Witness Number: W0581

Witness Statement of: GRO-B
No. of statement: WITN0581001
Exhibits: N/A
Date of statement:

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 I was born on GRO-B GRO-B. I am married to GRO-B: W (GRO-B) who was infected with Hepatitis C by blood transfusion at Queen Charlotte Hospital in 1989.

Section 2: How Affected

2. W has also provided a witness statement to the Inquiry (**WITN0580001**), in which she outlines the history of her infection and subsequent treatment. I will not repeat this information at length here myself and refer to her statement for chronological detail, but I will provide a brief background to enable me to explain how we were both affected as a consequence of her infection.

3. W received contaminated blood while undergoing an emergency operation after the birth of our second daughter, GRO-B The transfusion took place while W was an in-patient at Queen Charlotte's Hospital in London in GRO-B Our first daughter

GRO-B was only sixteen months old at the time. I was not directly involved in the decision to provide W with the transfusion and I do not remember being advised on any possible risks of infection.

4. We knew nothing of W infection with Hepatitis C until her GP was contacted by the National Blood Transfusion Service in 1995. The intervening period was a very difficult time for us both. W health was badly affected. She was chronically tired, her pre-existing mobility problems became far worse, and we thought that she was suffering from chronic post-natal depression. At the time we did not understand why she was so unwell. It was incredibly difficult for us as a family.

5. After W was diagnosed with Hepatitis in early 1996, she began attending regular clinic reviews at the liver clinic at Kings College Hospital. To begin with W liver health was simply monitored. From mid-2000 the clinical staff at Kings became increasingly insistent that W should undergo an experimental new therapy using the drug Interferon. Both W and I became very uncomfortable with the way that she was being pressurised to undergo Interferon therapy. W resisted the pressure and refused to have the therapy, and this led to us breaking contact with Kings College in 2006.

6. After breaking with Kings College W took only homeopathic remedies from 2006 until she was referred to a consultant liver specialist at Queen Mary's Hospital in 2013. Homeopathy helped considerably with the symptoms W was experiencing, but we never expected it to deal with the underlying illness. Soon after W began attending Queen Mary's she underwent a further biopsy and this established that she had sustained Stage 6 cirrhosis of the liver. The situation looked bleak, and it was suggested that she may need to have a liver transplant. Fortunately however, a new drug became available called Sofosbuvir. W was one of the first people to receive this treatment in the UK and it really did turn out to be a wonder drug. By March 2015 her Hepatitis infection had cleared.

7. I feel that we have never been provided with sufficient information about the consequences of W infection. After W was first informed that she had been infected we were expecting to be provided with leaflets or other documents explaining the illness in depth, and advising on the different treatment options, but there was none of this. Particularly at Kings College the doctors seemed very reluctant to provide information and most of what we learned we discovered ourselves; from the internet, other patients in hospital, or from other non-specialist doctors.

8. During the course of her treatment W asked a lot of questions but she felt that they were never properly answered. As she has a medical background she often had a good idea of what was going on and so she would ask for test results and other information, but her doctors were always quite evasive and reluctant to pass these results on. It was as though they did not want to give too much information as they felt this would be to shoot themselves in the foot.

9. I also do not think that we ever really received a proper explanation of the possibility that W might pass the virus on to other people. I do remember being told at Kings College when W was first tested that there was a slight risk that I might be infected through our sexual contact but this was never properly explained. Again it was through sources other than W doctors that we developed an understanding of the precautions that we needed to take.

Section 3: Other Infections

10. I am not aware of W having received any infection or infections other that Hepatitis C as a result of being given infected blood or blood products.

Section 4: Consent

11. I have concerns about the way that W was treated at Kings College hospital in the early 2000s. At that time we were essentially

told by medical staff there that Interferon treatment would cure her Hepatitis C. At first I was very enthusiastic about this prospect. However, by this time we had already received a report from the expert witness Dr Hamilton who was assisting Evill Coleman, the solicitor's firm we had instructed. Dr Hamilton was quite pessimistic about the Interferon treatment and so we already knew that there were people in the medical world who were far less certain about the prospects for the therapy. This doubt was certainly not reflected in the way that the staff at Kings College seemed to view Interferon. Although I was enthusiastic at first about its potential as a cure W herself was reluctant. She felt that something odd was going on and that people were speaking to us in a strange way. She felt that we were the subjects of a study.

12. Over time I started to notice everything that W mentioned and began to realise that she was right. At Kings College we met other patients who were undergoing the therapy already, particularly haemophiliacs and we saw first-hand that Interferon had the potential to cause severe problems and side effects. We also came to understand from our own research that W was especially vulnerable to the negative side effects as she suffered from back and leg problems. I began to feel that W was being bullied into taking an untested and potentially dangerous 'cure'.

13. It seemed that the authorities felt that they might have a solution to the problem that they had caused and that this would mean that they would not need to provide the full detail of the mistakes that they had made. We felt that the Government and others wanted to be perceived as having a cure when they told people they were infected, without really knowing the full consequences of the treatments. It was as though they were using people as guinea pigs. The response of Government exacerbated the impact on us both.

Section 5: Impact

Up to diagnosis

14. In the seven years before we knew anything about the infection W was hugely affected. We thought at the time that she was suffering from postnatal depression and she lacked focus and the ability to concentrate and found many things challenging.

15. She had difficulty with her leg and back before 1989, but after the blood transfusion things became even more difficult for her. At that time we didn't know what was causing things to be so hard for her and this certainly added to the emotional and psychological stress we experienced as a family. I simply could not understand why W was so bad. I found it difficult to understand and regret now that I became impatient at times. It was as though everything was against us. I feel now that I could have been more understanding.

16. Although the most significant burden was obviously on W the difficulties that she was having affected both of us. At that time our children were very young and I had to do a lot to help with nappies and childcare as well as household chores at the same time as I was working. It made me very tired and the stress of the situation was huge.

17. After we found out about W infection and came to understand how badly affected by the virus W was, the strain on our relationship became much less. We became closer and determined to go on. I am proud of how we came together and of how we have been ever since.

After diagnosis

18. When we knew about W infection, we began to attend hospital regularly and this added to the practical strain caused by her illness. The regular hospital appointments meant that we needed to arrange

child care cover. I became so tired that I felt zombie like at the time. There were so many things that we had to do.

19. W began receiving Disability Living Allowance in the late 1990s and has had difficulties with her leg and back for a long time. The Hepatitis C infection was never properly considered when assessing her disability. It was never fully recognised and no one has done any research on the link between Hepatitis and mobility. Her condition became very bad in the late 2000's and early 2010's before she was cured of Hepatitis C. At that time she needed a lot of care. Although W Hepatitis infection has now cleared many of the health consequences remain. She continues to have problems with her back and leg. We feel that this is related – it is clear to us that her back and leg problems have been exacerbated by the infection.

20. By profession GRO-B GRO-B. W and I actually met through GRO-B GRO-B. I was running a GRO-B business on GRO-B in London and W had a background in GRO-B, a field in which I specialised. Before the birth of our second daughter GRO-B, W used to help with the business. After the birth of GRO-B she became so unwell that it became impossible for her to help. It was a very sudden change. After coming out of hospital it was as though she was a different person. She had undergone a major operation, but she did not have a normal reaction or convalescence.

21. Over the years I have at many times not been able to do as much GRO-B as I wanted because I have had to care for my wife. My ability to earn money and accrue a pension was greatly affected in the time before we knew W was infected because I had to help her and my young children. In the early nineties interest rates started getting very high. It was much more important to me that I was able to devote additional time to W and our daughters and so I could not do the additional work required to keep up with increased expenses. As I was unable to pay the bills my business failed.

22. I would say that my quality of life was drastically changed as a consequence of W infection, before we knew that it had happened, and even more when we discovered that it had. At times I have had to care totally for W. I could have done a lot more for society in terms of GRO-B but this has not been possible because I have had to care for W.

23. I became a GRO-B in 1998. I was motivated to do this largely because I thought that the role might make it easier for me to continue helping W. I found that it doesn't work like that in reality, in fact GRO-B requires a huge amount of time GRO-B and it was very difficult to balance this work with providing the necessary support to W and my daughters.

Section 6: Treatment/Care/Support

24. Initially there was no care, then after W was diagnosed there was the early interferon treatment that even the doctors in Kings College seemed to be suspicious of.

25. The whole approach at Kings College seemed to be based on a preconceived idea about who we were and what we needed. W sought additional treatment from the Royal London Homeopathic Hospital via a referral from her GP. There was a nurse specialist in the Institute of Liver Studies at Kings who we had particular difficulty with and she pressured W particularly hard. She thought we were mad for taking an interest in other forms of treatment like homeopathy hospital. She thought that W had a chip on her shoulder because of her disability and she saw me as not fully understanding things. It was like she put us into categories and it really seemed as though she was simply brought in to get people to take a 'cure'. I fully supported W in her decision to disengage with Kings College and rely solely on homeopathic treatments for several years.

26. There was not adequate counselling or psychological support to begin with. It is much better now. In the past we felt that Kings College was

offering 'counselling' but only to support their agenda of Interferon treatment. The nurse we were seeing seemed to think that the only counselling W required was to deal with the doubts that she had about the interferon treatment.

27. The Inquiry provides support through the Red Cross and you can be awarded money for counselling through the England Infected Blood Support Scheme. We haven't taken that up as we feel that we are largely past that. We would certainly have benefited from Counselling in the early 1990s when things were at their most difficult.

Section 7: Financial Assistance

28. As I have already mentioned, the consequences of W infection have had a large financial impact on us. Unfortunately, we lost both our house and our business in the mid nineties. The truth of the matter is that W infection changed our lives forever and one large aspect of this was the financial impact.

29. I first knew in the early 2000s that a trust was going to be set up to provide financial assistance to infected people. At that time we had also instructed a solicitor to pursue a compensation claim.

30. We were first informed about the existence of a separate government compensation scheme by our solicitor GRO-B He told us that the government had agreed to make these payments in addition to any money recovered though a personal injury claim. We eventually received £20,000 from the Skipton Fund in 2005. When it was found in 2014 that W had suffered cirrhosis we received a further payment of £50,000 under the scheme.

31. The level of payment for Stage 1 infection from the Skipton Fund was very low considering what had happened before 1996, and the financial difficulty we experienced before the award in the early 2000's. Our family had suffered terribly financially at this time. There were times when we desperately needed financial support and in many ways the

Stage 1 payment was too little, too late. Similarly the Stage 2 payment that we received does not truly reflect the scale of losses we have had financially because of W infection over the 30 year period since she was infected.

32. I was aware that there were other trusts that were assisting infected people such as the McFarlane Trust in Scotland. We knew that the other Trusts were giving out some quite helpful things like money for counselling. I feel that we could have benefitted from such extra help particularly in the earlier stages of infection. It seems unfair that the level of support received differed even though people had all been infected in a similar way.

33. Another problem with the way payments were made was the delay. W did not receive her first payment under the scheme until 2005, nearly ten years after she first discovered that she had been infected. In fact the delay was such that a lot of people had died before they were helped.

34. W has been unable to work and has had to rely on welfare benefits for her income. When accessing benefits it would have been better if Hepatitis C and infected blood had been recognised as an important factor in people's health earlier. Even now when applying for Personal Independence Payments, no acknowledgement seems to be made of the impact that Hepatitis C infection has had on W health and mobility. It has been more through W back problems that we have accessed the welfare system, but we feel that Hepatitis was an important part of why W was affected so badly by her back and leg problems. We have always struggled to have this acknowledged and considered by those considering her benefits.

35. There have been delays all along from the Government and others. This has caused resentment and extreme hardship and suffering. More appropriate financial and practical measures early on could have made things better for us, and for many others.

Section 8: Other Issues

36. I feel that the help and support we received would have been far better if the infected blood disaster had been officially recognised earlier. There was no help until about 2005. W was infected in 1989 and so for a considerable period of time there was no proper support. Even now some doctors don't seem to understand what had happened.

37. Having Hepatitis C is something some people associate with drug addiction and so sufferers often feel more hesitant to talk openly about their infection. We have met people at the Hepatitis units at hospital and have talked to people at the Hepatitis Trust who have experienced very bad discrimination over this. Partners have even separated because of the perceived dangers of being with someone with Hepatitis C. This social stigma has made the whole situation with W infection all the more difficult to deal with. The failure of the government and the NHS to provide information about what happened has compounded these difficulties. The secrecy of the authorities in an already delicate situation has made matters worse.

38. If the Government and health authorities had made it clear from the outset to the general public that there had been a medical disaster and people had been infected with Hepatitis C then I believe that I would have felt very differently. People would have been seen as victims and would not have had to justify their infection. It was the lack of knowledge about Hepatitis C and the sense of something to hide which caused the stigma.

39. We have fears that NHS England are still not engaging with the Inquiry in a fully responsive manner. They still do not seem to comprehend how people have been affected by this scandal. Those infected have been helped on an ad hoc basis because of the consequences of the infection rather than being acknowledged as victims of a major medical disaster.

40. The government and health authorities should have admitted responsibility in the beginning and made clear the consequences of what has happened. They should have provided proper counselling and not rushed into perceived solutions to the situation without proper preparation and research backing. Proper recognition of the scale of the disaster should also have involved a realistic financial assessment of the effects on people early on and not many years later as this has caused many people enormous hardship and suffering.

41. We would hope that the Inquiry elevates the recognition of contaminated blood products to what it is – a national medical disaster. The authorities should then address the consequences of what has happened in its entirety and not in an ad hoc way as events force them to take action. The full extent of what has happened to victims and their families should be recognised and fully addressed.

Statement of Truth

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

Signed GRO-B

Dated 26/03/19