don't remember if the consultants talked to me about vCJD. I do not recall them giving me any information about the condition.

4.Consent

21. I believe I was tested without my knowledge. I believe the doctors knew various things before they told me because they tested me so frequently; especially liver function tests.

22. I refer to the aforementioned **Exhibit WITN1532002** which confirms that I was tested for HIV on three occasions: 18 July 1985, 11 March 1986 and 09 June 1987. I was not aware of these tests at the time.

23. I was tested periodically every 2 to 3 months. Subsequently the cycle of tests went to every 6 months. I don't know if I was tested for research but I could have been because I was tested all the time, I was not told what the tests were used for.

5.Impact

24. I suffered from jaundice of the eyes and skin as a result of Hepatitis. It felt like I had been run over by a steam roller. As a result of the horrendous side effects I took 3 months off work. I felt really ill and continuously suffered from fever. Additionally, I had a lot of abdominal pain which meant that a simple task such as sitting down and reading a book was a struggle.

25. I am used to blocking out the bad stuff as I grew up with Haemophilia which comes with so many problems and limitations. It is almost too difficult to recall the specific detail and it is difficult to separate it from Hepatitis. Following the infection of Hepatitis B my health suffered and then I got better and returned to normal which meant that I could return to work. Eventually I cleared Hepatitis B.

26. The period of time during which my health was stable lasted a few years until Hepatitis C started showing negative symptoms.

27. The media portrayed Hepatitis C in a very difficult light as it was repeatedly mentioned in conjunction with HIV. It affected my health physically as well as creating worries for me in relation to my professional life. At the time I was working for a UK GRO-B on a top secret project. There was so much about Hepatitis and HIV in the press that my colleagues assumed I had all of the infections as they were aware that I was a haemophiliac. It was a very awkward atmosphere at work which made me think that I was in a difficult situation and it made me worry about the struggle of finding a new job had I lost this one.

28. Despite this, I do not think I was treated unfairly as I kept the job I was doing. However there was a real undercurrent that made me feel awkward because stigma surrounding Hepatitis C was widespread which was a lot more prevalent in the later years.

29. My social life suffered as a result of the stigma. I lost a lot of friends who assumed that I had been infected. One minute they would happily come around to our house but the next minute they were gone. It stopped me from going drinking to the pub. If I had a pint of beer it would make it feel ill the next day. It got quite bad at times. People didn't know really if they would be infected by me. I just got a feeling that people were keeping me at a distance. It was ignorance on their part. They would hear things on the TV or the radio. I recall there was an advert advising people to refrain from drinking from the same glass. My wife and I became blinkered; we just tried to get on with it.

30. In or around 2000 I cleared Hepatitis C. I underwent a 6 month treatment recommended by the doctors to clear the virus. Before this treatment there was no treatment which was made available to me for Hepatitis C. It turned out to be a terrible treatment with really awful side effects. I do not recall the name of the treatment but I had to intravenously inject myself every week. It was a spring loaded puncher that injected the quantity of medication from the tube which felt quite lethal.

31. Additionally I ingested many tablets every day. I knew I would feel horrible after I had the injection. As a result of the treatment I lost my hair and eyebrows, I felt nauseous, suffered from vomiting, diarrhea and weight loss. I recall that my sleeping pattern was irregular and I remember sleeping for 24 hours one day. If I drank any alcohol it would affect my liver so I would feel feverish and bloated but I was not a heavy drinker. I was also very lethargic and depressed throughout the duration of the treatment.

32. At the end of the treatment the doctors were constantly testing my blood for the Hepatitis C virus monthly, then every 3 months and then every 6 months. After a couple of years they stopped testing because they said my body had cleared the virus.

33. I do not believe there were any obstacles or difficulties in obtaining treatment for Hepatitis C when it became available. They offered it and I took it. There were only two options either take it or leave it. I do not know if treatment could have been made available to me earlier.

34. I never went to the doctor or had treatment for depression despite suffering from depression for many years. I became anxious during the time leading up to injecting myself with blood for Haemophilia. Every time I injected myself I was frightened that there may be other infections in the blood products that I was unaware of.

35. Having Hepatitis C had an effect my general thinking and concentration. At work I needed to concentrate most of the time and I found it difficult to do that following the treatment. I found it hard to concentrate for long periods and it physically slowed me down. Although it affected my work I continued to work.

36. I don't think my parents were badly affected because I was away from home and married at the time.

37. As regards to my wife, GRO-B she is an ex-nurse so she has a better understanding of my condition and the medical treatments I went through. My

condition also affected her and she intends to provide a separate statement to the Inquiry about this.

6.Treatment/Care/Support

38. I do not think we have had a lot of support with Hepatitis C. However, if I ever needed to ask Dr Matthews or Dr Rizza anything there was no trouble in getting answers.

39. I recall there were two other doctors in Oxford who were abrupt and uncaring.

38. No counselling or psychological support has been made available to me.

7.Financial Assistance

40. In or around 2005 I received the Stage 1 payment of £20,000 from The Skipton Fund.

41. In the last 3 or 4 years I have been receiving regular payments. It was initially around £250 per month and it is now £333 per month from the EIBSS.

42. It is an ongoing nightmare claiming for specific items. The Fund make it as awkward and as difficult as possible making reaching their criteria very difficult. When I had Hepatitis C I needed a special bed. It was very difficult to prove it was related to Hepatitis C. I also applied to the EIBSS to obtain help for funding but my application was refused. I think the forms are designed to cause confusion.

8.Other Issues

43. The Government has left this until the last minute when most of the people have died. There were 4,000 Haemophiliacs during the 1970s and now there are less than 700. I am concerned about the length of time it has taken for this tragedy to come to light.

Anonymity, disclosure and redaction

44. I would like to apply for anonymity.

45. I do not wish to give oral evidence.

Statement of Truth

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

Signed... GRO-B ....

GRO-B

Dated.29th..June 2019