Witness Name: GRO-B
Statement No: WITN1230001
Exhibits: WITN1230002-9
Dated: June 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 GRO-B 1966 and I live at GRO-B GRO-B with my wife, GRO-B My surname at birth was GRO-B (as shown on some of my earlier medical notes). My mother remarried in 1974 and my stepfather adopted me, giving my surname GRO-B

2. My wife GRO-B has also provided a Witness Statement to the Inquiry (Witness Number GRO-B).

3. This witness statement has been prepared without the benefit of access to my full medical records. Some of the the documents I have in my possession are exhibited to this Statement where relevant.

Section 2. How Infected

4. I have severe haemophilia A, diagnosed when I was teething at 9 months old and having continuous bleeds to my gums. There is no known history of haemophilia within the family. My mother was surprised to learn that she was a carrier and my haemophilia was a worry for her. I had significant/heavy bleeds into my ankle and elbow joints as a child. My mother made a conscious decision not to have any more children. I am an only child.

5. I first received treatment as a baby at St Mary's Hospital, Portsmouth. As a child I then received treatment under the care of the Department of Haematology at the Worthing and Southlands Hospitals. I was transferred upwards to the Guy's and St Thomas' Haemophilia Centre on several occasions. I have been treated at Guy's and St Thomas' on a permanent basis since my early twenties under the care of Professor Ingram, Dr G Savidge, various other doctors and most recently Dr Graeme Thompson.

6. I started home treatment when I was around 12 years old. We had a freezer to store the treatment. At first they gave me cryoprecipitate to take home, before I was moved on to Factor VIII (FVIII) concentrate which they said was a better product. There was no warning of any risk and we did not receive much information other than that it was a 'better' product.

7. I refer to **Exhibit WITN1230002** being a copy of my UKHCDO patient record. According to that record I was first given FVIII concentrate (Oxford FVIII) in 1971 and then FVIII (BPL) and Travenol/Hyland/Hemofil FVIII in 1977. I do not believe the UKHCDO patient record to be accurate. I refer to **Exhibit WITN1230003** being a hospital record of a Haemophil prescription back in 1970. I was also given a lot of Haemophil in 1974, the year I was sent to Guy's and St Thomas' Hospital with a suspected appendicitis. I refer to **Exhibit WITN1230004** being some hospital records from that time. I had a bad reaction to the Haemophil

treatment, feeling very unwell with stomach pains and running a high temperature the day after the treatment.

8. I am co-infected with the Human Immunodeficiency Virus (HIV), the Hepatitis B Virus (HBV) and the Hepatitis C Virus (HCV) from contaminiated FVIII concentrate.

9. I cannot remember exactly when or how I found out that I had been infected with HIV. I was traumatised at being informed of my HIV status and believe that I have blanked a lot of the detail of that time from my memory as a coping mechanism. I refer to **Exhibit WITN1230005** being two letters sent by Dr Roques to Dr Savidge in 1985. Dr Roques reports to Dr Savidge of me expressing concern about the AIDS scare in February of that year. I have no recollection of this. I have no recollection of taking or being informed of the result of the subsequent HTLVIIII positive test result in the September. Incidentally, my GP (Dr GRO-B) was not informed that I was HIV positive until some 15 months after my HIV positive test results. He was extremely disgruntled about not being kept in the loop and wrote to the Haemophilia Department at Worthing on 12th December 1986 complaining about it. That letter and a document confirming my HTLV3 positive test results in August 1985 is also referred to at **Exhibit WITN1230005**.

10. It wasn't until late 1997 that I was informed that I had HCV by a doctor of Australian origin (his name has escaped me) at Guy's and St Thomas' Haemophilia Centre. His words to me were "Now that we have your HIV under control, we need to look after your Hepatitis C". The doctor told me HCV would be more serious than the HIV and it was this infection that would probably kill me. He also added that there was nothing they could do about it at the moment.

11. The news that I had HCV came as a huge blow to me as I had started taking anti-viral drugs in July 1997 and my HIV had just become manageable. I had no clue that they had been checking my bloods for hepatitis. They used to check my tummy but did not say why. I refer to **Exhibit WITN1230006** being a hospital record seemingly noted by a Dr K Rice on 15th January 1997 that she had "Discussed HepC" with me and (below that entry) had "Given pt info HIV & HepC" on that date. GRO-B and I can only remember being told about HCV later that year after I had started taking HIV antivirals in July 1997.

12. I once asked Professor Savidge when he thought I had been infected with HCV. He told me without even checking his notes or looking at his computer that it was "1974", the year of my suspected appendicitis/bad reaction to Haemophil. It is inconceivable that I wasn't told I had HCV until 1997.

Section 3. Other Infections

13. I received a letter in 2004 telling me that I may have been exposed to vCJD. I couldn't act on that information. I remember thinking "well that's a hat trick then".

14. I refer to **Exhibit WITN1230007** being blood test report documents confirming that I was identified as having been infeted with HBV in Worthing in May 1992. I have recently uncovered these documents in my medical notes and records. To this day I have no recollection of this ever being mentioned to me. Evidence of infection with HCV 'at some time' in 1993 is also noted but I was not informed until 1997.

Section 4. Consent.

15. When the Haemophilia Department took blood from me they would never tell me what they were doing with it. I have seen in my medical records that they were

testing me for Hepatitis A and Hepatitis B throughout the 1970s. They did so without my knowledge or consent.

16. I had no idea that I had been tested for HIV and HCV and did not consent to it. My mother did not provide consent to such testing. In terms of research I refer to **Exhibit WITN1230008** being a letter from Dr Rist to Dr GRO-B advising him that my mother and I had been tested for HIV in 1985 as part of a confidential study of all haemophiliacs. We were not aware of it. Dr GRO-B's response to that letter is again referred to at **Exhibit WITN1230005.**

Section 5. Impact

17. Being informed that I had HIV had an immediate and catastrophic affect on me. The bottom dropped out of my world. I went off the rails, getting into trouble with the Police and falling out with my family. I had real issues with my step dad because of my bad behaviour and anger. I stopped taking my FVIII as I had lost trust in the world around me. I thought I would soon die anyway. I was in a very dark place and it was just all too much for me to handle, resulting in me having a complete psychological melt down. As stated, I have completely blocked out much of the period of my life after finding out I had HIV. I refer to **Exhibit WITN1230009** being letters and documents regarding my psychological state at that time and the attempts at suicide I made. I had blocked the memory of the trauma of how I felt at that time and I cried when GRO-B recently found these documents amongst my medical reocrds and I read them.

18. GRO-B and I met in January 1989. We married in 1992. When we met I was, I believe, in a state of denial. I didn't want the bubble to burst of how I felt when I was with GRO-B I told GRO-B that I was HIV positive in April of that year. GRO-B went with me to my haemophilia appointments Guy's and St Thomas'. It was only at one of the appointments we attended that it really hit home that I was

suffering from the virus and it could develop into full blown AIDS. I was reminded there in GRO-B's presence that they were keeping a careful eye on the HIV status.

19. I remember GRO-B and I were on a caravan holiday together and as we sat watching television, AIDS was all over the news and on the TV adverts. I felt very scared not only about my health but about people finding out that I was infected because of the associated stigma. GRO-B and I decided between ourselves not to tell anyone. No-one from GRO-B's family knew. We have had to lead a double life for all these years and it has been very difficult bottling everything up. It was particularly difficult for us at our own Wedding. It was supposed to be the happiest day of our lives, but in reality we were just worrying about how much time we would have together.

20. We bought our flat in GRO-B in 1991. Because we couldn't tell the building society about my HIV status, GRO-B assumed full responsibility for the mortgage and insurances. The girl we saw for mortgage advice was surprised at GRO-B's insistence that she earned the most and would therefore do it herself (without me). I had missed a lot of schooling because of the haemophilia bleeds. I had a job when I left school in an electronics factory and then in 1990 as a washing machine service engineer. I found it difficult enough to work with having haemophilia but having HIV (and HCV without knowing it) left me extremely tired and run down and I was often sick. I eventually lost my job and couldn't successfully obtain another without being dishonest about my HIV status. GRO-B suggested that I stopped working at this time because she was worried about my health. I was very worried and depressed, and I didn't know how long I had left to live and neither did she. She wanted me to focus on staying well for as long as I could.

21. Before we began living together and then married in 1992, GRO-B and I had a meeting with the Haemophilia Nurse, GRO-D, to discuss our future

plans. She asked us about children and we responded by saying that we had assumed that we would not be able to have any. At this, GRO-D commented "Good" as if satisfied with the response and could, in effect, tick a clipboard response and move on. We have since found out that there were options we could have considered in order to be able to start a family. We had no information or advice about the matter. We were dismissed. It is our one big regret not to have had children. GRO-B and I always wanted to be parents and it was hard when all of GRO-B's siblings were having children of their own. We had no alternative but to tell people that we just didn't want children, which could not have been further from the truth.

22. I resisted taking anti-viral drugs for a long time. I knew that I would need to take a lot of medication on a frequent basis if I began using them and that they (AZT then) came with horrendous side effets. My doctors wanted me to start taking them but I no longer trusted them. I had a fear of becoming very ill.

23. By 1996 my health was on a downward spiral and the doctors assured me that the drugs were helping a lot of people. Dr Savidge was very blunt and to the point (something I actually appreciated) and told me that I had 10 years to live, at most without treatment. This came as a huge shock to me and, upon the subsequent advice of the Australian Doctor, I started taking the antiviral drugs in July 1997. The side effects of the treatment were horrible. I felt worse than ever and very tired. I also had very bad diarrhoea and GRO-B and I could not make any plans with friends that involved us leaving the house. The doctors would frequently change my medication and the doses to alleviate the side effects and it slowly started getting better. Once it was under control, I was then informed by the Australian doctor that I had HCV.

24. I have now been on antiviral drugs for the last 20 years which means my viral load is currently undetectable. However, I have had to live with the side effects of daily medication and will do so for the rest of my life.

25. In or around 2002 they first mentioned Interferon as a possible HCV treatment. I lost my mother in 2006 and I remember that it was around that time that they were trying to get me to take Interferon. I remember feeling backed into a corner with Terry Wong (my hepatologist), Dr GRO-D (HIV) and the Haematology Nurse all in the room togher trying to persuade me. Terry Wong was particularly unpleasant to me telling me "You are going to die" (without it). I said I wanted to speak with Professor Savidge and he said to me honestly he didn't think it would work because of my Genotrype being 1a. I therefore refused but the hospital staff continued to push me into taking the treatment.

26. I agreed to take the Interferon treatment in January 2009, after it was arranged for me to first speak to someone who had been through the treatment before (for 14 months). That person (now a very good friend) told me that the treatment would be absolute hell but unless I tried it, I would never know the outcome. My treatment was planned for 16 weeks. I was also extremely apprehensive about what excuse we could give to our friends for being unable to see them for that period of time. The treatment was hell. I would inject myself on a Sunday night and within an hour I would be drained of energy, have a terrible flu and would be sweating and shivering. By Thursday and Friday I would just about start to feel a little better and then Sunday would come back around. I would look at the Interferon pen and think to myself 'do I really want to do this?'

27. I couldn't eat and lost a lot of weight whilst on the treatment and I became very anxious and depressed. I wouldn't wish what I went through on anyone. I suffer with anxiety and depression to this day. Getting on the train to London every month during the treatment was particularly awful. After 12 weeks of the treatment they called me in and said that they would be taking me off the treatment as it wasn't working. This was a real blow to me. Terry Wong said there were no other treatments available so they would just have to "keep me

alive" until something else was available. In the meantime and between 2010 and 2015 my fibroscan levels were rising.

28. I cleared HCV with a second course of treatment, namely the new Harvoni drug in 2015/16. I was repeatedly told that the treatment was very expensive which annoyed me. I would tell them that I didn't care how much it was going to cost, as they gave me the virus to begin with. As did GRO-B I was told by Dr Babu that I would have to come off one of my HIV drugs (and stop my blood pressure tablets, although that wasn't an insurmountable issue) for at least three months to be accepted, meaning I would miss my slot for Harvoni treatment. Because of this Dr Babu had to appear on my behalf before a panel at Kings College and fight for me to be allowed on the drug. He had to promise to monitor me on a weekly basis to convince them that I was a suitable to start the treatment. He called me immediately afterwards and said I was able to start. Despite it being just before Christmas, I opted to start the treatment immediately as I was so eager to get rid of the virus.

29. The side effects of the treatment were bad, but much more bearable than the Interferon. The hardest thing about it was having to go to London (from GRO-B) every week for the monitoring/blood test. It was a long way to go and it was exhausting and very expensive for us to go back and forth every week. Fortunately, this treatment cleared the virus.

30. I have fibrosis and am on the verge of cirrhosis. My consultant, Terry Wong, has told me that I am not out of the woods yet and that I could still develop liver cancer despite having cleared the virus because of the damage done for over 40 years of infection. The worry never goes away. GRO-B like me, lives with the worry every day. We have struggled alone and without support being unable to confide in close friends and GRO-B's family members to incude her mother. Our deepest regret is that we weren't able to have children. We could never plan for a future. GRO-B has always shouldered the financial burden of just getting by.

31. Despite my HIV being undetectable and my HCV being 'cleared', I still live every day with the knowledge that I have HIV. Similarly, there are no guarantees the liver cancer will not come back. I do not feel very different since 'clearing' the virus and I still get very tired and suffer with brain fog. The doctors do not have the answers to everything. I have to take a complex and potent cocktail of drugs to manage my HIV levels and some of the drugs are harmful to my liver.

32. My mother always blamed herself for what happened to me. It was bad enough for her that I had haemophilia. It was only after she died that I found out that she was taking anti-depressants. She found it to difficult to talk about it to me.

33. GRO-B and I have lived with the fear of stigma and rejection and have never felt able to confide in even our closest friends. She and I have often felt bad about our lack of honesty and decided to tell a few of our very closest friends when I was about to embark on treatment. GRO-B and I told my best friend, who was the best man at my wedding, and when we told him and his wife they were absolutely gob-smacked. At first it seemed to make absolutely no difference to them but they have now grown distant and make excuses to not see us. Another friend who we would spend hours on the phone with on a weekly basis also became very cold after learning about my infections.

34. GRO-B has struggled since the death of her mother in 2011. She told some of her family I was having having Interferon treatment because I had a liver condition back in 2009, without specifying that I suffered from Hepatitis C but they have distanced themselves from us as a result. Her brother refused to have me in her mother's funeral car and her sister has actually hung up on her when GRO-B was discussing HCV with her after GRO-B blurted it out that I was infected. As I get older I try not to worry about what other people think, but I still do not want people thinking that I got my virus through sleeping around or taking drugs and I worry abou GRO-B

35. I have never had any problems with dental care as I have had the same dentist for 30 years. He has since moved into dental implant work but he explained the situation to his replacement who was fine with it (although I have had to pay for private dental care as they are no longer NHS funded and I did not want to search out and make contact with an alternative at the risk of rejection upon disclosure of my circumstances). I have not suffered from any stigma from medical professionals, who have all been good in that way.

36. I have never been able to obtain life insurance and it is extremely expensive to obtain travel insurance. It costs around £300 for a trip and I was once quoted £600 just to insure myself for a 10 day trip to America. When we went to America just after we got married, I had to get a visa from the Embassy with a waiver that my HIV (contracted through contaminated blood from the USA) was stable. I was nevertheless stopped on entry and carted away to the side for an hour to question me.

37. I have been unable to work since 1991 and GRO-B and I have struggled financially with just one salary coming in, augmented by Severe Disability Allowance before changing to ESA and Mobility Allowance (for a car) before changing to PIP.

38. When I had to apply for my ESA, I had to visit a doctor to assess and confirm that I needed the payments. When he saw me and learned of my health issues, he was shocked that they had sent me to see him and asked me what I was doing there. He said that I clearly qualified and there was no need to go through this. Despite this, three years later they called for me to be assessed again. I don't understand why I need to keep going through this; I shouldn't have to continually explain what is wrong with me and why I need support. It is waring.

Section 6. Treatment/Care/Support

39. I cleared HCV in May 2016 after a course of the Harvoni treatment. I had to fight for the Harvoni treatment due to the cost of the drug and the possible interference with my HIV drugs. They were repeatedly telling me how much it was going to cost (£45,000). My consultant, Dr Babu, had to fight for me to receive the treatment in front of a panel at Kings College Hospital. However, despite clearing the virus I have been informed by my liver consultant Mr Terry Wong that I could still get liver cancer in the future due to the damage that has been done to my liver over the last 40 years. I therefore continue to have regular check-ups, scans and blood tests.

40. I was not offered counselling or support at any time around my diagnosis. The only time GRO-B and I were offered support was when I started the Interferon treatment. It was helpful having someone to talk to and it gave GRO-B and I the opportunity to properly express how we were each feeling, which is something we were never really able to do.

41. Guy's and St Thomas' has generally been a very good Centre. Professor Savidge was straight-talking but he was always very honest with me. Dr Graham Thompson was really good to us and was helped me in writing a letter in support of PIP (when the mobility assessment changed) on the Friday before he died from a brain haemorrage, two days later on the Sunday a year or two back. He was a good man and his death really knocked me for six. Our Haemophilia Nurse has moved on. As a haemophiliac you build up a level of trust with your team that is important especially when your faith in the medical professionals has had to be rebuilt.

Section 7. Financial Assistance

42. I was a party to the 1991 litigation and had to sign a waiver to receive the payment. I was told that if I didn't sign the waiver then nobody would receive a payment. I had not then been informed of my HCV diagnosis.

43. When the MacFarlane Trust was first set up I received the initial ex gratia lump sum payment and then around £150 per month as income. We also received some grants from the Trust, including money towards new windows (they would not pay all of the cost) and a much needed new boiler when it packed up (although we had to obtain three quotes and then await a decision from the Board). The MacFarlane Trust became increasingly difficult to deal with as time went on, placing hurdles before us and seemingly avoiding paying out. The staff were rude at times and resulted in me simply not wanting to bother trying.

44. If someone's boiler breaks, they do not have time to go and ask for three quotes and fill in all of the forms and documents, wait for the application to go through, wait for the Board to consider the request and eventually make a decision as to whether you are deemed worthy of payment. It is impossible to do anything quickly and people in need do not always have much time to wait before they suffer hardship.

45. Due to the incompatibility between my HIV medication and Harvoni, I had to go to London on a weekly basis for tests (at a weekly cost of £60 or £70). When I asked the MacFarlane Trust to pay for our trains to London, which were becoming a considerable expense, they emailed me saying it fell outside their guidelines. We were directed to compete an expenditure form, obtain approval and proof from the hospital to which we responded "no change then" for being supportive, forget it. They then wrote again and said they would help.

46. When I was having a Hernia operation in London we asked the MacFarlane Trust for support so GRO-B could stay in a hotel close to the hospital for three nights, preferably the one across the road from the hospital. They offered a mere £65 per night as a budget for suitable accommodation. That did not cover the cost of anything at all anywhere near to the vicinity of the hospital. They never understood or wanted to understand that HCV had knock on problems with other conditions so my liver condition was causing a problem with what was ordinarily a routine operation. We had no alternative but to pay the additional costs ourselves as I couldn't worry about GRO-B travelling across London alone.

47. I received the Stage One Payment from the Skipton Fund but was refused the Stage Two payment despite St Thomas' trying on several occasions because of the damage to my liver. At the suggestion of the Haemophilia Nurse I reapplied for Stage Two and the SCM payments because of my state of mind and the severe depression and anxiety that I suffer with on an ongoing basis and was ultimately successful.

48. I always worry about what will happen with GRO-B when I go. I have never been able to get insurance and there are no guarantees that the payments available through EIBSS will be paid upon my death unless I die with either HIV or HCV related illnesses. We cannot get a life policy full stop.

Section 8. Other Issues

49. We would like the assurance of guaranteed payments. We have no financial certainty and I worry about what support my wife will have when I die. Moreover I feel that we should be fast tracked through any DWP benefit assessments.

50. I would like this Inquiry to find out WHY and WHO changed the course of my life and so many other haemophiliacs. I know that if I hadn't met GRO-B in 1989 I would have succeeded in taking my own life. I was in a very dark place and with

no support or understanding from the doctors at this time I was left to face this alone.

51. What I find so hard is listening to everyone given their evidence. We have all faced this alone and yet dealt with it all in a similar way. It is like listening to my story over and over and over again. It would be 4,600 (haemophiliacs) statements, far too many mistakes and the ones that have paid the ultimate price 'death' that we owe to get to the truth. Most of us were children. Why did this happen and who allowed it to happen? We need to make sure that this never happens again.

Anonymity, disclosure and redaction

52. I would like to apply for anonymity.

53. I would not like to give oral evidence to the Inquiry.

Statement of Truth

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

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

Dated.....12 . 7 . 19..........................