Witness Name: GRO-B
Statement No.: WITN2820001
Exhibits: 0
Dated: 14 February 2019

WITNESS STATEMENT OF GRO-B
INFECTED BLOOD INQUIRY

Section 1: Introduction

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

2. I am a retired teacher. I have been married to GRO-B: W since the GRO-B

3. W and I have five children born 1980, 1982, 1984, 1989 and 1992.

Section 2: How Affected

4. W and I met at university; we got married when she was employed as a Sister in an Intensive Care Ward at a local hospital.

5. W received a blood transfusion following a post partem haemorrhage after the birth of our second child on GRO-B 1982. I recall having to leave the hospital after the arrival of our daughter to look after our son who was at home with his great-aunt. I returned the next morning; on GRO-B and I saw

that W was attached to a bag of blood. There is a photograph dated GRO-B which shows that this took place. On GRO-B on our wedding anniversary, W suffered a thalamic bleed and during the course of her treatment and recovery blood tests showed irregularities in the liver function test results. Further investigations eventually identified the fact that W had contracted hepatitis C. W was diagnosed with hepatitis C on 9 November 2012; she then went through a traumatic six month treatment programme at Manchester Royal Infirmary from February to July 2013.

6. W does not suffer from a bleeding disorder.

7. On GRO-B 1992 W gave birth to our second child at St Mary's Hospital in Manchester; she suffered a post partem haemorrhaging which led to her receiving three units of blood. Those units were transfused over the course of two calendar days; her transfusion began on the GRO-B 1992 and continued into the GRO-B

8. To the best of my knowledge and recollection we were given no information or advice regarding risks involved in having the transfusion. Indeed, following the haemorrhage the transfusion was delivered seemingly as standard practice.

9. As a result of the tests in 2012 it was found that W had contracted hepatitis C (HCV), genotype 3.

10. I am relaying this information from what W has told and from my experiences following the events as they unfolded. W was told by her GP at the GRO-B on the 9 November 2012 that she had HCV.

11. When W returned from the GP she told me that the GP had provided information about how the HCV could have been contracted; including that it could have been contracted by way of a blood transfusion, and she referred

W to the hepatology department at Manchester Royal Infirmary (MRI), who she saw soon thereafter. The consultant at the MRI made a formal diagnosis of HCV and suggested treatments with ribavirin and interferon, explaining the potential and likely impacts of these treatments.

12. I think that the GP and the consultant at MRI together provided adequate information to help understand and manage the infection. I was not present at the GP appointment when W was told but I was when the referral to the MRI occurred. The consultant explained very clearly about the infection and the treatment programme. At the end of January 2013 we attended an introductory talk at a unit in MRI where the specialist staff explained more about the impacts of the treatments.

13. Information about the infection and treatment was appropriate as soon as it became known about the infection, but, the HCV could and perhaps should have been diagnosed earlier; at the latest when the irregularities in the blood test results were found. I believe that they should have been followed up thoroughly. On several occasions it seemed that the initial assumption was that the unusual liver test results were a result of alcohol abuse. At least two nurses, on separate occasions wanted to refer W to the Alcohol Dependency Unit at the MRI. Thinking about this more broadly, I believe that there should have been a screening programme for everyone who received a transfusion from the Blood Transfusion Service to check whether they might have become infected.

14. W told me that the GP was astonished to find that W had contracted HCV and has been a huge support to her over the years. By the time we got to the consultant W knew that it was almost certain that she had contracted hepatitis C. The consultant confirmed the initial GP diagnosis; he ruled out the possible drug misuse and alcoholism, he was not judgemental and was thoroughly professional in his approach. An information introduction session was set up at a unit at the MRI to explain the infection and treatments, and the

risks associated with infecting others. W and I attended with approximately 15 other people and this felt uncomfortable for us both because our potential infection status was being disclosed to others. The session was conducted very professionally and we learned a great deal but think that we would have preferred to have had this information conveyed to us privately.

15. During the introduction session at the MRI we were informed about the way in which the virus could be passed on and implications of doing so.

Section 3: Other infections

16. I do not think that W received any infection other than hepatitis C.

Section 4: Consent

17. I do not believe W was treated or tested:

18. Without her knowledge; or

19. Without her consent; but

20. If they knew the risks of receiving a blood transfusion then I do think that she was treated without being given adequate or full information.

21. W consented to take part in an HCV research programme being run through the University of Manchester at the MRI gastroenterology and hepatology unit to follow up on treatment. She fully consented to this.

Section 5: Impact

22. The effects of the HCV on W were not apparent to us for many years.

23. In retrospect though, there were occasions during the 30 years; between the

transfusion and the diagnosis, when issues of fatigue or anxiety or feeling the cold could have been associated with the virus.

24. There is a suggestion from the GP that the thalamic bleed in 2012 could have been linked to the HCV.

25. The main effects of having the virus were seen during the treatment for it and this is discussed below.

26. The treatment consisted of taking interferon and ribavirin for a period of six months.

27. When W was diagnosed the treatment followed soon thereafter. The main problems that we faced in accessing the treatment were associated with the logistics of getting to the treatment and included the time taken to travel to the hospital, the cost of the travel, the cost of and ability to park.

28. I do not know whether there are any other treatments which might have been available to W

29. W was treated with ribavirin and interferon; the physical effects of which were severe and included 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 W self confidence and self esteem. She suffered from a range of anxieties, including night-time panic attacks and trauma. The tiredness, constant coldness and feeling unwell made it difficult to keep her motivation going. Throughout the treatment, W anxiety levels were very high and she would frequently wake up in the night feeling terrified about the future and unable to sleep. W often became very agitated with the constant itching which really got her down. The stigma attached to being infected with hepatitis C caused her to feel dirty and affected her self esteem and confidence. The feelings of being

cold and the fatigue remain.

30. On at least two occasions when W was being seen by a doctor who was not her own GP (who knew and understood her condition) she was treated as if her condition was the result of alcohol abuse and this caused her great distress.

31. The impact on W private, family and social life has been to restrict her activities for a range of reasons including her fatigue and anxieties. The physical and mental demands of the treatment had a profound impact on her and this remains. We had to cancel a continental holiday (losing money as a result). I have felt the effects of W illness and treatment myself. During the six months of her treatment she was so tired and incapacitated by the drugs that I took on all the domestic activities of the household including the shopping, cooking, cleaning and washing etc. W lost her confidence in driving and so I drove us both everywhere. Her night-time anxiety attacks would keep us both awake for long periods thus making the problems of her fatigue greater. GRO-B

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GRO-B When W was diagnosed with HCV we had to inform our five children and their partners so that they could go to be tested. All were clear of the virus but the anxiety this caused to them and to us was great. I was no longer working full time during W treatment and recovery which meant that I was able to cope more easily with the impacts referred to above W had just finished her role as senior tutor at the sixth form college and was due to start a reduced role in another department when she had the thalamic bleed. She could not start that immediately and when she did go back it was on a phased return. This was during her treatment for HCV. This return to work was partly on the advice of the staff at the HCV clinic who suggested that keeping busy was one way to reduce the psychological impact of having the virus and the treatments; although the impact of working during the treatments was to increase the level of fatigue significantly, so when she came home all she could to do was to rest or sleep.

Section 6: Treatment/Care/Support

32. W was on a waiting list for psychological help from the LEA Trafford for several months before it became available.

33. I have had no counselling or psychological support (apart from W) during the process. W had several sessions with an LEA Psychologist up to March 2013 and then twelve more sessions into 2014. From November 2015 she found and paid for 12 private sessions and from May 2018 to the present has been having regular counselling.

Section 7: Financial Assistance

34. W has received financial assistance from the Skipton Fund which is now the England Infected Blood Support Scheme (EIBSS).

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

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37. The process of applying for the Skipton Fund initially was very difficult and stressful because although the consultant was happy to support the application, it took him many weeks to complete his section of the form. The application was then rejected by the Skipton Fund because he had not provided actual evidence that W had received a blood transfusion from Saint Mary's Hospital. This was very disappointing as the onus was then put on W to provide the evidence. W contacted the records department of Saint Mary's Hospital and they informed her that her records had been destroyed because their policy was not to keep them after a period of 25 years of elapsed treatment. This was devastating news but undeterred, she asked her GP if she could help to find evidence in her GP records. Eventually they identified an obstetric record which stated that she had been transfused with three units of blood in 1982 for a postpartum haemorrhage. At the same time, W came across a photograph of herself in hospital just after having had her baby which showed that she was having a blood transfusion, the back of the photograph was dated GRO-B She therefore resubmitted her Skipton application and it was accepted.

38. Subsequently, W has applied for the SCM payments through the English Infected Blood Support Scheme (EIBSS). Once again, her GP fully supported her application and it was successful. The process of this application was fairly straightforward and the staff at the EIBSS were helpful and supportive.

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40. GRO-B

Section 8: Other Issues

41. There are no further documents that I would like the Inquiry to see.

42. I am very pleased with the detail, breadth and scope of the Terms of Reference and in the main I hope that the many questions that are asked or raised by the Inquiry will be answered fully, honestly and thoroughly.

43. In relation to the withholding of information; W visited the Blood Transfusion Service around 1987 to donate blood. She provided a sample and later was told that she could not be a donor. It was never explained why; she assumed her blood type was not what was required and left it at that but we wonder now whether there is more information behind this especially given what we know now.

Statement of Truth

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

Signed: GRO-B

Full Name: GRO-B

Date: 12th February 2019