Witness Name: GRO-B
Statement no: WITN18200001
Exhibits: 0
Dated: 10 December 2018

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF GRO-B

Section 1: Introduction

1. I, GRO-B, will say as follows. My date of birth is GRO-B My address is known to the Inquiry..

Section 2: How Infected

2. In August 1987 I had a hysterectomy at GRO-B in GRO-B I had been diagnosed with cervical cancer and was told that if I did not have the hysterectomy I would not survive. When I came round I was told that during the operation I had needed a blood transfusion and that I had been given three units of blood. I was not given any warning before the operation that this might happen. I was not told anything about the risks of infection before or after I received the transfusion. I did not think anything of it at the time.

3. In January the following year I had my right ovary and my appendix removed, again this was at GRO-B in GRO-B I am not sure whether I received a blood transfusion during this procedure. I do not recall being told anything about a transfusion on this occasion. These were the only two operations that I

had before being diagnosed with Hepatitis C, I was infected during one or the other.

4. In late 1992 I went to give blood. I had not given blood before. They did a finger prick test and I gave a full donation. A few weeks later I received a letter from the National Blood & Transplant Service which stated that I had Hepatitis C. The letter stated that I should make an appointment with my GP.

5. I went to see my GP within a week or so. He did not know anything about Hepatitis C or what it was. I did not know what it was either; I did not have a computer at that time and did not look anything up. My GP did not refer me to a specialist there and then. He did not know what to do and nor did I. He was not worried and so I did not think that it was anything to worry about.

6. I understand from my records that around one year later in November 1993, my GP wrote to a Consultant Surgeon at GRO-B in GRO-B The letter states: *This lady was found to have Hep C antibodies when screened by the blood transfusion service in November 1992. They recommended that we refer her to the local gastroenterologist for further management. I am arranging LFT's [sic] and will forward a copy of these. I have been unable to find information about Hep C to advice [sic] this patient about management prognosis etc. I wonder if you have any information or references which would be of interest.*

7. I do not know why it took one year for my GP to refer me to a specialist. I just think that he did not know anything about Hepatitis C. He did not tell me that he would be referring me, I received a letter out of the blue stating that I needed to go to an appointment at Bangor hospital in January 1994. The specialist took my blood and did a check of how many spider veins I had, and that was all. I don't recall everything that I was told at this appointment but I do not think that I was told about how the infection might affect me or about the risks of others being infected.

8. I returned to see the specialists around three or four times over the next couple of years; this was just so that they could check me over and carry out liver function tests. I don't recall being told how I contracted the infection. I was told not to drink because I could develop cirrhosis, and not to share razors or toothbrushes. They told me at one point that they could no longer detect the virus.

9. I did not know that anyone else had this infection, I thought I was the only one with it. I was only 28 or 29 when I had the hysterectomy and so I was in my early thirties when I was diagnosed. I had a little boy and I just got on with it.

10. In around 1998 I moved to Scotland. Through the news I had heard bits and pieces of information about Hepatitis C which made me realise that my infection was more serious than I had thought. In around 2001 my new GP referred me to a specialist in Edinburgh. This is when I found out that it could be a death sentence.

11. I was not given adequate information about the infection when I was first diagnosed. It was only when I arrived in Scotland and saw specialists there that I understood about the infection. I did not know that it could kill me like it has so many other people. I did not know that there was a risk that I could pass it to others. I had a little boy and was scared that I had somehow infected him. When I first found out I would not even kiss him in case it could be passed on that way. I was also shocked to find out that it could be passed on to sexual partners. I now know that it is very unlikely that it can be passed to others except by transfusion, however at the time I was terrified.

12. I should have been told a lot sooner. I should not have had to wait until going to give blood for the infection to be picked up. They know which transfusions were infected and they know who received this blood. They knew which units of blood I had and that it was infected. They should have contacted me and others earlier to explain what this infection is and how we should go about getting help.

Section 3: Other Infections

13. I believe that I also contracted the herpes virus via the blood transfusion in 1987 or 1988. There is no other way that I could have caught this.

Section 4: Consent

14. I do not know whether I have been treated or tested without my knowledge, consent or for the purposes of research. However if the National Blood & Transfusion Service had not told me, I do not know when I would have found out.

Section 5: Impact

15. I have had Hepatitis C for over 30 years now so I feel that it has always been with me. I have been tired all my life, that's the main thing. If I do something I have to lie down afterwards, I have fallen asleep in the car before. If I go to work I have to go to bed as soon as I get home.

16. I started to receive treatment for Hepatitis C in 2002. I was accepted onto a trial for Peginterferon and Ribavirin. I had the treatment in Scotland. They wanted people to go on the trial and so there were no difficulties in getting on it. I had the treatment for 12 months. It was horrendous. I lost about half of my hair, I felt constantly tired, even more so than I had been. I could not work and spent most of my time in bed. I felt very depressed. I was being sick, I could not eat and I lost around 2 stone. I had this horrendous cough, I just could not stop coughing. I had to give myself injections once a week and took tablets twice per day. I have been left with terrible arthritis in my hands and fingers.

17. They say that this treatment is worse than chemotherapy, it was the worst 12 months of my life. If they had told me that is how it would affect me I never

would have gone on it. And I did not even clear the virus. I thought that was going to work, that is why I did it. I thought I was going to be free of it. But it did not work, I was devastated.

18. I started a second treatment, Harvoni, in around November 2015. This was a more reasonable treatment. I took tablets instead of injections. It did affect me: I lost a little bit of hair, put on weight, and felt very sickly particularly at the start of the treatment.

19. I feel the same now as I did before; I just carry on as always. When you are working and bringing up a family you just have to get on with it. I have recently started to get Vitiligo all over my legs, arms and hands. I believe that this is a side effect of the treatment.

20. I do not know of any other treatment that I could have had for Hepatitis C that was not made available to me.

21. I do not think that I have been treated differently as a result of having Hepatitis C.

22. I have only told my husband, my son, and the partners that were serious enough that they needed to know. I have not ever told anyone else. I never talk about it with anybody, I would not want people to think I am a drug addict or that I am unclean in some way. I feel that I have had to lie my whole life.

23. When I found out I just felt unclean. HIV and AIDS were happening around the time that I found out and I felt just as bad as that. People do not understand, they think it is something that they can catch. That is why I haven't told anyone.

24. It has stopped me from doing a lot of things in my life, it is always there. It stops me because I am tired all the time. It has ruined my life. I wanted a career in nursing or midwifery but I knew that I would not get in because I would not pass

the health checks. I had to take low paid work as I did not have the energy to train for a job with a higher wage. I did have a job in a factory but I had to leave because it was too much for me. I now work as a part time carer. If I had gone on to do the job I wanted to do I would be earning more than I am now.

25. Hepatitis C does not have an effect on my work but it does have an effect on my day. I get up at around 9am but before I go to work at 3pm I have to go to bed for a couple of hours, and then I go straight to bed again when I get back. When I am working I don't have any life at all, it is only on my days off that I can do other things

26. If I ever cut myself when I cook I have to throw the whole lot away. I was told not to drink because I could get cirrhosis; as a result I have very rarely had a drink. I drink only on high days and holidays. The infection has not had an impact on my friendships because my friends do not know about it.

27. My husband was quite upset because he used to be a blood donor, and has been told that he cannot give blood any more. We are now divorced, I do not think that he ever tells anyone about it. My son was 8 when it happened, he is nearly 40 now. I told him about it when he was in his teens and soon he knew more about it than I did. He was always worried that I was going to die and leave him.

Section 6: Treatment/Care/Support

28. I have not faced any difficulties or obstacles in obtaining treatment, I think I get reasonably good treatment. I am not one for going to the doctors, I would rather just stay in bed and hope that it will pass.

29. I have never been offered counselling or psychological support. I think It would have helped years ago just to get my head around it

Section 7: Financial Assistance

30. In around 2003-2004 my GP at the time said that I would be eligible for the Skipton Fund. I applied to them for assistance soon afterwards.

31. I received the £20,000 lump sum payment and £500 winter fuel allowance. Now I am under the welsh scheme, WIBSS, and I receive £4,500 per year.

32. I did not find the application difficult, I applied to Skipton and they contacted my GP. It was very quick, I think it was over and done with in about 6 weeks. The process was reasonably easy once I found out about it, but I don't know if I ever would have found out about it if my GP had not told me.

33. I think that the people infected in Scotland got a pay out of £30,000 with no annual payments. I think this is unfair and that they sold Scotland out. Personally I can't say that the money doesn't come in handy; I am glad that we got something. I am glad to be alive and still receiving it.

Section 8: Other Issues

34. What angers me most is that they knew that they were doing it. If they didn't know fair enough it would be no one's fault but by a certain point they knew and they kept giving people the blood. I think that is unacceptable, they knew that they were putting people's lives at risk, they were basically giving us a life sentence.

35. Generally I think that any questions that I have asked my specialists have been answered. However I do feel that information has been withheld from me because of the time that I had to wait before I was diagnosed. From what I understand, every unit of blood has a number and they know where each unit was from and who it was given to. My GP in Wales did not know anything about

it but it was the people who found out about the contaminated blood that should have provided me and others with information and advice. I should have been told what Hepatitis C was and how it could affect me and others. When I first found out I did not know and I did not think anything of it.

36. I would like the Inquiry to investigate why so many people have died, why it has taken this long for these questions to be asked, and why my life has been ruined. I want the Inquiry to try to make sure that something like this will never be allowed to happen again. I count myself as one of the lucky ones because I am still here, I'm not bedridden, I can enjoy the simple pleasures of going out and doing a bit of gardening but I don't know what is going on in my body. Periodically I have a blood sample taken to test my liver function. So far it has been ok, but will it start to affect me more? I don't know. After 30 years the damage is done.

Statement of Truth

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

Signed GRO-B

Dated 10 December 2018