Witness Name: GRO-B
Statement No: WITN0196001
Exhibits: None
Dated: 12 December 2018

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 November 2018.

I, GRO-B will say as follows: -

Section 1. Introduction

1. My name is GRO-B My date of birth and address are known to the Inquiry. I am 51 years old and live at home with my parents. I suffer from severe Haemophilia A.
2. I intend to speak about my infection with Hepatitis C. In particular, the nature of my illness, how the illness affected me, the treatment I received and the impact it had on my family and me.
3. Thompson's solicitors currently legally represent me, however I am content that the Inquiry team investigators take my statement. A representative from Thompson's, Olivia Smart was present during my interview.

Section 2. How Infected

4. Haemophilia is in our family. GRO-C GRO-C

5. When I was a few months old, I took a tumble in my baby walker and suffered a bad bleed. My mum took me to hospital, where the doctors initially thought my parents had beaten me up. I was then diagnosed with severe Haemophilia A.

6. A few years later, I suffered another bad bleed. I think it was in the kidney. I remember mum bathing me in the hospital. Here, I was given Cryoprecipitate through an intravenous drip.

7. I was treated with Cryoprecipitate for the next 14 years. Whenever I needed it, I would be taken by ambulance to hospital. It took 2 to 3 hours to get treatment following the start of a bleed, by which point the damage was already done. Sometimes I needed to be in hospital for 3 to 4 days afterwards.

8. At the age of 14, I required a knee operation. This went wrong and I was told that I would be in hospital for 6 weeks. I came out 7 months later. The operation had gone wrong and due to arguments between the doctors and surgeons at the hospital, the plaster cast was too tight and left on for too long. This resulted in a dropped foot.

9. I was treated with Factor VIII concentrate for the first time when I was about 14 years old. I was pulled into the Haemophilia Centre in Edinburgh and told about this new treatment (Factor VIII). They told me I would have to self-inject it.

10. My GP stored my Factor VIII at his surgery, so that I could go there for it if I needed it. This worked a treat for 3 to 4 months.

11. I then began storing it at home. Factor VIII was a game changer. It resulted in a big life change for me. Whenever I felt a bleed coming on, I went into the fridge, mixed my own Factor up and then took it. I didn't have to go near a hospital. Nine out of ten times, I was almost

straight back to normal after taking it. I was able to play some sport, whereas before this was impossible.

12. I have been on home treatment for the last 30 odd years. I usually only take it when I need it, but sometimes I take it in advance to cover myself, if I'm going to a Celtics game for example. I also take it 3 days out of 7 when I'm on holiday, just in case. I don't like to take it too regularly in case of inhibitors, which would stop it being effective.

13. I was infected with Hepatitis C through infected Factor VIII between 1978 and 1984. Other haemophiliacs and me now just assume that any batch we were given during that time was infected.

14. Risks of infection through Factor VIII were never explained to me before I was given it.

15. At the age of 14, my parents received a telephone call from Professor Ludlem, Head of Haematology, at the Edinburgh Royal Infirmary. He told them to bring me to a meeting that evening.

16. We arrived at the meeting and there were 100 odd people there. They were all haemophiliacs. We were told that there was a chance that we had contracted HIV from one rogue batch of Factor VIII. This was not true; there was way more than one infected batch. They said that they didn't know who did and didn't have it, but this was also not true.

17. About a week later I was called into my doctors surgery and the Dr told me I didn't have HIV. He said something had showed up, but then disappeared, on reflection this was most likely the hepatitis but he didn't tell me.

18. I was later told that I had something else, another infection, but they didn't know what it was. They called it non-A and non-B Hepatitis, but they knew, they definitely knew. I was told that there was no treatment for it and I just had to get on with it.

19. A man in Glasgow had triggered this meeting. He had two sons' with haemophilia, who had contracted HIV. He had gone to the Daily Record with his story and they had contacted Edinburgh to see if the situation was the same there.

20. Professor Ludlem later told me that my unknown infection was Hepatitis C. This was sometime between 1993 and 1996. It was bitter

devastation. He told me in person in general conversation during a regular meeting.

21. Very little information was provided. I was told not to drink or have kids. However, this advice kept changing and all the information that I was given was contradictory. He kept saying that things like having kids were okay, then changing his mind. It was quite confusing. It definitely wasn't adequate information to manage my infection.

Section 3. Other Infections

22. I do not believe that I have received any other infection as a result of being given infected blood products. However, I was given emergency treatment in 1999 in Devon. I may have contracted vCJD from that, I may not have. I have never been tested because at this point I would rather not know.

23. I still fear HIV will come back to haunt me. I am totally reliant on doctors' tests and what they have told me, and I still fear I may later be told I have it.

Section 4. Consent

24. As a young lad my parents would have been the ones who gave their consent for my blood to be taken. My father does remember that from 1978 onwards I was called in for more blood tests.

25. Nowadays, they always ask and I give my consent,that said I do not know what they are testing for.

Section 5. Impact

26. After being told by Professor Ludlum that I had an infection, but they didn't know what, I didn't leave the house for 3 to 4 weeks, and only left my room for dinner. I was suffering from depression but this went undiagnosed for pretty much the rest of my life. Plus big mood swings.

27. From 1990 onwards, I was tired, fatigued and had no energy. My concentration was going, my head wasn't in the place it should have been, and I was having panic attacks, anxiety problems and trouble sleeping. I didn't know what was causing all of this.

28. I have also suffered through other people's infections. In the 90's, personal friends and family members with haemophilia started dying of HIV. This took a toll on me mentally. It was just horrendous. Four of my close relatives died. I am the only one left, the lucky one if you can call it that.

29. My uncle was one of those people. He died in 1994 and was also infected in 1978 to 1984. I sat and watched him die, screaming with pain. It was terrible. I would never put anyone else through what I have seen. He was always complaining of the most horrendous headaches, this was the HIV.

30. I have now developed a sense of humour to cope. Be it good or bad, it is my control system.

31. As a result of my infection with Hepatitis C, I have developed further complications. I have bladder problems including bladder erosion, incontinence and bad pains, the muscles in my bladder which control the flow have wasted away. In 2003, I was rushed into hospital and the doctor thought it was bladder cancer.

32. Professor Goldberg has made a direct link between Hepatitis C and bladder problems. He has given presentations on this and written about it. It is a medically recognised link.

33. I now have a catheter, but as soon as this stops working, I will need to go and have my bladder removed.

34. I also suffer from joint problems as a consequence of internal bleeding over the years.

35. I recently developed pains on the right side of my liver and had a fibre-scan to try and find out what was wrong. It took 5 attempts to get a reading, and the result was off the scale. I have had further blood tests and an acid test. They all came back abnormal but I don't know why? I am currently waiting on another scan and I am scared it could be cancer.

36. As far as other medical treatment, such as dental care is concerned, I have not had a problem, I use the dentist at the hospital. There was an occasion when I was undergoing treatment for my bladder problem that the Dr's all wore masks and gloves and mentioned that they couldn't use the equipment on me because it was to a bigger risk, this was only four years ago, it was like going back to the dark days. I complained and had a personal apology form the surgeon.

37. I have received various treatments for my Hepatitis C. I was given my first round of Interferon in 1999. This was my first batch of the "evil treatment" I later received a second round of Interferon and Ribavirin.

38. The first round of treatment changed my life. It made me go "off my head". About 5 weeks after starting the treatment, I felt ill. I was sat in the Haemophilia Centre at an appointment and said that I didn't feel right. I was told it was just a cold or something and to go home. I was given a telephone number to call if things got worse and told it would be answered "24/7".

39. I went home and could feel myself getting angrier and angrier. I didn't feel in control of my own mind or body. I felt strange and had weird thoughts in my head that I'd never had before, suicidal thoughts. I tried calling the telephone number but nobody answered.

40. The next morning I woke up with no control whatsoever over my body. I didn't know what was going on in my head and I just wanted to end it all. I was in the same shell but it wasn't my head. I smashed the house up and caused thousands of pounds worth of damage. I went completely loopy. I even got on the roof and sat there swinging my legs. I was threatening to jump; I wanted to end my life.

41. My dad managed to talk me down and got me off the roof. He then called my GP, who came to help. The GP tried giving me Diazepam but it didn't work. I was then taken to the Royal Edinburgh Hospital (Mental Health) and given drugs. A few hours later I was okay again, but it took me 24 hours to recover properly.

42. When I returned home, I didn't have any memory of smashing up the house. It was very frightening. I could have murdered someone and

not known I'd done it, my head was that bad. If it wasn't for my dad I would be dead. He saved my life and I do mean, saved my life.

43. The Interferon was supposed to be the "best thing since sliced bread", but clearly it wasn't. My life has been a total nightmare since then. I still get angry very easily and my personality has totally changed. I am less trusting in people, I flip-out easily and I have no confidence. My sleeping pattern is crazy.

44. In 2002 I was given the second round of treatment. This was Interferon which I injected into my stomach every day, and Ribavirin. After taking the Interferon, I felt totally drained within 6 hours. The Ribavirin made me anaemic.

45. This round of treatment worked and the virus was negative, but after 6 weeks I had to come off it due to mental problems and the Hepatitis came back. The mental problems weren't as bad as the first time but they were still bad. I would start crying, have emotional breakdowns and be very angry. There were stages when I was driving my car and I would just start shouting at motorists and forget where I was going.

46. In 2006, Professor Hayes at Edinburgh Royal Infirmary told me that a new drug had come out. After my last experience I really did not want to take the drugs, I kept saying I didn't want to take it because I didn't want to risk side effects. The Professor said, "come on, get this" and so in the end I did. I vetted everyone I dealt with prior to taking it, and made sure that I had support and infrastructure in place in case I went mental again.

47. The treatment was in tablet-form; I had two tablets in the morning and two in the evening. I didn't even know I was on treatment. I sailed through and it cleared my Hepatitis C in a week. I continued taking it for 12 weeks.

48. Being infected with Hepatitis C has seriously affected my private, family and social life. I got married for the first time in 1991. This lasted 2.5 years, but broke down **GRO-C** During the marriage, her family were nasty regarding my infection. **GRO-D**

49. I had a couple of relationships after that, but they also broke down due to the Hepatitis C.

50. I met my current girlfriend about 8 years ago and things are good. She lives in Lancashire and I won't move down there because I don't trust the hospitals.

51. I made a lifestyle choice not to have kids because I feared that they would get Hepatitis C.

52. The stigma associated with Hepatitis C and HIV has hugely affected me. I had a big group of friends at school, but this changed between the ages of 14 and 16. The headlines associated Haemophilia with HIV everywhere and people thought, "one's got it, they've all got it".

53. Teachers and students walked away from me at school, and I became isolated. My friends disappeared and family of friends gave me different glasses to drink out of, which they would then put in buckets instead of washing them up. I didn't see the point in going back to their houses. Pubs didn't even want to given give me glasses to drink out of. I barely went out.

54. I was fighting off the stigma of HIV and I didn't even have it. It was a nightmare. Even to this day, I mention Haemophilia and I get blanked. People cotton on to my illness straight away because they can see it; it's hard to hide. I am very guarded and keep my past infection on a "need to know" basis.

55. My education, work-life and financial situation also suffered. From a young age, I was made to feel different due to my Haemophilia. I was held back at every opportunity. I didn't feel the point in going to school. I was never allowed to do joinery or things like that, and there was only so much English and arithmetic that I could do. I wasn't allowed to participate in sports and other students were warned to be careful around me. It was hard to fit in, I was segregated. This became worse after HIV became more within the public domain.

56. After school, I went to college to study a business course. I passed first year, but couldn't go back for second year due to my bleeds.

57. I then went to work at Toys-R-Us, but I couldn't last long on my feet. I worked 4 hours a day and then became too tired. I knew something

wasn't right, but I assumed it was the Haemophilia. I now know this was due to the Hepatitis C.

58. Haemophilia has always prevented me getting jobs. As soon as I mentioned it, heads would drop. When I didn't disclose that I had Haemophilia, I would get jobs and then they would find out and I would be sacked for not disclosing it. It was a crazy "merry-go-round".

59. Being unable to work made financial hardship kick in big time. The financial effects were devastating and if it wasn't for my dad I would have been on the streets.

60. I have had a strange relationship with my mum because of my infection. She treated my differently to my brother, he was not affected by the Haemophilia. Dad, however, gave me my freedom. He treated me as a normal child and let me do what I wanted.

Section 6. Treatment/Care/Support

61. I get counselling from the Haemophilia Centre. I have been having it for the last year and a half. This was for panic attacks and anxiety. At first, they wanted to give me drugs but I said no and I changed my counsellor.

62. My new counsellor is a breath of fresh air. I have sessions 2 or 3 times a month and I find it very helpful. She has a different approach to drugs and instead talks to me. She listens and explains and isn't judgmental.

63. From my experience, when I was at the hospital some throw away comments that I had made to a nurse for instance about the way I had been treated would end up in my notes. Now I have faith in my counsellor that what I say to her remains confidential.

Section 7. Financial Assistance

64. In 2004, I received a stage 1 payment of £15,000.00 from the Skipton Fund. I also received £30,000.00 from the Scottish Government in December 2016 and £1,000.00 worth of heating payments.

65. The Scottish government will be giving me more money from 15 December 2018. This will be £1,545.00 a month. However, the £1,000.00 I previously received for heating is going to be gradually taken back from this.

66. I would prefer the money in one lump payment rather than monthly instalments because I don't know when I'll be gone. If I die tomorrow, nobody gets the rest of the money I'm due. It would help me plan and budget my life.

67. The process for applying for the compensation was fairly straightforward; I did not have any difficulties.

Section 8. Other Issues

Between 1981 and 1982 I went on holiday to Chichester with my parents. Beforehand, I had been told by Professor Ludlum not to take Factor VIII in England because it's "poison". I went into hospital with a bleed and told the doctor I didn't want to be treated. He said, "to be truthful Mr **GRO-B** this is safer than the stuff they are giving you in Scotland. Take this, and then when you go back, tell them that you don't want to take the Edinburgh stuff anymore". I had one shot of Factor VIII in Chichester.

68. In the late 90's and early 00's, there was a Factor VIII shortage in Scotland. This was about the same time that I was first being treated for Hepatitis C. I went to Edinburgh Haemophilia Centre to pick up my Factor VIII prescription and was told that I wasn't allowed it due to the shortage. They said that I was being put back onto the old Edinburgh factor and told me that they couldn't guarantee that it was free from infection. They wanted me to sign a form to say that whatever happened, I wouldn't sue them if I contracted HIV or any other infections. I refused and they said okay but you can't take any of the other factor home. I then had to go back to my old routine of going into hospital whenever I had a bleed, and they said that they would use the new factor. I had previously been told that Edinburgh factor didn't exist anymore so, this was very odd.

69. At one point, they were using factor from America. This should not have happened.

70. There shouldn't have been any new cases of HIV in Scotland from the 80's onwards, however there have been and continues to be so today.

71. I campaigned outside the Scottish Parliament screaming for justice. I wanted to go to London too, but I didn't have the funds. A fellow campaigner, who has been prolific from day 1, has papers and dossiers that prove that Scotland knew what was happening in the mid 70's. He went to the police with this information but was warned off. This was Mr Robert MacKay and his wife Alice MacKay.

72. In 1999, I went to see a solicitor Edinburgh; I think it was Mackie's about how I was infected. They took one statement but it went no further. I also asked for my medical notes at this time and was told that they had been shredded. The notes I wanted apparently did not exist.

73. The Penrose Inquiry was a "whitewash", people just had to say it never happened and that was that, it was done away with. The feeling in my community is 100 per cent that.

74. Whilst I am very happy that this inquiry is underway it is for some, 20 or 30 years too late. Most people with Haemophilia died in the 1990's.

75. I think that people with Haemophilia should be treated differently to transfusion patients with regards to the Inquiry. A distinction should be drawn between the two. The difference is that, we had no choice, we were just given this. "This is your treatment just take it'

76. From this Inquiry, I want people to be held to account. Money doesn't really come into it, but it does help. From the money I have received, I can now live instead of just surviving.

77. I think there should be criminal charges for those responsible. I believe people used the concentrate knowing that it was infected and they should be in jail. If they were regular people on the street they would be in jail for mass murder.

78. After all these years it is very refreshing that you have listened to what I have had to say.

79. I would be willing to give my evidence in person to the inquiry if required.

Statement of Truth

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

Signed **GRO-B**

Dated 12/12/2018