Witness Name: GRO-B
Statement No.: WITN0192002
Dated: 4th July 2019

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF GRO-B

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 11 March 2019.

I, GRO-B will say as follows: -

Section 1. Introduction

1. My name is GRO-B My date of birth is GRO-B 1949 and my address is known to the Inquiry. I have listened to oral witnesses and read many transcripts during the recent Inquiry public hearings and I have decided to make a supplementary statement of additional comments regarding my illness, the impact it had on me and the treatment of it.

2. For the first time, listening and reading about other people's experiences has concentrated my thoughts, but also enlightened me.

Section 2. How Infected

3. Contrary to other people's experiences, my transfusion was not a life saving or life enhancing experience. As stated in my original statement, I had been admitted to GRO-B for a tonsillectomy and was found to be anaemic - I seem to recall my hemoglobin count was about 10. I think the transfusion was a quick fix.

4. I still have a blood card from the Regional Transfusion Laboratory in Leeds, lab reference GRO-B dated 24 June 1981, which was given to me after my transfusion and shows my blood group.

5. I have requested my medical records from Leeds NHS, and I finally received confirmation from them in Mid June 2019 that they are gathering information for me. I am not confident about what they will find, as the transfusion was 38 years ago now.

Section 3. Impact

6. After I was diagnosed with Hepatitis C in 2001 and attended St James' Hospital I was not offered any treatment for 3 years. I believe that they were waiting for my condition to worsen before they would treat me, to ensure that it was cost effective. This put an enormous emotional strain on my husband and me - it was all we thought about. At the time it was a death sentence made much, much worse by the fact that I was not being treated.

7. The treatment only began in November 2004 after my second biopsy in April of that year. The treatment was conditional on me having a test for HIV, which I found extremely distressing. Thankfully it came back negative.

8. During the process of deciding whether I was suitable for the treatment I was also asked whether I had had any suicidal thoughts. It was a one off question and there was not any talk of providing me with any support or counseling.

9. I was extremely worried that my treatment could be stopped at any time, dependent on results or any issues that occurred. Part way through the treatment I had a problem with my eye that could have resulted in the treatment ending. It was a very, very stressful time.

10. My file at the Hospital had black and yellow radioactive type stickers on them, which were clearly visible. I fully appreciate the need to inform staff of the potential risks in treating me, but I did not think the stickers should have been seen by anybody seated in the waiting room, etc. This is yet another example of being treated like a leper, which could have been handled much more sympathetically and subtly.

11. As stated in my original statement I have been on medication since the end of the Hepatitis C treatment, as my thyroid function was knocked out by the treatment.

12. I also suffer from shortness of breath, which I thought was only due to the debilitating Interferon and Ribavirin treatment, and therefore would improve over time. As we started going on longer walks again I fully expected this to improve, once I had built myself up again, but it never has.

13. My GP, Dr Patel at GRO-B dismissed me as a neurotic and emotional woman when I asked him about my shortness of breath. He said that even if the treatments had caused it, then it had happened and there was nothing to be done about it. After everything I had been through I was left feeling like I was bothering him. I think that this experience has contributed to me never really seeking any answers again. I rarely see a Doctor at all anymore, even though I have changed Practices to get away from Dr Patel.

14. My dentist consented to me continuing to receive treatment at my current practice, but I had to have appointments at the end of sessions, to allow them to clean down the room. I understood this, but also thought that they should be doing the clean down anyway - they knew about my condition, but there could have been any number of unknowingly infected people receiving treatment at that practice. I understand from the Inquiry that some people were refused treatment by their dentists, so perhaps I should consider myself fortunate...

15. Like many of the other witnesses I suffer from brain fog, fatigue and lack of energy, shortness of breath, itchy skin, aches and pains. I know I am not as 'Sharp' as I used to be - I was always the person to go to for reading and implementing instructions and I have always been an avid reader, but now find it more difficult to recall characters and events.

16. I have heard and read the comments from one witness about the comments attributed to Edwina Currie in The End of Innocence and I am appalled and disgusted by them.

Section 4. Treatment/Care/Support

17. I was asked at the end of my treatment if I would consent to the details of my case being passed on to the Trent Study of Patients with Hepatitis C Virus Infection. I completed the information form on 1st June 2005 and I have not heard anything since.

18. I have never been given any information regarding the possible risks of infection with vCJD.

19. I have never been advised of the extent of the scarring to my liver, apart from being told that it had worsened between the two liver biopsies.

20. At the final appointment at St James' Hospital, when I was given the 12 months clear result and discharged, I asked the Nurses if my liver would recover. I had read that it is the one organ that can regenerate. I was told that they did not know and the only way to find out was to have a further liver biopsy, but they would not be offering me that.

21. I have not had any check ups, etc for my condition since I was discharged 14 years ago. Surely that is not right!

22. I have seen and heard from Inquiry witnesses that many have regular fibroscans and check-ups. I had not even heard of a fibroscan before the Inquiry.

23. As a result of following the Inquiry public hearings, I made the decision to go to my GPs to ask for a Fibroscan of my liver. I was astonished to find that the GP had no idea what I was talking about. He had never even heard of the Infected Blood Inquiry!! I could not believe it! I informed him that all GP practices should have received a letter advising them to offer testing. He said that he had not seen any such letter and that he would ask his colleagues if they knew anything about it. He did not know what a Fibroscan was and has offered me an ultrasound scan, which he said is the first step in seeing the condition of my liver now.

24. As previously stated, none of my family have been offered testing. But, because of the Inquiry, my husband has now given a blood sample for testing and, thankfully, it has come back negative. Surely he should have been advised to get tested a long time ago. How do they expect to eradicate this disease when people who are potentially infected are not offered testing?

Section 5. Financial Assistance

25. I believe, cynically, that the announcement on the 30th April 2019, the first day of the witness statements being heard, that regularly payments would be increased, was to avoid the chances of lump sum compensation being discussed before the end of the Inquiry and beyond. How many more will die before then?

Section 6: other comments

26. It is 38 years since I was infected and it was 20 years before I found out, by chance, because I was donating blood to give something back after my mother-in-law's recent transfusions, whilst she was Ill with bowel cancer.

27. I think that enough evidence has already been presented to the Inquiry to show that much of this could have been prevented - at the time of my transfusion the risks were known by the medical profession, but not by me.

28. There has been so much suffering that could have been avoided.

29. 38 years and still no closure.

30. It has been, and still is, a life sentence.

Statement of Truth

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

Signed GRO-B

Dated 4th July 2019