Witness Name: GRO-B
Statement No.: WITN2959001
Exhibits: 0
Dated: 10 September 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF GRO-B

Section 1: Introduction

1. My name is GRO-B My date of birth is GRO-B My address is known to the Inquiry.

2. I am married with four dependent children. My mother is GRO-B: M who was infected with Hepatitis C. She and my brother GRO-B had provided statements to the inquiry. For information about how my mum became infected please refer to her statement W1826 – statement of M

3. In terms of whether information was provided to my mum in advance of her receiving the blood transfusion, as above, please refer to her witness statement W1826.

4. Mum was infected with hepatitis C only.

5. Mum has set out in a lot of detail how she came to find out that she had become infected with hepatitis C. For this detail, please refer to witness statement W1826.

Section 3: Other infections

6. I believe that my mum was infected with hepatitis C only.

Section 4: Consent

7. In terms of the consent process, again, please refer to my mum's statement W1826, as above for further information.

Section 5: Impact

8. Please refer to my mum's statement W1826, as referenced above. I provide information below about the impact that I believe the infection has had on my mum's life and on my life.

9. Once I knew that my mother had Hepatitis C I became a person who worried. I worried a lot I might get it and I worried a lot about when it was going to kill my mother- I feared my parents dying and that she was going to die really soon but be horribly ill first. I had visited my mother in King's hospital and on the liver ward there were all these sick yellow shrivelled up people who were clearly dying.

10. I worried about when this would happen to her and would it be soon as in the news or media as these blood viruses were often portrayed as being a death sentence that, as a child, I assumed would be quite quick to set in and she would get ill soon. So I asked myself when would it happen and which appointment would bring the bad news? It sort of hung over me - worrying me.

11. I worry a lot now – I worry about all my family members getting ill, about my children being ill or dying. I also suffer terribly with depression and feelings that my life just was not as good as it should have been.

12. At some point, I took to secretly taking comfort from food over those first few years. The effect of using food all these years as a way to deal with emotions can clearly be seen as I am now very overweight/morbidly obese. I blame Hepatitis C entirely for that. I did not have anybody to talk to about my mother's illness and it was not necessarily discussed at home, I did not receive guidance or counselling and none of my teachers at school ever checked up on me.

13. It was a shameful secret that we had hepatitis C in the family and so I had nobody to turn to about it. If I was upset or worried about my mother and her appointments or treatment, I used food to secretly comfort me. 27 years on I am still trying to unpick this eating disorder but it is clearly brought on by this time in my life and my mother's illness.

14. Watching my mother be ill on the first batch of Interferon was scary. She was very brave and I remember her learning how to do her injections. She would become sick in supermarkets because of the fluorescent lighting – the treatment made her sensitive to. If she was ill when we were out, she had little pouches of Lucozade and Lucozade tablets in her handbag. I would make sure she had supplies of these because she suffered from low blood sugars. In addition, she lost some of her hair because of the treatment. We had medicine in the fridge and needles and sharps boxes in the house.

15. I think I've blanked everything else out about the treatment to be honest as I was scared. It was just like she was a cancer patient with her hair loss and being sick in the bathroom and being so tired and weak. I know that she kept working hard and going to work and being a great mum. I remember such anger at her losing her job and those nasty people.

16. She continued to go to work while on her medicine but the employers at her GRO-B fired her because she was ill. I remember she went to a tribunal and won the case that she had been unfairly dismissed. From then on I hated people who were prejudiced and ignorant against people with blood viruses. The stigma surrounding this virus was painfully obvious to me and because of the stigma the infection was a secret to be kept.

17. After my mother lost her job, we moved house. Once the treatment finished, it was a bit better. But the medicine had not cured her, all the effort and pain had been for nothing and there was a feeling of great sadness that treatment had not worked and she still had this terrible virus lurking. I still worried she would die and she still had appointments and biopsies. She was often very tired. She had to wear a million garments in bed to keep warm.

18. I still didn't talk about it to anyone- I told my best friend once as teenagers about it but not much detail. I hid the secret to protect my mother. I felt it was a secret as ignorant people had judged us before and fired her so I felt it was best not to say to anyone to keep us safe. I still don't tell anyone unless it is absolutely necessary.

19. As an adult, doctors have tested me every pregnancy a million times for HCV just in case because I have the illness Obstetric Cholestasis during pregnancies. Each time my liver results would start to change and I would become ill and tired and so they would test me again for HCV - and each time I had a little bit of fear in case all the other tests had been wrong. What if I had been given it, what if this time I had picked it up somehow?

20. Also each test gave me again a feeling of the doctors and nurses being snooty towards me and that I was dirty as we had Hepatitis C in the family. Of course there was never any interest in learning how she had got it – just a raised eyebrow.

21. In 1999 mum tried treatment again, but this is mainly a blank for me apart from her carrying her medicine and needles in a cool bag on the plane when we went on holiday. She didn't like supermarkets again and I know she was sick but I'd moved out of the family home by then to go to college. I was always disappointed for her when treatment didn't work as it made her so tired. I wanted her to have a cure; I did not want my mother to die. The treatment made her so ill that I know she promised my father that she wouldn't take any more because it made her really ill and it didn't work.

22. Mentally, I have been left with a constant sense of not being good enough. The day I was given my bag of blood in hospital with contaminated stickers on and the shame of how I felt has lingered and started the cycle of feeling not as good as other people. We were the family who had been given a nasty virus in our house, we had to take care sharing toothbrushes, towels, where razers were, if we fell and cut ourselves we had to take care.

23. If my mum cut herself a huge wave of fear would go round the room and she would move everyone away and shout at us to stay still while it was cleared up and covered – even if just a small scratch. What a fear to grow up with in your early pre-teen and teenage years. The stigma surrounding the virus, the shame, and the secrets - as a child I of course did not know that there were thousands of others affected too. I thought we were the odd ones out. So I have never felt quite good enough in life and this has given me low self esteem and confidence; I believe this has contributed to my eating disorder.

24. Now the illness has gone, but it has left her with side effects- the panic around children's safety which we now know is a side effect of one of the drugs she was given was very hard for us. With 4 children, she is often scared about their safety if they are out with her and me at the swings or walking along the road. This has caused many arguments! She has been left with brain fog and tiredness. She is not quite the person she was and that leaves you with a feeling of great sadness sometimes.

25. I met my husband after mum had finished most of her drug treatments and it is very hard for him to understand why I still find it hard to let go of my teenage years and how worried and scared I was during those years. For people who have not gone through something like this it is hard for them to understand and so our relationship is strained sometimes when I am still hurting myself through comfort eating or worrying constantly as he feels I should "be over" the incident now.

26. There is happiness the virus has gone but there is a frustration she feels at the money she receives now that would have helped during the drug trials and treatments - not 25 years later when she's not struggling to hold down a job and take the treatment to stay alive. She should have been given financial support then so she didn't have to work so hard while she was so ill.

27. I remember in 1992 when I was 11 having the blood test at the doctors. We all went along and I remember it being told to us that it was for finding out our blood groups. I think that later when we were told that it wasn't for that really, but to see if we had Hepatitis C, it started the whole feeling of Hepatitis C being a bad thing/a secret/shameful - which was a general 80s and 90s attitude towards blood viruses and diseases anyway.

28. When my test came back inconclusive, I went to King's hospital where my mother had become a patient. I again was only about 11 and I remember that day vividly and know that I've hated that day ever since. We were in a clinic with other patients with hepatitis and HIV and the nurses were very rude to my mother. It seemed to be that they thought and treated her like she was a dirty person who had done something wrong to get the illness.

29. She had this bad virus that dirty people or drug addicts or prostitutes had, which I knew my mum wasn't, but people didn't give you the chance to explain and instead judged her and me.

30. I think that nowadays people would be willing to help you whatever way you had contracted the virus – there is less shame and stigma perhaps. But back then it was assumed my mother had got it from doing something wrong and there was nobody willing to listen to you explaining it was via transfusion. For whatever reason, we were made to carry our samples to another area upstairs in the hospital. The nurse ensured that our samples and bags were covered with warning stickers and "contaminated blood" stickers and so carrying my bag of "contaminated" blood upstairs with its warning stickers on and people seeing in the lifts made me feel ashamed of myself, my mum and this terrible virus we had in our lives.

31. I did not tell people that my mother had this illness as already at the ages of 11/12 I knew that people would back away and judge people who had these blood viruses. I remember staying at my best friend's house one evening when my mother went to hospital for a biopsy and there was this air of sympathy from her mother that I recognise now quite well - when people feel sorry for you because you're going through a bad thing. I don't know if my friend knew what was wrong with my mother but I worried that her family might not be kind to us anymore if my mother had this bad virus. It wasn't like she had cancer which people knew was bad but unfortunate- this was a scary illness you might pass to them and so we were a potential danger.

32. When my mother was on Interferon medication, she continued to go to work, but the people at her GRO-B fired her because she was ill. I remember she went to a tribunal and won the case that she had been unfairly dismissed and from then on I couldn't stand people who were prejudiced or ignorant to others. In particular when anybody said anything bad about HIV or Aids or Hepatitis I'd get really cross with their ignorance of thinking you could catch it by kissing or just touching. I did my year nine English talk on prejudice and Aids to hopefully educate some minds and my favourite film is Philadelphia as he won his case for being unfairly dismissed too.

33. The stigma still surrounds blood viruses and as I said, whenever I have been treated during pregnancy and tested for HCV I note that medical staff never want to know why my mother has the illness. Staff don't seem able to understand that I wouldn't magically have the virus just because my mother does – there are still individuals within the medical profession who seem ignorant.

34. My brothers are 7 and 9 years older than me and were either gone or were at home less when my mother had her treatments. I believe I was impacted the most living with my mother.

35. I do not talk about that time with my eldest brother which is strange. Earlier this year I did talk to my other brother about it. He told me he found it very hard to see my mother, a great clever lady reduced by the infection and treatments to not remembering details, having brain fog, losing her job and then struggling with the side effect of the nervousness around children's safety. He tells me that it has hindered his relationship with her as the arguments they had when his children were on a trampoline for example made relations strained.

36. My dad would have suffered the most in the family watching my mum be ill. He would care for her, helping to run the house when she was ill, still going to work himself. In addition, he had the money worries when she lost her job. I know that he had high stress levels because of the treatment mum tried and made her agree never to take it again (although she did not listen to him!)

37. They had money worries and would have benefitted greatly from having some financial support packages or care packages or counselling in place. He did talk to a close friend eventually but only after about 6 years I think. In the meantime he suffered quietly like we all did with the secret. I wonder if the stress levels perhaps contributed to the massive heart attack he had in 2000 that killed him.

38. My mother was unfairly dismissed from her job because she was on the interferon medication. Financially I imagine this would have been very hard and I remember my parents being worried about money a lot.

39. Between 1997 and 2000 I suffered with large headaches most days. I missed a lot of school and did not receive the grades I should have done. Doctors gave me different scans and medicines but nothing physical was found but I would spend days in pain and wanting to lie down. Doctors kept telling my mother and father that I was stressed. Maybe at the time I did not perhaps recognise that I was stressed. Now I wonder if it was all just too much and that it was stress that caused these issues. I missed a lot of school and failed my exams. Now as an adult I suffer with anxiety/worry and depression and about being so obese from my eating disorder. I do not have much self confidence anymore due to my size and health and so do not apply for the jobs and opportunities in life I would really like.

Section 6: Treatment/Care/Support

40. No counselling has ever been made available to me even though I would have clearly benefitted from it at the time and still would now.

Statement of Truth

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

SIGNED **GRO-B**

DATED ....10 September 2019......