Witness Name GRO-B
Statement No.: WITN4154001
Exhibits: None
Dated: 6th August 2020

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF GRO-B

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 23rd April 2020.

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

Section 1. Introduction

1. My name is GRO-B. My maiden name is GRO-B. My date of birth is GRO-B GRO-B 1954 and my address is known to the Inquiry. I intend to speak about my experience of becoming 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 my family and our lives together.

2. I wish to remain anonymous for this statement for privacy reasons.

Section 2. How Affected

3. To the best of my knowledge, I was infected after receiving either a blood transfusion or plasma after a hysterectomy at GRO-B around 1989, I

cannot remember the exact date of my operation. It was Dr Lowe that was in charge of my care during that time. I remember the day I was having my hysterectomy, just before I was put under anaesthetic, I asked the nurse if it was going to be Dr Lowe performing the operation. I had wanted him to do the procedure, because I had been a patient of his for many years. At that moment, he came out from an adjoining theatre, wearing rubber gloves that were covered in blood. He said he was finishing another operation and that I would be the next operation after that. That was the last memory I have of that operation before I was put under general anaesthetic. I woke up around two days later. My sister came in to visit me and said I had looked as white as a sheet and that I had been hooked up to a number of drips, but she could not say what they were. I could not say exactly which blood products I received or in what quantity I received them, because of that operation. It could have been plasma or a blood transfusion or both that I received but I do not know for sure.

4. Before I had my operation, there was no discussion about any potential risk of infection from receiving blood products as part of the operation.

5. I was diagnosed with hepatitis C after my GP, Dr GRO-B GRO-B had taken some blood from me at my home to perform tests, sometime in the early 1990s. I remember My GP had come round to check on the progress of an abscess I had developed on the wound from my hysterectomy. I had been feeling very ill after the operation and the abscess was making me feel worse. I think the blood tests were just routine as far as I can remember, to see if everything was okay internally. When the results of the blood test came back around two weeks later, Dr GRO-B came to my home to see me again. He told me that I had contracted hepatitis C. I had no idea what that meant. I asked him how I could have got that and he told me it could be from something like handling money. That didn't make any sense to me because I had worked in shops all my life and I had never heard of anything like that happening. He then said if it wasn't that, then it was probably something I had contracted whilst in hospital for my hysterectomy. I have been anaemic my whole life so I would regularly have my blood tested to check my iron levels so I know if I had contracted hepatitis C before that

operation, they would have found it. Dr GRO-B didn't seem to know very much about the infection. He was trying his best to explain it to me but I didn't have a clue what he was talking about. I had heard of people contracting hepatitis B in tropical countries, but I had never heard of hepatitis C before. Dr GRO-B then referred me to the Glasgow Royal Infirmary.

6. All he really told me about the infection at this point, was that it was an infection he had seen in drug users before. He knew that wouldn't be how I had contracted it but I think that was his way of trying to explain it. That's when he suggested I could have been infected from handling money. He gave the impression that the infection wasn't something to worry about but I think that was because he didn't know much about it.

7. The information I was given that day was not adequate for me understand the infection at all. I still didn't really know what the infection was when he left, I didn't really get any answers that day.

8. I don't think the information about my infection could have been provided to me earlier than it was. As I was regularly having my blood tested for my iron levels, it would have shown up in those tests before my GP found the infection.

9. Dr GRO-B was almost a family friend, so despite him not knowing a lot about the infection, he was very good with me when he came to see me.

10. I was not given any information about cross-infection at my diagnosis.

Section 3. Other Infections

11. I have not received any other infections other than hepatitis C as far as I am aware.

Section 4. Consent

12. I do not believe I have ever been treated or tested without my knowledge or consent.

13. I think I have been tested for the purposes of research. I couldn't say exactly why but I feel I've had blood taken from me so many times in the past and I would always be asked so many questions about my health all the time I just feel they were trying to figure something out. The questions would always be about my lifestyle, things like whether I drank a lot, whether I had ever used drugs or whether I had a lot of sexual partners. They would never explain why those questions were relevant.

Section 5. Impact

14. The infection has had quite big impact on me mentally. It always made me feel like I could deteriorate at any time. I remember I would go for liver biopsies every six months or so after my diagnosis. During an appointment for one of these biopsies at Glasgow Royal Infirmary, my doctor, Dr Pofadopalus, told me that I would be lucky to reach fifty four. I cannot remember exactly when he told me this but it was roughly around 1990 or 1991. The infection felt like a death sentence. That was the first time I really knew how serious this was. I remember I kept thinking about my family and about my children and what would happen to them if this infection killed me. That fear still affects me to this day. Before I cleared the infection, it was all I could think about. It made me into a clean freak, I was so worried about passing the infection on to my family. I even started wearing rubber gloves around the house because I was so worried. My two boys would always ask me why I was wearing them but I couldn't tell them why. The infection was never out of my mind and that was exhausting in itself.

15. It wasn't until around two years after my diagnosis, that I started to experience physical symptoms from the infection. I started to feel really tired all the time, it was just constant fatigue. I used to have trouble sleeping as well. That made me a lot less active than I used to be, I just didn't have the energy anymore. During that time I had to look after both my parents due to their health. First

my Dad and then after he died, my Mum took ill and I looked after her as well. Looking after them when I was dealing with the fatigue was physically and mentally exhausting. I just had to keep going and going and there were times I didn't know how I was going to continue with it. After my Mum died I felt like I couldn't take anymore, but I had to keep going.

16. I now suffer from heart problems and I have an enlarged heart. Those issues started around five years ago. I take beta blockers to treat this. I could not say for sure whether that was caused by hepatitis C or not.

17. My infection was initially treated with Interferon injections that I would self-administer, at home. I cannot remember exactly when I started that treatment but I think it was around a year or two after my diagnosis. I received this treatment through the Glasgow Royal Infirmary. I received around ten doses of that treatment before I had to stop taking it due to how it was affecting my mental state.

18. The Interferon treatment caused severe depression and it made me really angry, I used to have a lot of mood swings. I remember once I was out at the shops with my son and I thought somebody had looked at him funny. I went absolutely bananas, I just started screaming at this woman and I couldn't really say why. That was very out of character, I was not like that as a person. The treatment just made me quite volatile.

19. After my failed treatment with Interferon, many years later, I asked Dr **GRO-D** about what other treatments were available. That was when she told me about the second treatment I received around four years ago, I cannot remember the name of this treatment. She initially told me that this treatment was too expensive. That made me very angry, I told her my life is expensive. I had contracted the infection through no fault of my own and I didn't think she had any right to be telling me that it was expensive. Shortly after that I was offered the expensive treatment. That conversation was the only difficulty I have ever

faced in accessing treatment. I still do not know why I had to wait so long for a second treatment, beyond it being as expensive as Dr GRO-D said.

20. Around four years ago, Dr Gillespie, my doctor at Glasgow Royal Infirmary offered me a new treatment that had become available. I cannot remember what this treatment was called. The treatment lasted for around three months. I was tested at the end of the three months and I had successfully cleared the infection. I still go to Glasgow Royal Infirmary every six months or so to have tests to see if the infection is still clear.

21. My successful treatment didn't have any side effects at all as far as I can remember.

22. I do not believe there were any treatments I could have received that I was not offered.

23. My infected status did not have any effect on my treatment for anything else.

24. The effect of the infection on my family life was horrendous. I was frightened for my children, I was frightened for my grandchildren, the infection left me in a state of fear all the time and that changed how I was at home. I was even scared to make someone a sandwich in case I nicked my finger or something. Even when I started wearing gloves all the time, I was still scared. The family would always ask why I was wearing gloves and I didn't know what to say to them. I didn't want to explain my infection to them. I felt embarrassed. For years, I have had my own cutlery, plate, bowl and cup and that's been my way of dealing with it.

25. I wouldn't say that I had a very active social life before my infection but when I was dealing with it, I didn't really go out at all. I just didn't want to, I felt like I didn't have the energy and I was frightened I would infect other people.

26. I have never suffered from any of the stigma associated with a hepatitis C infection. I knew that my infection came from my hysterectomy and not from drug use or anything like that, so I knew it wasn't my fault and that was enough for me. I didn't really tell a lot of people either.

27. The fatigue caused by my infection, meant that I had to stop working sometime around 1991/1992. I was working part-time as a GRO-B There would be times when I would literally be falling asleep at work. I would go for my tea break at lunch, put my head down and I would be out. My colleague would often have to come and wake me up. I think she was quite worried, because she said it couldn't be right that I would fall asleep on the spot so often. I eventually had to leave the job after a year because I was so tired all the time I couldn't keep going. About a year after I left the job, they phoned me to ask if I wanted to come back. I tried to start working again but I just didn't feel right, I wasn't well. I felt terrible letting them down after they had offered me the job back. I stuck it out for as long as I could, but I had to leave again after six months. The exhaustion of it was too much. Trying to continue working through that exhaustion was affecting my home life as well. I would come back from work and my children would be wanting their dinner but I was too tired to cook. I would often just bring pies or sausage rolls from the GRO-B for them but I think they were pretty sick of them after a while. I used to be a really good cook, making home cooked meals, but I didn't have the energy to cook anymore. The kids weren't used to me being like that. It really upset me that I couldn't keep my job, I loved working GRO-B

28. The financial effect of that was terrible. Having to stop working meant that I had to get by on benefits alone and that was really tough. I had years on just the lowest level of basic benefit and that was very hard on the family.

29. I didn't tell my sons about my infection when they were younger because I didn't want to frighten them. They would often ask why I was wearing plastic gloves around the house, but I didn't feel it would be fair to tell them, it would have scared them. When they were older, I told them about my infection and they were shocked. I think that explained a lot of the things, they had asked me about, when they were younger. They were both very supportive about it

though. I do remember my youngest son was angry about what had happened to me. He kept telling me to go to a lawyer.

30. My sister knew about the infection from the start but she was very upset when she found out. She wanted me to go to a lawyer as well, she said what the NHS had done to me was unbelievable.

Section 6. Treatment, Care and Support

31. I have never received any emotional support of any kind because of my infection. The most care I have received is at my six monthly biopsies, and even then I am asked briefly how I am doing and then that is it for another six months. Sometimes at my appointments, I can be speaking to a doctor face to face for less than ten minutes. I can't really see how an appointment that brief, could count as care or support.

32. I was referred to a psychiatrist after my failed treatment with Interferon because of the effect it had on me psychologically. I can't remember what his name was or exactly when I saw him, but I was in a hell of a state afterwards. I didn't know why I had been sent to see him to be honest. He was talking about my family and how my father had died. Those topics were very upsetting for me to talk about and I left my first session in tears. I thought it was a bit of carry on, for him to keep trying to bring all that up. I didn't go back to him after that.

33. I have never been offered any psychological support or counselling directly because of my infection. I don't know if I would have wanted anything like that but it certainly wasn't offered.

Section 7. Financial Assistance

34. I have never received any financial assistance due to my infection. I am being advised in this interview about the existence of SIBSS and I have been advised to look into this option.

35. I feel very misled that no one told me that financial assistance was available. Not one doctor or nurse has ever told me that there funds that I could apply to. It was very hard for me to hear that these funds existed because I have gone through so many years of financial hardship because of my infection.

Section 8. Other Issues

36. I have nothing else to bring to the Inquiry's attention.

Statement of Truth

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

Signed GRO-B

Dated 20/9/2002.