Witness Name: GRO-B
Statement No.: WITN2044001
Exhibits: WITN2044002 – WITN2044006
Dated: 28 September 2022

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF GRO-B

Section 1. Introduction

1. My name is GRO-B I was born on GRO-B and my address is known to the Inquiry. I am 47 years old, married with a daughter aged ten and a son aged seven.

2. I intend to speak about my mother, GRO-B: M, and her experience contracting hepatitis C via a blood transfusion, the treatment she received, and the impact it has had on her life and our family's life. I would like my witness statement to be read in conjunction with my brother, GRO-B: B witness statement GRO-B as he was infected during birth through a secondary infection.

Section 2. How Affected

3. When giving birth to me at Southampton General Hospital in GRO-B my mum haemorrhaged and lost a lot of blood. I do not know the cause. It was an emergency situation and she had to receive a blood transfusion. To the best of my knowledge there were no questions asked or consent requested, she was simply given four pints of blood via a transfusion.

4. My mum did not know anything about the infection for many years. Growing up, I remember she would always get out of breath, she had aches and pains in her sides and she often wasn't able to do much physical work, if any. She felt something was wrong but she was not sure what. Although she went to the doctors a number of times over the years, she was not diagnosed with hepatitis C until around 2007. She was diagnosed with liver cirrhosis shortly after.

5. My mum's initial symptoms were investigated by her GP, GRO-B however I can see from her medical records that she was diagnosed at GRO-B by GRO-B I have exhibited **WITN2044002** which is a letter from GRO-B to my mum's GP explaining that her blood tests for hepatitis C were reactive, as was the further testing they had done, but that they were awaiting the RNA and genotype test. When they diagnosed mum with hepatitis C, I understand that the doctor was very blasé about it. The doctor acted like it was minor, almost as if it was a cold or an 'every day' kind of thing. There was no empathy towards the horrible diagnosis they had given my mum.

6. I am not sure how she found out that the infection was due to the blood transfusion however it seems likely that this link was drawn by GRO-B as it was discussed in **WITN2044002**. I just remember that when she told me about the diagnosis, she also explained to me and our family that she was infected because of the transfusion she had received during my birth. I remember she sat

us down and told us all at once, we were all very tearful. I didn't have great knowledge on the subject. We were told that my dad, myself and my five siblings would need to be tested. I believe that there were yearly tests at the start, possibly more often than that for my dad, and these took place at the GP surgery. Following the second test, my brother was diagnosed with hepatitis C. I was not aware of this at the time, but after review of a letter from GRO-B to my mum, I can see there was also concern one of my sisters had been infected with hepatitis B and possibly hepatitis C **[WITN2044003]**. Although unconfirmed how she was infected, my sister had the antibodies to the hepatitis B virus and as my mum was infected with hepatitis B herself from the blood transfusion it seems likely to me that she was infected through a secondary infection from my mum.

7. My mum was transferred to the GRO-B to speak to GRO-B GRO-B straight after her positive blood test, and he provided mum with further information about the virus. She was told not to share towels and other things. I believe mum and dad weren't allowed to be intimate and there was some sort of guidance given to them.

Section 3. Other Infections

8. My mum was infected with hepatitis C. After review of her medical records it appears she had also been infected with hepatitis B but cleared the virus naturally. She was diagnosed in August 1977. I have exhibited **WITN2044003** which refers my mum being infected with hepatitis B as a result of her blood transfusion

Section 4. Consent

9. In terms of consent for the original blood transfusion, the situation was life or death so my mum had to have the blood transfusion and was not physically able to consent.

10. I do not know whether she gave her consent to be tested for hepatitis C.

11. My mum definitely consented to treatment for the hepatitis C.

12. I believe my mum was used for the purposes of research in relation to the treatment of the hepatitis C. Whenever I spoke to my mum about the treatment they were always putting her on different trials. I asked why it was always a trial and my mum explained that this was because there was no definitive cure and they were trying different drugs to suppress the disease and cure her. I remember that for some of the trials she struggled to get on them because she was overweight, due to her underlying diabetes, and not healthy enough. There was often a reason why she couldn't start a treatment, during the trial for the trial. She was used as a guinea pig.

Section 5. Impact

13. My mum suffered emotionally and mentally but she would never show it, not until much later on. The virus had a massive impact on her physically and mentally which in turn affected her children.

14. Even from a young age I can remember my mum's memory was shot. She used to call it brain fog, and I asked what that meant, she said she just forgot all the time. She couldn't concentrate for very long either, not because she was bored but because she was physically unable to. I remember she couldn't read books

because she would literally just fall asleep. She always tried to play with us when we were younger but you could tell she was struggling with energy levels and she was constantly out of breath. My mum could fall asleep at the drop of a hat, she would drift off anywhere and this intensified when she was undergoing treatment. Sometimes she just couldn't get up and you would have to grab her to help her out of her chair.

15. My mum was always coughing, and although she was a smoker, this seemed to worsen during her treatment. She would always complain of headaches, and she used to shake constantly, almost like she had Parkinson's disease. I asked her once why she was shaking so much and she was it was age but I said, 'mum you're not that old'. Her appetite left her too, she would hardly eat anything. She would usually have no breakfast, we were lucky if she had a sandwich for lunch, and a cracker with a bit of cheese in the evening. She lost a lot of weight but her stomach would flare up like a balloon. She had to go to hospital to have it drained every six to nine weeks. It was really painful for her. I'm not sure if that was as a result specifically of the hepatitis C, her damaged liver or the treatment she was receiving.

16. She was generally unwell, she had issues with her thyroid and other health issues such as black marks on her chest and fluctuating blood pressure. When she had an illness, it wasn't like a normal person's reaction. If she had a simple cold, she would be out for days. She was immunosuppressed I believe. My mum was diagnosed with diabetes in 2016, which I was believe was as a result of the hepatitis C. She was also tested for breast cancer and liver cancer. In terms of the breast cancer, I don't know whether this was as a result of the hepatitis C or if it was something else but she passed away before it was confirmed.

17. After review of her medical records, I can see my mum underwent three different types of treatment for the hepatitis C. She first underwent 52 weeks of treatment

with Pegylated Interferon and Ribavirin in September 2009 which caused her headaches, fatigue, back pain and muscular pain among other things. The doctors noted that she was responding well to the treatment and it looked as though she was cured. Her HCV RNA was checked in December 2009 and unfortunately it showed as detectable **[WITN2044004]**. It was suggested the next treatment would have to be clinical trials.

18. Next she commenced a round of Sofosbuvir, Ledipasvir and Ribavirin from 26 November 2014 until 18 February 2015 for 12 weeks. She relapsed around one week post completion of treatment so the doctors recommenced with Sofosbuvir/Ledipasvir and Ribavirin from 23 March 2015 to September 2015 but for 24 weeks instead. Unfortunately the virus had simply hidden from the tests and it came back with a vengeance barely two months after her finishing the treatment. The doctors confirmed in October that the hepatitis C had come back **[WITN2044005]**.

19. I remember before her diagnosis, my mum liked a drink on a Friday, and after she was told that the hepatitis C had gone she brought home a bottle of Lambrini and celebrated with us. She still had cirrhosis of the liver in the final stages but we all hoped her health would get better, she'd go on the transplant list and everything would improve. She was put on the list but was taken off it due to her ill health. She was not told that she had been taken off until she asked where abouts on the list she was. They told her she was not well enough to have a transplant. This was at the beginning of November 2016. We lost her on **GRO-B** **GRO-B** 2017.

20. It was an incredibly stressful and emotional period in all our lives. Our mum didn't just have to cope with the virus and its symptoms, but also the worry she had for her children. She probably didn't tell us half of was actually going on.

21. I think there was an assumption by the medical teams that treated her that my mum had used drugs during the 1960s. She felt discriminated against. We didn't go around talking about the hepatitis C because of the stigma related to it. We kept her diagnosis under wraps because of the link to drug abuse. Those who did know were close family members, she never got much support from other immediate family or her siblings, she was just kind of left alone. I don't know if that was stigma related.

22. I'm the eldest of six siblings. I felt that I had to cope well and be the strong one because I was the head of our family. I had to be strong for my siblings to support them. Even prior to my mum's diagnosis, her health affected us all in different ways. By the time she was told about the hepatitis C, I was an adult and had moved out. We all had our own coping strategies

23. My sister GRO-B was lost and had a 'I don't care' attitude. She was depressed and drank a lot, which led to her self-harming. I am not sure if that was all to do with our mum as she is gay and I think the stigma of this also affected her, but mum's health definitely had an impact. I have a young family, as do B and GRO-B. I think we dealt with it in a 'well you have to just get on with it' way. I don't think I had time to grieve or feel sorry for myself. I don't think I will ever get over losing her. The last few years of her life were so difficult for her, going through the pain and suffering of the treatment.

24. The hepatitis C had an impact on everything including my mum's social life. Her friends would come to see her but they were very careful and wouldn't hug her. People are stupid when it comes to the virus, it cannot be transmitted through touch or even saliva, blood only. But people don't understand and think hepatitis is a dirty, disgusting word. Her friends didn't come round as much as they used to.

25. My social life was non-existent because I was always there for mum, taking her for appointments, looking after her. My siblings and I all were – it was about focusing on mum.

26. In my personal life I was quite highly strung and short tempered, I brought my troubles to work. I had to learn to be calm and not let it affect me when I first found out because I didn't want it affecting her. I think I took my frustrations out at work; I was emotionally unstable but trying to cope with everything.

27. It massively affected my mental health. I cried because my mum was dying and she had been dying since the day I was born. I had to live with that, especially during my mum's life. I thought to myself, perhaps it would be easier if I wasn't there – she had brought me into the world and now she was dead because she took that blood. You do blame yourself and it affects you mentally but then at the same time I thought to myself, 'stop GRO-B this is not about you it's about mum, you've lost her and you have to get some sort of justice'. I will get justice for her.

28. In terms of affecting education, it certainly did for poor B. He lost the last years of school because of his diagnosis with hepatitis C. He wanted to get an education and go to university but he couldn't because of the treatment. I don't know how he got through it, he had such a rough time. He is a very strong lad and he coped really well. Nonetheless it will affect him for the rest of his life, even though he is now cured of the hepatitis C, because he doesn't have the education that he wanted.

29. It didn't affect myself GRO-B in terms of education as we were adults by that point but without a shadow of a doubt it affected my youngest siblings – GRO-B. They were obviously living at home so they saw what mum was going through and how ill she was. They didn't come out with A-levels or degrees and GRO-B is not working, she still lives at home. It affected her really badly. GRO-B is doing quite well; he has a job as a lorry driver which is long hours and he lives

at home but he is coping well and more mentally stable. Considering what B has been through, he is doing really well – he has a beautiful daughter, is marrying his fiancé and has a mortgage, plus a responsible job even if it's not necessarily the one he would have chosen for himself. GRO-B does not work because he has a medical condition that he has had since birth and so is on the higher disability living allowance. He is fine and copes well with his young family. I don't see my sister as much because of the distance between where we live.

30. My dad has been an absolute rock since my mum's death. He has changed so much, almost like he is mum come back. When mum was about, dad was often moody and stroppy, looking for an argument and highly strung. I think that was because he had to deal with so much, he was caring for mum and constantly worried about her and her health which was a big burden to carry. I'm surprised by how well he's coped since she's gone. He didn't have much to do with the finances but he has had to deal with it all. He's much more approachable now. I asked if he ever wanted himself a dolly bird but he said he was a one woman man and he would die a widower. He's not one for emotions but he told me not to worry, he would be fine, although I've seen him with a tear in his eyes before. He was definitely affected but again, to what level, I don't know. I think parents often try to protect their children from these things.

31. I didn't live at home so its difficult to know how much my parents struggled financially. I think they always got by and mum used to tell us not to worry, everything would work itself out, 'it always does'. If they didn't have the money, they wouldn't buy it, they didn't use credit cards or loans. I think going back and forth to hospital with parking and petrol. had an impact financially too. My mum did work, she was a driving instructor and started own her own driving school in the 1990s. She did well and had a couple of cars and drivers. She was starting her franchise but because of her illness she had to stop doing that and cease trading. After her diagnosis she was no longer employed or working at all. My

dad worked on the trains but he had to stop because he became mum's full time carer. He was always there to help her to the point that he was showering and dressing her, taking her to the toilet and making all her food. He sometimes had to carry her and we ended up getting her a commode by the end. He had to give up his job a few years before we lost mum because when she was on treatment or in pain he couldn't leave her alone so financially they lost out on quite a lot.

Section 6. Treatment/Care/Support

32. My dad confirmed that my mum wasn't offered any form of counselling in relation to her infection with hepatitis C. I certainly wasn't and my siblings weren't. It wasn't until she went into a hospice that any form of counselling happened at all but it wasn't official, I think it was there if you wanted it.

33. As I outlined above in my statement, mum often wasn't entered into certain trials for treatment of hepatitis, **WITN2044006** is an example of the issues she faced entering into some of the clinical trials due to the entry criteria for them. The exhibit contains two letters, the first was from my mum dated 1 October 2014 questioning why she was not included on a trial as she believed she should have been. The second was from **GRO-B** to my mums GP and to my mum, dated 23 October 2014, which outlines a number of reasons she could not be included in a certain trial, including her diabetes and other liver disease parameters.

Section 7. Financial Assistance

34. I know she applied to the Skipton Fund. I do remember she received an initial payment and then a further top up payment when she was diagnosed with cirrhosis of the liver. My dad confirmed that they received two initial payments, he thinks they were for £30,000 and then either £10,000 or £20,000.

35. I did not recall her receiving regular monthly payments but my dad think she received about £1,200 per month. My dad no longer receives financial support. I do remember her applying for grants and they were always turned down.

36. It looks as though the GRO-B University Hospital were the ones to refer her to the Skipton Fund. Within **WITN204403**, they explain what evidence would be of use in applying to the scheme.

Section 8. Other Issues

37. In a way, I feel like my mum was murdered. The contaminated blood took my mum away from us too early. She was only 61 years old when she died, she was too young. It wasn't right. We also had a medical negligence case relating to the treatment mum received in the last few years of her life. This again highlights the NHS getting it wrong. We recently received the news that it is unlikely to be pursued because the hospital has lost my mum's medical records for the last few years of her treatment. If we don't find them, it is hearsay – it's almost like if it's not written down it didn't happen.

38. My siblings and I all feel the same. The inquiry moving forward is about justice to us, not money. We want a letter of apology from the government. I know that no amount of money could bring her back and no letter will either but currently, they are not owning up to it. The government has, and always will, push it back under the carpet unless they take responsibility and apologise.

39. Some people have been fighting this for over thirty years but we have been fighting for fifteen as we only found out in the early 2000s. As I said, first and foremost we want an apology but I do think there should be compensation

because it would be nice for dad to do something for mum – she's not got a headstone. It would be good to know dad was supported and financially secure.

40. We want justice. We want them to realise that what they were doing was wrong. I can't even get my head around it after all these years. This is not about money, money is what causes these problems, this is about mum and all the other thousands of people who lost their lives. Nothing anyone can do or say will change the past but it will make the future better. We can create a better future for our children so that nothing like this will ever happen again.

Statement of Truth

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

Signed .. GRO-B ....

Dated ..28 | September/2022