Witness Name: GRO-B
Statement No: WITN1319001
Exhibits: WITN1319002-5
Dated: September 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 of GRO-B. My date of birth is GRO-B 1971. I currently live with my long term partner of 16 years.

2. As a result of receiving contaminated blood products, I was infected with Hepatitis C. I was cleared of the virus in 2003.

3. This witness statement has been prepared without the benefit of access to my full medical records. If and in so far as I have been provided with limited records the relevant entries are set out in the medical chronology at the end of this statement.

Section 2. How infected

4. I suffer from severe Haemophilia A and was diagnosed as a baby. I was initially treated at GRO-B under the care of Dr GRO-B GRO-B.

5. I am not sure about names of the blood products I received from GRO-B. The following are the names of products I know I've received: Factor VIII, Porcine Factor VIII, Autoplex, Cryoprecipitate, Feiba, FIX_9A (BPL) and Novoseven.

6. Obtaining my medical notes from GRO-B has been extremely difficult. They initially said they no longer had any records for me but after various letters and emails, including one to the Chief Executive, and using Public Inquiry powers some notes miraculously turned up! I now have a CD containing my notes; although I am still not convinced they are complete.

7. In 1988 I was transferred to the Royal Hallamshire Hospital (RHH) in Sheffield. I received my medical records from the RHH without too much difficulty. I have been a patient there since from approximately 1988 to the present day.

8. I was given infected blood products from 1972 or 1973 to 1989 at the GRO-B. I was 18 months old when I first received treatment.

9. I was exposed to Cryoprecipitate, Factor VIII concentrate, Autoplex, Feiba & Porcine Factor VIII (all before heat treatment was introduced) on numerous occasions as I was treated for bleeds relating to my haemophilia. I developed an inhibitor to Factor VIII and the inhibitor was only discovered after being treated with Cryoprecipitate and Factor VIII numerous times. This was all during the early 1970s through to the 1980s and I believe this is how I came to be infected. I attach at Exhibit WITN1391002 a copy of the records from the UKHCDO which show the treatment I received.

10. I was never advised of being exposed to any risk of contracting blood born viruses through treatment. My parents and I were only told about the risk of developing an inhibitor.

11. As a result of being given blood products I was infected with Hepatitis C.

12. I was approximately thirteen years old when my parents and I were called in to GRO-B for some blood tests as they were aware of some infection. A couple of parents were called in. We were not told what we were being tested for. My parents became aware of HIV through media and presumed that's what the tests were for. I was given the all clear from HIV. At that stage Hepatitis wasn't something that was talked about and very little was known about the virus. I believe it was years later as a patient at the RHH that a virus known as non A non B (NANB) Hepatitis was talked about, but not with any cause for concern.

13. As a patient at the GRO-B my mum has no memory of ever being told about Hepatitis C. I have found, via my notes from the GRO-B and the RHH, that I had abnormal liver function tests that were never conveyed to me. There is reference in 1992 from a doctor indicating that they could not see a Hepatitis C test. This is attached at Exhibit WITN1319003. I cannot remember being asked or told about this test, but, as a Haemophiliac, I was always having bloods taken. The test in 1992 came back positive but I have no memory of sitting down with a doctor and discussing the results or the impact of the virus. It was always played down until a few years later when the doctors pushed for me to start treatment as my liver function tests continued to deteriorate. My mum can recall NANB Hepatitis being discussed at SCH but it was never discussed in detail.

14. We were told it would never be an issue; however looking back at my notes I can see how my liver function tests were abnormal and yet this information was never passed on to my parents.

15. I cannot find any reference in my notes that says the doctors sat down and discussed the Hepatitis C with myself or my family.

16. I consider that information should have been provided to me earlier. I should have been told as soon as the hospital were aware and according to the notes I have obtained from the RHH, they were aware in 1991 that my liver functions test results were abnormal but this was not conveyed back to me as a problem. This was around when I was a teenager. I feel I could have changed my lifestyle accordingly if I was aware. I have recently obtained some notes from the GRO-B (after lots of chasing and being told there were none) and it appears that I was having regular liver function tests when I was approximately 11yrs old (in 1982). My mum has no memory of them talking to her about doing these tests or discussing the results.

17. Upon receiving my notes I have noticed that my liver function test results were abnormal. The doctors were obviously aware that my results were not good but the seriousness was never communicated to me or my family, I was never told the reason why the results were going up – it was never spoken about as anything to worry about. The first realisation of how serious it was came when I was advised to try Interferon treatment - this was when the virus was known as Hepatitis C.

18. No information was given about the risks of others being infected as a result of the treatment with blood products. At the time it was glossed over and was deemed not to be an issue – it was just one of those things – often referred to as NANB Hepatitis and I was told it would give me no problems.

Section 3. Other Infections

19. I believe I'm at high risk of being exposed to vCJD. I received a letter in 1997 advising that patients that had received blood products were classed as high risk when it came to vCJD. They were aware there were some implicated batches from a donor that subsequently died from vCJD and the letter asked if I'd like to know if I'd received blood products from the implicated batch. I was advised that I had not received any of the contaminated batches but if they became aware of any further batches I would be informed. It has always been at the back of my mind that there were some batches that slipped through the net. Little is known about vCJD so it has always been a worry.

20. I have suffered for years with unexplained viral symptoms such as fevers, joint swellings (not bleeds) that the doctor's have never been able to diagnose – these could all be related to contaminated blood products. I feel like my immune system has been damaged. I have had verrucas for most of my adult life that I cannot get rid of despite trying everything possible. I also have unexplained rashes, itchy skin and hair loss. I will never truly know the extent of my exposure to viruses. I attach as Exhibit WITN1391004 a copy letter from Dr Stewart at Scunthorpe General Hospital dated 20th August 1985 which refers to his agreement with my GP that I had some kind of intercurrent virus and he refers to the "remote possibility that Autoplex, the matrial which he uses to treat his haemophilia could transmit a viral infection".

21. I understand from my records that results show there is evidence of past infection with Hepatitis B and Parvovirus.

Section 4: Consent

22. I cannot say one way or the other whether I was tested or treated without my knowledge or consent or for the purposes of research. I was having regular blood tests at clinic

appointments but I was not always aware of what I was being tested for. I would not know if I was being tested for the purpose of research. After obtaining some hospital notes it is apparent that they were checking my liver function on a regular basis.

23. I have been shown at Exhibit WITN1391005 a copy of a consent form signed by me in March 2010 and a letter dated 16th December 2010 to carry out research into the investigation of gene variants associated with resistance and susceptibility to HIV-1 infection in HIV-1 exposed but uninfected individuals with Haemophilia A. To the best of my knowledge I have received no further information despite the letter referring to "continuing work".

Section 5. Impact of the Infection

24. Having chronic Hepatitis C has caused me to suffer life altering mental health issues. I suffer with terrible anxiety and worry which results in palpitations and stress. I have been diagnosed and treated for both depression and anxiety. Most days I feel drained, low and flat in mood and energy, although I force myself to try and function normally. I live in a small village; only my family and partner know about my condition. I have been constantly living in fear that someone else may find out and as a result I will be treated differently. As a result of my Hepatitis C diagnosis I am now left with F2 fibrosis and worry about this constantly which adds to my anxiety.

25. I have suffered for years with unexplained viral symptom such as fevers and joint swellings which the doctors do not attribute to Haemophilia. These could all be related to my Hepatitis C infection. I feel like my immune system has been damaged. As mentioned above I have F2 liver fibrosis. I suffer from chronic fatigue and what I would describe as 'brain fog.' I struggle to concentrate, feel exhausted all the time and feel my mental health has suffered as a result of the infection.

26. My first treatment to clear the Hepatitis C was a course of Interferon and started on 14 November 1995. I finished that course in April 1996. However I have also found in my notes reference to this treatment lasting a year so I am unsure whether my first course of treatment was 6 months or 12. This course was unsuccessful.

27. In January 1998 I started a course of Interferon and Ribavirin. I suffered a heart attack in February 1998. Initially the doctors were unsure if this was caused by the treatment but it was later decided that it had been caused by Factor IX (BPL 9A).

28. In April 1999, after the Consultant Cardiologist confirmed the heart attack wasn't down to the Interferon, I was given the go ahead to start again. This course began again in March 2001. I completed the course in August 2001 and initially tested negative for Hepatitis C. However a further test in January 2002 came back positive for Hepatitis C and the doctors confirmed the course had not been successful after all.

29. In October 2002 I was started on PEGylated Interferon & Ribavirin, the course was completed in March 2003 and I was successful in clearing the virus.

30. All the treatments I have had have contributed to my mental and physical health problems.

31. I didn't really have any difficulties in accessing these treatments – all treatments were relatively new at the time. I tried them and the doctors were pleased that I was happy to give them a go. My liver function tests were very abnormal; therefore I didn't really have any option but to try them as the long term consequences of not trying would have been worse.

32. Although today's treatments have a lot less side effects and clear the virus quite quickly these were not around at the time I was treated. Therefore, I do not believe there were treatments that should have been made available to me.

33. The Interferon treatments I had were all extremely difficult to endure. Each course of treatment lasted a number of months and the physical and mental effects were horrendous each time. I was physically sick throughout (especially after taking the tablets) resulting in a loss of appetite and huge weight loss. I suffered extreme flu like symptoms, including chills, fevers, and also suffered from itchy skin, hair loss, rashes, muscle pain and inflammation and insomnia due to the inability to cope with symptoms. To then find out, on two occasions, that the treatment hadn't been successful further added to my anxiety and depression knowing I was going to have to suffer all the above if I was to try the treatment again with no guarantee of success.

34. Due to my Hepatitis C status my partner and I had delayed our plans to start a family of our own. After I was finally cleared of the virus and we decided to make plans we discovered

my partner had some medical issues of her own that would mean the best hopes for us would be via IVF treatment. During some initial consultations my Hepatitis C was discussed and although I had been cleared there was a question mark over whether they would accept us for treatment as I was still classified as 'high risk' when it came to storage of samples in their laboratory.

35. This added to my anxiety at an already difficult time and we had to wait some months whilst the virologist and doctors discussed our case amongst each other. We were advised if we were refused IVF treatment in Sheffield we may have to travel to Liverpool as they had a specialist team that would accept high risk patients. Liverpool is over 120 miles away for us and it would not have been practical or affordable to travel all that distance especially considering that sometimes you require 2 or 3 appointments a week. We were finally accepted at Sheffield after an anxious few months wait.

36. The only people that know of my Hepatitis C infection are my immediate family and my partner. I have never felt comfortable or wanted to tell anyone else. I have always felt it was best to keep it to myself as I was never sure how my friends would react if I told them. I didn't want to be treated any differently. I didn't want to be the victim of malicious rumours and gossip. Living in a small village, news travels fast and people can be very quick to make presumptions.

37. I shied away from relationships in my younger days as I was aware I had a virus but nobody knew what it was or how it was then transmitted or treated. It has always been a difficult subject to have with partners as you can never be sure how they'll react, but you cannot not tell them so it's a conversation you must have. It prays on my mind now that when I was in school and wasn't aware I even had Hepatitis C that I could have unknowingly infected a fellow pupil without knowing via a playground scuffle, when suffering with a nose bleed or your usual childhood cuts and scrapes.

38. When the news started reporting on Haemophiliacs contracting HIV people would question whether I had it. I could answer honestly and say no. My mother was advised by letter dated 26th February 1987 that my blood test for the AIDS virus was normal and that I had no signs of the infection. I was further tested in 1995 and again that test was fortunately negative. Hepatitis C has been reported on more recently and some people have asked me the same questions. I have always felt the need to lie and say no. I then usually try

and change the subject as it is not a conversation I have ever wanted to have with anyone outside my family.

39. Looking back now I think the Hepatitis C virus massively affected my school work. Whilst having Haemophilia wasn't easy anyway as I was always suffering from bleeds which resulted in my missing out on a lot of school, I was always tired and struggled to concentrate. I especially noticed this when I was in my last years at secondary school and college. I believe this is when my liver tests were coming back abnormal and this greatly contributed towards my struggles. In the end I left college early as I couldn't cope with my Haemophilia and general fatigue.

40. I have been unable to work due to all of the above. I wouldn't have been able to hold down a job whilst I was on Interferon treatment as the side effects were so bad. As mentioned above I had the treatment 3 times and basically lost 3 years of my life to that.

41. During my 'best years' whilst all my friends were finishing college and starting new careers I was struggling with Haemophilia and the effects of Hepatitis C. I had so much going on in my life medically that holding down a job would have been impossible. I have therefore spent my entire life on benefits. The benefits I were initially given were promised for life but in recent years as new schemes have been introduced those promises have been squashed and I have found myself jumping through hoops, filling out form after form, trying to answer yes and no questions when the answer is neither yes or no to be awarded with what I would describe as pittance to live on.

42. My parents are by no means wealthy but if it wasn't for their help and support over the years and for their assistance when they helped me buy a house I don't know where I would have ended up. To this day benefits are only awarded for a certain length of time, the timescale as decided by the benefits office, so any day you could come home to find the dreaded brown envelope asking you to reapply and start the process of jumping through hoops all over again. There is no financial security.

43. As mentioned above the only people who know of my Hepatitis C virus are my immediate family and my partner, all of whom have been very supportive over the years. It was incredibly difficult for my parents to discover their son has been infected with Hepatitis C. It was particularly difficult on my mum who was my main carer when I was a child.

Section 6. Treatment/care/support

44. I have never been offered counselling. I recently completed the special category mechanism form for the EIBSS with one of my nurses. After hearing my story my nurse asked if I had ever had or been offered counselling. I advised not but to be honest this is not something I'd be interested in. I have always been a very quiet, reserved person. Perhaps during the worst period it would have been helpful but after all these years, I have learnt to cope on my own. I have noticed on the EIBSS website they do offer money towards counselling but I understand it is a limited amount.

Section 7. Financial Assistance

45. I follow groups like 'Tainted Blood' online that keep me up to date with any new schemes or financial help that is available.

46. On the 17 September 2004, I received a one off ex gratia payment of £20,000 from the Skipton Fund. Since 20th November 2016 I have received regular payments of £3,500 per year. This includes a winter fuel payment of £500.

47. I have also applied to the Caxton Fund for various grants over the last few years to help towards the costs of things like household items and IVF treatment.

48. From October 2017, the EIBSS offered the Special Category Mechanism payments and I received monthly payments of £1,262.50. From April 2018 to present this amount was increased to £1,500 per month. Furthermore, from December 2018 to present, I also became eligible for £479 per month.

49. I feel the trusts are not fit for purpose. The process of applying for financial assistance is demeaning and degrading and makes you feel like you are begging for help whilst their representatives, who make the decisions as to whether you are entitled to assistance, are being paid a salary out of our funding. The money given to run these trusts could have been given to those infected or affected and cut out the middle man.

50. However out of all the financial institutions, the Caxton Fund I felt were really helpful. We applied for a course of IVF treatment and as it was something a bit different they looked outside the box and used their discretion in order to help us. They were very understanding

and we usually dealt with the same person to keep consistency. I received a few grants off them over the years and felt they were always helpful although I still don't agree we should have to ask in the first place; we should be financially independent from grants.

51. The newly appointed NHS EIBSS I have found to be less understanding and quite difficult to work with. Now all the trusts are joint I get the impression they have more work than they can manage. It can sometime take weeks for a response and if you email it is almost guaranteed you'll receive a response from a different person each time. Quite often it is left to us to have to chase them up for a reply. They stick to a very strict criteria and do not deviate from this – if it's not on their list it is not even considered. Their responses are often short and sharp like they begrudge you any help.

52. My shower recently broke and I applied via EIBSS for a replacement. I sent all the correct paperwork and quotes as requested to be told in order to be given a grant I would have to contact my home insurance first to see if they would cover the repair or replacement before they would look to release 'public funds'. When I explained my excess was more than the shower and that the shower was very old so not worth repairing I was told I still needed the appropriate paperwork from my home insurance. After going round the houses I got the confirmation I needed from the insurance and they finally approved my application. What was frustrating was whilst I was chasing around I was without a shower.

53. My partner was sadly made redundant from her long term job of 14 years in 2018 so we applied for the income top up. It was very hard to prove she didn't have an income and the EIBSS made this difficult for us. She claimed Job Seekers Allowance initially but when that ended EIBSS insisted on her proving she couldn't claim any other benefits. No matter how many times we said there wasn't anything else to claim for they insisted on proof. In the end she had to make a further application in order to get a letter back to say she wasn't entitled. Not everyone wants to claim benefits but they insist you should if you're entitled before they offer any help!

54. Under the Caxton foundation we were very grateful to be funded a round of IVF which sadly wasn't successful. We applied to EIBSS for any assistance if we were to try again. We were not asking for the full amount but anything they could offer. We received a very blunt letter back to say they could not offer any help as 'its not on our remit of support'. It was disappointing that our case wasn't even considered or looked at further, as mentioned earlier they only work to a strict criteria and have no interest in deviating from this.

55. As mentioned earlier the money given to the trusts and their employees could be divided amongst those infected and affected to increase their regular payments – perhaps to a level that offers financial security without the need for trusts or grants. People should not have to ask for help so they can live their lives comfortably and move on from this dreadful disaster.

Anonymity

I wish to remain anonymous during this process and I do not want to give oral evidence to the Public Inquiry. I understand that my statement will be disclosed and published on the Inquiry website.

Statement of Truth

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

GRO-B

Signed GRO-B ....

Dated 7/10/19