Witness Name: GRO-B

Statement No:WITN1719001

Exhibits: WITN1719002 - WITN1719006

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 but I am known as GRO-B and I live at GRO-B I was born on GRO-B in GRO-B and have GRO-B sisters and GRO-B brother. I am a GRO-B and during the communal riots in GRO-B our house was burnt to the ground with all our personal belongings and medical documents. I was forced to leave as the GRO-B were being targeted in the Civil War and came to the UK in GRO-B aged GRO-B I am married and I have GRO-B sons who were born in GRO-B and GRO-B I am currently working for the GRO-B GRO-B

2. I provide this witness statement in response to a request under Rule 9 of the Inquiry Rules 2006 and understand that my wife GRO-B also intends to provide a statement to the inquiry.

3. I am providing this statement without the 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. When I was around GRO-B or GRO-B years old I got a cut and was taken to GRO-B GRO-B. When they took a blood sample from me, it was always labelled as '*disease unknown*'. I heard these samples were sent to the UK for analysis. I was diagnosed with severe Haemophilia A when I was between GRO-B and GRO-B years old and have a clotting factor of less than 1%; however, I remember having a relatively normal childhood.

5. My dad was extremely careful in GRO-B and he used to come and get me from school at lunch and 5 minutes before school ended to make sure I was safe with the rush to leave. I never did any sports, never attended any school trips and never went to friend's parties or anything.

6. Whenever I had an external bleed my mother would bandage me with either ice or a coffee and sugar home-remedy mix. If this bleed led to an internal bleed, the affected area of my body would be bandaged and ice cubes or a cotton bandage soaked in Epsom salts would be applied. There was no treatment such as Factor VIII or other blood concentrate products available in GRO-B to treat Haemophiliacs.

7. My father died when I was quite young and being his eldest son, I was expected to provide for the family. I remember attending school and I had my career path lined out for me in the GRO-B industry. It is what I always wanted to do. When I was GRO-B I obtained a GRO-B GRO-B and then worked in GRO-B I decided to train as a GRO-B and when I moved to the UK in GRO-B I began studying with GRO-B GRO-B while supporting myself by working at GRO-B and sat the GRO-B GRO-B which I finished in GRO-B

8. About 1 month after I moved to the UK, in or around GRO-B I had a severe bleed in my leg and was treated at GRO-B I believe that I

was given 15 bags of cryoprecipitate and Factor VIII and I was infected with Hepatitis C from around this time. I exhibit my notes from GRO-B and the UKHCDO which show the batches that I was given at Exhibit WITN1719002.

9. I was treated by GRO-B at GRO-B who was very surprised that I had not had any treatment and had so little joint damage being a severe Haemophiliac. I then moved to GRO-B then GRO-B and many others until now, where I am with GRO-B From 2009 until today I am at GRO-B GRO-B for the treatments of my Hepatitis C mainly with GRO-B I was also referred to GRO-B GRO-B in 1995 for a liver biopsy. I also was admitted into GRO-B after a car accident on GRO-B GRO-B so they dealt with a bleed on that occasion.

10. No information was given to me about the risks of Factor VIII concentrate. The only information I was given about Factor VIII was the name of the new product when I was changing suppliers.

11. I was told I was infected with Hepatitis C in June 1992 in a letter from GRO-B GRO-B of GRO-B A booklet on Hepatitis C was included but there was nothing offering me an appointment at this stage. As I am not a doctor, I did not understand what they were telling me in the letter. This should have been done better. I attach this letter dated 29 June 1992 and the booklet at Exhibit WITN1719003.

12. I had appointments every 4 months or so and I think I was told in person at the next routine appointment. I was GRO-B years old with my whole life ahead of me. I was shocked and speechless. I was not given adequate information about the infection in the appointment.

13. For about 4 years no one at the Haemophilia Centre referred to or mentioned Hepatitis C. Then in or around 1996, GRO-B the senior nurse at GRO-B told me that they were going to start to treat me for

Hepatitis C. I do not understand why it took such a long time from telling me in 1992 to starting treatment in 1996.

14. I was told in a letter around 1998, by either GRO-B or GRO-B about passing the infection on. It was just a general letter and said about using a condom. I got married in GRO-B but we did not have children for GRO-B years as we were worried about passing the infection on.

Section 3. Other Infections

15. I remember receiving a letter in regard to being potentially exposed to the vCJD virus. From my notes I can see that I received letters in 2011, 2004, 2005, 2009 and 2011. I exhibit the Patient vCJD Exposure Assessment form dated 7 September 2004 with a handwritten note at the bottom saying no '*implicated*' batches received here at Exhibit WITN1719004.

Section 4. Consent

16. I cannot remember if I was told that I was being tested or treated for Hepatitis C or HIV and so cannot remember if I was given adequate information in this regard. However, I was tested many times and attach a copy of all my testing by GRO-B Haemophilia Centre for HIV and Hepatitis at Exhibit WITN1719005.

17. I do not believe that I was ever treated or tested for the purposes of research. I was referred for the GRO-B trial treatment in around 2014 or 2015 however I was not selected and no one got back to me.

Section 5. Impact of the Infection

18. I was shocked upon seeing the letter in June 1992 informing me that I had been infected with Hepatitis C; I did not understand what they were talking about. I was very worried after talking about it all in the appointment. I did not know how fast the infection was going to develop and what would happen to

me. I was finding it hard to eat from worry and I did not know who to talk to as my family all live abroad. My mother, GRO-B sisters and a brother live in GRO-B and another sister lives in GRO-B I did not know what the impact of telling people would be, so I decided it was best not to say anything.

19. In 1992 and 1994 I went to GRO-B to see my family but I did not tell my family about my infection either. They wanted me to emigrate to GRO-B as all my friends were there too. However, I knew that I would not get through immigration due to my infections and conditions and so I would make up excuses to my family as to why I could not go. I also shied away from my friends due to this as I was very affected mentally; I always avoided them and made up excuses, but I would have liked to emigrate there. My sister in GRO-B also wanted me to move there too but I could not, for the same reasons.

20. I eventually told my family of my infection in around 1996. It was a very hard conversation to have and I felt isolated. No one really understood what Hepatitis C was at that time, except my brother, who by then was working in the GRO-B for a GRO-B and so he understood about the infection and was very shocked.

21. Around this time my family were worried about my mental health and my mum was trying to arrange a marriage for me but she did not want to tell them about my condition. I rejected her suggestions a lot. My GRO-B introduced me to my future wife. When I met my wife I told her myself straight away about my Hepatitis C infection.

22. In GRO-B tradition it is customary for the husband to receive a dowry from the wife and her family. It was normal to demand around GRO-B and some land in GRO-B however due to my infection, I felt too guilty to ask this of my wife as she was already going to have to live with me having this infection. Her dad therefore did not pay a dowry to me and I missed out on this. In 1999 I tried to bring an action against the NHS for infecting me but was told not to

pursue with it as it would be unsuccessful and a waste of my time. I attach evidence of the loss of dowry at Exhibit WITN1719006.

23. On 24 February 1998 I had a liver biopsy and soon after this my wife, who has a lot of medical knowledge, and I both went to GRO-B to discuss the biopsy. I was told that my liver had very little damage and I could live to 100 years old with it. After the GRO-B biopsy appointment I did not take the infection as seriously as it was played down there and said there was little damage to my liver. I therefore thought I was a bit safer.

24. In total I had 4 treatments for Hepatitis C. In 1996 I had a failed Interferon monotherapy which stopped half way due to me constantly suffering from headaches, vomiting, and insomnia. I was told it was eating my white blood cells and drastically dropped my red cells, which is why I became anaemic and suffered from those symptoms. I remember being very depressed when I was told there was no positive responses to the interferon treatment.

25. I married in GRO-B but GRO-B told me they could not give me any more treatment at that time, as we were trying to conceive through IVF. We went for IVF treatment twice in England from 2002 to 2004 but it did not work. Then we went to GRO-B for the IVF treatment in 2006 and it was successful and we had our first child in GRO-B . Soon after this, I started a second round of Hepatitis C treatment in 2008.

26. In 2008 in GRO-B I had a treatment of Interferon and Ribavirin, but stopped due to neutropenia after about GRO-B months. I suffered from many of the same symptoms, including losing a lot of weight, headaches, insomnia, turning pale, and becoming very angry. My oldest son was only GRO-B months old and so this was very difficult to manage as there was no one to support my wife, with our child and dealing with me.

27. In 2011 I was referred to GRO-B as GRO-B said they could not cope with any complications and GRO-B had a specialist team. Again my treatment was the same as in 2008, namely Interferon and Ribavirin. These drugs did not work before in 2008 and so I was not very optimistic.

Although I initially responded well and the treatments were working this did not last long and the treatment did not work.

28. In 2011 I suffered the same side effects as in 2008. I was also just constantly angry and really suffered from personality and mood changes, however, this time it was more intense as I took the treatment for GRO-B months. I felt suicidal throughout the period of treatment. I suffered many complications from the 2011 treatment. My haemoglobin levels dropped and I had to have about 3 or 4 blood transfusions at GRO-B I also lost a lot of hair as a result of these treatments; I had to take my son with me as I had no one to look after him as my wife was at work.

29. In 2011 my condition was quite bad and so my wife was taking sick notes to my work; they said that if I was not back at work in 6 months then I would not be paid. I managed to get back to work before this and I said I would work as normal because I did not want less pay and I needed the money.

30. By around the end of 2015 I was fatigued and regularly had night sweats and a non stop cough for months on end. I lost a lot of hair and I got respiratory infections as I was more vulnerable to them. I struggled to sleep and had a fever regularly. All this was difficult to deal with and I was constantly stressed.

31. In January 2016, I took my fourth treatment called Harvoni with Ribavirin for about GRO-B months. This also gave me side effects including headaches, becoming very weak, a loss of appetite and anger issues; however, all the side effects were better than in 2011. I completed the treatment and it worked and I cleared the Hepatitis C virus. Hepatitis C ruined my liver but after my treatment in 2016 my Hepatitis C cleared and my liver recovered. If I did not go for treatment in 2016 I would be dead. Every year I have a fibroscan to monitor the state of my liver.

32. While I was on these treatments I lost interest, drive and enthusiasm to do anything. This was very unlike me as I am normally very energetic and a go-getter; no one would have known I am a Haemophiliac or was infected with

hepatitis C. Even though I have cleared hepatitis C I still feel tired and sleepy with feelings of lassitude and sometimes hopeless disinterest.

33. When I had hepatitis C I avoided my social life with cousins and friends who wanted to visit from abroad. I always made excuses so they would not come over. I even missed my GRO-B I didn't go and again had to make excuses. My family knew why I didn't come but I had to make excuses for everyone else.

34. My final treatment, Harvoni, was delayed from 2014, when I first found out about it, to January 2016. They were telling me it was going to come out but NICE had not approved it yet. I asked if I could buy it myself in the meantime but was not allowed to and so. This treatment was therefore delayed for about 2 years. As soon as it was approved I was give the treatment. I believe that I was given the second batch that GRO-B received.

35. While I was waiting for the Harvoni treatment I was told that I was being referred for a trial in GRO-B in 2015 but they never contacted me.

36. GRO-B sent me to GRO-B for any dental work and special dental treatment. I last went there in 2018, when they told me that I can go to a normal local dentist now.

37. I never told anyone about my infection apart from very close friends and my family, so I never really suffered much stigma, apart from my discrimination at work. I was bottling everything up and did not talk about anything I was going through, with anyone. I did not want to express myself as I was worried about how people would react. I was worried about potential stigma and people assuming things, such as me having HIV. I did not want people to keep asking for information about me and the infection all the time and so I thought it easier to not tell anyone.

38. I suffered massive implications at work due to my infections. I had to leave GRO-B due to my Hepatitis C infection despite just obtaining my

qualification in 1992; the year I was diagnosed. I moved into an GRO-B GRO-B

39. In 2015 my line manager went off sick so I was passed to another manager GRO-B who was not interested in me. In September 2015 after my standard review, I was given nothing to improve on. Also in September 2015 I went for a fibroscan and my liver condition was in a very bad state. I was told that I was on the verge of cirrhosis. This was a very dangerous stage and I was having frequent blood tests to monitor my condition. GRO-B were very helpful as was the consultant, GRO-B

40. In January 2016 everyone at work knew I was having Hepatitis C treatment but I do not believe that they took this into consideration with their treatment of me. My line managers were written to and told of the side effects I was facing due to the treatments and I still went to work while I was on treatment for GRO-B GRO-B until I had to be signed off for GRO-B

41. I returned to work around GRO-B but within about a week I was called in for a meeting and given a warning. They told me my performance was very poor and below the 10% threshold; but they did not take in to the fact I was not even at work during the GRO-B and so that was why my performance was obviously lower. They treated me horribly and I felt that they were just trying to push me out. I appealed the decision and it was reversed. This was the first time that this had happened.

42. In GRO-B they told me I had GRO-B months to find another job in another GRO-B They didn't let me continue my job in the meantime and I just had to just continue to apply for jobs. I had appealed my warnings and even after going back to GRO-B he said he was appalled. There were many other jobs in the department I was already in that should have been offered to me but were withheld from me. My union rep was with me in these meetings and he got very angry with my employers. All my appeals were refused.

43. This *'mental torture'* made me miss a lot of sleep and caused me a lot of stress. I told the occupational health team and both of my managers and they took no action and ignored me. They asked me if the stress was from work and I confirmed this. I had such trouble sleeping that I had to get sleeping tablets from the GP and was on them for 2 weeks.

44. When I was doing applications to other departments and they asked me why I was moving, my managers said not to tell them why I was moving and not to worry. I refused this as I felt they should know that I was a Haemophiliac but my department never wanted to put anything in writing. The other departments that I was applying to were sure that my department GRO-B would be able to make special adjustments for me. I suffered clear discrimination.

45. Around GRO-B I moved to GRO-B The manager here was not worried about my health conditions as I had good experience. The manager allowed me to be very flexible and made special arrangements for me. It is the same pay as my previous job in GRO-B

46. My wife had to start working part time through my treatment. She had to travel to GRO-B quite often as her dad was in hospital for GRO-B in a coma and died in GRO-B ust before I started my treatment that year. My wife went through huge stresses during this time in looking after me, our children and also the regular trips to see her dad.

47. My infection made my wife suffer a lot and she was very strong through everything. Things got worse everyday and I could not manage myself and so she would always check up on me. She is a big optimist and she always believed a treatment would come. She never let me talk about death and has always been very positive. She had to call off work many times and could never say the reason why. She was good and took a lot on for me and the family. She could never tell anyone and had to deal with it all herself.

48. The impact on my family was varied when I eventually told them of my condition as they did not understand the implications of the infection. Only my brother really understood as he was working in a GRO-B My children do not know of the infection as they are only GRO-B They just knew that dad goes to nurse GRO-B to have injections.

49. I came to the UK to escape a civil war and then ended up getting infected here in UK.

Section 6. Treatment/care/support

50. I had psychological assessment once from GRO-B after my treatment in 2016. It was not really counselling though as they sent me there just to talk and fill in forms and that was it; there was no actual counselling. I was never offered counselling otherwise and I just went to that appointment like they said.

Section 7. Financial Assistance

51. Nurse GRO-B from GRO-B told me about the Skipton fund in 2004. I applied and they gave me a stage 1 lump sum payment of £20,000 in October 2004.

52. The application process was straightforward; I completed form and gave it to my consultant. That was the only dealing I had with them and I thought they were fine.

53. We now get a £1,500 payment monthly from EBISS. This started in 2018. They rejected us first but then reviewed it and we started to receive payments. We are not eligible for a top up family payment as our income is more than £19,000 a year so we did not apply.

Section 8. Other Issues

54. The implications of this scandal are huge. I came to the UK to escape a civil war and come and study. In 1992, just after I had finished my studies, I was effectively barred from going to GRO-B as I had intended, due to being told of my infections. I was not allowed to return to the rest of my family abroad due to my infections.

55. My wife is a dual citizen so I had an easy route to GRO-B and both our families were there and always wanted and requested us to come and settle there. My wife especially always wanted to go back to GRO-B We were blocked from doing so due to my infection and it is now too late with my age of GRO-B and circumstances.

56. Haemophilia is my fate or Karma, but I believe that my infection with hepatitis C was a mistake, but I have to take a positive outlook and be happy that I was only infected with hepatitis C and not also HIV.

Anonymity

57. I would like my statement to be anonymous.

58. I would like to provide oral evidence to the Inquiry, provided it can be anonymous.

Statement of Truth

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

Signed.. GRO-B .....

Dated.....16. 5. 2019.....

Medical Chronology

(This summary is not intended to be exhaustive but sets out key points in the records relevant to the Statement)

25/6/2018 letter GRO-B to GP. His fibroscan result was 5.8kPa and his liver ultrasound reported a stable appearance, his bloods also remain stable

March 2017 fibroscan

May 2016 hep C PCR revealed that he has cleared hep C

12/1/2016 Treated Hepatitis C with Ribavirin and Harvoni treatment. Duration 12 weeks

May 2015 letter GRO-B to GP. Fibroscan liver stiffness measurement 11.8kPa. This would make him eligible to funding for directly acting antiviral agents and we are currently working with GRO-B GRO-B in order to achieve funding for this

20/11/2014 letter GRO-B to GP. His hepatitis C is being monitored at GRO-B Hospital and I understand that he will be considered for further treatment with novel therapy once there is NICE approval

Sept 2014 Fibroscan 10.3kPa

28/3/2014 letter GRO-B to GP. With respect to hep C I have explained that there will be new treatments available towards the end of this year that could offer him the prospect of a cure without the requirement of interferon.

Mar 2014 Fibroscan 11.8kPA

18/10/2013 Fibroscan 7.8kPa

8/4/2013 letter GRO-B to GP. With respect to his hep C his fibroscan has increased from 6.4kPA to 9.1kPa. This would be consistent with progressive fibrosis. I have therefore explained there are 3 options. The first option would be to treat with the current licensed therapy for hep C genotype 1 which will be triple therapy including Pegylated interferon, Ribavirin and a protease inhibitor (either Boceprevir or Telaprevir). There would be the same side effects that he has previously suffered with Pegylated interferon including neutropenia and thrombocytopenia but additional side effects might include nausea and anaemia with Boceprevir, or a rash with Telaprevir. As he has previously been a null responder to Pegylated interferon and Ribavirin the chances of a sustained virological response would be at best 30%. The second option would be to wait until future treatments are

available. Phase 3 studies of some interferon free regiments have now been completed and it is likely that these will be licensed I the future, although this may take up to 2 years. The third option would be to send his details to GRO-B for consideration of entry into clinical studies which may give him access to interferon free regiments prior to licensing, although this of course cannot be guaranteed.

26/3/2013 Fibroscan 9.1kPa

2012 Fibroscan 6.4kPa

2011 I am sorry to note that he had failed to respond with pegylated interferon / Ribavirin which was discontinued after GRO-B months treatment. He has mild to moderate liver function derangement but this has been stable during the last few years

2011 Discontinued after GRO-B due to severe haematological toxicity (neutropenia and thrombocytopenia). Non-responsive, two optimal dose pegylated Interferon plus Ribavirin

18/3/2011 began treatment pegylated Interferon plus Ribavirin

March 2011 letter GRO-B to GP. As you should be aware, your patient has been notified that he has an increased risk of vCJD. Your patient was exposed to a risk of vCJD following treatment with UK sourced clotting factors for a bleeding disorder. Refers to paper published in the Lancet on February 5th. Professor John Collinge and colleagues at the MRC Prion Unit, University College London have developed a blood-based assay for the detection of prion activity of vCJD. www.nationalprionclinic.org

15/6/2010 he has been troubled by recurrent chest infections and bouts of a non-productive cough since October 2009

27/11/2009 Hepatitis C status +ve, attending Lewisham, awaiting consultant appt at KCL

July 2009 letter from GRO-B to client. Re previous vCJD letter. We now know that this patient had been treated in the 1990s with UK plasma-sourced clotting factor (Factor VIII). Two batches of factor VIII were sourced from plasma pools that included plasma from a single donor who later developed vCJD. These batches are called 'implicated' batches because they are linked to a donor who subsequently developed vCJD

Feb 2009 letter from Lewisham Hospital to client. A person with haemophilia who has been found to have evidence of the infection that causes vCJD in his spleen at post mortem

Aug 2008	Discontinuation of pegylated Interferon and Ribavirin due to neutropenia
23/7/2008	Hep A Ab Positive
April 2008	began pegylated Interferon and Ribavirin treatment
April 2008	He has recently become a father after successful IVF in GRO-B We have been delaying his Interferon and Ribavirin treatment for approximately five years because of this. I note his recent liver function tests show deterioration with ALT now greater than 200 iu/L and I think it is probably expedient to start treatment.
28/6/2007	GRO-B We discussed briefly the pros and cons of therapy today and I emphasised an approximate 50% estimated success rate with his genotype after 48 weeks of treatment
3/4/2007	the success rate for combination therapy with pegylated Interferon and Ribavirin is about 60% at GRO-B which is actually higher than elsewhere
4/2/2005	UKHCOD 09 Patient vCJD data – assessed date. At risk 1980 – 2001 - yes. Patient notified - no
20/9/2004	vCJD letter to client
7/9/2004	Patient vCJD exposure assessment form. Handwritten note at bottom – no implicated batches received here
5/2/2003	letter GRO-B to GP. He has remained well and asymptomatic regarding his hep C infection. Since he was last seen in the clinic he has been married and his wife has currently attending GRO-B Hospital for IVF treatment
Oct 2001	Hep C – Genotype 1B, viral load 6.4 x 10(5)ml
19/10/2000	RTA. Hit from behind
9/5/2011	at risk of variant Creutzfeldt-Jakob disease
1998	liver biopsy – minimal inflammation and fibrosis
July - Dec1996	Interferon monotherapy. Undated letter by GRO-B states he tolerated his interferon monotherapy reasonably well in 1996 with mild, self-limiting depression, flu-like symptoms and malaise lasting for about 6 weeks
1992	hep C diagnosed
20/6/1991	UKHCOD 07 Patient HIV data – date form completed

6/2/1988 Bleed L calf. Tender. FVIII 195 x 8 8Y3529 – first treatment with Factor VIII

24/4/1987 first treatment at GRO-B – Haemophilia Centre. R calf bleed. Given Cryo x 15 bags. Also noted HIV Neg