Witness Name: GRO-B
Statement No: WITN2580001
Dated: 22nd April 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF GRO-B

I provide this statement in response to a request under Rule 9 of the Inquiry rules 2006 dated 12th December 2018. I adopt the paragraph numbering in the Rule 9 request for ease of reference.

I GRO-B will say as follows: -

1. Introduction

1. My name is GRO-B My date of birth is GRO-B GRO-B and my address is known to the Inquiry. I intend to speak about my infection of hepatitis C which I contracted from a blood transfusion in GRO-B In particular, the nature of my illness and how the illness affected me, the treatment I received and the impact it had on me and my family.

2 How Affected

1. In GRO-B I had to have a hysterectomy at the GRO-B GRO-B subsequently I had to have a blood transfusion during the operation. I did not know about the transfusion until after the operation.

I went back to working as a GRO-B after the operation. My relationship with my husband broke down shortly after my hysterectomy.

2. In GRO-B, GRO-B years after my hysterectomy operation, I received a letter from the doctor at the GRO-B stating that I may have contracted hepatitis C from the blood transfusion I received. The letter gave information as to what hepatitis C was, but no further information other that I need to get tested. I then went for blood tests and a biopsy. The biopsy was an awful experience and I was ill for some time after it. I then had to wait for the results which caused me much distress. I then found out my results from the blood tests and biopsy from my GP. He told me I had hepatitis C. My GP told me that I would need treatments, but he did not tell me any details of these treatments that I would need, or how they would affect me. He just referred me to the doctor who completed my hysterectomy. The GP did offer me therapy for my mental state. Initially I said no but on reflection it would have benefitted me, but I was never asked again after that. Until my diagnosis I had never heard of the infection hepatitis C, nor was I given any beneficial information from the GP about my future prospects or how the infection would affect me.

3. I was referred to the doctor that completed my hysterectomy at the GRO-B, and only then was I given information of further tests and necessary treatments that I would need. I only received an information sheet about the infection, but I was not given any further information to pass onto my family to explain about the risks of spreading the infection. From the further tests, it revealed that I had cirrhosis of the liver. That could have been prevented if I had found out I had hepatitis C sooner. Once I found out the seriousness of the infection, I felt compelled to inform my family, as I was unaware of what the future held for myself. Which was a very emotional conversation to have with my loved ones.

3 Other infections

1. As far as I am aware, the only infection I have contracted at any time is the hepatitis C.

4 Consent

1. Since I have been diagnosed with my infection I have always been told when and why medical staff were taking blood from me. I am not aware of them treating or testing me without my knowledge. When I had gone into hospital in GRO-B because of my hysterectomy, I had the blood transfusion during the operation, so I was not asked specifically for my permission. After my hysterectomy when I was told of the blood transfusion there was no mention or warning of possible risks from the blood transfusion.

5 Impact

1. My main issue, with having been infected with hepatitis C is that mentally it never leaves me. I never stop thinking about it. It is always on my mind. I suffer from bouts of depression and worry that my cirrhosis will get worse. I sufferl with insomnia due to the constant worry.

2. Physically, I have chronic fatigue, I am always tired, and I have constant itchy skin and I would scratch myself until the point of bleeding. I was diagnosed with cirrhosis, and since then I have had to have yearly tests on my liver and the constant worry of it turning cancerous.

3. When I was told I had cirrhosis the treatment was Interferon. I was told I needed to have 6 months of the treatment, but because of funding issues, I was only given 3 months initially, despite it showing some

improvement in my condition. I then changed doctors and I had to fight to get the further 3 months of treatment. This was a very stressful period, as no other medication was offered to me other than the Interferon. Eventually, I received the further 3 months of Interferon treatment. After this I had to then go for regular scans and blood tests. Finally I found out that the treatment had been successful and that the hepatitis C was dormant, but I still have cirrhosis.

4. The mental effects of the treatments were that I was always worrying whether they were going to work, or was my future going to be limited. I worried how this would affect my children and their wellbeing.

5. Physical effects of the treatments were my hair started to thin, I had shortness of breath and palpitations. Tiredness became worse and worse. I have constant joint pains, and I now suffer from arthritis and weak joints.

6. With regards to how my infection status has impacted upon other medical and dental care, I have always been embarrassed when going to the dentist or doctors or hospital appointments. When I would tell the various individuals about my infection they would react with horror. When I told various individuals about my infection, I felt they treated me differently and would then take precautions, like wearing rubber gloves, protective glasses, red stickers, etc, which made me feel dirty.

7. My medical and dental files would have a visible red sticker on them to warn that I had hepatitis C, which made me feel ashamed and embarrassed.

8. When I found out I had been diagnosed with hepatitis C the impact that it had on me and my family was one that caused me great concern and worry. It impacted me with regard to relationships. I was married, but that relationship ended around the time of my hysterectomy. Just before I found out I had hepatitis C, I was involved in a new relationship. However, once my diagnosis was confirmed and I told my

GRO-B, he ended the relationship out of fear of catching hepatitis C and of the future prospects our relationship would have. This caused me great heartache and caused me to lose a lot of confidence, which has taken me years to rebuild. I felt very lonely. After that I have not tried or wanted to have another relationship due to low self esteem and confidence, and a fear of having to tell them of my infection and fear of how they would react.

9. I had friendships, but I did not tell them about my infection simply due to the stigma that surrounds hepatitis C. I would have had to experience feeling ashamed and embarrassed all over again while I told them and then worry that they would no longer want to be around me. Due to this, I ended up not socialising and just staying at home.

10. The diagnosis of my infection has impacted on my family, especially my GRO-B. My eldest GRO-B was living at the family home when I received my diagnosis. GRO-B felt like she was unable to leave home at the time, as GRO-B felt I needed to have GRO-B for support. GRO-B would not attend GRO-B if it was away from home, as GRO-B did not want to leave me for any length of time. Due to this GRO-B missed out on pursuing GRO-B career further. GRO-B also felt worried and unsure of my future. Having the constant worry of test results coming back negatively or treatments not working. My GRO-B was at GRO-B at the time, we did not tell GRO-B initially because we didn't want GRO-B to worry. I don't know how I could have coped without the support of my GRO-B who stayed at home with me. GRO-B did offer to come back from GRO-B but there was no way I could have upset GRO-B people's future careers.

11. GRO-B my GRO-B had to be tested for the virus which was a daunting and stressful time, as I had the fear that I could have passed the infection onto them. Thankfully, that did not happen, and they did not get the infection. However, I constantly worry about the possibility of passing it onto them or others around me.

12. The impact that my family and I face with regards to the stigma of hepatitis C, is that everyone relates it to drug users and people having promiscuous sex. There is also the stigma around cirrhosis everyone thinks it is to with alcohol misuse. You constantly have the feeling that if people find out they will talk about you and think completely the wrong thing. If my family and/or I have to tell someone of my hepatitis C or cirrhosis, we feel a pressure to inform them of how and why I have the infection or condition. Due to this, I never tell anyone unless I have to as I find it hard to discuss.

13. When I found out I had hepatitis C I was working as a GRO-B due to the amount of time I needed off for the medical appointments I had to tell my employer I had hepatitis C. I felt my employer was very unsympathetic and isolated me from the other employees. My other employees found out and I was then made to use different cups and cutlery from the other employees. This made me feel very uncomfortable at work. I constantly felt like my colleagues were talking about me. Due to this, I felt embarrassed and no longer wanted to work there so I left.

14. I did not work for a couple of years, until I got a job in the GRO-B GRO-B. However, due to my constant fatigue I could not work full time, so I only worked part time. I worked there for a few years until they found out I had hepatitis C. I then felt obligated to resign. Eventually, I got another job as a GRO-B, again I could only work part time due to the constant tiredness.

15. The financial effects that I had due to being infected with hepatitis C were that I could only work part time due to constant fatigue. However, in GRO-B I did receive financial payments from the Skipton Fund (now Business Service Organisation) around £1,200 a month and I still get them. I have found the payments helpful, but if I was able to work full time my financial prospects could have been higher. With that being

said, I received them in GRO-B, this was GRO-B years after my diagnosis of hepatitis C.

6 Treatment/Care Support

1. I face significant difficulties in obtaining my treatment. I was told I needed to have 6 months of the treatment Interferon, but because of funding issues, I was only given 3 months initially, despite it proving successful. I then changed doctors and I had to fight to get the further 3 months of treatment. This was a very stressful period, as no other medication was offered to me other than the Interferon. Eventually, I received the further 3 months of Interferon treatment. After this I had to then go for regular scans and bloods tests, finally I found out that the treatment had been successful and that the hepatitis C was dormant, but I still have cirrhosis.

2. I was offered counselling support from my GP when I first found out I was infected with the virus, but I was never offered that again even after my treatments. I feel it should have been offered to me on more than just one occasion.

3. I ended up contacting other people with cirrhosis that I had met from the GRO-B in the GRO-B. Myself and GRO-B individuals I befriended ended up starting a GRO-B in the GRO-B. The GRO-B continued to thrive and is still in existence today. The GRO-B helped me to meet other individuals who were in a similar situation to me. It helped me to rebuild my confidence and to become sociable again and also just to be able to talk to people who understood what you were going through.

7 Financial assistance

1. I have received payments from the Skipton fund, which I was informed of via a letter from them. However, I was never told of any support schemes, trusts or funds that were available to me because I had been given contaminated blood.

2. I have received payments of £1,200 per month from the Skipton fund since GRO-B.

6 Other Issues

1. I previously sought legal advice from GRO-B in GRO-B but it was not taken any further. I had wanted to take a case against the NHS.

2. I have been asked if I would like to put any questions to the Inquiry; why was the blood not screened? Why did it take so long to be dealt with? How could it have happened? Why were the pharmaceutical companies not screening the blood? Why were so many people's records destroyed?

Statement of Truth

I believe the facts stated and this witness statement are true.

Signed…… GRO-B …

Dated………22/4/19………………