Witness Name: GRO-B
Statement No.: WITN1892001
Exhibits: 0
Dated: 12 February 2019

WITNESS STATEMENT OF GRO-B
INFECTED BLOOD INQUIRY

Section 1: Introduction

1. My name is GRO-B My date of birth and address are known to the Inquiry.

2. GRO-B

Section 2: How Infected

3. On GRO-B 1982 at around 11.00am, I gave birth to my daughter; my second baby, at St Mary's Hospital in Manchester. It was a normal delivery but during delivery of the placenta the umbilical cord broke leading to a post-partem haemorrhage. As a result of this, I was given three units of blood over the

course of twelve hours beginning the evening of the GRO-B 1982 and ending during day time hours on the GRO-B It was an interesting experience because I was receiving the blood rather than administering it; which I had done previously, so I remember that I was monitoring carefully what was happening. I remember the first unit was administered in the evening. Midwives came to put the blood up on a drip stand and to check the procedure that was supposed to have been followed, was followed, which included checking your name and date of birth, the batch number against the bag, the blood group and rhesus. I do not recall signing to receive the blood or being told anything about the transfusion except that I have a recollection of being told that my haemoglobin level was low and I needed a transfusion to replace the blood loss. I cannot remember if I was told how low my haemoglobin level was. I have been told that my St Mary's records have been destroyed but I have checked the records that I have managed to retrieve and they do not contain any further information on this. I have a photograph dated GRO-B GRO-B when still in hospital following the birth of my daughter, where it is possible to see the blood being transfused into my arm. I did not realise it at the time, but this photograph has transpired to be very important. This photograph and a record I have retrieved from my GP evidenced the fact that I was given three units of blood in 1982 for the port-partem haemorrhage and both can be provided to the Inquiry if it would be helpful.

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

5. I do not remember anybody saying that there was a risk of infection before I received the transfusion.

6. I was infected with hepatitis C.

7. On 31 May 2012 I became ill with a severe headache which came on in intense bouts of acute pain over the course of a few days. While the pain abated from time to time, it remained. I was admitted to The Wythenshawe Hospital the

following week. I recall that the casualty doctor was very concerned about my liver function test results which he indicated to me were highly raised. The first thing that he asked me about was my drinking habits and he appeared more interested in this than the acute pain I was feeling in my head. I can remember feeling embarrassed and upset that the emphasis seemed to be on this rather than the pain, the reason I had been admitted. I was shocked by the subject matter of the questions that were then put to me; this was the first time I knew there may be a problem with my liver and I had never before considered that my alcohol consumption had been in any way excessive and so I could not understand why the doctor's questioning was primarily focussing on my alcohol consumption. I was subsequently taken to an admissions ward and finally discharged without a diagnosis. The headaches continued with intense bouts of acute pain from time to time. Around one week later I was readmitted to hospital. The consultant ordered an MRI scan which showed that I had suffered an intra-cranial haemorrhage into the thalamic area of my brain which was causing the acute pain. I understand that this was caused by high blood pressure. It was thought that the blood would be re-absorbed as it wasn't a large bleed and I was discharged on the understanding that my GP would follow-up on the bizarre liver function test results. I do not understand why the hospital did not investigate the liver function test results when they discovered they were raised.

8. Over the following months and on discussion with my GP, I stopped drinking alcohol altogether with a view to repeating the blood tests several weeks later to see if the lack of alcohol had affected the liver function tests at all. On returning to my GP for these results, it was decided that the lack of alcohol had not made any difference to the liver function test results and that there must be some other cause for the abnormal results. I recall discussing with my GP that they were all very high. My GP ordered another set of liver tests including one for hepatitis C. I was called back to the clinic to discuss the results.

9. I attended the GP surgery on 9 November 2012 and without my husband who

was at a funeral at the time. My GP gave me the information about my positive hepatitis C result with great kindness and sensitivity. Had I known that there was the potential for such a serious diagnosis then I might have waited until my husband was free to accompany me. The GP and I explored the possible cause of this infection from my previous history and we could not identify any possible means of contracting this infection except through a blood transfusion which I had received in GRO-B My GP immediately referred me to the Hepatology Unit at Manchester Royal Infirmary and reassured me that I could be treated effectively. I received an appointment to see a consultant hepatologist in mid-January 2013 and my husband came to the appointment with me. The hepatologist tried to establish the means of infection; he was discreet and subtle in the way he approached it, he was also sensitive, thorough and informative about the condition and the implications for treatment. He gave us specific and detailed information about the risks of my infection to others and suggested that anyone who had close contact with me should be tested also. He also informed my husband and me about the Skipton Fund and told us that he would support my application.

10. I do believe that I was given adequate information to help me to understand and manage the infection. Following on from this appointment I was invited to attend a preliminary treatment meeting designed to inform new patients about the possible side effects of ribavirin and interferon and how to manage the treatment effectively including the administration of a weekly injection. The nurses who ran the meeting were very supportive and informative and the meeting was very informal. However, it was alarming and alienating to be part of a group whose participants clearly had a different lifestyle to me and who had contracted hepatitis C in a variety of different ways. I found this quite stressful; my husband and I felt uncomfortable in the situation and I wish that I could have been treated in a more confidential way.

11. What is difficult to accept is the length of time that passed from the provision of the blood to me in GRO-B to the point at which I was diagnosed in 2013. This is

period of 30 years. I have asked myself whether there should have been a test for those who received a transfusion from the Blood Transfusion Service, as standard. Only recently, it has struck me as strange, the fact that the Blood Transfusion Service would not allow me to give blood when I tried to do so back in the late 1980s or early 1990s as I recall, which I believe was before the arrival of my fourth child. I remember going to the regional blood transfusion centre near Manchester Piccadilly train station and giving blood as a sample and later being told that they could not use it. I did not think anything more about this at the time. I thought perhaps they had too much O Positive and did not need my blood. Now I question whether they knew and did not tell me. It was also disappointing that the diagnosis of hepatitis C was not made at the hospital where I was admitted with the cerebral haemorrhage. My abiding memory of this traumatic time was that the doctors at the hospital had assumed that my bizarre liver function tests were a result of consuming too much alcohol and it seemed to me that they had categorised me in this way and therefore no further consideration was given to a differential diagnosis. This was very upsetting and I felt stigmatised by their reaction to me. Hepatitis C could have been identified at the least six months earlier and treatment started as a result.

12. I believe the test results and information about the infection were communicated in an appropriate and sensitive way; although I would have liked to have had my husband with me at the time for support.

13. Aside from the information provided by the consultant hepatologist about the risk to others of being infected I was also given leaflets by the hospital which provided positive information about diet and living with hepatitis C. As a result of the information provided my husband and children went for tests.

Section 3: Other infections

14. I believe I have been infected with hepatitis C only.

Section 4: Consent

15. Since the blood transfusion from which I received infected blood was given 30 years ago, I honestly cannot remember whether I was informed of any risk of receiving a blood transfusion at the time. From my training as a nurse, my considerations at the time were about ensuring a matching to the blood type and acknowledging that as being the overriding risk. I believe that had I been told that there was a risk other than a mismatch risk, I would have remembered that and given I only lost three units of blood I may not have consented. I had full confidence and trust in the care that I was receiving to not question whether the blood transfusion was an essential part of that care. If I had known that the blood they were giving me might carry a risk of infection, I would have considered the pros and cons of receiving it more carefully and whether I could have replaced it myself. I certainly do not remember being given any information about the possible risks of infection.

16. I do not believe I was treated or tested without my knowledge, or

17. Without my consent,

18. I cannot say whether I was given adequate or full information as I do not know what information was available at the time,

19. I have been part of a research project as part of attending treatment at Manchester Royal Infirmary but fully consented in respect of this.

Section 5: Impact

20. Figuring out the impact of the hepatitis C on my life generally has been difficult. We are dealing with a period of 30 years of not knowing. On reflection, it was a time in my life that was the busiest of my life. My memory is telling me that I did not suffer from significant mental or physical effects during the period of my not

knowing. I think that perhaps had I known I was carrying an infection I might have attributed certain symptoms to it but this did not happen. I have not been able to see any medical records thus far so cannot say with confidence what symptoms I have had over this period.

21. Prior to diagnosis the only physical effect I recall is that around six months after having my daughter in GRO-B I had an episode of severe abdominal pain which lasted several hours but then lessened so I did not seek medical advice at this time. Since being diagnosed the obvious main physical effects have been that I am frequently cold, often very tired and I do experience itching. Mentally I have suffered many episodes of anxiety and of low mood. This was initially related to concern about the far reaching effects of the condition, the stigmatisation and not being able to talk about it generally as people did not seem to understand. I have often thought that people at work and sometimes friends and family with whom I shared the information doubted that I got the infection from the blood transfusion and that there must have been some other cause.

22. My GP wondered if the chronic hepatitis C infection could have been related to the cerebral haemorrhage I had in 2012. I am unsure whether there is research proving a connection. I understand that the effects of the infection can be very broad.

23. I was treated for six months with ribavirin tablets and interferon injections which started in early February 2013, and am pleased to say that the virus is clinically undetectable.

24. Once I was diagnosed with hepatitis C, there were no difficulties or obstacles in receiving appropriate treatment. My GP was excellent, acting quickly to refer me and once referred to Manchester Royal Infirmary, I was diagnosed and treated within a short time frame.

25. I was told by the hepatology nurses that other treatments which had fewer side

effects were being developed but were not available to me at that time.

26. I was treated with ribavirin and interferon. I was relieved to hear that because I was infected with genotype 3, I was more likely to react positively to the treatment. The statistics they had available demonstrated this. However, the physical effects of the treatment were chronic fatigue and lack of energy, poor appetite, weight loss, hair loss (extreme thinning), feelings of nausea, skin itchiness leading to insomnia, feeling cold. Mentally, the treatment affected my self confidence and self esteem. I was determined to keep working at all costs but this became extremely difficult as I was starting a new role and I felt I had to keep to the commitment that I had made. The tiredness, constant coldness and feeling unwell made it difficult to keep my motivation going and to be creative in the way I wanted to be in this exciting new role. Throughout the treatment, my anxiety levels were very high and I would frequently wake up in the night feeling terrified about the future and unable to sleep. I often became very agitated with the constant itching which was quite depressing at times. The stigma attached to being infected with hepatitis C caused me to feel dirty and affected my self esteem and confidence.

27. My condition has not apparently made any difference to any medical or dental treatment I have received since diagnosis.

28. The occurrence of the diagnosis and the treatment was so close that it is difficult to separate the impact of each.

29. The impact of the diagnosis of hepatitis C was devastating and traumatising to me and to my family. While my overriding concern was the infected status of my husband and my five children, I was relieved that the medical profession would realise that I had been not lying about my alcohol intake and there was a different reason for the liver results. My husband and children all had blood tests which fortunately proved negative for hepatitis C. It was a time of great anxiety and dread, that someone else in the family could have also contracted

the condition through me.

30. My husband was extremely supportive throughout the whole time I was ill; from as early as the cerebral haemorrhage symptoms to date. He did everything for me in terms of practical support, for example: cooking; cleaning; washing and all other household jobs. There is no way I could have continued to work without this level of support as I was exhausted much of the time. He was very worried about me and I am sure, very frustrated but he never once showed anything but kindness to me during the whole time of treatment. It was a horrible time. My family were also very supportive, particularly my brothers, sisters and their partners. My children and their partners were also supportive but my husband and I tried to protect them from being aware of the real impact the treatment was having on both of us.

31. Our social life was greatly affected. I can remember meeting up with friends and having to come home early because I could not cope with the noise and the energy required just to be there and to be sociable. I remember my overriding feeling was one of like hitting a wall with trying to be sociable and I felt like screaming or crying when I was in the situation, and I found myself having to leave early. Most times I would just not go out as I could not cope with it. My best friends understood but there was a general lack of understanding about what was wrong with me and how it was affecting my behaviour. I did not want to constantly explain to people and certainly to those who were not my best friends, about what was wrong with me.

32. My husband and I were not able to go on holiday during the treatment and had to cancel some of our plans, resulting in financial loss.

33. At the time, my son was planning his wedding the following year. This should have been a time of joy and excitement but I was not well enough during the treatment to be actively involved in the wedding planning and this spoiled it for me. Even choosing a dress for the occasion was exhausting. I can remember

two friends coming with me and helping me with dressing and undressing, carrying dresses I had rejected back to the rails and generally trying to keep my spirits and energy up so that a dress could be bought and we wouldn't have to do it all over again.

34. Although my close family and friends understood how I had contracted the virus, it was horrible to feel that I was still a source of infection to others. At work, I was very careful about who I told about my treatment for fear of colleagues not understanding. This added another level of anxiety and fear.

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35. In terms of the education, work-related and financial effects:

36. I do not believe there were any educational effects;

37. Regarding the work-related effects, I was supposed to be starting a new role at the college I worked at in September 2012 but I was unable to start this role until November 2012 because I was not well enough to go back to work after the cerebral haemorrhage. At this time in November I was also diagnosed with hepatitis C and the hepatology nurses encouraged me to carry on working if I possibly could. I therefore devoted all my energy into this and my husband's support allowed me to do this throughout the treatment. However, after the treatment which fortunately was successful after six months, I found that my mental health was very fragile and I was struggling to cope at work and at home. I was able to access psychological support during this time which was very helpful and it made me realise that the impact of what I had been through was pervasive and damaging. Although I tried many strategies with cognitive behavioural therapy to reduce my anxiety and lack of confidence, I felt that

working was having a detrimental effect on me generally and so reluctantly I decided to retire in April 2014. I have struggled with coping with retirement. I have since often regretted this decision because I always enjoyed working but it seemed sensible at the time.

38. Regarding the financial effects, although I continued to receive a salary during my treatment, I believe that I would have continued to work for longer before retiring if the impact of the disease and the treatment had not been so devastating. This obviously has had significant financial consequences.

39. My husband and I have shielded a lot of people from this. At the time, my children had moved on with their adult lives and were not living in the family home to see the impact of the infection and treatment on me and my husband. I worried that my second child; the daughter who was born just before I had the transfusion, might think that she was somehow responsible for it, so I worked hard to ensure that she understood that it was not her fault.

Section 6: Treatment/Care/Support

40. I have not faced any obstacles in obtaining treatment, care or support since I was diagnosed with hepatitis C.

41. Soon after I was diagnosed with hepatitis C, I asked my GP if she would refer me for counselling. I had to wait a few weeks but was offered cognitive behavioural therapy counselling soon after this short wait. This was very helpful to me at that time. The quality of this therapy was exceptional and made a huge difference to how I coped throughout the treatment. This was the first opportunity that I had to talk about what I had been through. After six months of this weekly therapy, I was discharged on the understanding that I could have a "top-up" of sessions in the future if I needed it. I was nervous about the fact it was ending and in truth I did not want it to but I understand resource is limited. A year later, I requested the "top-up" which was made

available to me after a short wait. Although this was less useful in some ways, I was grateful for the opportunity to re-engage with cognitive behavioural therapy. I attended the session every week for around four months. Recently, in 2018, I requested another course of counselling and this is ongoing at the moment. Although I had to wait for this for several months, it has been a lifeline and very healing. I am very hopeful that this will not end any time soon.

Section 7: Financial Assistance

42. I have received financial assistance from the Skipton Fund which is now the England Infected Blood Support Scheme (EIBSS).

43. My consultant hepatologist told my husband and me about the Skipton Fund after our first consultation with him, in January 2013. He said that he would support my application and he did but the initial application was rejected because the consultant was unable to provide evidence that I received a blood transfusion before 1991.

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45. The process of applying for the Skipton Fund initially was very difficult and stressful because although my consultant was happy to support my application, it took him many weeks to complete his section of the form. I had to keep phoning up. This was then rejected by the Skipton Fund because my

consultant had not provided actual evidence that I had received a blood transfusion from Saint Mary's Hospital. This was very disappointing as the onus was then put on me to provide the evidence. I contacted the records department of Saint Mary's Hospital and they informed me that my records had been destroyed because their policy was not to keep records where a period of 25 years had elapsed from the last treatment. This was devastating news but undeterred, I asked my GP if she could help me to find evidence in my GP records. She asked the practice manager to go through my records and eventually they identified an obstetric record which stated that I had been transfused with three units of blood in 1982 for a postpartum haemorrhage. At the same time, I came across a photograph of myself in hospital just after having had my baby which showed the blood being transfused into my arm. The back of the photograph was dated **GRO-B** I therefore resubmitted my Skipton application and it was accepted.

46. Subsequently, I have applied for the SCM payments through EIBSS. Once again, my GP fully supported my application and I was successful. The process of this application was fairly straightforward and the staff at the EIBSS were helpful and supportive.

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48. **GRO-B**

49. I think that the impact resulted in harder work and emotional distress for my husband. He has a "get on with it" approach to life and he saw the need to care

for me as being another obstacle to get through. However, his sleep was disturbed most nights during the treatment by my night terrors and intense periods of itching. He would hold me and talk soothingly to me until I was calm again. It must have been distressing for him and added to his own exhaustion.

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GRO-B I think that perhaps I was too sick to notice the impact it was having; too self-absorbed. I was working really hard to just keep going. I was totally focussed on getting through the treatment. Despite everything, I stuck rigidly to the treatment programme. My brothers and sisters were very supportive. GRO-B GRO-B It was better to get through it together. I was fortunate to be able to talk through this with my counsellor at the time.

Section 8: Other Issues

50. For me the Inquiry is about establishing exactly what happened, when and why. The timeline of everything is crucially important. I am particularly upset about the fact that successive governments; since they have known about hepatitis C being given in blood transfusions have done nothing responsible about trying to identify the people who have received them. I think this is an appalling omission; a negligence to the citizens of this country. It cannot have been that difficult to do when you really think about it. Even if every GP wrote to all of their patients, asking if they received a transfusion during a certain period of time, this would make a substantial difference. Certainly no one has ever contacted me about it.

51. I have concerns about the completeness of my medical records and particularly

because they would have assisted my memory in the completion of this statement. I have tried to be as honest as possible in conveying my story and hope that my memory has served me well but appreciate that 30 years is a long period of time to remember all of the detail of this story. I have tried to acquire the relevant records from St Mary's and was told that they were destroyed when 25 years since my last treatment had elapsed. I am in the process of requesting others records through my solicitors and I would like to submit a supplementary statement should that be appropriate.

Statement of Truth

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

Signed: GRO-B

Full Name: GRO-B

Date: 12 · 2 · 2019