

ANONYMOUS

Witness Name: GRO-B

Statement No.: WITN0400001

Exhibits: **WITN0400002**

Dated: 31/01/2019

06 FEB 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 19th December 2018.

I, GRO-B will say as follows: -

Section 1. Introduction

1. My name is name is GRO-B My date of birth is GRO-B 1950 and my address is known to the Inquiry. I am a retired pub landlady and care worker and I intend to speak about my infection with Hepatitis C (HCV). In particular, the nature of my illness, how the illness affected me, the treatment received and the impact it had on mine and my husband's lives.

Section 2. How Infected

2. I was infected with HCV in 1972 after receiving a transfusion at Northampton General Hospital after an ectopic pregnancy.

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3. I had to have major surgery to remove my fallopian tube during which I was given a blood transfusion. I was in agony and I would have otherwise died with the pregnancy. After the surgery I had to spend two weeks in hospital and then I spent further time on a rehab ward. This is the only operation I have had.
4. I was not aware of the need for a transfusion before the procedure and was not informed of the transfusion afterwards. I would not have refused the transfusion as I would have died from the pregnancy otherwise.
5. I have been giving blood since the late 1960s. I used to go twice a year as that is all they allowed at the time. I would say I have donated between 15 and 20 times and I continued to do so after my transfusion as I was not aware of any infection or even the transfusion.
6. I took a break from giving blood for 3 years whilst I moved to Northampton and Cornwall before returning to Portsmouth and eventually Seaford. I returned to donating blood shortly after moving back to Portsmouth.
7. I found out that I had been infected between 1998 and 2000 when I went to donate blood at the Downs Centre in Seaford. This is over 25 years after my transfusion.
8. Shortly after that donation I received a letter telling me to go and see Dr Elliott of Seaford Medical Practice who then arranged further tests.
9. I went to see him and I had a blood test to find out what it was. It was HCV. He is a brilliant doctor and he was as good as gold. I was not given much advice in relation to it, with what to do or what not to do. I was in a state of shock, crying a lot and not knowing what was happening.
10. Dr Elliott got me an appointment in Brighton to see the Hepatitis nurses because it is the best place locally. The Brighton nurses were brilliant, they just took over.

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11. I was put on regular appointments but I was just going for scans to begin with, to see how much damage had been done. Eventually in 2010 I started medication because it had started getting too bad.

Section 3. Other Infections

12. I was infected with HCV only from the transfusion.

13. Due to the HCV, I have developed Cirrhosis and the liver is bad. There is no chance of it repairing itself.

14. I went for an MOT test when I was in India around 7 or 8 years ago. They said to go and see my doctor because I have a liver problem. It wasn't a very nice hospital, but they were spot on.

Section 4. Consent

15. I was not aware that I would be having a blood transfusion and after the operation I was not told of the transfusion or of any risk of infection.

16. I do not believe I have not been tested or treated for the purposes of research.

Section 5. Impact

17. I did not notice any physical effects or symptoms with the HCV, even looking back at things now. There was nothing at all, I was lucky like that. Although this did mean my illness went undetected for longer.

18. As I was unaware of both the transfusion and the infection there was a huge risk of infecting my husband [GRO-B] whom I met in 1983 long after I was infected.

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19. After being diagnosed with HCV, I suffered with depression and spent 4 years taking Citalopram on 40 milligrams per day. I came off it about 3 years ago, but my husband's recent health issues mean I am back on it again, I take 20 milligrams per day now.
20. As a result of the HCV, I have got Cirrhosis. I am told that it so bad that there is no chance of it repairing itself. There is no medication or prospects for my liver, I just go for tests every 6 months to see where things are.
21. I do not have cancer just now, but that is why we are healthy eaters, we are just trying to keep going.
22. Initially I had 11 months of medication. I had to self-inject the Ribavirin once a week and take Interferon pills twice a day. It was awful. I was really bad on this medication.
23. I had a lot of physical and mental side effects over the 11 months. I was hallucinating in my sleep. The hallucinations were really scary where I couldn't sleep again after I had experienced one. Every time your eyes close it happened again. That was horrific.
24. On a scale of 1-10 with 1 being normal dreams and 3 being nightmares the hallucinations were a 5 or a 6 - well beyond nightmares. You could never predict it, they just came and went.
25. I was still depressed but I was alright with this after taking the Citalopram as it was quite strong. I thought myself lucky to be getting some treatment, even though you have to be strong willed to take the full course. I concentrated on getting better.
26. I was also really anxious, I would shake and my confidence completely went. I used to be a driver but, on this medication, I was frightened to drive the car. I was frightened to meet people, even my family which was very unusual for me.

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27. The drugs made me tired, I couldn't concentrate and I had memory loss. There was also itching. My arms felt like they had prickles all over them. I had a dry mouth all the time.
28. Another part of it was muscular pain after the injections. The pain used to come on within a day or two of each injection. My muscles would really hurt, but apart from that I was alright.
29. The medication almost cleared the HCV. If the figures that related to it started in the tens of thousands, then it had dropped down to a couple of hundred for example. However, traces returned and they said that I was going to get it back again.
30. There were no other drugs available at the time for HCV. When I was told that the HCV had not gone completely I was really upset. I had a few tears, but the nurses were so good.
31. In 2015 they called me after the clinical trials for Harvoni had finished. I was on Harvoni for 12 weeks. I have now been clear of HCV for about 2 or 3 years. I had waited for 2 years in between the treatments.
32. As far as I can remember there were no side effects of Harvoni. I was really dreading that happening again.
33. My infection with HCV did not have too much of an impact on my friends and family as I did not tell many people. I did not want anyone to know.
34. With those I did tell I told them not to worry as I would be on medication. If I cut myself I would not let my husband touch me unless he had gloves on, but I could look after myself so we did not need to prepare too much. Overall, they had good reactions.

Section 6. Treatment/Care/Support

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35. I did not have any issues with obtaining the treatments I needed. I was always top priority because I desperately in need.
36. Other than Harvoni not being available when I finished the course of Interferon and Ribavirin, there were no obstacles to treatment for me.
37. There was psychological support available. The doctor advised me that counselling was available if I did not want to go on pills for my depression. I chose to take the medication.
38. I understand that there is help available from the Inquiry and the Red Cross if I want it.

Section 7. Financial Assistance

39. When I was informed of my infection I was largely retired. I was still carrying out casual paid work as a care worker to help friends out. During my 11 months of treatment I was getting so ill that I had to give those jobs up, I just could not go all the time anymore.
40. I was not aware of the Skipton Fund for a few years after I was told of my infection. A nurse at Brighton informed me of it.
41. As soon as the nurse told me about Skipton I wrote to the hospital in Northampton to look for my medical records from the operation. They wouldn't accept me as I had no evidence of the transfusion.
42. Eventually Dr Elliott helped me by sending a letter to Nick Fish at the Skipton Fund. The Investigators have taken a photograph of this letter and it is exhibited as **WITN0400002**.
43. I have now been accepted for the Skipton Fund (EIBSS). In June 2015 I received a singular payment of £50,000. From then until August 2017 I received £1,229/month. In April 2017 this went up to £1,500.

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Section 8. Other Issues

44. I have given blood a number of times since being infected with Hepatitis C. What has hurt me more than anything is that I have been giving bad blood. I know I did not know of the infection, but that's the worst part.
45. I do not have a record of how many donations I gave after the transfusion but in total I believe I have given 15 - 20 donations, some of which were after the transfusion. I do not know my blood donor reference number.

Statement of Truth

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

Signed GRO-B

Dated: 2-2-2019