Witness Name: GRO-B
Statement No.: WITN5398001
Exhibits: WITN5398002-003
Dated: 15 April 2021

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 30 March 2021.

I, GRO-B, will say as follows: -

Section 1. Introduction

1. My name is GRO-B. My date of birth is GRO-B 1960. My address is known to the Inquiry. I live at home with my husband GRO-B GRO-B and son GRO-B I intend to speak about being infected with hepatitis C. In particular, the nature of my illness, how the illness affected me, the treatment received and the impact it had on me. I wish to remain anonymous for the statement.

2. I have other family members who have been infected with hepatitis C as a result of receiving infected products. I will only discuss my own situation in this statement as I am unaware of what their wishes are in relation to this.

Section 2. How Affected

3. I am a carrier of haemophilia B. The condition is hereditary. My father had haemophilia B and the condition was passed onto me. Dad wasn't diagnosed with haemophilia until I was a young child probably about 5 or 6 years old. This would have been the late 1960s. I was not made aware that I was a carrier until I was a teenager. Dad was a mild haemophiliac. He had a few bleeds throughout his life and procedures where he received Factor IX products.

4. I have not had many treatments throughout my life. I have received fresh frozen plasma and Factor concentrate when I have. These treatments have been given to me on a precautionary basis. I received treatment when I gave birth to my daughter in GRO-B When I received this, it was decided I would need Factor IX, I can't recall the exact product now. This was not given to me as a result of an emergency, it was just given to me. I would like the inquiry to note, that when I gave birth to my son in GRO-B, I didn't receive any blood products and I was absolutely fine.

5. I also received treatment in the early 1980s when I had my wisdom teeth removed. In the 1980s I had a miscarriage and had to have a DNC, so I received treatment then as well.

6. The three times I did receive treatment, there was no conversation about the risks associated with taking the treatment. There was no conversation at all.

7. My consultants used to be Professor GRO-D and Professo GRO-D and I was treated at GRO-D

8. In my family I was the first family member to be diagnosed with hepatitis C and that was how I became aware of the condition. In 1995/1996 I was told that my son had to have a hepatitis B inoculation. I spoke to

my daughter's consultant Dr McClure about this, and they recommended that he should get this and then said that I should get it as well, it was recommended that our "hep status" should be checked. This took place and at that point I was diagnosed with hepatitis C. I have identified an entry in my medical records noting this discovery of my hepatitis C infection which I exhibit under **WITN5398002**. This is a letter from Dr Paul Eynaud to Dr Glyn Williams dated 3 February 1998. In this letter, Dr Eynaud describes how I was found to have anti-Hepatitis C antibodies and had tested PCR positive for Hepatitis C antigen following hepatitis C status checks performed on my son GRO-B and I a few years prior.

9. I was never contacted by any haemophilia department asking me to get tested, it was all by chance I was tested along with my son. When I was diagnosed, I went to Ayr Hospital. I was given information about the condition, about what it was. Dr McClure was very helpful before I went to Ayr and explained a lot to me as well. When I went to Ayr, it was confirmed that the infection I had was active, and I was then referred onto Infectious Diseases Department at Crosshouse Hospital. Once I was referred there, they then gave me information about how to protect myself and others from spreading the infection.

10. I was devastated when I received the diagnosis. I had a young daughter with GRO-B to raise, I was worried about my husband being infected, and I was distressed about the stigma associated with it.

11. At the point I was diagnosed I was offered interferon and another drug to treat the hepatitis, but because of the type of hepatitis C that I had, it only had a 15% chance of clearing it from my system. The side effects from it were pretty awful so I decided not to take it then. I had a child with GRO-B I needed to be well enough to care for her as well. My husband was tested and his test was negative.

12. I phoned GRO-D and told them that I had been infected and then my impression is that my other family members were called into GRO-D to be tested for hepatitis C as well. I believe everyone was given very little information and left devastated and unclear about what the prognosis would be.

13. I was mainly dealt with out with the Haemophilia Centre for the hepatitis C, so I had no relationship with them. There was no requirement for me to attend the centre because I was a carrier. I don't believe that my lack of attendance at the centre is the reason for me not being diagnosed until 1995, because my other family members attended the centre. I am quite angry about the Centre as they knew who had received the affected products and never told them which of course left open the chance that the infection could have been passed onto others unknowingly.

Section 3. Other Infections

14. I have not received a notification letter about having been potentially exposed to vCJD as I haven't received any treatment during the period where this was a risk. My son has received this letter though and he hasn't received any Factor. He received this letter around 2004, I can't recall exactly now.

15. I didn't want my son GRO-B to receive treatment because of the risks, I didn't want to take him to GRO-D at all. I was put under quite a lot of pressure about this and told that the treatment was safe as it was heat treated. I had to sign all sorts of disclaimers declaring that if he had a bleed the hospital would not be liable etc. Thank God I refused, because then of course it turned out it wasn't safe as it came out about the risks of vCJD. What makes me so angry about this is that there were clearly no lessons learned for this to have then occurred again. GRO-B has never had anything but recombinant, so I am not even sure

why he even received that letter. It's a horrible letter to receive and it made me realise how much they couldn't be trusted.

Section 4. Consent

16. I am not aware of ever being tested or treated without my knowledge as I was not there regularly, but if wouldn't surprise me that they have when I did go. I certainly wasn't given full information when I received the products themselves.

Section 5. Impact

17. My physical health over time has been ok. I have attended six monthly/ annual appointments at the hospital to do liver function tests.

18. I fell out with GRO-D in a big way because of this, and I refused to take GRO-B at all, and I certainly wouldn't take gone myself for anything. I can't remember the details now, but I do recall being challenged on this and basically told that I was following the doctors' orders for my daughter (in relation to her GRO-B) but not for my son.

19. My fears about the kind of treatment my son GRO-B might receive were compounded when it was recommended he have his tonsils and adenoids removed in surgery at GRO-B Hospital in 1997. GRO-B had had recurrent ear and throat infections since he was a baby, and this eventually led to the procedure to remove his tonsils and adenoids being suggested by the ENT surgeon he regularly say at Ayr Hospital. I did not want GRO-B to receive factor concentrate during the procedure because of the infection risk it posed. I pleaded with GRO-B to treat him with recombinant for the surgery instead, but they repeatedly refused. Whilst I was fighting for GRO-B to receive recombinant, his ear

and throat infections eventually led to him giving my daughter GRO-B a chest infection which required treatment with IV antibiotics. This led to me writing to the company who manufactured recombinant explaining the situation and asking if they would supply it on a named patient basis on compassionate grounds for GRO-B's procedure. Both our haematologist from Ayr Hospital and GRO-B's Consultant wrote letters of support to the manufacturer for our request. The company granted our request and GRO-B's procedure went ahead at the GRO-B GRO-B. I refused to allow the operation to be done at GRO-B because of their attitude. They were very unhappy that the recombinant was supplied in this way and made their feelings known. I had to fight to protect my son and it made me feel like nothing had been learned with the risk those treatments posed.

20. I was advised that I had to tell my dentist that I was infected and when I did, he refused to treat me. This left me with a lot of problems with having any dental treatment after that. It was the embarrassment of it. At that point people didn't know that the blood products could have infected me, everyone assumed it was from misusing drugs. I ended up having to have an operation because I wasn't able to see a dentist. I had abscesses. It was because I couldn't get dental treatment.

21. One of the most distressing aspects of hepatitis C came for me in 1999. Due to her GRO-B my daughter had a GRO-B. I couldn't be considered as a donor. She was extremely ill, and it was deemed that she needed a donation from a living donor which was quite rare at the time. It should have been her mum that gave her this and it was devastating I couldn't do this for her. It should have been her mum. Fortunately, she was able to get a lung from her uncle and another from her father. It was a success however sadly she passed away in GRO-B. I do question if I could have helped her with that.

22. I had treatment a few years ago and it fortunately cleared the hepatitis C. At present it is "not detectable". I have identified an entry in my medical records which describes my successful treatment which I exhibit under **WITN5398003**. This is a letter from Dr Jose Fernandez-Montero to Dr GRO-B dated 11 March 2019. In this letter, Dr Fernandez-Montero describes me having previously completed a 12-week course of Grazoprevir and Elbasvir which resulted in viral eradication of the virus. In 2006 I was diagnosed with breast cancer and started chemotherapy. During my treatment my liver was badly affected and the viral levels in my blood became extremely high. The chemotherapy was stopped after 4 doses because if they gave me any more I would have needed a liver transplant. It has left me with an uncertainty and worry that the cancer could come back because the treatment was not completed. I remember my oncologist told me that she had never treated anyone who also had hepatitis C. It meant they had to take specialist advice from GRO-D about the chemotherapy.

23. When I was offered interferon in the early 1990s that was the only treatment option there was nothing else available. After this I was offered it on an ongoing basis so I do believe I was offered what was available over time until the point when I did accept treatment.

24. When I did take the treatment, the side effects were rubbish I felt pretty bad. It was worth it because it cleared the virus, but I just didn't feel good on it. I was on the treatment for twelve weeks. My family looked after me during the treatment. After I completed treatment I was given one follow up appointment to check which confirmed the test was clear. Even though the viral load is less than 12% it doesn't mean there is nothing there though.

25. I did tell medical professionals about the virus to prevent any risks despite the stigma I was exposed to. It was embarrassing. I found myself having to justify it every time I said it, that the infection had not come from drugs, it had come from blood products.

26. I was unwell after the breast cancer and simply couldn't work then. I was not too unwell before this.

27. There were financial impacts to not being able to work. We had a business and we ended up losing the business from the pressure. We had a large retail business with about 60 stores. My husband and I ran it, but when I stopped because of the cancer and damage to my liver, I couldn't ever return to this.

Section 6. Treatment/Care/Support

28. We have never been given or offered any psychological support from anywhere. We have been left entirely on our own which has left us feeling quite isolated. I would have appreciated the psychological support at the time, but now, there would be very little point.

Section 7. Financial Assistance

29. I have received money from the Skipton Fund. My doctor told me about the fund many years ago, I can't recall when but it was quite a number of years after I was diagnosed. I applied to the fund and received the money straight away.

30. I am now in receipt of money from SIBSS.

31. I receive stage 2 payments. The way the categories have been set up are wrong. The explanations about the categories are unclear. I have learned that there are children who have lost parents from this infection and are not eligible for payments

Section 8. Other Issues

32. I have no other matters to raise for the inquiry's attention.

Statement of Truth

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

Signed GRO-B

Dated Jan 31, 2022