Witness Name GRO-B
Statement No: WITN1436001
Exhibits: WITN1436002-03
Dated: February 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. My date of birth is GRO-B and I live at GRO-B GRO-B GRO-B GRO-B

2. I am married with two children who are twins.

3. I was infected with Hepatitis C following treatment with contaminated Factor VIII concentrate.

4. This witness statement has been prepared without the benefit of access to my full medical records. If and in so far as I have been provided with limited records the relevant entries are set out in the medical chronology at the end of this statement.

Section 2. How infected

5. I suffer from severe Haemophilia A which was diagnosed at birth as we were aware that there was a family history of Haemophilia on my mother's side.

6. I was treated at the Oxford Haemophilia Centre from when I was born until I was 30 years old when I moved away.

7. I received Factor VIII concentrate from the time I was 13 months old. There is now shown to marked **WITN1436002** a copy of my treatment record.

8. My doctor was Charles Rizza. I was also seen by Dr Matthews and Sister Anne Raw.

9. I don't know exactly when I contracted Hepatitis C as I was treated regularly for bleeds. When I was around 5 years old my parents started me on home treatment. I was then started on prophylaxis treatment from the age of about 7 so I was given Factor VIII 3 or 4 times a week to help reduce my bleeds.

10. As a child I was unaware of the dangers of Factor VIII. My parents trusted my doctors implicitly and took everything they said as gospel. My parents' recollection is that they were told the risks were so small of anything going wrong with the new treatment (Factor VIII) that it was no different from the small risk of side effects from taking any off the shelf medicine.

11. I found out I was infected with Hepatitis C when I was 12 years old. I was told the news at a regular 6 month clinic appointment. I was seen by a new doctor (as happened frequently; I rarely saw the same doctor twice in clinic). She flicked through my notes and confirmed the usual basic information with me – age, height, how much factor I was having. She then said "oh, and you're Hep C positive". At this point my mother said "what?" and started crying.

12. I was left sitting on the bed whilst my mother and the doctor spoke as if I wasn't even in the room; they talked about how I might die, get cancer, need a liver transplant and be infectious to others. I didn't know how I was supposed

to react. I didn't cry. I was in shock. I also felt embarrassed that they were talking about me so I pretended not to be listening.

13. I can only assume that the doctor must have found Hepatitis C in a previous blood test result which had been taken at an earlier clinic appointment.

14. I wasn't given any more information about Hepatitis C other than what I listened to whilst I sat on the bed on the day I found out. My mother and I didn't speak on the way home. Even if I had questions I would've been too scared to ask them.

15. There is now shown to me marked **WITN1436003** a copy of the Hepatitis C Checklist from my notes that confirms I was told my diagnosis on 4 August 1993 and that I was not already aware of my result. My first Hepatitis C positive test result was, according to my records, dated 27 February 1992; more than a year before I was informed.

16. I also note that I was tested for HIV from 2 May 1985. Luckily my test results were all negative.

17. I didn't find out more about Hepatitis C until I was a lot older. I spent my teenage years knowing that I might die, get cancer or need a transplant but that I probably wouldn't survive a major operation.

18. I believe that the doctor should have sat me down and explained what Hepatitis C was, how I got it and the prognosis. She should have told me what treatment I might need in the future and asked whether I had any questions. She should have made sure I understood everything and let me know that I could talk to someone if I needed to. She should also have given me the opportunity to ask questions without my mother present.

19. When I was about 20 years old I was informed, whilst sitting in the waiting room at the Haemophilia Centre, that I had received many batches of Factor VIII in my childhood that were infected with HIV that I should be "pleased" that I didn't have HIV. They wanted to take blood from me to look at my DNA because it seemed I had a natural immunity to HIV.

20. I didn't feel lucky. The odds of having haemophilia, contaminated blood products and the immunity altogether are minuscule and the reality is that I was put at risk. I also feel an enormous amount of guilt that other haemophiliacs have not been as "lucky" as me and that many have died including children.

21. When I spoke to my parents about this they recalled a time when I was a young child and suffered from cold/flu like symptoms for about 6 weeks. Apparently the doctors at the Haemophilia Centre were very worried about me and I believe this may have been around the time that I was treated with HIV infected Factor VIII. My grandfather received the same contaminated Factor VIII and has the same natural immunity.

Section 3. Other Infections

22. I have been informed that I have been exposed to batches of Factor VIII that were contaminated with vCJD.

Section 4. Consent

23. My parents were never asked if the hospital could test me for HIV or Hepatitis C.

Section 5. Impact of the Infection

24. When I was diagnosed with Hepatitis C I was only 12 years old. I was petrified and stunned as the doctor explained that my life expectancy was now greatly reduced and I might need a liver transplant in the future or develop cancer.

25. The news greatly affected my relationship with my parents. From that day on I was unable to speak to them properly or be myself. Family get togethers

make me feel very anxious and generally I try to avoid them whenever possible.

26. I avoid telling people that I have haemophilia because it is linked with Hepatitis C.

27. I struggled to make friends at school. I couldn't explain why I had about 70 days a year off sick and didn't do PE because I wanted to keep my haemophilia a secret.

28. As a teenager I was very depressed and frequently cried myself to sleep believing I would not live past 30.

29. The feeling that I am unable to tell people who I really am has made it complex for me to talk to people, especially about myself.

30. In my early 20s I started to suppress my depression and anger but my anxiety wouldn't go away. I started work as a trainee services engineer but quickly gave it up because I didn't see the point in pursuing a career because I still believed I would be dead before I was 30.

31. Shopping and crowded places increase my anxiety. I use self service tills where possible so I can just pick up items and avoid conversations with unknown people. I find I am unable to ask for help if I need it. Going out I need to have a plan of where we are going, parking etc. Any changes to the plan make me agitated which upsets my wife. I like to repeat trips which I know are safe.

32. I no longer trust doctors or nurses and I dread hospital appointments particularly as it usually means I have to talk about myself to people I haven't met before.

33. I was promoted to Manager at work but my anxiety was so great (being the main focal point) that I resigned due to anxiety and fatigue. If the office is crowded it increases my anxiety and I am too scared to ask for help and have

to wait until it quietens down. I cannot go to team building events or the Christmas Party because of my anxiety.

34. My wife and I had fertility problems. IVF was not possible at Bristol because of my Hepatitis C. I was refused access to the emergency laboratory as I would contaminate it and offered donor sperm which frankly made me feel worthless. The only option for IVF was London.

35. Going to the hospital in London was a disaster. The stress of getting there, parking, meeting the doctor who was rude to us made us decide to go to GRO-B instead. The stress of changing Hospitals from London to GRO-B was immense, we had to apply to the local council for exceptional funding which took nearly 6 months of waiting and uncertainty for the permission to change to GRO-B and in doing so meant that we were reduced to one IVF attempt instead of the three we could have had in London or Bristol. If i didn't have Hepatitis C all of our treatment could have been taken care of GRO-B Bristol.

36. GRO-B was a 6 hour round trip for us and it took nearly 20 visits. Our eggs would be stored with others who had viruses which put us at risk. The room had to be deep cleaned after I had given a sample which made me feel dirty. This all impacted on my relationship with my wife.

37. Talking about these issues has made me relive a lot of memories and feelings of depression. My doctor has now put me forward for counselling.

38. From when I was 14 years old I have had what I can only describe as a "cloudy head" and chronic fatigue. It has impeded my ability to concentrate and affected my school work and GCSE results.

39. The chronic fatigue is ongoing – even after getting 8 hours sleep I feel tired. I find it difficult to engage with my young children who want to play when all I want to do is sit on the sofa and go to sleep. On average I find that the best I can do is watch TV with them which isn't really interacting with them. I feel this is affecting our relationship especially as they are too young for me to explain things to.

40. My energy levels have not improved since I cleared Hepatitis C in January 2018. I always hoped that clearing the virus would give me my life back. I have missed out on things for so long and now I feel like there is no light at the end of the tunnel. This only increases my mental health problems.

41. My wife is a great support to me. She does a lot of things for me including cooking my meals as I find it too tiring to stand and prepare the ingredients and cook for the time required.

42. I work in an office as an GRO-B and find I am chronically fatigued throughout the day. I cannot focus properly on my work. I make mistakes due to lack of concentration and the cloudy feeling in my head. Sometimes it is so bad I find myself fighting to keep my eyes open as I desperately want to go to sleep. Last year I did nearly 100 less quotations than my other colleagues.

43. I find driving tiring at the best of times and going to Bristol for hospital appointments is draining. Going to GRO-B for our IVF treatment was exhausting even if I was only the passenger.

44. My brain fog was so bad one Sunday that I struggled to help my 5 year old daughter with her maths homework. It took nearly an hour longer than it took my wife to help her twin brother with the same homework as I got stuck and confused by a simply question. Now she doesn't want me to help her with her homework.

45. My late maternal grandmother and grandfather always felt responsible for me having haemophilia and being contaminated with infected blood products. They didn't want children when they got married after WW2 because they didn't want to pass on the haemophilia. Their doctors convinced them that, in the future, there would be a cure for the condition and that if they had a daughter who was a carrier and who then had a son everything would be "fine". My grandmother already lost a daughter at the age of 6 months and the thought of me now dying due to my haemophilia always made them feel guilty for having my mother rather than just stopping the line.

Section 6. Treatment/care/support

46. I wasn't offered any counselling prior to October 2017 when I had a very long conversation with my doctor during a routine check up at the Bristol Haemophilia Centre. My grandmother died the year before and I was struggling with her death. I tried to put all my feelings away in a box in my head which contains all the problems/traumas from my life including HCV. There was no room left and I found myself getting very depressed and crying in the morning whilst taking a shower.

47. I spent many weeks having long conversations with the haemophilia nurse as I felt more comfortable talking to her than a counsellor as she knew the history of the Contaminated Blood Scandal. I am not cured but I am better than I was. My doctor also wrote to my GP and said it would be good for me to have counselling if it could be arranged.

Section 7. Financial Assistance

48. In 2004 I received the Stage 1 payment from the Skipton Fund. I only found out about this from the Haemophilia Centre.

49. Since EIBSS was set up I have been receiving the standard monthly payments for Stage 1 HCV but I have bene awarded the SCM for Stage 2 payments.

Anonymity

50. I would like to apply for anonymity.

51. I do not want 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...........

Dated 28/2/19