ANONYMOUS

Witness Name: GRO-B

Statement No.: WITN5126001

Exhibits:

Date:

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 05 January 2021.

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

Section 1. Introduction

1. My name is GRO-B My date of birth is GRO-B 1963. I reside in Edinburgh and details of my address are known to the Inquiry. I live with my partner of 17 years and I work full time for a major assurance company, based in Edinburgh. I have one grown up son.

2. I intend to speak about my infection with Hepatitis C (HCV). In particular, the nature of my illness, how the illness affected me, the treatment I received and the impact it had on my life.

Section 2. How Infected

3. In around 1981, I was given an anti-D immunoglobulin injection (anti-D). I think this was either at the Western General Hospital in Edinburgh or at the Edinburgh Royal Infirmary. In around 1983, I was given an anti D injection once again, at one of the two hospitals mentioned above. On both these occasions I was given anti-D after terminating a pregnancy.

4. Being in hospital for these pregnancy terminations was difficult, and given the type of procedures I was having, I was not really treated with much respect or kindness from the medical professionals in charge of my care. It is never pleasant to have to go through something like that, but it was made worse by the fact that terminating pregnancies was very frowned upon and stigmatised at the time.

5. It very much felt like a 'let's get this done and dusted' kind of attitude from the medical professionals treating me during these procedures, rather than them being understanding and considerate of the difficult situation I was in. They seemed to look at me like I was just a silly, young girl and I don't remember the doctors even bothering to speak to me before or after the procedures.

6. I was told by a nurse on each occasion that I would need an anti-D injection before I left the hospital. I was told this was necessary in order to protect any future pregnancies as I was rhesus negative, but I was not given any more information about that. I was not told about any risks associated with this injection on either occasion, and at the time I did not even know it was a blood product. I thought it might have been something like a vitamin injection, and nothing was explained to me about what it contained. I did not question what they were giving me, as I was young and trusted the treatment they said I needed.

7. I gave birth to my son in 1989 and I was once again given an injection of Anti-D. I was again not given any information about what this injection was or any risks associated with it. At some point I mentioned the anti-D injection I had been given to my mother, and she said something about my uncle having needed a full blood transfusion when he was born as he was rhesus negative, but his mother was rhesus positive. I think that was the first time I realised that anti-D injections contained blood products.

8. From around August 2006, I was working as a contractor in financial services. I had my own company and I was working long hours and commuting to and from GRO-B every day from Edinburgh. I was earning very good money at the time, around £400 a day. I was a single parent and lived at home with my 18-year-old son. I had been seeing my current partner for around 3 years, but we were not cohabiting at that time.

9. Around this period, I began to feel extremely exhausted to the point that I remember lifting my fork to eat became hard work. I suffered bouts of severe diarrhoea and my weight dropped to under 8 stone. At 5ft 7inches, I became very thin. I continued to feel like this for 3 or 4 months, putting it down to long hours at work and the long daily commute. My partner had seen my health decline and kept saying that he felt something was not right with me, and encouraged me to go and see my GP.

10. I had become so exhausted and unwell that I was unable to continue with my contracting role in GRO-B and gave this up in January 2007. I took a significantly lower paid temp job closer to home, as I could not maintain the level of commitment required for my contracting role and the long commute involved.

11. I visited my GP at GRO-B GRO-B in Edinburgh in January 2007 to explain how I was feeling and to try and get to the bottom of what was going on. I had a very good relationship with my GP, and she said that she would run various blood tests to rule out possible causes for the way I was feeling. This was quite a lengthy process as various different tests she had run came back negative, but eventually, some months later, she tested me for HCV.

12. Sometime in March 2007, my GP called me on a Friday evening at 6pm and asked me to come to the surgery for an appointment on the following Monday. I spent the whole weekend worrying and thinking about what she wanted to tell me so urgently.

13. At the appointment on Monday, my GP explained to me that my blood had tested positive for HCV. She seemed very shocked and surprised by this diagnosis, and it felt like she did not expect someone like me to have become infected with HCV.

14. My GP said that there was a 5% chance that my son could have been infected with HCV in the womb. She also suggested my ex-husband and current partner get tested, as there was a risk that they could have become infected through sexual contact.

15. At this appointment, my GP did not really ask me any questions about how I came to become infected, and I think she knew I did not fall into the usual 'at risk' categories. However, as soon as she told me that HCV was a blood borne infection, I immediately said that the only way I could have come to be infected was through the anti-D injections I had been given on 3 different occasions. She quickly discredited this, saying that anti-D injections in Scotland could not have been infected with HCV as it was heat treated. She was very adamant about this not being the source of my infection.

16. My GP told me that she would refer me to the HCV clinic in Edinburgh, and they would offer me a course of treatment to help me clear the HCV. She also said that I needed to start on a course of anti-depressants right away, but did not really explain why exactly. I was very against this as I'm not a fan of anti-depressants and not a big believer in them, but she was insistent that I needed them so I agreed.

17. My GP did not really give me any warnings in relation to cross contamination or any measures I should take in order to protect against my family or friends becoming infected with HCV. I feel that she was quite unfamiliar with HCV, and may have not had many other patients who had this diagnosis.

18. I was absolutely devastated by the news of my diagnosis and I left the surgery in a daze. I remember spending the next few days going over and over it all in my head, wondering how this could possibly have happened if it was not as a result of the anti-D injections. I had not had any tattoos, had never taken intravenous drugs and was not sexually promiscuous. I had lived in a number of shared houses when I was younger, and I wondered if I had accidentally used someone's razor and become infected through that.

19. I decided to do my own research about anti-D, and whether it could cause HCV to be transmitted. I read online about a group of women in Ireland that had become infected with HCV as a result of anti-D injections, and had to protest and campaign significantly to be recognised by the government. This just solidified in my own mind that the anti-D injections were the cause of my HCV.

Section 3. Other Infections

20. I do not believe I was infected with any other infections as a result of the anti-D injections. If I had been infected with another infection, it would have probably manifested itself by now.

Section 4. Consent

21. I was not asked to consent to the anti-D injections I was given on 3 different occasions; I was just told that it was something I needed to take in order to protect future pregnancies. I think that I should have been given an explanation as to what the anti-D injection contained, and the risks involved with this. I was treated like a silly girl and just told the care I needed, as opposed to getting to make the decisions myself.

22. I'm not sure if I would have gone ahead with the injections If I had known the risks involved. I think I would have likely had the injection due to the risk to future pregnancies if I did not take it, but I should have been given the choice. It may have made me contemplate having children in the future if I had known about the associated risks with anti-D.

23. I consented to the Interferon and Ribavirin treatment I received for the HCV. The risks of the treatment not working were explained to me.

Section 5. Impact

24. It was very traumatic to find out I was infected with HCV, and the associated mental effects were very difficult to deal with. I felt ashamed and confused about how I had become infected, especially as my GP was telling me it couldn't be the anti-D whereas my research online said something else. I became depressed and withdrawn.

25. I was very worried about the risk of having infected my son, partner and ex-husband with HCV, and asked them to go and get tested. My partner was very supportive of me, but my ex-husband became really horrible about the whole thing. I remember him calling me on my

birthday while I was out for dinner with my partner, shouting at me and saying that our son could be infected with HCV thanks to me. This was the start of people being quite horrible and unsupportive towards me following my diagnosis. It taught me that having HCV wasn't something you should openly talk about.

26. After I told my son about the HCV, I felt like he was a bit ashamed of me. Although he was concerned about my health, I think he was just a bit shocked and embarrassed by the whole thing. He was 18 at the time, and still living at home with me. Thankfully he tested negative for HCV, as did my partner and ex-husband.

27. When I shared the news about the HCV to my family and friends, they were far from supportive and I was stigmatised with a 'you brought it on yourself' kind of attitude being shown towards me. It was very hard not to have family support during such a difficult time, but I was lucky to have my partner who stood by me.

28. One of my trusted friends from my inner circle told another close friend of mine that any glasses I drank from or plates I used while at their houses needed to be disinfected or thrown out. I confronted her about this and she tried to explain it away, saying what she meant was that they needed to disinfect things before I came over, to prevent me from picking up further infections like a cold. I didn't buy this at all, and especially given she was a social worker, I think she should have approached the situation better and been more understanding of what I was going through.

29. Needless to say, I lost some friends of over 20 years due to the HCV. I had a close group of 4 friends before my diagnosis, but now I only speak to 2 of them. The way I was treated felt like the same kind of ignorance and fear that was associated with HIV back in the day. Although HCV is a blood borne disease, it felt like I was contagious.

30. Before starting the HCV treatment, I continued to have the same symptoms I had suffered with prior to my diagnosis. I just felt tired all the time, I was rapidly losing weight and I was unable to go into work some days due to severe diarrhoea. My finances continued to suffer as I was no longer earning good money now I was working in a temp job, and this was made worse by the fact that I was not paid for the sick days I was forced to take.

31. I was also suffering from 'brain fog' and struggled with the inability to connect my thoughts and remember processes. For a long time, I put this down to stress, but looking back it was clearly as a result of the HCV. In February 2008, I got a job with a famous American bank in Edinburgh, however, I failed to make a good impression and struggled on in that job for 5 years. Tasks that previously would have been easy for me became difficult. I never got promoted about level 1, which definitely should have happened.

32. I had taken anti-depressants from the time I was diagnosed, which as I mentioned above, I wasn't happy with having to do. The anti-depressants I had first been prescribed made me very unwell, and if I took them even an hour late I felt a whooshing feeling in my ears and like my head was going to explode. Eventually my GP switched me to a different type of anti-depressants, and I later learned that the anti-depressants I had initially been prescribed had been taken off the market. I'm not sure what the mental impact would have been on me if I had not taken anti-depressants as suggested.

33. Sometime after my initial diagnosis of HCV, I received an appointment to attend the HCV clinic at the Edinburgh Royal Infirmary. At this initial appointment my diagnosis was confirmed, and I was told I would receive a call to start a course of treatment in the next few months. I was told the HCV genotype I was infected with, and luckily, it would only require me to have 6 months of treatments, as opposed to a year.

34. I began my treatment at Edinburgh Royal infirmary in November 2008. The treatment consisted of weekly interferon injections and daily ribavirin tablets. The ribavirin tablets had to be taken at specific times of the day and I was very regimented about making sure I took my medicine correctly.

35. I had an initial appointment when starting the treatment where I was shown how to inject myself with Interferon. This had to be done weekly, and I didn't find it too difficult to administer. I had been warned that there was a risk of the treatment not working for me, so I wanted to make sure I was following all the relevant advice and taking my medication exactly on time.

36. I did not see the same consultant each time, but I had a specialist nurse assigned to me and she was fantastic and a great support. I wanted to maintain my job and not let anyone know I was having this treatment, and she went out of her way to accommodate me. She would meet me at the hospital at 6am once a month for a consultation and for me to pick up my treatment, so I could go to work afterwards. I was very grateful that she would go out of her way to make this happen.

37. As I was trying to hold down a job, I took my injection every Friday evening after work in order to give me the longest time to deal with the horrible side effects of the injection before work resumed on Monday morning. I could feel the Interferon coming up my veins, and within 2-3 hours, the flu-like symptoms had already developed.

38. I knew I would be very unwell over the weekend, so I tried to be organised and have everything I needed in the house so I would not need to go out. I did not socialise or make any plans over this period, as I knew I would not be well enough to do anything. By the following Thursday I would start to feel better, but then I had to take the interferon injection the next day and it would all start again.

39. The side effects of the HCV medication were horrendous. Much of my hair fell out over the course of the treatment, leaving me with bald patches. I developed painful gums and went on to be diagnosed with Chronic Periodontitis. I have since had numerous teeth removed and wear a plate. I still have to visit my dentist every 3 months for very painful gum treatment. I also became very breathless, to the point where I could barely speak.

40. At one point, I became so breathless that I went to my GP who asked me to attend Western General Hospital in Edinburgh immediately. My treatment at the Western General during this time was truly horrendous, and I do believe it may have been as a result of the stigma associated with HCV. I was in hospital for 4 days on this occasion.

41. I informed the consultant treating me at the Western General about the HCV treatment I was on, and I asked him to contact my consultant at the Edinburgh Royal Infirmary in order to find out whether I should take my Interferon injection, but he didn't bother. Instead he kept questioning me about the source of my HCV in front of a number of other doctors, making me very uncomfortable. I told him I did not know how I came to be infected and I don't dwell on it because it doesn't matter, but he seemed very keen to know.

42. This consultant also made jokes about the treatment I was on, even joking with the nurses that Ribavirin 'sounds like a Mexican dance'. They refused to let me take my Interferon injection, which alarmed me as I did not want to jeopardise my treatment by missing a dose. My partner had brought the injection to the hospital and asked the hospital staff to keep it in the fridge, but they had forgotten about it and left it out. I was already so unwell that it was awful to have to worry about these additional issues.

43. The first night I was in hospital I was kept in a store cupboard type of room, all by myself. It was definitely not a room where patients were

usually kept. I think they wanted to keep me isolated as they thought I was infectious, but there was nowhere else free to put me as the hospital was so busy.

44. The next day they moved me to a winter ward which was usually closed at that time of year. It was just me and a Turkish lady who did not speak English on the ward, and it was absolutely filthy. There was a used adult diaper left in the bathroom for days, showing it wasn't being cleaned regularly. I even saw a nurse drop one of her gloves of the floor and put it back on, which is so unhygienic. It was not the way you expect to be treated in hospital and it felt like they were scared of treating me.

45. I was told that the breathlessness I was suffering could be as a result of a blood clot on my lung and I would need to wait until Monday for further tests to confirm this. I was pretty much left alone and ignored after that. I told the doctors that I felt they weren't taking me seriously and I was concerned that I was missing the HCV treatment I knew I should be taking. I do think my poor treatment may be as a result of prejudice, as I think they might have thought I was a junkie due to me having HCV.

46. In the end, I decided to discharge myself from the Western General and go straight to see my HCV consultant and specialist nurse at the Edinburgh Royal Infirmary. Thankfully, they said delaying the injection a few days would not cause the treatment to fail, and I took the Interferon injection I had missed.

47. During the HCV treatment, my white blood cell count was so low, my GP was very concerned and contacted the Edinburgh Royal Infirmary, who told her this was a normal and an expected side effect of the treatment.

48. Thankfully, after 6 months on the Interferon and Ribavirin, I cleared the HCV infection. However, I continued to suffer from significant

breathlessness. I felt like I was not getting answers from the NHS so I sought private medical care through BUPA, as I had medical cover through my work at the time.

49. The private doctor treating me did multiple tests to see what was causing the breathlessness, and concluded that a section of my heart had swollen up. This was likely to be a result of the ribavirin. This was treated with medication, and my breathlessness improved over time.

50. Until I was diagnosed with HCV, I was very ambitious and had only recently set up my own business doing consultancy work. However, I wasn't able to cope with that level of work physically or mentally and I had to put my health first. This is why I decided I had to take a much lower paid temp job, as I mentioned above.

51. As I was struggling financially, I asked my bank for help. They told me to sell my house and move into a bed sit. I was so mentally and physically worn out by this point, I sold my house and my son had to move in with his father. Years later, I complained about the way the bank treated me and was awarded £3,000 in redress for their treatment of me. I never managed to get back on the property ladder after the mess my finances got into; my credit score became too compromised.

52. I was lucky that I did not need to apply for travel insurance or any other financial services during the time I had been diagnosed with HCV and until I finished my treatment. I think if I had applied during that time, I would have struggled to get cover. I now get life insurance through my work.

53. Having to sell my son's childhood home and ask him to move in with his father did affect our relationship. Although he had had a close relationship with his father, it was devastating for him to watch me sell the home he had lived in since he was 5 years old. I moved in with my partner, but my son refused to spend time with me at my partner's

house. If I had been able to keep my home, he could have lived there for many more years.

54. In addition to the difficulties of finding out I had HCV, I also found out that my brother had died suddenly of a heart attack. I actually found this out through a radio appeal which was looking for my brother's family, after a neighbour had found him dead. His death really pulled the rug from under me, and I fell to pieces. I was on anti-depressants at the time on the advice of my GP, and in hindsight they may have helped me cope.

55. My son took his uncle's death very hard as they had a close relationship. My brother's death and my HCV diagnosis both happening within such a short space of time really affected my son, and he turned to alcohol for comfort. He is now a stage lighting engineer, but still struggles with alcoholism.

56. To this day, my family pretends that I never had HCV, even though it was such a difficult period of my life. I was so unwell that I felt like I was having chemo therapy, but they largely ignored my ill health and the side effects I was suffering. I remember my mother commenting that I should change my hairdresser as my hair was thin and a mess, completely ignoring the fact that I was on medication that was obviously causing hair fall and thinning.

57. As I have already mentioned, I was lucky that I had a very supportive partner to help me through this awful time, and we are still very happy together. I also had a few friends that stuck by me.

58. I felt that I was very much left to cope alone with the HCV, as it was all made out to be my own fault and not that serious. Although I am grateful that I received the treatment that I did, I will never fully recover from the trauma as well as the stigmatisation and ignorance associated with HCV that meant I was not really worthy of my family's help and

support. I can never forgive them for the way they treated me during this time.

Section 6. Treatment/Care/Support

59. As I discussed above, I was lucky to receive HCV treatment at the Edinburgh Royal Infirmary and to have such a supportive HCV nurse, who went out of her way to accommodate me. At times I did feel like a 'guinea pig', for a treatment that was very new to the market and the side effects were not that well known at the time. However, I was cured within 6 months, and I have to commend the HCV unit at the hospital for this.

60. When I informed my dentist about the HCV, I understood she would have to mask up and take precautions in order to prevent cross-contamination. However, she was not very sympathetic about the whole situation and there seemed to be some stigma towards me because I had HCV, which made me feel uncomfortable.

61. I was never offered any counselling and I still suffer from anxiety periodically. Prior to my diagnosis, I had not suffered with this.

Section 7. Financial Assistance

62. I believe I found out about the Skipton Fund through my HCV nurse at my first appointment with her, before I had started treatment. I made an application to the Fund for financial assistance, but my application was quickly rejected on the grounds that anti D could not have been the cause of the HCV infection.

63. I decided to appeal this decision and in February 2008, the appeal panel rejected my appeal. They said that there was no record of me having received a blood transfusion, and I had only received anti-D,

which was considered without risk of infection of HCV as British anti-D had never shown a link to infection. However, they mentioned that foreign anti-D had been linked to infection. They also only mentioned me receiving anti-D on one occasion, when I had actually received anti-D 3 times.

64. As the anti-D given to me had not been confirmed as heat treated, I do not understand how a risk of becoming infected through this source could be completely denied by the Skipton Fund. It is clear from my research that anti-D has caused HCV among women in the past.

65. After my appeal was rejected, my partner said that I should try and take the issue further. Although I was upset by the unfairness of the decision by the Skipton Fund, I felt like I could not put any more time or effort into this cause, and I just needed to focus on getting my health back on track.

Section 8. Other Issues

66. I followed with interest all the Inquiries about the infected blood scandal, really scanning for any information that anti D could be involved. It would mean a great deal to me to discover that anti D was the root cause of my HCV infection, after my doctors and the Skipton Fund were so quick to reject this as a possibility.

67. Given the financial hardship I went through as a result of the HCV, financial support would be helpful, and I am going to apply for this support to the Scottish Infected Blood Support Scheme. However, nothing can compensate me for such a terrible time in my life and the suffering I went through.

68. I feel blessed to be cured and I am thankful that I had access to great HCV treatment, when I know others were not so lucky. The main thing I want from this Inquiry is the truth and to find out what really happened, and how it was covered up for so long.

Statement of Truth

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

Signe GRO-B

Dated 28 · 4 · 2021.