Witness name: GRO-B
Statement no: WITN1098001
Exhibits: WITN1098002-3
Dated: March 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 and I live at GRO-B GRO-B My date of birth is GRO-B I grew up in GRO-B Northern Ireland. When I was 18, I went to the University GRO-B in Scotland, where I did a 4 year degree in GRO-B I gained my professional GRO-B qualifications in GRO-B and then relocated to GRO-B I am the GRO-B for a GRO-B I married in GRO-B and have two children, a GRO-B aged GRO-B born on GRO-B and a GRO-B aged GRO-B born on GRO-B

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

Section 2. How infected

3. I have mild Haemophilia A, which I inherited from my maternal grandfather, via my mother, who was a carrier. I am the eldest of GRO-B children, and have GRO-B brothers and a sister. None of my siblings have haemophilia.

4. The blood product I received was Factor VIII. In 1987, I was given Factor VIII when I fell off a toy bicycle and injured my head. In 1991, I was given Factor VIII when I banged into a fence post and hurt my shoulder.

5. On both of these occasions, I was treated at the GRO-B GRO-B ("the Hospital"). I also attended the Hospital, if I sustained internal bleeding when playing sport. On occasions I attended GRO-B in GRO-B Northern Ireland. This was close to where my maternal grandparents lived and was ultimately more convenient than attending the Hospital.

6. I was given Factor VIII in 1987 and 1991. I had had three blood samples taken and retained on 12th May 1987, 12th March 1991 and 14th January 1994. I was HCV positive on the two latter samples. In 1994 GRO-B requested that the earlier sample be tested. I attach as Exhibit WITN1098002 a copy letter from GRO-B GRO-B to GRO-B dated GRO-B and GRO-B response dated GRO-B confirms that the first sample was negative and confirms seroconversion during the 4 year period between the first and second samples. I therefore believe that it was the Factor VIII treatment received in 1987 which was infected with HCV.

7. I was not infected as a result of a relationship with another person.

8. I do not believe that my parents were given any advice about the risk of my being exposed to infection from blood products. Factor VIII was the known treatment for haemophilia, so it came as no surprise to my parents when I was given this treatment. My mother knew about Factor VIII, because this was the treatment given to her father.

9. The infection I was given was Hepatitis C.

10. My parents found out that I had been infected with Hepatitis C when my consultant, GRO-B sent them a letter dated GRO-B informing them that about it. There is now produced to me at WITN1098003 a copy of the letter. The infection had been revealed in the results of tests carried out on me in March 1991 and January 1994. It took GRO-B over 3 years to give them these results. I was 11 at the time. I found out about the infection when I was between 16 and 18. I had to carry a card so that doctors could see the level of Factor VIII in my blood. I became curious about the reference in one of the cards to "Non A/B Hepatitis". (At that time, I believe Hepatitis C was described in this way.) I asked my parents about this and they explained that I had Hepatitis C.

11. I cannot comment on whether the information should have been provided to me earlier, but I have strong views on how the information was given to my parents. The information should have been given to them as soon as the results came through. GRO-B should have telephoned them to explain the results, and to give them some words of comfort. Sending a letter was a very cold and sterile way of informing them of something so shocking.

12. My parents knew that they should not touch my blood and I grew up knowing that I should not let anyone help me if I was bleeding. My siblings did not know of my condition as my parents did not discuss it with anyone. It was a secret between me and my parents.

Section 3. Other infections

13. I did not receive any infection other than Hepatitis C, as a result of treatment with Factor VIII.

Section 4. Consent

14. I was treated and tested without my knowledge.

15. My parents would have provided consent for me in 1987 and 1991 for the Factor VIII treatment because I was a child at the time. I do not believe that I was treated without their consent, however had they known that the treatment came with a risk of infection, I do not believe they would have consented.

16. My parents were not given adequate or full information about my treatment prior to it being administered.

17. I do not believe that I was treated or tested for the purposes of research.

Section 5. Impact

18. As far as my mental health is concerned, I have tried not to let the diagnosis bother me too much. I am glad that I was the only sibling affected, as I am better able to cope with the situation than they would have been.

19. I have been physically affected by the infection, insofar as I have had to declare it when applying for jobs. One summer, I applied to lead a Camp America trip for kids. I was initially selected but was turned down after the medical, because I was considered to be too much of a risk. As a child, I did not notice any physical effect but I have experienced more fatigue as I have got older. I am also aware of the increased viral load which I carry.

20. While I was studying in GRO-B I was under the care of the Haemophilia Centre at the GRO-B I was offered a one year course of Interferon and Ribavirin. The side effects of these drugs are flu-like. I could not afford to have flu while I was studying, so I declined the treatment at that time. I was told to reconsider it at a future date.

21. In GRO-B I went to work in GRO-B and, in the same year, got married. This was not a good time to undergo treatment.

22. In GRO-B I returned to GRO-B with my family and I decided that the time was right to have the treatment, as I had been hired to set up an office and was effectively working alone. I explained the situation to my employer and he was supportive and allowed me to work in a flexible way. I told my in-laws, as there were side effects from the drugs, which they would have noticed. I had not previously told them that I was infected with Hepatitis C. They expressed extreme shock at the news of the infection.

23. I did not have any difficulty accessing the treatment, but it was a hard process to undergo, and involved having one injection per week and taking 5 tablets a day for 48 weeks. The side effects were weight loss and a pale appearance, due to the reduction in red blood cells. I looked like a ghost.

24. Mentally the drugs were causing me anxiety and depression. On many days during the 48 week treatment I was hard to be around and just wanted to sit in a room in the dark on my own. It was a difficult time for my wife and young children.

25. Unfortunately, the treatment was unsuccessful. My consultant was devastated and suggested that we do another round of treatment adding in a third drug to the combination. I did not want to experience the side effects again and told my consultant that I did not think I could do it. He then told me about a drug called

Sofosbuvir. This was a new drug, which had not yet been approved by NICE, but which was showing more than a 90% success rate and required only a 12 week course of treatment of one tablet per day with minimal side effects. I agreed to try it as soon as it was available.

26. Some time later, Sofosbuvir was approved in GRO-B I was referred to a liver consultant and expressed a desire to start the medication immediately. I was then turned down for Sofosbuvir, because my condition was not considered to be sufficiently advanced to justify giving it to me on the NHS, which gave priority to patients with cirrhosis of the liver. I was unhappy about this because I had not contracted Hepatitis C through lifestyle choices. My infection was the result of a mistake made by the NHS. Ironically, I was too healthy to be a priority.

27. In GRO-B I returned to GRO-B and discovered that a trial of a drug using the same ingredients was being carried out in Australia. The doctors running the trial had access to a generic version of the drug made in India. I decided to take part in the trial, and to pay for it myself. I had a telephone consultation with an GRO-B and he advised me to do two 12-week courses of the drug because of the previously unsuccessful treatment in 2012/2013. The drug was sent to my parents and they brought it GRO-B for me. This was easier than sending it to GRO-B where mail can take up to 3 months and can often go missing.

28. The drug was successful and I had no side effects. In fact, I felt better after 2 or 3 days and my sleep improved. The cost of the treatment was $3,600, which I paid myself.

29. As far as other medical and dental care is concerned, the dentist always uses single-use tools when I undergo treatment and takes great care.

30. The impact of my infection on my private and family life was that my parents and I had a secret. My infection was the elephant in the room and they referred to it as "the other thing". They were very embarrassed about it. I think one of my siblings knew about the infection, as I was particularly close to him, but I don't believe the others knew. My maternal grandmother knew, and I have recently discovered that my GRO-B died from Hepatitis C. That was around 26 years ago. The knowledge of how he died would have added to my parents concerns about me. I told my wife about the infection before we married and she accepted the situation. I did not tell her parents until I underwent the treatment in 2012. They were initially very shocked and prayed for me, as they are deeply religious.

31. There is definitely a stigma attached to having Hepatitis C. I never normally discussed my situation. However, towards the end of my first treatment, there was an occasion when I felt that I had to explain the situation to some friends. I was attending a wedding reception in GRO-B and was asked why I was not drinking. I explained that I had Hepatitis C as a result of a mistake made by a hospital. I remember my friends taking a step back when I told them.

32. My education was not affected by having Hepatitis C.

33. As far as work is concerned, the worst period was during the first treatment, when I had dark days, did not want to see anyone, and felt depressed. Fortunately, I was the only person in the office and did not have to pretend to colleagues. My ability to do my work has never been affected and I have not been limited as far as jobs are concerned.

34. The impact on my family has been set out above.

Section 6. Treatment/Care Support

35. The only difficulty I faced when obtaining treatment was being rejected for the new drug on the basis that I was not sufficiently ill.

36. I have not been offered counselling or psychological support. I would not accept this if it were offered.

Section 7. Financial assistance

37. In about 2002, I received a lump sum of £20,000 from the Skipton Fund. I have received an annual payment from them since April 2017. This is £3,500 per annum, and increases with RPI. I also receive a winter fuel payment. The pre-condition of my receiving assistance was confirmation from a doctor that I had been infected with Hepatitis C from infusion of blood products. The confirmation was provided by the Haemophilia Centre in GRO-B whose care I was under while I was studying in GRO-B at the time. On receipt of the lump sum in 2002 I was forced to tell my bank about my circumstances, in order to satisfy them of the source of funds.

Section 8. Other issues

38. As a young boy, I contracted an infection through no fault of my own. This had increasing repercussions for me during the course of my life, not in the least being refused treatment by the NHS because my condition was not considered to be sufficiently serious. The decision to sign up for the Australian trial was not a light one, but I am very glad that I took this step as the infection cleared up and I was able to take part in a forum where others who had been infected were sharing their stories. The NHS wanted me to return to GRO-B for further treatment, but this would have been hugely disruptive for me and my family, and I feel strongly that the NHS made a mistake and that they should have put it right at my convenience, rather than expecting me to come to them.

39. I would like to remain anonymous when my statement is published.

40. I am willing 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 ....

GRO-B

Dated...5 March 2019...