ANONYMOUS

18 MAR 2019

Witness Name: GRO-B
Statement No.: **WITN0435001**
Exhibits: **WITN0435002**
Dated: 15-3-2019

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF GRO-B

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 21 January 2019.

I, GRO-B will say as follows: -

Section 1. Introduction

1. My name is GRO-B My date of birth is GRO-B 1954. My address is known to the Inquiry. I married my husband, GRO-B in GRO-B and we have two children together.

2. I intend to speak about my infection with the Hepatitis C virus ('HCV'), which I contracted as a result of receiving a blood transfusion during an operation in 1986, but I was only diagnosed with HCV in 2014.

3. In particular, I intend to discuss the nature of my illness, how the illness affected me, the treatment that I received and the impact it has had on my life and the rest of my family.

4. I confirm that I have chosen not to be legally represented and that I am happy for the Inquiry team to assist me with my statement. My husband also assists me, as sometimes my memory is not very good with names and dates.

Section 2. How Infected

5. I was infected with the HCV in 1986 after receiving five units of blood at Nuffield Hospital, GRO-B. Initially I went to the hospital to undergo a hysterectomy, I do not remember the exact date. The consultant who carried out the operation was Dr GRO-D.

6. After the operation, Dr GRO-D told me that during the surgery he had also removed my appendix. I was shocked, as he had never previously told me that he was going to remove it. I asked him why he did it and whether it was inflamed or there was something wrong with it. But he said no, it was neither inflamed nor damaged. Despite that and with no specific reason or consent, he removed it.

7. After the surgery, I was in so much pain that I remember it was unbearable. Later that day, I became really ill and my blood pressure went very low. The doctor told me that I had internal bleeding. Around midnight, I was taken down to the operating theatre again for another operation. It was found out that when my appendix was removed, the area had not been sealed properly and so the second operation was required to seal the area up again. I was so weak that the doctor decided to give me five units of blood to stabilise me.

8. At that time, I did not receive any warning or information regarding the risks associated with blood transfusions. It was the first time that I had a blood transfusion and I did not receive any further until 2001.

9. I remained in hospital for approximately five days and then I went home to recover. It did not seem to get better like I thought it would and I could not

understand why. When I went to the doctor and I told him that I was not feeling good, he told me that I had just had a hysterectomy, recovery would take time and that there was nothing wrong with me, it was all in my mind. Nothing happened for years. I kept on not feeling well and doctors kept on saying it was all in my mind.

10. In November 2014 I noticed a lump in my throat. I showed it to my husband and to my current GP. The GP immediately sent me to the hospital where the doctors told me that I needed to undergo surgery as soon as possible.

11. My tonsils were taken out and I was informed that they found out that I had B-Cell Non-Hodgkin's Lymphoma and that it had spread to my neck as well.

12. The consultant, Dr Richard Gale, Consultant Haematologist at GRO-B Hospital, told me that before beginning chemotherapy I needed to be tested for HCV and HIV; the test results showed that I did not have HIV but that I had HCV.

13. I remained under the treatment of Dr Gale, but he also referred me to Dr Bird at GRO-B Hospital who specialised in liver diseases such as HCV. I was also referred to a specialist nurse, Beverly Clark who often dealt with HCV.

14. I first met Beverly in August 2015. Beverly was very good. She gave me a better understanding of HCV, explaining to me that it was not contagious and that my children would be alright because I became infected after I had them. Beverly also told us about Skipton Fund. She made us - my family and I - feel better.

15. Whilst I believe Beverley explained to us everything about HCV in a clear and simple way, I believe that my GP in 1986 could and should have done more to find out what was causing all the problems that I was having.

Section 3. Other Infections

16. To the best of my knowledge, I do not believe that as a result of being given infected blood products I have contracted any other infections other than the HCV.

Section 4. Consent

17. I have been asked if I believe I have ever been treated without my knowledge or consent and the answer is yes, I believe I was treated without my consent in relation to the removal of my appendix in 1986 which resulted in me having to receive a blood transfusion containing contaminated blood. There is no mention of the removal of my appendix in the discharge papers from the hospital.

18. To the best of my knowledge, I do not believe I have ever been tested without my knowledge or consent.

19. I have also been asked if I believe I have been tested for the purposes of research and to the best of my knowledge the answer is no.

Section 5. Impact

20. It is very difficult for me to describe the mental and physical effects of being infected with HCV and diagnosed 28 years later. After the two surgeries in 1986 and the blood transfusion, my recovery was slow. I kept wondering why I was always tired and weak. I simply could not cope with everyday life.

21. As I mentioned above I continued to not feel well following the operations and the transfusion. I was really worried.

22. I eventually saw a consultant psychiatrist, Dr GRO-D. He was really horrible to me. He continued to say that it was all in my mind. Everyone

kept telling me the same thing: it was all in my mind. They did it just to try to shake myself out of it, but I could not. GRO-D sent me to what was formerly known as GRO-B Hospital for around ten to twelve weeks. This went on for years. I was put into different mental health units because I kept saying something was wrong. These institutions included GRO-B Psychiatric Unit, GRO-B Hospital and a hospital in London; I do not remember the name.

23. I was put on a lot of medications whilst in the mental health units and those medications made me feel worse. I was like a zombie, I felt horrible and I often had brain fog. I cannot remember some details of that period. But I remember that when I was put in the hospital in London, people used to come into my bedroom at night. I used to wake up and they would run away. They were pinching things from my room.

24. I felt I was such a burden to everybody; I could not cope with that and a few times I tried to take an overdose.

25. Eventually, I managed to get off those really strong drugs. It took a long time and my husband helped me. When I came off them, I felt somewhat better, but I was not completely right yet. At that time I had no idea that I had HCV.

26. The impact on my family over those 28 years (until my diagnosis and treatment for the HCV) was really bad. My kids and my husband really suffered; I could not bring up my kids properly and their education was affected. The children were often looked after by friends and family whilst my husband was at work. We had to cancel two holidays because I could not cope with the stress of the trip. On one occasion, my husband booked a trip to Disneyworld, Florida. I was unable to go and my husband said that it was not fair on the children to cancel another holiday. So, I stayed home and my husband took the children to Florida.

27. I have not really held down a job, as I was unwell for so long. My dad had a shop – a gentleman's outfitters - and I worked a little bit with him; but this

was years ago. To be able to pay the mortgage and run the house we had to rely solely on my husband's earnings.

28. When I was finally diagnosed with HCV, following the diagnosis of B-Cell Non-Hodgkins Lymphoma, it was a shock. I was honest with my family and I told my children and friends that I had HCV. However, at the beginning, I would not kiss anyone goodbye, including my grandchildren, as I was scared about passing on the HCV.

29. My chemotherapy for the lymphoma was delayed, as my consultant was worried that if I had chemotherapy, it could worsen HCV. However, the lymphoma spread and the lump began pushing onto my windpipe. It was scary; I was really struggling to breathe. I was taken to GRO-B Hospital and I started chemotherapy in the ward itself. I received chemotherapy every three weeks, for three months; I lost all my hair and my teeth and I stopped having a social life, as it made me very ill. I then received radiotherapy for 21 days.

30. Due to the steroid medication I was given, I developed osteoporosis. I have a curvature in my spine and my left shoulder has dropped; that has been annoying, difficult to live with and extremely painful.

31. I had to wait at least a year to take any medication to cure HCV. I could have been put on Interferon, but Beverly said that the side effects of Interferon were very nasty and that they were currently working to get the go-ahead for a new drug called 'Harvoni.'

32. Sometime in 2016, I was approved to start the Harvoni treatment; it lasted for around two months. I did have some side effects, such as horrible nightmares. On one occasion, I went to lie down and I thought all these people had been up to see me and I also dreamt that I had a baby. During the treatment I kept on having brain fog. Once I completed the course of Harvoni, I became another person; I could not believe it. My friends and family were really shocked to see how well I was after all those years of illness.

33. I have been asked if HCV had any impact on receiving and accessing adequate dental care. I can confirm that the answer is no.

34. I have been asked about any stigma or shame associated with HCV. To be honest, I feel more shame associated with the mental health problems I experienced before I was diagnosed with HCV, than when I actually found out I had HCV. I feel really guilty about that. My son and my daughter saw a lot of things they were not supposed to see and I think that it has affected them.

35. If none of this had happened, I would have brought up my kids, looked after my family, had a job. I would have been really happy. I would have enjoyed life and gone on lots of holidays; I love travelling. My life has been ruined. I am constantly monitored as due to HCV I now have liver damage and my blood count is very high.

Section 6. Treatment/Care/Support

36. I have been asked whether I faced any difficulties in obtaining treatment, care and support in relation to my infection with HCV. As mentioned above, I had to wait for over a year to access the Harvoni treatment.

37. This happened because certain amounts of the drug were being allocated to each region. As the GRO-B region did not qualify to receive the drug, their allocation was given to GRO-B and so I was able to access the drug before other people on the list.

38. I did not have private health insurance at the time and I have just been very lucky in being able to access the new cure.

39. I have been asked whether I was ever offered counselling or psychological support as a consequence of being infected with the HCV. I can confirm that the answer is no. The main professional support I had was Beverly.

Section 7. Financial Assistance

40. Beverly told me everything about Skipton Fund; I believe she told me to contact Skipton Fund when I first went to see her. Later she also told me that I could get some compensation.

41. My husband contacted the fund and filled in the relevant forms. He always told me that they have been very helpful on the phone and that the process was not complicated. However certain reports needed to be completed by the consultant and so the process was a bit slow. Beverly helped us with this and chased up the report.

42. My husband also told me that it took some time for him to be able to speak to an appropriate person at Nuffield Hospital. The matron then wrote and explained to us that the records were all normally destroyed after eight years. She further advised that the logbooks tracking blood coming into the hospital had been archived, but many were damaged **[WITN0435002].** They later told us that this logbook showed that on the day when I had the surgery, five units of blood (of my same blood group) had arrived from GRO-B blood bank.

43. In November 2015, Skipton Fund sent me the stage one payment of £20,000. In April 2016 I received the stage two payment of £50,000. I then started to receive monthly payments of around £1000; it has now increased to approximately £1500 per month.

Section 8. Other Issues

44. As mentioned above, I have made some comments about the lack of care I received from the physicians who treated me. However, I feel it is only fair to give credit to my current GP, Dr GRO-B at GRO-B Medical Centre, GRO-B Dr Gale and Beverly Clark. Without them, my life now could have been totally different.

45. I have been asked whether I have been involved in any group litigation or campaigning group in the past and the answer is no.

46. I am not sure what I am expecting from the Inquiry. I just hope that the Inquiry will find out how it happened and who allowed it to happen.

Statement of Truth

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

Signed GRO-B

Dated 15.3.2019