Witness Name: GRO-B
Statement No.: WITN2280001
Exhibits: none
Dated: 3rd January 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 3rd January 2019.

I GRO-B, will say as follows: -

Section 1. Introduction

1. My name is GRO-B. My date of birth is the GRO-B 1962. My address is known to the Inquiry. I am living with my wife GRO-B and my grown up son GRO-B. I also have a grown up daughter, GRO-B who is married. I intend to speak about my infection of hepatitis C. In particular, the nature of my illness, how the illness affected me, the treatment received and the impact it had my family and I and our lives together.

Section 2. How Infected

2. I had haemophilia type B before I received a liver transplant. The severity of my condition was considered mild. I was diagnosed with this from birth.

3. I have no idea of the names. The doctors changed the products regularly. I didn't need treatment that often as well because I was considered mild. I would be treated maybe, a couple of times a year at the most.

4. I was under the care of GRO-B Hospital, Glasgow up until the age of 14, after then I was transferred to Glasgow Royal Infirmary. I was registered with GRO-B as a child up until 2001 when I moved to GRO-B. Now I am registered with GRO-B The treating doctor who saw me when I was at GRO-B Hospital was Mr Devuison. When I transferred to Glasgow Royal Infirmary on the 19th August 1976 I was under the care of Professor Lowe and now I am under the care of Professor Tait.

5. I don't know. I believe it was in the early 1990s but I can't tell you dates. I was more likely infected at the Royal Infirmary Glasgow because they were using the products. When I was at GRO-B Hospital, they were treating me with plasma. I have also had a blood transfusion when I was younger. I had teeth taken out and they could not stop the bleeding. I ended up needing 18 pints of blood. That is the only time I received a transfusion as far as I am aware, but I cannot recall the exact year. This information will have to come from my medical records. No doctor or hospital has ever come out and said clearly, this is when you were infected so it is difficult to judge.

6. Glasgow Royal Infirmary contacted me out of the blue and asked me to go into the clinic. I would go to the clinic at that time every 3 months to provide bloods, in order for them to check my factor 9 levels. Haemophilia B, your body does not produce factor 9, so the doctors would top me up with what I was missing when required. So I went to for this routine visit and the consultant, I cannot recall their name, told me out of the blue that I had hepatitis C. There was no warning he was going to say anything, he announced this and that was it. The consultant walked away without providing information about what was going to happen, there was nothing at all. There was no treatment for it at the time, no one seemed to know anything about it. We were just given this

little leaflet and told to go home. At the time there was no internet of course, so I was left fairly confused. I had no understanding of what I had or what was possibly going to happen. The leaflet itself was very basic and had very little information. After that, the hospital would contact me every so often to check my levels and see how the virus was progressing and then eventually years later, they offered me a treatment.

7. There was never any information about the possible risks from receiving these treatments. It was really just a case of, this is what you are getting. I relied on the doctors to tell me what the treatment was going to be and what was going to help me. There was never a conversation about risk.

8. There was hardly any information at the point I was diagnosed. He just said to me what it was, hepatitis C and walked away. He said it was a virus, a blood borne virus that attacked your liver. I had no active physical symptoms at this time so it was hard to comprehend the severity of it with no real indication from the doctor.

9. No, what would have helped, would have been more information about what the virus would do to you in the long term. Information on if it could be cured would have helped my understanding. I have done 5 treatments now to clear this and so far 4 of the treatments have failed. As of the 23rd January 2019 I am showing as being clear of the virus.

10. We don't know how long the doctors knew, they told us when they said they knew I had it, it is difficult to answer this.

11. The information was basic. It was a regular clinic appointment when they told me. I had absolutely no warning, I was taken into a wee room with a doctor and a nurse and told. No one said this could possibly kill you, that realisation didn't come until much later.

12. I was given no information about the risks of others being infected. I didn't know anything about this, the only information I picked up later on, was from the internet and from the media in the 1990s.

Section 3. Other Infections

13. I was told there was a risk I had been exposed to Variant CJD. I can't recall when this was, just that it was a while ago. The Haemophilia clinic at Glasgow Royal Infirmary contacted me and advised me of this possibility. That was a difficult one because it can affect your brain. There is no test in existence to confirm it until after you have passed away. The effect on me receiving this information was not significant however. When they told me about this I had so much going on, this was just another thing to add to the list. I was going through a hip operation at the time, I had a liver transplant and I have never had procedures refused to me so it has not featured heavily to this point in my life.

Section 4. Consent

14. I didn't know we were going to be tested for hepatitis C back when I was diagnosed. It was just a case of a routine blood test to check things, that is the one I am aware of.

15. My answer to this is the same as point 14.

16. Yes, I didn't get the full information about what the virus would do to me. This information didn't come until later. This made me feel better when I had more understanding of it, however too much information can be a bad thing. GRO-B: W took it quite badly when we fully understood, she was upset by the realisation of what could ultimately happen to me. I didn't take it badly though.

17. Yes, through my own consent. I had a liver transplant on the 15th May 2012 and I agreed to provide samples etc to Edinburgh Royal Infirmary as I am no longer considered a haemophiliac because of the new liver.

Section 5. Impact

18. It makes you tired, it makes you feel sick, I had brain fog, my eyes would become glazed, and I would check out from what was going on at points. Sometimes I would feel good and at other times I would have bad days. I had no energy to do anything really, I slept for long periods of time. Mentally it has not affected me, I have got on with things. The treatments I received, which I discuss below did affect me mentally however. Ultimately the hepatitis did cause my liver to deteriorate over the years to the point I needed a liver transplant.

19. The virus ultimately took hold of my liver and I developed cirrhosis. My liver function was really low and I was admitted to hospital in April 2011 to be assessed for a liver transplant. It was the Edinburgh Royal Infirmary. When I was admitted I went through an assessment period for a week where they assess if your fit enough physically and mentally, if your capable of coping with a liver transplant. They do this because you're essentially getting someone else's liver which can affect people psychologically in different ways. I saw surgeons, psychiatrists and doctors throughout this week. I had endless tests, MRIs, CT scans, and I had blood tests taken twice a day. I was on exercise bikes and all sorts. They were checking everything, mentally it was quite exhausting and then on the Friday I had to wait while the doctors decided if I had passed their tests. I had and I was placed on their transplant list. There was a sigh of relief when they told me this, but then came the realisation that this is a very dangerous operation. I had no idea when I would get the call. Ultimately I was on the waiting list for 14 months. Then at 1am in the morning on the 14th May 2012 I got the call. We rushed through to Edinburgh in the middle of the night, and then I had to wait 12 hours before I was taken into theatre because the liver was coming from, wherever it was, to Edinburgh. So there was a big wait as well. I was lying in a bed for 12 hours waiting to go. I

couldn't sleep, I was apprehensive, nervous, I just wanted it to happen. To explain as well, when you get the call, it's not just you. They always call two people. The way it works, you might be the 2nd person, but if the 1st person isn't fit enough, you get the liver. So I was waiting, not knowing if I was 1st or 2nd. There was that real possibility that I could have been sent home again. After 12 hours, they came to me and said, get ready, its time. W sat in the hospital with me for the full 12 hours. She stayed in the hospital for the full week I was admitted, the hospital provided her with a room. I was ultimately admitted for 12 days in total before I got home. I remember when I first came around, I was just grateful to be actually awake, I was grateful to see W she sat the whole time, waiting for me. It was an 8-hour operation and W sat there the whole time in the family room just waiting. It was a lot of pressure for her, because it was a family room, she had people coming through there all day with their own things. All she could do was sit there. There was a relief for both of us at this point, that it was over. Everything went fine, I can't really comprehend the first 24 hours after I woke up from the operation. I was full of tubes and in the intensive care unit. I was there for 24 hours and then I was moved to the high dependency unit. Then 3 days later I was moved up to the general ward. They got me up and on my feet as soon as I was able, and it was all go from there. Now nearly 7 years later, this liver is now damaged due to the hepatitis C. There is scarring on it now. I had a biopsy and I have been warned that if it keeps going this way, it'll be back to requiring another transplant. My only hope now is that the doctors can get rid of the virus before this liver is too damaged. Otherwise it will get to a point where the damage is too severe and it won't repair itself.

20. I have received treatment for the hepatitis C, 5 times and 4 of the times it has failed. The 1st time, it was in the mid 90's, I received Interferon and Ribavirin. That was just hellish, a living nightmare, I fell into a deep depression, I didn't want to get up, I was arguing with W constantly. It got to the point where the kids ended up periodically having to stay with their Gran for a couple of days here and there because we were fighting all the time. They were young at the time, age 3 and 7. The treatment was just terrible stuff with what it did to you. 12 weeks into this treatment, they did a test and there was no change

to the virus, so they cut me off. No improvement, so no point continuing. The 2nd time, I tried the treatment again several years later, I can't recall the exact details now, but this treatment also failed. The same test was done after 12 weeks and it came back with the same results.

21. The 3rd treatment was Harvoni, and Ribavirin. I started this treatment on the 29th July 2015. Again 12 weeks later, the same test was done and there was no improvement so they stopped again. Of course this was now after the 1st transplant. There was a big gap between the 1990s and 2015 but still the same result. I have hepatitis C, type 1 you see, that is one of the most difficult strains to clear. The doctors said, Harvoni was the "bees knees", this was going to be the thing that cleared me. It also failed.

22. The 4th treatment was VOSEVI. I started this on the 24th October 2017. I finished this treatment and this time it worked, to a point. They stopped the treatment after 3 months as the virus was showing as undetectable, but when they did the 12 week follow up test, it had come back.

23. The 5th treatment. I started this on the 6th August 2018. This course consists of Ribavarin, Sofoubi and Mavyret. I have been on this for 6 months. I finished this treatment on the 20th January 2019. So far, it is working, I have had checks done and the virus is gone, but I've been down this road a number of times now, so I reserve final judgement. I do feel different this time though, the fog has lifted out of my head, I feel clearer, my eyes are clearer. It feels like something has lifted out of my body this time. I feel clean. It's hard to explain, but it is like night and day compared to how I was feeling before. Even with all the side effects. I get quite bad headaches, a wee bit tired now and then and I do have fatigue. There's no depression now though, no more fighting with W maybe I get an upset stomach but that is it now. This is extremely mild compared to previous experiences with the treatment.

24. I don't believe there were any. If any, it would have been that it is a long process to go through for you to get a liver transplant. There is a liver committee that sit either Edinburgh or Glasgow and decide on what your treatment is going to be,

then they have to apply for funding for the treatment as the anti-rejection medication is expensive.

25. No I wouldn't say so, the doctors have given me everything they can give for the hepatitis C and the liver at this point.

26. As I describe above, the effects of treatment the first time were brutal. Pure hell. In the 1990s it sent me into a deep depression. It meant that my children had to have regular visits with their Gran as W and I were arguing too much. It was a horrible period for us both. I lost a lot of weight, I developed a horrible brain fog, I couldn't function and after all of that, the treatment failed. It has failed 4 times now.

27. There have been no other issues; I don't like going to the dentist. I was given antibiotics when I was born, which resulted in the enamel in my teeth being destroyed as they were very brittle. This led to me being in and out of the dentist as a child which I didn't really enjoy, but after the transplant, the doctors gave me a lot of antibiotics as well and my teeth all collapsed. I have Perthe's disease which has meant I need an operation on my hip. This is currently scheduled for the 28th January 2019. This is not related to the hepatitis C, but has meant I have to inform the doctors to make sure everyone was aware of my infection so everyone is careful to avoid transmission. I feel this is appropriate.

28. I didn't have a social life in the 1990s, even into the new millennium. W and I had to work very hard at our marriage to come back to a good point in our marriage for a long time after that 1st attempt at treatment. Then there were several more attempts at treatment which meant we kept going through it again and again. I didn't have a social life; the bad hip I have, also stopped me going out socially all the time. This is a condition I have had throughout my life as well. GRO-B: S our son, was GRO-B so he was age 3 or 4 when we had our hardest time, his older sister GRO-B They would go for regular visits with their Gran; a form of rest bite for us, as there was too much tension in the house. Now, GRO-B: S&D don't talk about it with us very much. They

have never spoken about it. They know the problems, they have the information, but we have not discussed it with them and they do not ask.

29. There is always a stigma out there, but I wouldn't say this was an issue that I experienced in great amounts with our own family and friends. I only tell people if they need to know. My close friends, are understanding about it, but there is an overall stigma. It is a dirty disease, people say ignorant things, like it is from drugs etc. I think there are a lot of people who don't understand what the illness really is and how the haemophilic community really got this. Referring back to the dental story, my teeth all collapsed after the treatment, I was told to go to the local dentist to get treatment. I didn't. I was frightened to admit to a dentist that I have this infection, for fear of how a dentist would react.

30. There have been no educational effects from being infected for me.

31. I stopped working in December 2010. That was when I became really ill before I had the liver transplant. I was a maintenance building manager, basically I managed the communal areas of a building which had about 2,500 occupants in it. I worked full time and this was completely fine until 2010. My liver took a dramatic decline from this point and I was not well enough to work after this. I made the decision at this point to take early retirement on medical grounds. '

32. The insurance is a difficult one, especially travel insurance. Insurance is very expensive for me. A lot of companies won't insure me. I received one year of wages when I fell ill in 2010, and received the ex gratia money which helped to manage and pay these extra premiums around insurance. If the ex-gratia money hadn't come through that would have been a struggle, but there was also the fact that **W** works full time for the Inland Revenue, so we were ok either way.

Section 6. Treatment/Care/Support

33. The care I have received has been fine through the years, I have no complaints about this. Counselling might have helped to understand the infection and the gravity of what

we were facing though. Particularly with the arguments with W in the early years when I was going through treatment.

Section 7. Financial Assistance

34. I cannot recall when I found out exactly, it was through the haemophilia clinic at the hospital and the media.

35. I applied to the Skipton Fund and I received £25,000 ex gratia. I was considered stage 1, then I applied to be a stage 2 a couple of times, but my bloods weren't bad enough to be granted this. As soon as I went on the waiting list for a transplant, this all changed and I was automatically granted stage 2. We were given a further 2 lots of £25,000 and a monthly payment of £1,250 from Skipton. I have never received anything from any of the other trusts. When SIBSS took over from Skipton the amount we received in a year rose from £15,000 to £27,000 per annum. This started in April 2017 but was backdated so we received a further lump sum of about £12,000 due to the back dated payments.

36. It was just a case of filling out forms and asking the Consultant at the hospital to support the application.

37. The only obstacles were the couple of times I was refused the stage 2 status because I had not reached the stage 2 threshold. This was in 2008/2009.

38. Yes I had to be really ill to get to stage 2, which doesn't feel fair. I was already ill and not getting better, that should be enough.

39. The stages are wrong. It should be a case of you have this, your ill. It could last 30 years before things progress, but you will still suffer daily over those 30 years. This has happened through no fault of mine. Hopefully going down this process will address the wrongs that have occurred.

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Section 8. Other Issues

40. I have no other issues to bring to the Inquiry's attention. Thompson's Solicitors are recovering my medical records which I will be given an opportunity to review.

Statement of Truth ANONYMOUS

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

Signed GRO-B

Dated 13\1\2019.