ANONYMOUS

Witness Name: GRO-B
Statement No.: WITN2056001
Exhibits: [WITN2056002 – WITN2056014]
Dated: July 2022

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF GRO-B

Section 1. Introduction

I, GRO-B will say as follows: -

1. My name is GRO-B and my date of birth is GRO-B GRO-B

2. GRO-B. My full address is known to the Inquiry.

Section 2. How Infected

3. I contracted Hepatitis C from my mother, GRO-B: M, GRO-B GRO-B. I intend to speak about my mother and her experience contracting Hepatitis C, the treatment she received, and the impact that it has had on her life and our family life. I will also speak about my own experience of contracting Hepatitis. My mother has provided a statement to the

Inquiry, GRO-B. I request that my statement is read in conjunction with hers.

4. My mother was diagnosed with HCV in 2002 GRO-B. We do not know for sure how she was infected GRO-B

GRO-B

5. GRO-B

6. I remember when my mother told us that she had Hepatitis C, it was towards the end of 2002, and was around the time that Pamela Anderson was diagnosed and there was a lot of negative coverage of it on the news with people saying that there was no cure. I remember that we all had to be tested. GRO-B and I tested negative.

7. As a teenager I would often use my mum's razors but after she was diagnosed, she told me not to do this anymore. From that point on we did not use anything of hers which carried a risk of us contracting HCV. My mother told us not to use her nail scissors, cuticle cutters and tweezers, and basically anything else she could bleed from.

8. No information or advice was provided to me or my parents about what we should do in the event that we did become infected.

9. My mother started treatment for HCV in June 2003 with a weekly injection of PEG Interferon and daily Ribavirin capsules. She suffered a lot with the side effects and sought help from her GP.

10. In 2004 my mother was referred to Dr Foster who told her that she could start on a trial that was taking place at the Royal London Hospital. My mother started a treatment of Pegylated Interferon alpha 2 A, Ribavirin and Amantadine. She suffered from horrendous side effects and became very physically ill. At the end of the 18-month trial, my mother was told that the virus could not be detected. In January 2007 the virus was still undetectable, and she could finally move forward with her life.

11. I was diagnosed with Hepatitis C in 2005. GRO-B

    GRO-B

12. I received a phone call asking me to return to the clinic to collect my results. I thought I had some kind of sexually transmitted disease. When they told me I had Hepatitis C my world ended. I was shocked, and I told the nurse that I needed to go out and have a cigarette (I smoked at the time). The nurse told

me that I could go for one, but I must come back inside as she knew the gravity of what she was telling me. She said that they needed to tell me more about Hepatitis, however I already knew about it because of my mum.

13. My ex-boyfriend tested negative, so I knew I could not have contracted it from him. I knew that I must have got it from my mum. Telling my family was horrendous. I went home straight away and told my parents. I felt like my whole world had been flipped because I knew that Hepatitis stops everything, and there is so much stigma around it. I kept thinking; 'I'm going to get cirrhosis', 'I will never meet anybody', 'I'm going to die', 'I won't have kids.' I was really young, and it put a big full stop on my life.

14. My GP records state that the source of my infection is not clear **[WITN2056004]**, and GRO-B however materno-foetal transmission cannot be excluded. GRO-B

    GRO-B

15. When I was first diagnosed at the sexual health clinic, they could not tell me any more about the Hepatitis itself; only that I had it. I had a private blood test within a week of the diagnosis to confirm the level of the virus and the genotype. It was important for me to find out if I had the same genotype as my

mother. The blood test confirmed that it was the same, genotype 1a **[WITN2056005]**.

16. When I was going through treatment, the doctors told me that they thought that the negative result I had received in 2002 was due to a mix up or was a false negative. As my mum had the same genotype, it was too much of a coincidence for me to have got it from somewhere else. I do not know how long I had Hepatitis C for before testing positive in 2005.

17. The fact that Hepatitis is so contagious left me in a state of anxiety. For example, I couldn't stop thinking about what would happen if I had an accident and someone tried to help me which would make me panic about them coming near me in case, I infected them. Also being a woman and menstruating, it was petrifying knowing that I could give it to someone else. I walked around feeling like I was contagious and that I could harm others unintentionally. I remember each time I would cut myself shaving, I would have to bleach the entire bathtub just to be on the safe side.

18. Once we knew what genotype I had, I was referred to **GRO-B** **GRO-B** **[WITN2056006]**. In 2006, I started treatment of Interferon and Ribavirin **[WITN2056007]**.

19. **GRO-B**, I was told that Hepatitis was highly contagious, and it was transmitted via blood so I should not get pregnant because as a young female, the risk of transmission to my baby would be high. They also told me that it would be difficult for my body to process the virus and that I could get cirrhosis of the liver and die. They said that there was no cure

but that there was lots of funding to try and find one. I was told not to share toothbrushes, tweezers or razors with anybody, and to have protected sex.

20. I do not think that I was given adequate information to help me to understand and manage the infection. I did not know that it could really be managed, and I was not told about any preventative things that I could do. I was told about the impact of Hepatitis and what it would do to my body, and about giving it to other people but that was it. I was told not to drink alcohol whilst on treatment and not to take too much ibuprofen, as these negatively affect the liver.

21. I do think that more information should have been provided to me earlier. However, when I was diagnosed I got the impression that the medical professionals just didn't know much themselves. As there was no cure and there was so much funding going into finding a cure, I assumed that there was not much information out there. I saw my mum go through treatment, which was just a trial, so I got the impression that they just didn't know.

22. In relation to how results of tests and/or information about the infection were communicated to me, I felt that the doctors at the sexual screening clinic were cautious about how they told me. I was clearly taken aback, and when I said that my mum was Hepatitis C positive, they knew there was a link.

Section 3. Other Infections

23. I do not believe that I received any infection or infections other than HCV.

Section 4. Consent

24. I was treated and tested for HCV with my consent. I participated in a treatment trial GRO-B which I explain further in section 5 below.

Section 5. Impact

25. In terms of the physical effects of being infected with HCV, I was extremely tired all the time, and I lost a lot of weight. It was also hard not being able to do what everybody else could do. I could not drink alcohol and that was a big part of my social life before I was diagnosed.

26. The mental effects of being infected with HCV were very hard. Prior to receiving treatment, I felt that my life was going to end, and I was never going to get married or have children. I had seen my mum go through treatment and it was horrendous, I genuinely thought she was going to die. I thought I would be just as unwell.

27. It was also very lonely being infected with HCV. I did not know anybody else my own age who had it so nobody could relate to me. My mum had been married and had children. She had done everything that I wanted to do with my life and all of a sudden, I felt that I wouldn't and couldn't do these things.

28. I also suffered with anxiety about the risk of infecting other people. I felt that I would never forgive myself if I gave it to someone I loved. I really struggled during the pandemic as the risk of spreading Covid-19 brought back a

heightened level of anxiety linked to having had Hepatitis C that I had been able to block for a number of years.

29. I put all the anxiety, fear and worry that I experienced whilst infected in a box and locked it up. I believe that this has affected my mental health in the long term. Even now that I have received the all clear, the mental impact is longstanding.

30. I underwent my first round of treatment at the Royal London Hospital in GRO-B, where I received Interferon and Ribavirin. I lost weight, my hair thinned out and my nose was always dry and uncomfortable. I couldn't eat; I would feel hungry and go to take a mouthful but then I wouldn't want it anymore. I also suffered from extreme tiredness, aching joints, weight loss, weakness and feeling cold.

31. At the start of the treatment, I was told that my response was positive however after about 6 months I was told that my treatment would be stopped straightaway and there was nothing further they could do. I was told to go and live my life. That day my life was turned upside down. I had done everything by the book and it hadn't worked. **[WITN2056008].** I left the appointment feeling extremely panicked and thought that this was it for me, and that there was nothing else out there that could help me get rid of this virus. I was young at the time and went to the appointment by myself. I understand that it is difficult to give a person bad news, but the appointment was over as soon as they had told me, and I had to leave and process it on my own. In my opinion, it could have been dealt with a lot better.

32. The next few years were difficult, I felt that I was living a life where there was no certainty. My follow up appointments were infrequent but on one occasion

my doctor mentioned that there were clinical trials for new hep C treatments. This took me by surprise, and I was upset that I had not been considered. I burst into tears, I felt desperate because my first treatment had failed, and I thought I would never be cured. Eventually my doctor agreed to put me forward for one of the trials. If I had not got upset, I do not know whether this would have happened. I was contacted about the trial very soon after my appointment **[WITN2056009]** **[WITN2056010]** **[WITN2056011]**.

33. I was accepted onto the trial and started treatment in early 2012. I had no glimmer of hope until the clinical trial was offered to me **[WITN2056012]**. It was a big decision for me to do it. I told very few people that I was doing it, and I lost a lot of weight during it **[WITN2056013]**. There was a lot of pressure on me, and not a lot of living. Everything was hard. I was used to feeling unwell and exhausted, and not wanting to eat or do anything. I went through the motions hoping that the trial would work and feeling very scared in the background in case it didn't. I had lots of anxiety about it. There was no counselling offered to support me through this.

34. After 12 months of being on the trial I was told that I had cleared the virus. However, at the follow up appointment at **GRO-B** I was not told whether I was given the placebo or not, even though I was supposed to have been told after the trial had completed. I was unhappy about this. They told me that the trial I was on was global, so there was no feedback if I had had the placebo or not. That could only be confirmed once all the trials had been completed, so I never followed up and I moved forward with my life.

35. I do not know whether there were treatments that ought to have been made available to me but were not, as I do not know if there were other options available to me specifically. I know that my mum started the Alpha 2A trial, I

was not offered this but that may have been because the trial was unsuccessful.

36. I did not experience any further medical complications or conditions from the infection.

37. My infected status did not impact my treatment, medical and/or dental care for any other conditions. However, I did notice that at appointments the medical and dental professionals were very cautious of me. GRO-B GRO-B. I noticed that dentists were also very cautious around me, and I understand why they would be because they didn't want to get infected.

38. The protocol for after the trial has finished is that, if after a year the HCV is still undetected then you are deemed not to be infected as it is highly likely that the virus has gone. I do not think that this information has been provided to my GP as I still get a free flu jab, and I was given higher priority for the Covid-19 vaccinations. If my records stated that I no longer had HCV, I believe that I would not even be considered for these. In addition, I have had difficulty obtaining life insurance. I had to get private blood tests to prove that I was not infected.

39. The impact of being infected on my private life was huge. At the start of my relationship with my boyfriend (now husband), it was so difficult to tell him about the Hepatitis, it was an awful conversation for fear of rejection and judgement. Being on the clinical trial affected our relationship. He did not want to tell anyone about it due to the stigma and so he was very isolated. I felt responsible as I was the one who had HCV not him; he was very selfless throughout. It was a difficult thing for him to process, justify and rationalise. He

adored me but he didn't want his friends to know about the Hepatitis, so I had to respect his decision not to tell them. I felt as if it was a huge burden on him and he had nobody to share it with because of the stigma of Hepatitis and its association with dirty needles and prisons. I felt as if I was akin to people with HIV.

40. When I was on the trial I would be in bed by 20:00 pm every night as I was so tired all the time. I was working full time throughout and this took up all of my energy. I also had no social life. It was very lonely for my boyfriend (now husband) and it impacted our love life. I was told that the risk of infection to him was low because he was a continuous partner. I was so scared to give it to him. We did not share razors, tweezers, toothbrushes and always used contraception to prevent transmission.

41. I felt like it was a massive gamble to do the trial, but it was the only option I had because I wanted to get married and have children. It was difficult for him because there were no guarantees that we could have children. I had made it clear that I did not want to have kids if there was a chance that they could contract Hepatitis from me. I did not want them to see me being so unwell and have them think I was going to die and leave them behind. I had been through it with my mum and it was not good for my mental health.

42. In relation to the impact of being infected with HCV on my family life, it devastated my mum. She had been through it herself and she felt a sense of guilt. My parents were both devastated, and GRO-B

GRO-B

43. As a family we had just been through this with my mum, and now they had to go through it with me. My family found it incredibly hard. When the first treatment didn't work, they were all devasted. When I went on the clinical trial, I was having my treatment GRO-B GRO-B.

44. My mum didn't want me to go through with the trial initially, she said that I had a house and a mortgage to think about, but it was one of the first grown up decisions that I had to make for me. My mum knew how unwell she had been and really worried about me.

45. My infection caused a lot of emotional distress for my mum, dad, GRO-B GRO-B. Predominately my husband though, who lived through the trial with me and the years of uncertainty about my health due to no treatment being available.

46. In relation to the impact my HCV had on my social life, I had very supportive friends. I was going through hell and they went through it with me. A lot of social activity centred around drinking alcohol and I couldn't do that anymore. I would often avoid long social events as I did not have the stamina to attend. I would often leave weddings early and avoid anything too physical due to my lack of energy and strength.

47. I continued to work following my diagnosis and throughout my treatment. GRO-B GRO-B GRO-B. I found that my colleagues had a sheltered view of Hepatitis C and one person said that if they had it, they would be travelling the world and not working, as if I was going to die any moment! I remember people looking at me

in a different way, pitying me and judging me. They had a lack of understanding and empathy for what I was going through.

48. After that experience at work, I did not tell many people about my infection. It was not something I would disclose unless I felt very comfortable with someone. My mum also did not want people to know. When I was on the second round of treatment GRO-B, I was always asked why I didn't drink, and why I had lost so much weight. I was constantly playing a role and making up stories.

49. I had to work because I had bills to pay, and fortunately I had a supportive manager. During my first round of treatment, I did take some time off whilst I was in hospital, and I could not do long shifts due to the fatigue that I was experiencing. During my second round of treatment, I became ill every now and then and would take days off sick, however I did not take off any prolonged period of absence. I just worked and that was it.

50. I did not suffer any educational effects due to my diagnosis. GRO-B GRO-B GRO-B [WITN2056014].

51. In terms of the financial effects of being infected with HCV and the treatments that I have received; these were both free. I was also given a discount card to buy prescription medication. I was fortunate that I could still work during treatment as my mum had not been able to.

Section 6. Treatment/Care/Support

52. I did not face any difficulties or obstacles obtaining treatment as a result of being infected with HCV other than the delay in being offered a place on the trial as described above.

53. Counselling was made available to me as a consequence of being infected. GRO-B GRO-B. I am a positive person and to be in a room with other people who did not share the same attitude would have been difficult for me.

Section 7. Financial Assistance

54. I have never received any financial assistance from any of the Trusts and Funds set up to distribute payments. My mum has not been able to prove that she contracted Hepatitis as a result of a blood transfusion and so she has not received any support from the Trusts and Funds either.

Section 8. Other Issues

55. I hope that the Inquiry will achieve accountability and an opportunity for people's voices to be heard. I am doing this mainly for my mum but also for me. Although I had a tough time, my mum had it much worse than I did. I thought she was going to die; her second round of treatment was horrendous, and her body was like a skeleton. My life was thrown into a state of suspension for many years and the anxiety it has left behind will always stay with me. I think there ought to be a financial settlement or compensation for those who have suffered so that they can put it towards living their lives.

Statement of Truth

I believe GRO-B ated in this written statement are true.

Signed ………

Dated 27.07.22 ……………………………