Witness Name: GRO-B
Statement No.: WITN1996001
Exhibits: 0
Dated: 25.04.2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF GRO-B

Section 1. Introduction

1. I GRO-B will say as follows. My date of birth is GRO-B My address is known to the Inquiry.

2. I am married and have 5 grownup children. I previously worked as a registered nurse however I had to give up my job as a result of being infected with HCV. I could not carry on working because of the symptoms of HCV and the side effects of the treatment such as exhaustion and brain fog.

Section 2. How infected

3. I have mild Haemophilia A. When I was a child I was a patient at the London Haemophilia Centre at St. Thomas' Hospital. I have very rarely had episodes of excessive bleeding but if I had surgery I would need to have some kind of blood clotting product. I still carry a card in case I have an accident and require emergency treatment.

4. My two brothers are severe haemophiliacs. They were also under the care of the London Haemophiliac Centre at St Thomas' Hospital. As children they were often in and out of hospital and needed to have Factor VIII quite a lot. My brothers would have to go to hospital frequently for treatment following minor injuries or spontaneous bleeds; we lived in GRO-B which is quite a journey from St Thomas'. Eventually my mum was trained to inject Factor VIII and was given a supply to keep at home.

5. I was given Factor VIII twice when I was a teenager and hadn't required any other blood products until the last couple of years. The first time was in around 1975 after a tooth extraction. I was about 14 years old. My memory is that I was at school and my mouth would not stop bleeding, when I got home my mum phoned the haemophiliac centre at St Thomas' for advice. She was told by one of the doctors to give me one of the vials of Factor VIII that had been prescribed for my brothers.

6. The second time I was given Factor VIII was in 1976 after I had a tonsillectomy at St Thomas' Hospital. I was kept in hospital for a week to make sure that I did not bleed. I do not remember having a bleed after the operation; my understanding is that the Factor VIII was given as a precaution. My solicitors have been informed that St Thomas' Hospital does not have any records relating to my treatment there.

7. As far as I am aware no information was given to me or to my parents about any adverse risks of Factor VIII treatment or of the risk of me or my brothers being exposed to an infection from blood products.

8. I was infected with Hepatitis C as a result of being given Factor VIII at that time. My brothers both have Hepatitis C and HIV.

9. Around the time that my daughter was born in GRO-B I began to notice symptoms which I now believe are likely to have been caused by Hepatitis C. It was a

gradual thing; I had joint pains that I could never find a reason for, I had flu like symptoms which would make me feel rough for a couple of weeks and then would pass leaving me feeling fine for a month or so. Then the symptoms would start again and this would go on repeatedly. It did not at all occur to me that my symptoms may be somehow related to the blood products that I had been given in 1975 and 1976.

10. At that time I was attending annual appointments at the Kent & Canterbury Haemophilia Centre, they would test my Factor VIII levels and I think they would test my blood for other things too. I would sometimes see a physiotherapist at the Haemophilia Centre about my joint pain. It is quite common for haemophiliacs to be in pain if they have a bleed into the joint. I experienced this when I twisted my ankle badly. However the regular joint pain that I had was different, it was random and was not connected to other injuries.

11. Over the years I spoke to my GP and my haemophilia consultant about exhaustion. I did mention once to the consultant that I had an injection of Factor VIII when I was 14 but he brushed it off as if it was not relevant.

12. In 2004 I had a conversation with a Haemophilia nurse at one of my annual check-ups. He suggested that I have a test for HCV. I was given the results by my GP a few days later. I saw the positive result come up on his computer screen. I told the GP that I would discuss the results with the consultant at the Haemophilia Centre. I was not given any information by the GP but I was happy to find out more from the Haemophilia Centre.

13. The following day my husband came with me to see the consultant to discuss the results. I was crying and was in shock. After the GP appointment I must have either looked up Hepatitis C or spoken to a friend who was a pharmacist about the infection and the risks of passing it on to others. Either way I knew when I went in to see the consultant how serious the infection could be.

14. I don't remember receiving any advice from the consultant regarding the infection itself and how it would affect me. I do remember discussing measures to prevent passing the infection to others, for example not sharing toothbrushes and the risk of infection from open wounds. All of my family were tested for HCV and thankfully the results were negative. I briefly discussed treatment with the consultant; he suggested putting it off until later in life when there may be better options available. I remember him saying that he had told my brothers that they should wait to have treatment until their children were older.

15. I was advised by my consultant to take care of my liver, for example by not drinking much alcohol. I rarely drank alcoholic drinks anyway. Once I was diagnosed with HCV information was readily available. However, I do feel that the opportunities to identify the reason for my symptoms had been repeatedly missed. I was satisfied with the way the results were communicated with me; I felt that the symptoms that I had been experiencing for so long finally made sense.

Section 3. Other Infections

16. I am unaware of receiving any other infections through contaminated blood. I was tested for HIV after being diagnosed with HCV. The result was negative.

Section 4. Consent

17. I am unaware of being tested at any other time than in 2004 when I was first diagnosed. As far as I am aware I have not been treated or tested without my knowledge, without my consent, without being given adequate or full information or for the purposes of research.

Section 5. Impact

18. My primary symptom from HCV was exhaustion. I had other symptoms such as itchy skin, difficulty concentrating, difficulty talking and interacting with others but this was often due to exhaustion.

19. After being diagnosed I found it difficult to cope with the possibility that my blood could infect others. I became very focussed on the practical side of things like not sharing toothbrushes or cups, and covering open wounds. It was difficult having children around both in the home and outside as I was always worried that I would put them at risk in some way.

20. I became quite paranoid about people finding out that I had the infection, particularly because of my previous job as a nurse. I remember that there was a letter doing the rounds about a consultant who had found out that she had Hepatitis C; all of her patients had been brought in and tested. I had done nothing that could have caused my patients to become infected. However I was worried that people would find out and that my infection would be publicised by the hospitals that I had worked in. I was very stressed about it.

21. When I was first diagnosed I was told by the consultant that it was up to me when I wanted to receive treatment for the Hepatitis C but he suggested that I should wait until later in life. From what he said it did not sound as if treatment was important. He also said that new treatments were being developed but he didn't know when they would be available. However, over the next few months I sought advice from a friend who was a senior pharmacist, she said that I should try get rid of the virus as soon as possible. This was supported by the research that I had carried out myself.

22. I went back to the Haemophilia centre and said that I would like to have treatment for my Hepatitis C. GRO-B GRO-B In 2006 I started treatment with Pegylated Interferon and Ribavirin. They gave me the treatment once at the centre and

showed me how to do it myself. After that I had to inject myself once per week and take a tablet every day.

23. Some people compare the treatment to chemotherapy; it was horrible and made even worse because I had to give myself the injection that was making me feel so unwell.

24. My symptoms whilst on the treatment would follow a similar pattern every week. I would have a kind of flu for 5 days, I would then have a day where I felt a little better and then the following day I had to inject myself again. It made me feel sick a lot of the time, I had problems with my throat swelling up, I lost a lot of weight. It had a strange effect on my mind including paranoia, an urge to self-harm as well as suicidal thoughts. I was difficult to live with; I was stressed and tearful all the time.

25. I took this treatment for a year; they decided to give me the full whack for the whole time. Nowadays I think they give you a test after 6 weeks to check that the treatment is working.

26. When the treatment finished I felt really well, I was full of energy for about 6 weeks. Then almost suddenly I did not feel right, I started feeling really tired again. I went to see my consultant, I said that I knew it sounded strange but I felt as if the Hepatitis C had come back. He laughed at me a little and said that I must need counselling, he thought that it was in my head.

27. I was tested straightaway following my appointment at the Haemophilia centre. The results confirmed that the treatment had not worked. Despite the return of my symptoms I was very shocked that the Hepatitis C was back, I did not want to believe it.

28. After a couple of years I asked to be referred to Kings College Hospital. I was not very impressed with the liver specialists at Canterbury Hospital and someone had told me that the doctors at Kings were very good. I started to see

Dr Agarwal, he was really clued up about everything and the care was much better.

29. In 2014 Dr Agarwal told me that I had fibrosis of the liver. I began to have regular liver checks at Kings. My exhaustion was getting worse and I was finding it hard to function.

30. Later in 2014 I was accepted on a clinical trial of Ritonavir co-administered with Ribavirin. It was a double blind trial, half of the patients had a placebo. I was in the half that was given the placebo, but eventually I was also given the real treatment. It was very different to the Interferon and Ribavirin that I had taken before. This time I just had to take tablets everyday rather than having to inject myself. The course was much shorter and they could tell very quickly that the treatment was actively working. Following this treatment I was informed that I had successfully cleared the virus.

31. Although I no longer have HCV, the infection and the treatment for it have had a lasting and debilitating effect on my body. During the Ritonavir and Ribavirin trial I had to take the tablets with some sort of fat or dairy like a glass of milk. I started feeling very sick and having problems with my bowels. When the trial was over these problems continued. Following the treatment I was referred by my GP to see a gastroenterologist. I still have to see a gastroenterologist at a local hospital. I am now dairy and gluten intolerant.

32. The treatment damaged my thyroid; it caused thyroiditis and multi-nodular thyroid. I needed to take Thyroxine for a number of years, and I am still monitored for these conditions.

33. My symptoms tend to fluctuate a little but I continue to experience exhaustion and brain fog. I find these two things very debilitating and they affect my social interactions and memory. In addition I have problems with tingling skin, itchiness and blepharitis (inflammation around the eye). If I am doing something

physical I will need to sit down afterwards. There are times when I need a sleep in the afternoon. If I go out but am able to stay sitting down, I can usually last for a few hours. If it is an activity like walking I can sometimes last for two hours but often am worn out after just one.

34. The effect of the HCV on my family, personal and social life has been very restricting. Before and during the treatment I could not go to social events. Occasionally I would try to go out but then I would usually just have to go home. Some of my friends helped with meals and sometimes with shopping when we needed it. Even now after clearing the virus, I cannot really participate in family activities or go to social engagements and suffer the next day if I do. I frequently fall asleep early in the evening and in the afternoon as well as sleeping all night. Essentially, I have to plan my life around this constant exhaustion.

35. It has all been very hard on my family, particularly on my husband. He has been very supportive but there has been so much that we have not been able to do because I have been too exhausted. I know the treatment was particularly hard on him because of the way that it affected me. I think that me wanting to keep it a secret has been difficult because he has not been able to discuss it with anyone.

36. When I was diagnosed I told a handful of friends, some of whom are still supportive today. I still struggle to talk to people I meet about the Hepatitis C, and do not make a point of telling new friends. My family have also been very understanding. However when I was first diagnosed Hepatitis C was not seen as a problem, HIV was seen as the important one.

37. There was a stigma connected to Hepatitis C but it is not as bad as the stigma around HIV. On one occasion at an appointment with a liver specialist, a nurse said that she would not shake hands with me, she wrote on my notes that I had cirrhosis of the liver which was not true.

38. When attending medical appointments I found that until I said that I was a haemophilia carrier I was seen in a very negative light by medical staff. My HCV status would appear on their screen and they would associate it with drug addiction and sharing needles. I believe that everyone should be treated fairly and so when I attended appointments I would purposely not start by explaining that I had been given contaminated blood. However I noticed that the tone of voice and everything changed when the person I was seeing found out how I had contracted Hepatitis C. I saw one endocrinology consultant who had a very brusque manner until I told him about the Factor VIII and then he became warm and empathetic.

39. While I was working I sometimes witnessed stigma against patients who had HCV, it was very difficult for me to see this happen.

40. I trained as a nurse when I was 18. When I was diagnosed I was working for a GRO-B I had been working full time but had to cut my hours down because of exhaustion. On my days off I would have to lie on the settee all day. During the first treatment I reduced my hours even further and worked only two days a week. I managed to continue working throughout the treatment.

41. We later moved house and I started to look for similar work. Because of my symptoms I knew that I would not be able to work full time but I felt that it was important for my mental health to be around people and to go out and do something rather than stay in the house. I eventually got a part time job as a nurse in a GP surgery. However I found this role extremely difficult; I was very fatigued, I found it difficult to concentrate. When not working I was just resting and trying to recover. Eventually I could not manage any longer and was signed off on sick leave. It was during this time that I was offered the second treatment by Dr Agarwal.

42. After the second successful treatment I found a part time job as a nurse in a hospital clinic. However again I could not manage with the exhaustion. I could not think straight, I had headaches and joint pain. I failed my probation because of all of the days I had been off sick and so lost my job. I no longer felt able to

manage even a part-time job. I loved working as a nurse and helping people. But in a way it was a relief, not having to work meant that I did what I had the energy to do, but could rest at home when I needed to.

43. My inability to work has affected our family income. Despite being unable to work I cannot claim any benefits either. I was on ESA for a while but then they said that I was not eligible. I appealed the decision and had to go to an assessment. This was very stressful, I was asked questions that I could not answer straight away because of brain fog. During the assessment they appeared to believe me but then what they wrote down was totally different. I explained my symptoms and said that I can do a little bit but then am wiped out. My appeal was rejected; I was told that I was not eligible because I arrived at the assessment by myself and I looked okay in the waiting room. They said that I was not entitled to ESA because I was able to work a little bit of the time. I did not fight this decision because the whole process had been exhausting.

44. The one size fits all approach of ESA has been very frustrating. Undergoing assessment by people that have no understanding of HCV and its long term effects has been humiliating.

45. Two of my brothers were diagnosed with HIV when they were teenagers. One of them became very ill but pulled through. I was very concerned for them both. They were later both diagnosed with HCV but this was always considered as secondary to HIV which had so much publicity as high profile people died of AIDS. Fortunately both of my brothers survived long enough to receive medication that has kept the HIV at bay. It was not until I was diagnosed that I realised that my brothers had not received any treatment for HCV. This upset me as I understood the long term effects of the disease on the liver in particular. They have now both received treatment.

Section 6. Treatment/Care/Support

46. Since receiving treatment for HCV I have found it difficult to access co-ordinated specialist care for all of the different symptoms that I have or am still experiencing. I have rarely found doctors that have an understanding of HCV and the effects of the treatment, particularly of Interferon. For example at one stage following my first treatment I was referred to a rheumatologist. The consultant I saw was not at all clued up on the effects of Hepatitis C.

47. I did meet one consultant who knew what she was talking about when it came to Hepatitis C and the different effects that it could have. I had been having strange episodes of palpitations and feeling as if I was going to pass out. I saw her at the hospital where I worked at the time. She was really helpful, it was such a change from many of the doctors that I had seen before and that I saw afterwards. Around that time I was finishing work and so unfortunately could not continue to see her.

48. Visiting my GP over the years has been very difficult as they have little understanding of how to help and sometimes I feel that they think I am a hypochondriac.

49. I asked for counselling at the haemophilia centre in Canterbury. I wanted a particular person to talk to, someone that would understand about contaminated blood and Hepatitis C. I was put on the waiting list and offered an appointment after around one year. By that time I felt better, and did not think that I needed it any more. I am able to talk to my brothers which is helpful, and I also have a friend that had Hepatitis C and still experiences symptoms albeit slightly differently to me.

Section 7. Financial Assistance

50. I found out about the Skipton Fund at my first appointment with my haemophilia consultant after the positive test results. He completed the form; I signed it and

sent it off. It was a straightforward process. I received the stage 1 payment of £20,000 soon afterwards.

51. The Haemophilia Centre told me about the Caxton Foundation. I made a few applications for financial assistance. I was granted money to replace some of the windows in my house, the draft from the windows was making my aching joints worse. Caxton paid for some of my windows to be double glazed, but not all of them. They suddenly said that they could not pay for any more. I thought this was odd. We paid for the remaining work. I also received a grant from Caxton for a new washing machine, and advice from a benefits advisor employed by Caxton in relation to my application and appeal for ESA. This advice was very helpful.

52. I made other applications to Caxton which were refused. I needed new varifocal glasses, I ordered these through Specsavers who required payment with the order. When I sent the receipt to Caxton they said that they did not make retrospective payments and so would not refund me. More recently, just before Caxton was shut down they started sending me information for a debt advice service for help to manage my money. We were not in debt, we were just requesting some money towards an item, we did not need help from a money advice service.

53. Most of the time the staff from charitable trusts established for victims of infected blood were supportive although often they too would seemingly end up applying some algorithm to decide what support was available.

54. I am now receiving monthly payments from EIBSS. Having this extra money coming in really helps, it is like having a part time job.

55. It is shocking that HIV was treated in such a different way to Hepatitis C by the different payment schemes. My brothers' financial situations are very different to my own. Almost as soon as they were diagnosed with HIV they started to receive monthly payments. I believe that equal payments should have been

made to people infected with Hepatitis C and those infected with HIV. With the medication that is now available it is much easier for people infected with HIV to live a more fulfilled life. However many people who were infected with Hepatitis C continue to suffer debilitating symptoms even after successful treatment.

Section 8. Other Issues

56. I hope that the Inquiry leads to the truth coming out. I hope that the victims will be listened to and that the truth of this disaster will be made public so that those responsible will have to admit their guilt and will be held to account. I believe that better financial and healthcare support should be given to the victims.

Statement of Truth

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

Signed GRO-B ....

Dated ......25.04.2019.........