Witness Name: GRO-B
Statement No: WITN1718001
Exhibits:WITN1718002 – WITN1718007
Dated: April 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF GRO-B

I, GRO-B will say as follows:-

Section 1. Introduction

1. My name is GRO-B, I was born on the GRO-B in GRO-B, but spent four years in GRO-B I moved to the UK when I was 13 or 14 years old. I live at GRO-B with my wife. I have three children who are now grown up.

2. **This witness statement has been prepared without the benefit of access to my full medical records.**

Section 2. How infected

3. I was diagnosed with severe Haemophilia A in about 1970 shortly after I came to the UK; I had a serious bleed in one of my hips. I had an x-ray and the doctors could not see anything causing the bleed. It was decided that I needed an operation but when they opened me up I was bleeding internally. Thereafter I was treated at the Haemophilia Centre at the Queen Elizabeth Hospital Birmingham with fresh frozen plasma and cryoprecipitate.

4. According to the extract I have received from the National Haemophilia Database, which I produce as **Exhibit WITN1718002**, the blood products I received between 1970 and 2008 were; Kryoblin, Cryoprecipitate, Factor VIII (BPL), Factorate, Factor VIII (PFC), Profilate, Factor VIII HP (PFC) Recombinant VIII, Kogenate, Helixate, and Advate. I was one of the first patients to start home treatment with Factor VIII. This was much better than having to be on a drip for hours in hospital. Being able to self-treat with Factor VIII helped make me more mobile.

5. Between about 1970 and 1975, I attended the Queen Elizabeth Hospital Birmingham, Haemophilia Centre, Edgbaston, Birmingham, B15 2TH. I was under the care of Dr Peter Jones, Dr L.K. Harding, and various others.

6. Between about 1975 and 1980, I attended Leeds Haemophilia Centre, Hematology Outpatients, St James's University Hospital, Beckett Street, Leeds, West Yorkshire, LS9 7TF, and was under the care of Dr Swinburne and various others.

7. Between about 1980 and 1989, I attended the Haemophilia & Thrombosis Centre, Glasgow Royal Infirmary, 84 Castle Street, Glasgow, Scotland, G4 0SF, under the care of Dr Lowe and various others.

8. Between about 1989 and 1998 I attended Haemophilia and Thrombosis Centre, Royal Infirmary of Edinburgh, Edinburgh, Scotland, EH16 4SA. I was under the care of Dr Ludlum and various others.

9. Between about 1998 and 2016 I attended the Haemophilia Reference Centre, St Thomas' Hospital, 1st Floor, North Wing, Westminster Bridge Road, London, SE1 7EH. I was under the care of Mr Smith, Dr Wong, and Dr Savita Rangarajan.

10. Since about 2003 to the present, I have attend the liver unit, King's College Hospital, Denmark Hill, London, SE5 9RS, and have been under the care of Dr Abid Suddle and various others.

11. I was infected by blood products provided by the NHS at some point between about 1970 and 1980, either at the Haemophilia center in Birmingham or in Leeds. I produce as **Exhibit WITN1718003** a letter from the Queen Elizabeth Hospital Birmingham dated 18th January 2019 stating that my medical records from that hospital have been destroyed. I have been informed by St James' Hospital in Leeds that they also no longer hold any medical records relating to my treatment. Therefore, the only medical and treatment records that I have been able to access from these hospitals have come from my GP and National Haemophilia Database.

12. Whilst I was being given Factor VIII, I was told that it had been imported from America but no information or advice was provided to me beforehand about the risk of being exposed to infection from blood products.

13. I was infected with Hepatitis C as a result of being given NHS provided blood product.

14. Between about 1972 and 1975, I remember doctors talking about the risk of patients at the Haemophilia Centre contracting non-A non-B Hepatitis and that doctors were beginning to notice that patients at the clinic were having problems with their livers. At about this time, my GP also asked me to do a survey which asked about the condition of my liver; at the time I thought this was due to my medication.

15. In my GP records, there is a letter dated 07/11/1985 from the Glasgow hospital to GRO-B which I produce as **Exhibit WITN1718004** which says '*since* GRO-B *came to Glasgow he has had persistently elevated serum transaminases and as his hepatitis B surface antigen has been persistently negative, this probably reflects non A, non B hepatitis which is common in intensively treated Haemophiliacs*'. There is also a letter dated 10/01/1989 to Dr C Ludlam at the Edinburgh Haemophilia Centre from Dr Lowe at the Haemophilia and Thrombosis Centre in Glasgow, which I produce as **Exhibit WITN1718005** stating it '*seems possible that he has chronic non A non B*

hepatitis'. At the time that this letter was written, in January 1989, I had not been told that I might be suffering from hepatitis; I find it remarkable that my GP was receiving these letters and was doing nothing about it, not even informing me that I might have Hepatitis.

16. There is also a letter dated 12/01/1995 to GRO-B from Dr Ludlam at the Edinburgh Haemophila Centre, which I produce as **Exhibit WITN1718006** stating '*he will certainly have had HCV infection for almost the past 40 years and there is a good chance that he may have cirrhosis*'.

17. In or about the early 1990s, I was at a family event and met a family friend who was a surgeon in Canada. I told him I was a Haemophiliac and he asked how my liver was. When I said they were doing tests he just replied '*and you are drinking*?'. He didn't go into further details, but from that point on I realized that I might be doing my liver damage if I continued drinking alcohol and immediately reduced my alcohol intake to a minimum; I do not think it should have taken a chance meeting with a family friend for me to be made aware of this risk.

18. At a routine appointment in 1993 at the Edinburgh Haemophilia Centre I was informed in person by Dr Ludlum that I had Hepatitis C ("hereafter "HCV") and that I probably only had 5 years left to live.

Section 3. Other Infections

19. I received a letter regarding vCJD on 25/11/2002, which I produce as **Exhibit WITN1718007**, stating '*according to our records this patient has not received treatment with any batches implicated with variant CJD*'. Therefore, I do not believe I received any other infections.

Section 4. Consent

20. I strongly believe I was tested without my knowledge and consent: as set out above, I was not informed of the reasons for my liver function tests and

regular blood tests or that, as early as 1988, my doctors believed that I was likely infected with non-A non-B Hepatitis.

Section 5. Impact of the Infection

21. When I was told about my HCV infection, I asked my doctor what HCV was. My doctor told me it was a liver disease which had no cure. I was devastated because Haemophilia was not life threatening but suddenly I had a condition which could cause my death.

22. I do not believe that I was given adequate information to help me understand and manage my infection.

23. Being diagnosed with HCV had a profound mental impact upon me. I waited a couple of months before I told my wife about my infected status because I simply couldn't bear to tell her. We were having a small domestic argument at the time and I said '*do not worry: I will not live that long anyway*'. She asked what I meant and I explained that I only had 5 years left to live. It was utterly devastating.

24. I believe information should have been provided much earlier because my wife and I had three children by 1991; I might have been putting my family in danger of contracting HCV. I also think the Glasgow hospital should have told me that my liver was damaged.

25. Being infected with HCV has had a major impact on my private, family and social life: because of the symptoms of hepatitis and from the medication I had to take, for most of my life I have not been well enough to have an active social life.

26. As an adult, I didn't make a big deal about the fact that I had haemophilia because, after I started home treatment, I could largely live a normal life. I therefore didn't have to tell people about my condition. However, because nobody outside my family knew I was a Haemophiliac, I did not want to tell

them I had HCV because of the stigma attached to that disease and because they might get the wrong idea; I felt it was a disease usually associated with drug use and unsafe sex with multiple partners. My wife and I were so frightened about people finding out that I had HCV. I felt that at the time of my diagnosis, in the 1990s, that people with HCV were treated like lepers.

27. For over 35 years my wife, children and I have been unable talk openly with family and friends about what I went through; it still worries me what they might think about me should they find out and I am still concerned about the stigma associated with having HCV.

28. I was not given any information or advice about the risk of others being infected as a result of the infection. I learned about the risk infections to family members through the media.

29. Before I had my 3rd child I went for medical advice at the hospital because I had seen a link between Haemophiliacs and HIV in the news. I wanted to know if it was safe for me to have another child. I went to the Edinburgh Hospital and my doctor told me everything should be fine. Notwithstanding this advice, I remember that the nurse there always encouraged patients to take free condoms, which I assume was due to the risk of infection.

30. What has really annoyed me is that, despite the fact that I was suffering from a liver disease, rather than being treated by a liver specialist, I had a hematologist in charge of my care. I feel they should have immediately referred me to a liver consultant. Even at St Thomas' Hospital, a year before I underwent a liver transplant, I was still receiving treatment from hematologists at the Haemophilia center for my hepatitis, rather than being treated by a liver specialist.

31. I first received interferon treatment at the start of 1994. I took it for around 6 or 9 months. It was a clinical trial that I volunteered for. I had some early positive responses to the treatment, but unfortunately the viral load gradually increased. The side effects from treatment were quite severe: I had terrible

brain fog, developed a rash which covered my body and suffered from anaemia, fatigue and blurred vision. Unfortunately the treatment was unsuccessful and I did not clear the virus. This was a huge disappointment: I had gone through that awful experience during treatment without any benefit.

32. It was not until around 2001 that I was recommended to undergo combined ribavirin and interferon treatment. I think I was on the treatment for about 9 months; I was injecting 2 or 3 times a week and taking a tablet daily. Again, the side effects were really awful; I had the same problems as before but this time the anaemia and fatigue were even worse. I had virtually no energy and was in bed for a considerable period of the treatment. Again, this treatment was unsuccessful in clearing my infection.

33. By about 2003, my liver function had deteriorated significantly and I was experiencing terrible symptoms. I had almost completely lost my appetite, my stomach started to bloat and I became jaundiced. I can remember that at around this time my sister came to visit me and she could not recognize me at the airport because of how ill I looked. I could only manage prescribed liquid food called Fortisip, which was the only thing keeping me going for about 2 to 3 months.

34. Eventually, in or about 2003, I began to be seen by a liver specialist at the Haemophilia Centre in St Thomas', Dr Wong. He referred me to King's College Hospital for a transplant assessment. The consultant there said he would monitor me every 2 or 3 weeks, as they adjust the list regularly depending on how in need you are. They were doing regular MRI scans of my liver because nodules had developed and they did not know if they were cancerous.

35. In the years that followed this referral, my liver function began to decline and my symptoms became worse and worse over time; eventually I felt like a dead man walking.

36. In or about 2008, I was placed on the waiting list for a transplant. Whilst I was on the waiting list, I was not sure if I would get a liver or not. I was saying goodbye to everybody as I thought it may be the last time I would see them. I was also getting my wife ready for if I was not around. I was showing her how to pay the bills and manage the household finances so she could be self sufficient when I was gone.

37. Fortunately, I was not waiting on the list for long and I had my liver transplant on 13th July 2008.

38. The post liver transplant side effects I had were dreadful; I suffered from elevated blood pressure, severe changes in mood, elevated blood sugar, muscle weakness, kidney dysfunction, nausea, vomiting, diarrhoea, brain fog, lack of energy, anxiety, and headaches.

39. Shortly after my liver transplant, while I was still at the hospital my body had rejected the liver. They had to do a brain scan which showed white matter damage. For 3 days and nights I could not recognize my family and I saw people as monsters, becoming aggressive and manic for no reason at all. I also suffered from repetitive body movement behaviour like a crazy person over these three days whilst I was kept in hospital. At the time, it wasn't known whether these side effects were permanent. Fortunately, I stabilised after three days and now have no memory of acting this way; I have learnt about it from my wife and children who had to watch as I went through these terrible psychotic symptoms.

40. The new liver I received was Hepatitis B core positive; unfortunately you cannot be choosy when you receive a transplant. As I result, I have to take lamivudine 100mg daily. I will have to take this for the rest of my life.

41. In the years following my liver transplant, I had to stay "*ultra-clean*", as my immune system was dramatically affected; if I had caught any infection it could have had terrible consequences. I would catch a cold every winter and it would take me 5 or 6 weeks to fully recover. I therefore could not risk going on

the underground for 6 years and had to drive to work or worked from home as much as possible.

42. After I had the liver transplant, in or about November 2010, it was decided that I should have a third attempt at treating my hepatitis with ribavirin and interferon. The HCV had remained after my liver transplant and had severely attacked my new liver. My liver biopsy had shown that, within two years of the operation, my liver function had reduced dramatically. I was under the care of the liver unit at Kings Hospital when I had the third clearing treatment. I was very grateful to be under the care of someone who knew what they were doing with the liver, rather than being treated by haematologists. This time round the liver specialist gave me a blood transfusion to help with the anaemia. Every time they gave me regular blood transfusions which meant I could last on the treatment for another 5 or 6 weeks. This made the treatment more bearable as whenever I had a blood transfusion, it would temporarily remove the side effects of taking the medication, meaning that I could carry on with the treatment for longer. The treatment lasted over 12 months. Even though I was having regular blood transfusions, for most of that year I was unable to work.

At the end of the 12 months my HCV was undetectable and has remained at undetectable ever since; it is therefore believed that I successfully cleared my HCV infection. Over time, liver function improved.

43. I believe that, if I had been under the care of the liver unit for my first two rounds of antiviral treatment, I may have cleared the HCV and I would not have had to have the liver transplant. I believe I went through extra suffering because I was not under the right care. I should have received blood transfusions every time I was given antiviral treatment; this would have meant I was well enough to continue the treatment for longer.

44. I was able to work but had difficulty at work (not able to concentrate, lack of energy and other side-effects). When I was on HCV treatment I had to take

time off from work. From 2005 to 2008 my liver started to get worse, lack of energy, not eating properly again meant taking time off from work. I had to have time off work after liver transplant.

45. As a result of my treatment and the time I had to take off work, my career progression effectively stopped from 2003. Currently, I am struggling at work. I am planning to take early retirement because I am having such difficulties with concentration and "brain fog". At least 2 or 3 times a year I cannot cope at work physically and mentally and have to take time off. I feel that this is almost certainly as a result of physical and psychological effects of what I have gone through.

46. I worked for good companies who have been very good at allowing me time off when I am unwell and who have been very understanding. Whenever I have required time off, I have been lucky enough to take sick leave on full pay.

47. I got married in 1981 when I was living in Scotland: it terrifies me to think that all that time I was receiving contaminated blood products and I could have infected my wife and children with HCV or even HIV, if I had caught that. If I had known I was at risk, I would not have got married. I would not have wanted to risk destroying a woman's life.

48. Sometimes your partner suffers a lot more than yourself; they see the affect on you and it ruins their life. After I was diagnosed with HCV and underwent all of my treatment for this disease, my wife eventually fell ill with PTSD. She had to look after me, the children and herself all at once for so many years. She was there all through the difficulties before and after my liver transplant, when I was handing things over and getting ready to depart. That was an awful time for her. Once things had settled down and I was getting better after the transplant, my wife had a mental break down one day when she was at the shops. She suddenly did not know where she was, why she was there and, for a period of time, she could not function. She recovered after a few

years but has developed an autoimmune disease; this is thought to be trauma and stress related.

49. Because of the care I needed, my wife was not able to return to work after the children were grown up; this has meant that she has been unable to earn her own money since about 2003 to date as a result of my health difficulties.

Section 6. Treatment/care/support

50. I was never offered any counselling or psychological support arising from my infection with HCV.

Section 7. Financial Assistance

51. I was told about funds being available for victims of contaminated blood products by the St Thomas Haemophilia Centre, when a consultant informed me. The process of applying for the payments was simple and was carried out by my consultant.

52. The Haemophilia consultant at St Thomas Hospital did an assessment and helped me fill in the application form. I have been Stage 1 since 1980 and stage 2 since 1996, but only started to receive payments from 2004. I believe my amount should be backdated.

53. I received the Stage 1 Skipton fund payment of £20,000 on 1/10/2004 and the Stage 2 payment of £50,000 on 15/04/2005.

54. In 2017 I also received annually £15,150 and in 2018 I received £18,500 in addition to a £500 winter fuel allowance.

55. I did not face any difficulties or obstacles when applying for assistance.

56. I do not know if there were any preconditions imposed on my receiving these payments.

57. I do however believe that it is very unfair that Scottish HCV suffers who are eligible for the Stage 2 payment receive in excess of £27,000, compared to £18.500 in England. I believe this to be wrong, especially as I used to live in Scotland and everybody received the same contaminated products.

58. Before the first Skipton Fund payments were provided, I felt very much on my own financially. My children were in education, there were fees to pay and a home to run. I did what I could but it was always a struggle from my health side.

Section 8. Other Issues

59. Travel insurance is very expensive due to my pre-existing conditions

60. My haemophilia database records are not complete, and I have considered making a complaint about this as they do not seem to be taking any responsibility for finding out why so many of my medical notes have gone missing.

61. I have also seen that there are also lots of inaccuracies throughout my medical records. After virtually every hospital appointment I go to, I find that when doctor sends his letter to my GP there will invariably be 3 or 4 mistakes, whether this be about the medication I am taking or about what we discussed in clinic.

Anonymity, disclosure and redaction

62. I request anonymity and reaction of all information related to me and my family names mentioned in this document.

63. I understand this redacted statement will be published and disclosed as part of the Inquiry.

Statement of Truth

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

Signed............ GRO-B ..... GRO-B

Dated 20|5|2019.