Witness Statement of: GRO-B
No. of statement: WITN0580001
Exhibits: WITN0580002
WITN0580003
Date of statement: 26.03.2019

INFECTED BLOOD INQUIRY

WITNESS STATEMENT OF GRO-B

I, GRO-B
will say as follows:

Section 1: Introduction

1. My full name is GRO-B and my date of birth is GRO-B GRO-B. I have been married to GRO-B (GRO-B) since GRO-B GRO-B.

2. I was born in GRO-B and came to live in the UK in 1975. After arriving in this country I trained as a nurse in Birmingham and moved to London in 1978. In London I worked as an agency nurse for three months before becoming a permanent member of staff on the transplant surgical unit at GRO-B Hospital

3. In GRO-B I gave birth to my first daughter GRO-B in Hammersmith Hospital. My mother had died in childbirth and so I was concerned about possible complications when giving birth myself. I gave birth to GRO-B by caesarean section and the procedure went without problem.

Section 2: How Infected

4. Not long after I had GRO-B I became pregnant again, and in GRO-B GRO-B I was admitted to Queen Charlotte's hospital to give birth to my second daughter GRO-B. I have obtained copies of my Queen Charlotte medical records and these show that while receiving treatment at the hospital I was under the care of the Consultant Obstetrician Mr J. L. Osourne.

5. The initial plan was that I attempt to deliver GRO-B naturally, but this proved impossible as I lost consciousness and clinical staff concluded that I required an emergency caesarean. I was partially conscious for part of the time and I can remember hearing people saying that I was bleeding and needed a blood transfusion. They asked my consent to give me the blood and I agreed. Unfortunately, the complications worsened and I was haemorrhaging to such an extent that the doctors concluded the only way to deal with the problem was to perform a total hysterectomy. They woke me up to ask my consent. I couldn't breathe, and I remember that they gave me atropine to clear my airways. I signed a form to consent to the procedure. I understood at the time that I received 2 pints of blood.

6. Following the operation I spent about 10 days in hospital with GRO-B I was very badly affected by what had happened. I was upset and shaken. I remember that the thing which upset me the most was that my baby wouldn't take milk from me. I had given birth before and so I had an idea of how things were supposed to be, and I could tell it was different. GRO-B behaved very differently. I really felt like something was wrong but I couldn't tell what.

7. From the very beginning I felt that there was something strange about what had happened during the operation but no one really explained. From my perspective as a nurse, familiar with a clinical setting, I would have expected more explanation. I asked questions but they were

evasive and just said they would come back with more information. I couldn't be forceful as I was so physically affected.

8. It felt from the very beginning that they were hiding something. After I was discharged I discovered that I had actually been given more than two pints of blood, but I was not told this directly by the medical staff. Sometime later, a nurse came to see me at home to check on GRO-B and she left her notes, I think on purpose. When I looked at the notes I saw that it was written that I had actually been given 6 units of blood in total. It seemed from what I read that I was given 2 units of blood before being woken up to ask for consent, and then after this, they gave me 4 more. I do not think that people without a medical background would have been able to understand those notes.

9. After GRO-B birth and my operation I experienced what I would describe as, and thought at the time to be, a prolonged period of post-natal depression. I was chronically tired and had problems with my left leg. I was in a lot of pain and I went to my GP many times. I was prescribed morphine but I didn't really understand why I was being given such a powerful drug and I didn't take it. The tiredness affected me a great deal. I suffered with clouded thoughts and judgement and at one time I experienced hallucinations. I couldn't really understand why things were so bad. It was a really difficult time and went on for years. It got to the stage that I just thought it was normality.

Diagnosis with Hepatitis C

10. In November 1996 my GP GRO-B received a letter from the National Blood Transfusion Service (NBTS) informing him that I had been identified as a suspected recipient of contaminated blood. I have attached a copy of this letter as '**WITN0580002**'. A practice nurse contacted me and asked if I could come to the surgery to discuss something. At the time I didn't know what it was going to be about and thought it might have something to do with the problems I was experiencing with my leg. I was utterly shocked when GRO-B told

me about the letter and explained that it was likely that I had been infected with Hepatitis C. GRO-B was also outraged and shocked, and was uneasy that the Service had attempted to make contact with me through him. He told me that he would make them write to me directly.

11. I received a letter from the NBTS myself at the beginning of January 1996. I have attached this as '**WITN580003**'. This letter simply stated that the Service had discovered that the blood I had received at Queen Charlotte's hospital may have been: "carrying an infection known as the Hepatitis C virus which could have been passed on to you." The letter recommended that I attend a clinic in Collingdale for a blood test to establish whether I had been infected.

12. At first I was really angry. I immediately made the connection between the letter and the strangeness surrounding the operation at Queen Charlotte's. I was reluctant to go for the blood test because I was very worried about the outcome. At that time I did not know anything about Hepatitis C.

13. I went for the test at the beginning of February 1996 and the NBTS wrote to my GP the same month to inform him that the test had shown that I was a carrier of the Hepatitis C virus. In November 1996 I had a liver biopsy at Kings College Hospital which confirmed the diagnosis. It found that I had mild inflammation of the liver and mild fibrosis, and that this amounted to stage 1 liver damage.

Section 3: Other Infections

14. I am not aware of having received any infection other than Hepatitis C as a result of being given infected blood or blood products.

Section 4: Consent

15. As I have already said above I felt that the clinical staff at King's College Hospital in the mid-2000's were trying to force me to have a

treatment that I did not want to receive. This was first Interferon but then Pegylated Interferon. I felt that the side effects of both forms of the treatment were underplayed, particularly how this could badly affect people with back trouble such as myself. I felt like a guinea pig and was hounded on the telephone and at the hospital. I ended up crying on many occasions because of the pressure that they put on me to have the treatment.

16. Later I saw people at Kings College Hospital who were being treated with interferon. Many seemed to have reacted very badly to the treatment and had become jaundiced and very bloated. I heard from patients that Interferon treatment was causing them severe problems with their health and I felt that my quality of life would be better if I avoided Interferon treatment altogether and turned to homeopathy.

17. I felt that the Interferon information from King's College was inaccurate and not comprehensive enough for me to make an informed decision about treatment. I knew that there were significant side effects caused by Interferon and that these could cause me serious problems. I felt I was being pressured to take a treatment that was dangerous for me and this caused me a lot of mental and psychological anguish.

18. I have some concerns and confusion about some of the medical records. I am particularly confused by records that suggest I underwent a second liver biopsy in April 2000. It was apparently largely on the basis of this biopsy result that I was recommended to undergo interferon therapy. While this was a now some time ago I am absolutely clear that I would have remembered undergoing so invasive a procedure as a second biopsy, yet I have no recollection of this. Furthermore such a procedure would have left a scar and I do not have this. This seems to me to be a mistake.

Section 5: Impact

Treatment at Kings College

19. From my first referral the clinical staff at Kings in the mid 1990s had mentioned interferon therapy as a possible future treatment. Fortunately at that early stage the Hepatologist concluded that my liver function was not sufficiently severe to require the therapy and that at that stage they should simply monitor my progress.

20. My medical records suggest that I underwent a second biopsy in April 2000, but I have no recollection of this and thought I only had a scan. My records show that on the basis of the results of this biopsy my consultant concluded that the damage to my liver had progressed to moderate fibrosis and moderately active chronic hepatitis. It was from this point that the doctors at Kings College really began talking about the need for me to undergo interferon treatment.

21. At that time a new form of Pegylated Interferon was about to become available and they put me on the waiting lists for treatment. From the very beginning I was very suspicious of Interferon. At first this mistrust was instinctive and based on the way that the doctors and nurses talked about it, but over time I came to know some of the other patients who were already receiving this treatment. Many were jaundiced and were suffering serious side effects. I became extremely reluctant to have the interferon treatment and was uncomfortable about the motivations of the doctors. It was almost as though the NHS was desperate to find a wonder drug that would solve the problem that they had created, and that they saw this as a chance to avoid revealing the scale of the mistake that they had made. I could tell that the drugs were not really understood by the consultants and that there was an element of research in what they were doing.

22. Despite these reservations, which I expressed fully, Kings College were very keen that I should have the interferon treatment. The Clinical Nurse Specialist was particularly insistent and she contacted

me very regularly. I researched Interferon and found that there were particular problems related to people who had issues with their back and legs. These were my major complaints at the time. I approached my doctors to ask about this but they were very evasive and suggested that the material I was reading was sensationalist. It seemed as though they were trivialising the problems I was having with my back and leg. Everyone at Kings College seemed to view Interferon as a wonder drug and insisted that I was lucky to be a candidate for the treatment. They couldn't understand why I would be in the least bit reluctant. I was increasingly uncomfortable and resisted and began to feel very alienated and disengaged.

23. I didn't know much about homeopathy, but I read an article somewhere about homeopathic treatments and was interested in the approach. I thought that it would be a milder form of therapy and that I would have more control. The approach that Kings College were taking to the treatment made me feel very worried. I discussed homeopathy with my GP and in late 2001 he referred me to the Royal London Homeopathic hospital and I had a clinic appointment there in May 2002. They prescribed Bryonia and Magnesium Sulphate. I also took Selenium metal, Carduus Marianus, China Arsenicum. The homeopathic treatment definitely helped. It relieved the symptoms of my condition and I was able to take my life in a more positive way. I was able to focus on my children and their education.

24. Until 2006 I continued to have outpatient appointments at the Institute of Liver Studies at Kings College. Clinical staff continued to insist that I undergo interferon treatment, but I was so worried about the side effects that I continued to refuse.

25. The experience of having been infected made me feel very suspicious of the NHS and of the motivations of the people who were recommending the interferon therapy. I felt that the NHS was to blame for my situation and that influenced the way I thought of the service.

26. My final meeting at Kings College was with the nurse specialist. I became very distressed and was in tears. She continued to insist that I undergo the interferon treatment regardless of my distress. I was so upset that from that meeting that not long after this I completely disengaged with King's College.

Further Treatment

27. After breaking with Kings College the only form of treatment I took for the next 6 or 7 years for my hepatitis were homeopathic remedies. I felt that these were helpful but I did not expect them to cure the underlying condition.

28. In 2013 I registered at a new GP practice and my new GP referred me for a liver scan at Queen Mary's Hospital. I saw a consultant liver specialist, Dr Daniel Forton, in December 2013. Dr Forton recommended that I have blood tests and I underwent a further biopsy which showed that I had stage 6 cirrhosis of the liver. Dr Forton talked at this time about the possibility that the only remaining treatment option might be a liver transplant. I don't think that this is something that I would have agreed to. I have seen the difficulties experienced by other people who have had transplants.

29. Fortunately Dr Forton also explained that there was a possibility that I would be eligible to receive the new anti-viral medicine Sofosbuvir, which was about to be licensed in the UK. The drug is very expensive and was made available to only a limited number of patients. The very poor state of my liver meant that I was eligible to receive the drug in the first wave of patients. I read about Sofosbuvir on the internet and people were very positive and called it a wonder drug.

30. St George's was a very different place to King's College and I think that my positive reaction to the new treatment was because of this. I did not feel the same pressure at St Georges that I had at Kings College.

31. I began taking Sofosbuvir in combination with two other drugs (Ledipasvir and Ribavirin) in July 2014. It was a trial, but the effect they had was remarkable. By late March 2015 the Hepatitis C virus was undetectable in my body and my liver function was improving. Since then my condition has continued to improve steadily.

My Physical Health

32. I feel that I have been impacted in different ways at different times. As I have outlined there was a significant period following my initial infection when I did not know that I had been exposed to the Hepatitis C virus. At this time I experienced a variety of problems with my health. These issues were largely unexplained at the time, but I now understand them to have been related to my infection.

33. I now believe that early on after the infection in 1989 I was physically very impacted. My back and leg problems were made worse, and there were periods where my mental focus had completely gone. I did not want to be left on my own. My body was rigid. By the time I was first told about the infection in 1996 I was declared disabled and I believe the Hepatitis C infection I had been infected with had a lot to do with my deteriorating physical condition.

34. I was very upset when I had to be tested for Hepatitis C. Having a biopsy at King's College in the late nineties was very physically and mentally traumatic as this is a very invasive procedure. The treatments and procedures I underwent were not explained to me very well at the time and this added to my doubts and the fears that I had about medical treatment.

35. In the late 2000's and early 2010's I became very tired and withdrawn as the effects of the virus worsened.

36. Although my treatment with Sofosvobir in 2014 produced very good results, the treatment itself also impacted upon me. I experienced some hair loss but that has improved since the treatment concluded.

37. In recent years my low platelet levels have meant that my blood does not clot normally. I need to go to a specialist unit to have my teeth done and I must be careful if I get a bad cut because I may need assistance from specialists to stop the bleeding. I also bruise very easily.

Other Impact

38. My quality of life was made very poor in the years following my infection in 1989. I was completely out of things at times and could not mix socially as I did before. In fact I did not relate to my husband and children in a normal way at this time.

39. To begin with, my infection put a significant strain on my relationship with my husband, particularly before I knew that the physical difficulties I was having were related to Hepatitis. At that time I could not relate to my daughters and other people in a normal way. When I was told about the infection in the late nineties I was very angry, but this did make things start to make more sense and the relationship with my husband and family began to improve as we came to understand what had happened to me.

40. When I had my biopsy at King's College in the late nineties I had to take my children with me. The infection meant that I needed a lot of help with my children because I was not in a good state. The infection had meant that the dynamic of the relationship between me and my husband had changed. We both realised that I needed a lot of support with daily activities and my children and others around us knew this too.

41. I could not do things a normal mother would. I could not take my children around with me without considerable help (often from my husband). As my condition worsened and my children got older I felt more isolated from society because of my inability to go out and carry out tasks like shopping that I would have wanted to do but was unable.

42. In 1996 just after being informed about the infection I instructed the law firm Evill Coleman to act for me in relation to a potential compensation claim related to my infection. I hoped that my Solicitor might find out more information about what had happened to me. However, my solicitors told me that the Blood Transfusion Service and the Government were not going to release full information about what had happened. This had a great impact on me emotionally and psychologically. So many people have been damaged by this medical disaster and the Government and others appeared to be determined not to acknowledge how serious this is.

43. I am a qualified nurse. Nursing contributes a lot to society, but of course this was no longer a possibility for me. I was not able to practise as a nurse anymore. This has meant I have lost a lot of money in potential earnings. It has also meant that my NHS pension has been a lot lower than it would have been.

44. My quality of life took a downturn in the late 2000's to early 2010's as the symptoms of my infection worsened before I was treated with Sofosbuvir at St George's hospital. I became quite inactive at this time and did not get involved with daily living and my family in a normal way and did not involve myself in social situations enough.

45. Since the end of Sofosbuvir treatment I have been a lot better. Before I was cloudy in my mind, I had to really concentrate on things. Now this is much improved. Physically I still have mobility difficulties and I have second stage cirrhosis but my doctors are optimistic about things. My liver levels are coming back up and they are no longer talking about more severe forms of treatment such as transplant.

46. I never felt able to talk openly about my infection because of the social stigma of hepatitis. Although I have not suffered from overt discrimination, I do think that knowing about the infection changed the way that some people related to me. People don't tell you point blank that they are upset about it but there are sometime subtle differences.

For example I once had a dentist who was reluctant to continue treating me after she discovered that I had hepatitis C.

Section 6: Treatment/Care/Support

47. While receiving treatment at Kings College Hospital I was offered access to a counselling service, but the focus of this seemed almost entirely to deal with any doubts I had about the interferon treatment. The counselling did nothing to address the issues that had been caused by my original infection, the consequences of my illness, or the damage to my sense of trust that had been done by the manner in which things had happened.

Section 7: Financial Assistance

48. There have been many financial costs over the years associated with my Hepatitis C infection. I have suffered a huge impact on my career and earning potential. It was not possible for me to return to nursing following my infection, and in fact I have been so unwell since 1989 that I have been unable to engage in any paid work at all since that time. My family and I have incurred the costs of innumerable visits to hospital, the purchase of specialist equipment, the cost of medicines, additional telephone calls, extra heating, nannies and much more.

49. Although the reason I originally approached Solicitors in 1996 was not to seek compensation, but rather to find out more about what to what had happened and to hold someone to account, I became part of a group compensation claim which concluded in 2001. I received £12,000 in compensation. I was not really engaged with what was happening at that time as I was really tired and unwell. At the time I was going through a lot of pain and I used to go to the physiotherapist and come home. I used to sometimes sit down on the floor and just cry. I didn't think that was enough or representative of what I had experienced.

50. I do not remember well making an application for a payment under the Skipton fund, but I know from my records that I submitted an application in August 2005 and received a payment of £20,000 in November 2005. I used the money to buy things that I needed such as a wheelchair. I felt that the amount of this payment was very low given the financial devastation my family had been caused by the effects of my infection.

51. I received a Stage 2 payment after it was established that the damage of my liver had progressed to Stage 6 cirrhosis. This payment was for £50,000 which was a more substantial sum than before, but I still do not feel that the amount reflects the true scale of my losses caused by my infection and subsequent illness. I was also aware that the different schemes set up in different places were not consistent. I would have found help with living costs and specialist equipment valuable, but this was not open to me with the Skipton Trust.

Section 8: Other Issues

52. I have been greatly impacted in many ways by Hepatitis C and if I had been given information about the effects of the virus earlier it would have made a lot of difference to myself and my family. The effect on me was huge but it also impacted my family in various ways. For example my husband was put at risk of infection from me at this time.

53. What has most upset me about this whole experience is the abuse of my trust. I have long felt that people knew about my infection well before I was informed myself. I feel that attempts to cover up what happened have impacted on the way I have been treated. This has had many consequences and has damaged my faith in the National Health Service and the medical profession generally, and has undermined my sense of security. I feel that my trust has been abused by the organisations in which I should have the most faith. I feel I have been betrayed and lied to and I believe that the psychological and

emotional implications of this have significantly worsened my physical symptoms and have undermined my ability to recover.

54. Ever since I knew I was infected with Hepatitis C, I have been trying to get the hospitals and Government to accept responsibility and offer some sort of explanation of what happened. I have been met with a wall of silence. In a sense I have been lucky as treatment has eventually had a positive outcome. Others I have met have not been so fortunate, but I am left with lasting damage and a struggle to rebuild my trust.

Statement of Truth

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

Signed GRO-B

Dated 26/3/19