Witness Name: GRO-B ANON
Statement No.: WITN4313001
Exhibits: **WITN4313002 - 003**
Dated: 09 December 2020

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF GRO-B
ANONYMOUS

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 26 November 2020.

I, GRO-B, will say as follows: -

Section 1. Introduction

1. My name is GRO-B. My date of birth is GRO-B 1950 and my address is known to the Inquiry. I retired from full-time work about 5 years ago. My career and background was in education, mainly as a teacher but latterly up to my retirement, I was a university administrator.

2. I am very recently widowed, following my wife GRO-B death in GRO-B this year from GRO-B cancer. We did have two children early in our marriage but both died tragically very young from GRO-B GRO-B in the 1970's. We never had any more children.

3. I intend to speak about my infection with hepatitis C ('HCV'). In particular, the nature of my illness, how the illness affected me, the treatment received and the impact it had on me and the life that my wife and I had together.

4. I have chosen to remain anonymous as the only people who knew of my infection was my late wife and the medical professionals who treated me for my HCV and those medics who, when they were treating me for other things had a requirement to know about my infection with HCV.

Section 2. How Infected

5. My father was GRO-B and my mother was GRO-B I was born in GRO-B though I moved to GRO-B around 1966 when I was aged 16 to study medicine. I studied in GRO-B for two and a half years before I decided to move to London. I was unable to complete my studies in GRO-B due to financial difficulties.

6. When I arrived in the UK around 1971 I applied for a grant to complete my medical studies, however as I had only just arrived I was not eligible. I was told that I had to be a resident in the area for 3 years before I could apply for a grant. Regardless of this, I decided to settle in Cardiff where I went to the University of Cardiff. I worked as a technician at the GRO-B GRO-B in the haematology department. This would have been around 1973/74.

7. This involved taking bloods and analysing them to ascertain the patient's blood group prior to them having an operation. I had been trained in the use of a specialist machine whilst in GRO- which was used to analyse the bloods, the same type of machine that was used in my role in Cardiff.

8. I then moved on to the medical physics department and worked there for around a year. After this, I was still unable to get approval for a grant to complete my studies. In order to achieve this, I moved to London where

I got a Higher National Diploma (HND) in science from the London Polytechnic.

9. After graduating, I worked as a teaching assistant at a number of colleges in North London. I then settled at GRO-B College as a teacher in B-tech physics.

10. Towards the end of 1987, I was on my way to work at the college one morning when I was the subject of a vicious physical assault by a gang. I was walking past a pub near to home and on the way to the bus stop when someone started to verbally abuse me.

11. Someone with whom I shared a house at the time had apparently made a complaint to the police about the drunken, loud, violent and disorderly behaviour of a number of men in a nearby pub. In what I believe was a case of mistaken identity, the group of men then went on to attack me.

12. Whilst facing the man shouting at me, someone hit me in the side of the head from behind. This was followed by countless further punches all directly at my face. I was also hit with a knuckle duster during the assault. I think there were a total of 8 people attacking me. The attack left me unconscious and with a broken nose, fractured cheek and jaw. The police knew who was responsible, there were arrests but they were never charged. No witnesses were willing to come forward and I could not pick anyone from an identity parade. I was advised by police to move as I would not be safe. I did not move however.

13. I was taken to University College Hospital ('UCH') in London where I was evidently in a bad state. I was given lots of medication and painkillers whilst the doctors attended to my injuries. I was unable to see out of my eyes due to the bruising. Even to this day my eyesight in my left eye is poor and my tear ducts do not work. I was in UCH for around 6 hours before I was discharged with an appointment to return in two weeks to give a chance for the swelling to go down.

14. I returned to UCH two weeks later for x-rays to my face. The x-rays confirmed my broken bones, specifically to my nose, cheek and jaw. I was then told that I needed an operation to reconstruct the damaged parts of my face.

15. Around 10 days later, I went to UCH for the first of the x-rays to assess the damage. This was followed by numerous appointments. The doctors, one of whom I recall was Professor Morgan, performed the facial reconstruction operation on my nose. Professor Morgan advised me that they couldn't do much about my eye socket as they were worried it would damage my eyesight. Mr James was another clinician who was involved.

16. My jaw had not healed properly after a subsequent operation. I was struggling to bite and I ended up consistently biting my tongue. This had to be operated on again, which required the jaw to be rebroken and fixed correctly.

17. I had numerous operations at UCH to reconstruct the facial bones on the left side. I recall vividly that I was administered blood via a blood bag attached to a drip next to me. These blood bags were half yellow, which was the plasma at the top and half red, the blood which was heavier and sank to the bottom. My wife often visited me and remembered how I was always attached to a drip and a pole holding a bag of blood. My colleagues who visited me at the time all recalled this. I also remember the physician after one particular operation said to me that he would give me a blood transfusion as I was in such a bad way.

18. In relation to my treatment following the assault, I have found a record of my hospital visits. Though they don't identify what each visit entailed specifically, there is some handwriting at the top of this record which is not mine and I believe it to be one of the medics describing my injuries. I enclose this as exhibit **WITN4313002**.

19. My next major health concern did not arise for another 10 years, when in 1997 I was diagnosed with type 2 diabetes. At the time I was suffering

from fatigue and a general malaise. I felt like there was something wrong with me, so I was sent for blood tests that ultimately showed that I was diabetic.

20. For a number of years after this I had regular blood tests as part of my routine diabetes check-ups. None of these blood tests showed any sort of abnormalities as far as I was ever made aware.

21. I continued to struggle with regular episodes of tiredness. I also encountered an inexplicable pain in my right side, which sometimes spread to the back. This was especially noticeable when I was walking anywhere for a period of time. I felt like this for many years and simply attributed these symptoms to my diabetes.

22. In 2009 or 2010 I went for a regular diabetes check-up at the Whittington Hospital. I was seen by my usual consultant Dr GRO-D The consultant looked at my blood test results, which I believe comprised of 5 separate tests. As she was assessing my results, Dr GRO-D stopped at one particular blood test score. She made a phone call to my GP practice and afterwards she told me that I needed to go to hospital to see a specialist, though at this stage I had no idea what for. I had not heard what was said in the conversation with the GP but I subsequently realised that it was to do with my HCV.

23. Around 10 days later I attended an appointment with Professor Geoff Dusheiko at the Royal Free Hospital following the referral from the diabetes specialist at the Whittington Hospital. When I saw Professor Dusheiko he said that he had some bad news for me, and that I had hepatitis C.

24. When I heard this news, I had no idea what hepatitis C was. My wife was equally shocked and surprised, and we both simply asked for it to be explained. My initial reaction was one of fear that it was extremely serious and that I would die.

25. Professor Dusheiko explained to us what HCV is, and how it affects the liver. The professor asked me a number of questions to ascertain how I could have contracted HCV. He initially asked if I had been in contact with someone with HCV, or had ever been diagnosed with it before. He then asked if I had been an intravenous drug user, or been sexually promiscuous. When I answered "no" to all of these questions, he then asked if I had ever had an operation or a blood transfusion. I explained that I had a number of operations at UCH following the assault in 1987, and recalled that I had been administered blood on a number of occasions. My wife also described seeing me attached to a blood bag via an intravenous drip. This then seemed to be accepted as the cause of my HCV infection.

26. After this meeting, the nurses at the Royal Free Hospital gave me a number of leaflets detailing what HCV is. I was also told how to prevent transmitting the virus to others, for example by avoiding sharing toothbrushes.

27. Pursuant to this appointment, I had a fibroscan on my liver in May 2010. This scan showed that I had cirrhosis of the liver. Soon after this I was offered treatment.

28. I began a course of pegylated interferon and ribavirin in 2010. This treatment was described to me as a trial and I did consent to the treatment. The medication was self-injected into my stomach, which I hated from the outset.

29. The treatment had significant side-effects from the very start. I felt very tired and I had a yellow complexion. I also experienced pain in my right side almost all of the time, coupled with stomach pains and upset. I missed worked intermittently totalling about two weeks or so throughout the treatment, which was unheard of from me. My colleagues at work began to notice how much weight I had lost. In addition I began to get palpitations and I was breathless. I was prescribed with Warfin and

Betablockers. I should point out that am also currently under a cardiologist at The Wittington Hospital in London.

30. I phoned the nurse at the Royal Free Hospital to explain the side-effects I was experiencing. Straightaway she arranged for me to see Professor Dusheiko. When the professor saw me and I explained what was happening, he said that I should stop the treatment. It was having too much of an impact on my life. I stopped this course of treatment immediately after this appointment, around 7 to 8 weeks after beginning it.

31. I asked Professor Dusheiko what would happen next. He told me about new research and treatments available in America, though currently this was not available on the NHS due to the cost. He said that although he did not know when it would be available, he promised me that I was on the top of the list to receive the new treatment when it became available.

32. Professor Dusheiko kept his promise as, in early 2016, I was put on a course of new treatment for my HCV. This was again described to me as a trial treatment, but again I consented to receive it. I recall that one of the nurses said it would cost £30-40,000. The fact that they had made a point of saying how expensive it was annoyed me. I was frustrated at being made to feel guilty for receiving a treatment.

33. The treatment itself was comprised of sofosbuvir, ledipasvir and ribavirin and this lasted for 12 weeks. I took two tablets every couple of days and the hospital monitored my progress every 2 weeks. They took blood tests so see if it was working. After showing initial encouraging signs, Professor Dusheiko said that I should remain on the treatment for the whole course.

34. As I continued the treatment, my viral load regularly decreased at my check-ups. When I completed the course of treatment after 12 weeks, I was told that my HCV was all but cleared.

35. I exhibit a letter (**WITN4313003**) dated 02 May 2016 to my GP, Dr GRO-B Within this letter it mentions that my second treatment was a 12 weeks course of sofosbuvir, ledipasvir and ribavirin. That was completed in January 2016 and was effective. The letter goes on to say that I completed 12 weeks of Harvoni and ribavirin in January, so I am slightly confused as to what it actually was but either way it states that my viral load was undetectable at the end of the treatment in January, in February and again on the most recent test at that point on 20 April 2016. I should also point out that within this letter it states under the heading of 'Problems', '1. Chronic hepatitis C genotype 4, acquisition via blood transfusion.' This is the only documentary proof I have from an NHS source that I ever had a blood transfusion.

Section 3. Other Infections

36. I do not believe that I have received any infections other than HCV as a result of receiving infected blood transfusions.

Section 4. Consent

37. With regard to my facial reconstruction operations in 1987, I certainly consented to receiving treatment. However, I do not believe that I was explicitly warned prior to the operations that I would receive a blood transfusion. I therefore do not believe that I provided consent, though I probably would have consented to receiving a blood transfusion if it was deemed necessary but I was not aware and I was not warned of the risks associated with infected blood at that time.

38. It was explained to me that my two treatments for HCV were 'trials', and I consented to being treated with both of these trial therapies.

Section 5. Impact

39. I have felt extremely fatigued for a number of years, which I am now able to attribute to my infection with HCV. For a long period between 1997 and my diagnosis with HCV in 2010, I believed that these side-effects were all a result of my type 2 diabetes but now I think that the diabetes was masking the real cause of my fatigue, which I now believe to be the HCV.

40. My infection with HCV has caused me to feel a great degree of depression. Whenever I researched HCV and read about it, I was convinced that I would die, so this made me even more depressed. There is definitely a connection between HCV and depression. I started antidepressants for a short while, though I stopped these as they made me feel lightheaded and started to affect my work.

41. My wife was incredibly worried after my diagnosis with HCV. She was advised that she should be tested, though I do not recall if this was ever done. Although my wife and I remained close and intimate, we did not have sexual intercourse ever again, after my HCV diagnosis for fear of me transmitting the virus to her.

42. When people find out that you have HCV, they don't want to know you. They are scared to touch you. There is unquestionably a stigma associated with HCV. I don't hug or kiss people because of the fear of transmitting the virus. As a result, I chose not to tell people that I had HCV. I was always careful around people, being mindful not to physically touch other people. I was scared of being accused of passing something on to someone else. This frequently led to awkward situations where I would typically hold back from a normal greeting or hug, with no apparent explanation for this. HCV made me feel and most likely appear socially awkward.

43. I used to love kids and, after both my children died, it was sad for me not to be able to interact with other families' children. It has had a lasting psychological effect on me.

44. I was infected with HCV for a long time, since 1987, which I believe has caused a lot of damage to my liver. This was confirmed by a fibroscan that showed that I had cirrhosis of the liver. At this stage, I was given various options of a way forward, this included the prospect of a liver transplant and we discussed this. Naturally this caused me to feel a great sense of anxiety as I was worried about dying during the operation. I declined this as an option. I do not recall the other options put forward by Professor Dusheiko.

45. Around 2011 or 2012, after my first treatment had failed, I began to feel very ill. This was apparent to my friends and family, in particular with regard to the weight loss and my jaundiced face. I had lost two stone, looked increasingly ill and I was convinced that I was dying.

46. I was sent for an MRI to check for cancer due to my weight loss. Though this ruled out cancer, it identified gall bladder stones. I was given a date for an operation around 2015 or 2016 but this was knocked back by the medics because of the second course of HCV treatment that I was undergoing. Then after completing the HCV treatment, I decided against having the operation on my gall bladder due to its proximity to other organs including my liver. I was worried about the damage it could do, and my wife agreed that I should not have it done.

47. Dr Trembling, who took over at the Royal Free when Professor Dusheiko retired, sent me for a scan on my liver around 2 year ago. This scan showed a 4mm lump, which I would describe as like a 'grape seed', on my liver. The consultants told me that I should not worry about it and that people sometimes have these. It is unusual but is a result of my fatty liver. Although I was told not to worry, I am of course concerned about this, it may be a cancerous growth.

48. I try not to over worry about my health. If I worry too much about dying, it just makes me relapse into depression. I have regular check-ups and my liver is monitored. My next scan is this coming Saturday in London, and I also have regular blood tests. I still travel to the Royal Free because I do not want to risk dropping down the priority list by having everything transferred to Cardiff, where I now live permanently, since my retirement. When I was working I would live in London during the week and would come home to GRO-B in Cardiff at weekends.

49. I often felt that some dentists didn't want to know after I told them that I had HCV. Dentists would often ask me to come back next week, and sometimes they didn't want to treat me so would refer me to hospital. Referring me to hospital felt like an excuse explained in a diplomatic way. I do not recall any dentists or dental surgery names.

50. I have received dental treatment at both UHW and UCH as I still have pain in my jaw from the attack in 1987. It felt like regular dentists were frightened of me because of my HCV and happily let me be dealt with at the hospital dental facilities.

Section 6. Treatment/Care/Support

51. I strongly believe that my infection with HCV was not diagnosed soon enough. As a diabetic and under the care of the Whittington Hospital, I had regular blood tests. It took 13 years for one of the diabetes specialists to notice my high liver enzymes from these blood test results and to refer me to a specialist accordingly. I believe that this should have been noticed at a much earlier stage, and I therefore should have received treatment for my HCV sooner. This could have prevented the harm being caused to my liver over a prolonged and unchecked period of time. The cirrhosis could have been prevented from developing.

52. I was under the strong impression that the NHS could not afford the latest HCV treatments that were available in the US. Although the

research and technology were available, these treatments were not affordable to the NHS. I remember seeing US patients who travelled to the Royal Free to receive treatment because it was cheaper than in the US, yet this was not available to those of us on the NHS.

53. I have never been offered counselling or psychological support in consequence of my infection with HCV.

Section 7. Financial Assistance

54. Professor Dusheiko told me about the Skipton Fund soon after my diagnosis with HCV in 2010. He referred me and they sent me a form to complete. I completed the form and Professor Dusheiko signed it on my behalf. I was so low at the time and this gave me some hope.

55. I applied to the Skipton Fund in 2010 with accompanying documents showing the treatments I received at the UCH. I wrote to UCH to request my medical records to support my application but they said that they did not have them. This frustrated me enormously as, even though I was able to name the doctors that treated me and the year of my operation, the hospital could not find my records.

56. The Skipton Fund rejected my application on the basis of a lack of proof that I had had a blood transfusion. This was because my medical records had been destroyed. I wrote a letter in response explaining that I had written to UCH and they had confirmed that they could not be found. After this, I heard nothing further from the Skipton Fund.

Section 8. Other Issues

57. I am not interested in money, I just want my experiences to be heard and I want it to be acknowledged that I was in hospital, I received infected blood transfusions and that is how I got HCV. I want to do this for all the

other people who have been in the same situation and who have been denied and ignored.

58. My wife was diagnosed with GRO-B cancer prior to the coronavirus outbreak and lockdown in March 2020. After the lockdown had finished she was examined by a doctor and told that she had stage 4 cancer and just two months left to live. She died GRO-B months later. Although I have no way of knowing for sure that my wife's problems came from my infection, she was jaundiced just prior to her death. I mention this only because it is relevant to the purpose of this statement and not because I want to say that I believe that her death was related to my infection.

Statement of Truth

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

Signed GRO-B

Dated 9/12/2020