Witness Name: GRO-B
Statement No.: WITN2212001
Exhibits: None
Dated: 25th February 2019

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 28 January 2019.

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

Section 1. Introduction

1. My name is GRO-B. My date of birth is GRO-B 1966 and my address is known to the Inquiry. I am married to GRO-B and we have a GRO-B. I intend to speak about my infection with hepatitis C and HIV. In particular, the nature of my illness, how the illness affected me, the treatment received and the impact it had on me and my family.

Section 2. How Infected

2. I suffer from haemophilia B, which is moderate in nature. As a child, I had to attend hospital about once a year whenever I experienced bumps and knocks and these visits to hospital decreased in frequency as I got older. However, every time I had dental work done, I required treatment prior to that. I used to get Factor 9 in advance of dental work which would help with the swelling and bleeding. I also had to get Factor 9 following any dental work until the swelling and bleeding had stopped. As a grown-up, I received home treatment and received Factor 9 weekly for 18 months and then I received treatment at the Haemophilia Unit. However, this was very infrequent and I cannot even see the last time that I attended the Haemophilia Unit.

3. I have only ever received Factor 9 to treat my haemophilia. My haemophilia means that I suffer from a deficiency in platelets. The Factor 9 helps the blood to clot. It also helps with internal bleeding and takes away any swelling.

4. I attended curatorial hospital in Glasgow and until I was 14 years of age. At that age, I was transferred to the Glasgow Royal infirmary. I cannot remember the names of any doctors who treated me at Yorkhill. At that time, there was not a dedicated unit and I had to go through Accident & Emergency every time and was then admitted to a ward. I would have been under the care of consultant, but was mostly dealt with by junior doctors that were on duty for the ward. When I was transferred to the Royal Infirmary in Glasgow, they did have a dedicated unit, which was the Haemophilia Unit and I was treated by Dr Lowe, who was the more senior doctor and Dr Madhok. These where the two main doctors that I can remember. I received Factor 9 since birth, but only found out that I was infected in 1981, at which point tests were developed. However, I do not know how far back it goes. I could have been infected at Yorkhill Hospital or I could have been infected at the Glasgow Royal Infirmary. There is no way to know.

5. No advice was given to myself or my parents about the risk of becoming infected due to the administration of blood products. The Factor 9 would just have been administered and that is what the hospital told you that you required as a treatment. I would have been told that I would be tested for hepatitis A and B, as a child, as soon as the test was developed, but there was no warning of any risk beforehand. Due to the administration of these blood products, I was infected with both hepatitis C and HIV.

6. I found out I was infected when I went to the Glasgow Royal Infirmary for a routine test in 1981. Following that test, I was called back. I cannot remember being advised that anything was wrong, I just got a letter asking me to go back to hospital. At that appointment, I made with Dr Lowe who explained that at the routine appointment for a blood test, I had been tested for HIV and hepatitis C and found to be positive. I was on my own at the time and my parents hadn't come along. There was no prior notification that it would be beneficial for my parents to attend with me. My parents later went up to hospital to discuss with Dr Lowe themselves.

7. Very little information was given either to myself or to my parents at the time when I was told that I was infected with hepatitis C and HIV. I was given leaflets and told that they would continue to monitor my health. This still makes me angry. They were very matter of fact.

8. I was just provided with general advice which was contained in the leaflets for me to understand and manage the infection. The leaflets contained information about do's and don'ts relating to blood spills, unprotected sex, and things to do in order to maintain your general health. These things were not discussed with me at all. I was just left to read the leaflets.

9. I would have liked to have the information earlier. I believe that I could have been made aware of the risk that administering Factor 9 implied.

However, at no point where any alternatives to treatment discussed, we were just told that Factor 9 was what was available. I do not know if there were any alternatives to Factor 9 at the time. I do know that the blood products that I received for my home treatment latterly were heat-treated, but alternatives were never discussed.

10. I believe that the way in which the fact that I was infected was communicated to me was completely unacceptable. I was a teenager when I was told. Telling at boy that he has got HIV and hepatitis C leaves him completely devastated and numb. My parents should have been there when I was told. I was not present when my parents went to meet with Dr Lowe themselves, but it was very much the same matters that were discussed. They would have been told about treatment and life expectancy.

11. At that time, there were a number of drugs being developed and life expectancy was about eight years from the point of the infection. It was still early stages.

12. The way in which the infection could be passed on to others was never discussed with me. I was just giving the leaflets. The leaflets discussed the matter of blood spills, unprotected sex, things to do with general health, not sharing toothbrushes and other things. All these things were clear from the leaflets, but I would have appreciated it if they had been discussed with me.

Section 3. Other Infections

13. I do not believe that I have received any other infection or infections other than hepatitis C and HIV. I have been made aware that CJD was a risk. However, there are no tests for that. I do not believe that I have CJD as I do not have any symptoms.

Section 4. Consent

14. I believe that I have been treated and tested without my knowledge, without my consent, without being given full information and it wouldn't surprise me if I had also been tested for the purposes of research as I think this is a possibility. The reason why I believe this is because there was more known within the medical profession about the risks than was disclosed to patients or made public. They knew about the risks to haemophiliacs but this was never discussed.

Section 5. Impact

15. Being 17 and been told that you have got eight years left believe is devastating, you don't feel like there is any point in pursuing a career or going to university. It changes your perspective. Every time you go to the clinic, you are worried about the results of routine screenings. You become very aware of your general health and it completely changes your outlook.

16. I didn't suffer from any physical effects as a consequence of my infections. The physical effects came later when I went on treatment for the hepatitis C. The symptoms of being unwell came exclusively from the treatment. I was routinely monitored to check my viral load and determine the moment when it would be beneficial to go on treatment. My CD-4 count was being monitored and this would have indicated my ability to fight off the infection.

17. No other conditions or complications arose from the infections. There was some scarring on my liver, but that was not to a scale that would cause issues.

18. For my hepatitis C I received a treatment for 48 weeks. This treatment was Interferon, which I self-injected. I received weekly injections for the

duration of 48 weeks and responded positively to the treatment. The Interferon cleared the infection. Side effects, however, were horrendous. I suffered from nausea, exhaustion, anaemia, depression, and lost two stone in weight. I had this treatment when I was 28 years old in 2004.

19. For my HIV, I am on a treatment of the tablets once a day. One of the tablets is called Effaverenz, the other one is Abacavir. My viral load has become undetectable due to this treatment. I have been on this treatment since 2005. I wanted to deal with the hepatitis C before going on to the other treatment. Effaverenz causes sides side-effects such as vivid dreams but so far it hasn't caused any other complications. Other than vivid dreams, I would say I only have minor skin irritation. Vivid dreams are not nightmares, but they can wake you up and your mind is racing. On those occasions, it takes me an hour to go back to sleep. I take the tablets before bed. If you get up an hour later after you have taken tablets, they impair your balance. I would be dizzy for two hours if I did not go to bed after taking the tablets. If I forgot to take the medication and took it during the day, I would be dizzy until lunchtime. I would suffer from light-headedness and impaired balance. I have not suffered from any other side-effects due to this treatment. This is the only treatment I have ever received for HIV.

20. I have been offered other treatments as a result of the side-effects caused by his treatment. However, I have chosen not to change treatments as everything else is stable. Other treatments could have side effects and I don't know what they would be. It might be worse than the treatment that I am currently own. No one can predict how someone is going to react to treatment. I can manage the side-effects of the treatment that I am currently on.

21. There have been no obstacles to treatment. I was working with the hospital to determine the right time to go on treatment. I could have gone on treatment sooner, but I did not want to go on it until my

body was at a level where I actually needed it, which is why I was being monitored routinely. In the meantime I just did what I could to keep well.

22. I do not think that there were any treatments that should have been made available to me but weren't. It has always been a case of resisting going on treatment until it became beneficial for me. I would not say that my infected status has impacted on other medical treatments that I have received. I always received my dental care at Glasgow Royal Infirmary rather than at a local dentist. I know that this takes more time. I still go to my local GP, but I am not treated any differently from other patients.

23. I believe that there is a stigma about being infected with hepatitis C and HIV. I don't share the fact that I was infected with people. Being infected makes you more guarded about what you share with friends and family. At the time when I found out that I was infected, there was a stigma due to the general messages that you would see in the press and you just made sure that no-one found out that you were HIV-positive. Only my GRO-B, GRO-B, GRO-B, GRO-B know. No one else knows.

24. Becoming infected with hepatitis C and HIV has not really had an impact on my family activities and social activities. This has always been the case, except when undergoing treatment for my hepatitis C, when I was off work for three months. During the time I was receiving treatment for hepatitis C I wasn't physically able to be active.

25. Becoming infected with hepatitis C and HIV influenced my career choices, as I lost the option to go into the medical profession or even move abroad because I had to be near where I could get care.

26. I was off work for three months during my treatment for hepatitis C and then I went back to work. Prior to that, I would also have been off work if I had a bleed or required to be in hospital, but that is due to being a haemophiliac, not due to the infection or the treatment. People at work

don't know anything about the infection. Whilst undergoing treatment for my hepatitis C, I spoke to my manager and told him that I was receiving treatment for hepatitis C, but I didn't make him aware of the HIV.

27. Travel insurance is more expensive than if would be if I hadn't been infected with hepatitis C and HIV. I had no trouble getting a mortgage as I worked for a bank at the time when I bought my house. Also, I didn't lose wages when I was off work for three months during the course of my treatment for hepatitis C, but that is purely because of my employer's policy to continue paying wages for a period of six months in such cases. Had I been with a different employer, I could have lost wages.

28. My undergoing treatment for my hepatitis C affected my family. It only really affected my wife due to the symptoms that I was experiencing, as GRO-B was too young to realise what was going on. However, my wife was extremely supportive and the fact that I responded positively to the treatment made me want to continue. Had I not responded well, our circumstances could have been very different.

Section 6. Treatment/Care/Support

29. When my wife and I were looking to start a family, we saw a counsellor, Mary Hepburn about this together. I also saw a counsellor when I was on Interferon about my depression. We attended three consultations with Mary Hepburn. We were offered access to these counsellors through the Haemophilia Unit. However, no psychological counselling was offered to my wife.

Section 7. Financial Assistance

30. We found out that financial assistance was available through the Haemophilia Unit. We were contacted t by the trust and I remember that we received an initial payment from the McFarlane Trust, but cannot remember when this took place. Two years ago, I received further payments from the Scottish Government and I am currently receiving ongoing monthly payments.

31. I received an initial payment of [redacted] from the McFarlane Trust, plus [redacted] We also received a lump sum [redacted] from the Scottish Government, and are currently receiving ongoing monthly payments of [redacted]

32. In order to apply, we had to fill out application forms regarding our financial and family status. We did not have access to my medical records, so we had to give the trusts permission to access my medical records. Parts of medical records are known to be missing. I found out about this through the Penrose Inquiry, my medical records have gaps probably around the time when I could have been infected.

33. I did not face any difficulties or obstacles in applying for and obtaining financial assistance.

34. I would not say that there were any preconditions imposed on the making of an application and grant of financial assistance, other than validation of my health status.

35. My opinion is that it took far too long to get support to people who genuinely need it and some people have suffered very much, along with their families. The delay is unacceptable, especially when people are suffering from financial hardship, their family members are unable to work or have died.

Section 8. Other Issues

36. I have never been involved in any litigation as a result of my infection with hepatitis C and HIV. Regarding the Inquiry, I believe that openness from the Health Service and the Government is necessary regarding what they knew. The Inquiry has to be determined to get to the truth. An outcome such as outcome that the Penrose Inquiry had will not be accepted again by the people. Those who are accountable should acknowledge their errors and have a commitment to make things better for the future.

37. I was involved in the Penrose Inquiry and gave evidence in front of Lord Penrose. That was disappointing, the fact that the scope of the Inquiry and the questions posed were far too narrow. The Penrose Inquiry could never have the right outcome because of the way that it was being directed. I feel much more encouraged by the current Inquiry.

38. I would like to remain anonymous, as I am concerned about privacy and do not wish my employers to have knowledge of these issues.

Statement of Truth

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

Signed GRO-B

Dated 25/3/2019