

# ANONYMOUS

Witness Name: **GRO-B** **ANON**

Statement No.: WITN4292001

Exhibits: **WITN4292002**

Dated: 08 December 2021

## INFECTED BLOOD INQUIRY

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### WRITTEN STATEMENT OF **GRO-B** ANONYMOUS

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I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 02 July 2021.

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

#### Section 1. Introduction

1. My name is **GRO-B** My date of birth is **GRO-B** 1965. I live at **GRO-B**
2. I was medically retired in 2004, having worked as a **GRO-B** for Her Majesty's Land Registry for over 18 years. I live alone.
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.

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4. As my story relevant to this statement starts when I was an infant, I rely mainly on what I have since been told by my parents up to an age whereby I am able to recall directly.
5. I have had the anonymity process explained to me and I have decided to remain anonymous with regard to this statement. I do understand that if I criticise an individual, that they are entitled to know who I am, if my criticism is put to them.

### **Section 2. How Infected**

6. I was born in New Jersey in 1965. Although my parents were both English, my father was a GRO-B who was working in New Jersey at the time. I am the eldest of three children, I have a middle brother and a younger sister.
7. From day one I had medical problems. I was born deaf in both ears and with deformities on my left side, specifically my face, ear, eye, arm and hand. I was later diagnosed with Goldenhar syndrome in 1995 at Queen Elizabeth Hospital, Birmingham. This is a congenital disease that is present in infants when born, caused by an abnormality in a chromosome.
8. It took two or three operations to rotate my ear and stitch it in the correct position after my birth. This was one of many procedures I had to correct the deformity of my ear. I had a number of health problems and underwent countless medical procedures. When I was 5 years old I remember being kept in an oxygen tent when I had pneumonia and I have scoliosis of the spine, probably caused by deformity on my left side. I also needed speech therapy. Suffice to say, my general health aside from HCV has severely affected my life.
9. In my early years I spent a lot of time getting my hearing assessed. I subsequently had various hearing aids, leading to a bone anchored hearing aid which I have had since 1995.

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10. At some point when I was between ages 2 and 4, I have learned that I began to appear blue in colour. It was only then that the doctors realised that something was seriously wrong with me.
11. I was referred to [GRO-B] hospital where I underwent a number of investigations. A scan found that I had a hole in my heart. I needed open heart surgery. There was a 50/50 chance of surviving the operation and if I didn't have it, my life expectancy would have been just 19 years.
12. They were unable to perform the operation on me straightaway in those days, so I had to wait until I was 6 years old. The open-heart surgery was performed in 1972 at [GRO-B] hospital. The operation lasted for around 8 hours. I can remember bits of this time, including after the operation when I was kept in the Intensive Therapy Unit (ITU) and when I came around I remember seeing all the stitches in my chest, the scars of which are present to this day. I also recall seeing tape across my chest to help hold it all together.
13. I received a blood transfusion during this operation. My mother, was the same blood type as me but was expecting my sister at the time so she was unable to give blood to me. This must have been an option for the consideration to arise. My father said that I had been given 'good blood' from his friends and colleagues via American Red Cross. However, I later learned that though they may have donated blood it had been swapped by a blood bank to blood matching my own blood group. It was basically an exchange, which meant that the blood supplies were replenished but I was given other donor's blood. I don't think they knew at the time about contaminated blood. I cannot remember how many units of blood I received.
14. As a family we returned to the UK in 1973, not long after my open-heart surgery. We settled in [GRO-B] Manchester, due to my father's work.

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15. In 1976 I fell off a climbing frame onto my left arm. This necessitated in the resultant gash being stitched, after being rushed to GRO-B GRO-B A&E in an ambulance.

16. In late 1976 or early 1977 my GP referred me to University College Hospital ("UCH") to see Dr Jonathan Hazel, a consultant and ear specialist. I had a number of scans at UCH, one of which showed a severe infection in my left ear, most likely caused by swimming. They soon established that the infection was getting near the brain and it would need operating on. I duly underwent two or perhaps three operations at the Royal Ear Hospital in London, under the care of UCH trust.

17. On a number of occasions in around 1977, when I was aged 12, my father took me down to London from Manchester to see Dr Hazel at UCH. I sometimes had to be kept in the hospital as an inpatient.

18. Dr Hazel said to me one day that he needed to take blood tests from me, though he did not explain why. My father was not with me. Dr Hazel put me in his car and drove me to the ear, nose and throat hospital on Gray's Inn Road. I was taken into a room that was like a school science laboratory with old school-style desks. Not at all hospital like.

19. In the 'laboratory' a man in a white coat came over to me and asked me to put my hand out. He then used a glass slide (of the type used with a microscope) and swiped it across the top of my finger to cut it. He then took my finger and dabbed it on a number of slides already laid out on the bench.

20. My impression now when I reflect on this incident is that it was an unconventional way to take blood for a test and also, it certainly wasn't a sterile environment. The slides were not removed from clean, new wrappings or packaging of any sort, they were just on the table. The way in which these tests were performed didn't seem right to me even at that age, let alone now. I don't think I ever told my parents what happened.

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21. Although I underwent 3 ear operations at UCH between 1976 and 1978, I do not believe that I received a blood transfusion. I definitely don't remember being told that I had received blood and I think it is unlikely that these operations would have required it.
22. In 1984 I had 4 impacted wisdom teeth removed at Stepping Hill Hospital in Stockport. I recall that the hospital had a very bad reputation. Nurse Pink, who had no part in my treatment was a whistleblower in the late 1980s who highlighted the poor condition of the hospital.
23. The wisdom teeth operation was performed under general anaesthetic and when I came around I was on oxygen. It was not until the next day when I was told I was fit to go home. My mother had to carry me to the car. To my knowledge I didn't receive a blood transfusion during this operation but they didn't tell you much in those days.
24. I had a period of relatively good health after this, considering what I had gone through to that point. I got a job in [GRO-B] London, working as a [GRO-B] in Her Majesty's Land Registry. Despite working I was losing money because the cost of living was higher than my wages, so my father had to assist me financially.
25. I asked for a transfer on welfare grounds and, in 1988, I was offered a job in [GRO-B] I accepted this and have lived in the [GRO-B] area ever since.
26. In 2000 my health was starting to deteriorate. After a long walk my ankles puffed up. I was also experiencing chest pains. I saw my GP and he said that it was caused by heart failure. My GP, [GRO-B] at [GRO-B] Practice, referred me to a cardiologist at the local hospital in [GRO-B] The cardiologist prescribed me with some medication to regulate my heartbeat and said he would see me again in 2 years time.
27. Over this period my general health worsened. I went back to see my GP and he increased the dose of the medication. I was getting terrible chest

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infections and I was increasingly breathless at work. Someone commented that I looked blue.

28. I went to see the cardiologist for the second time in 2002. The cardiologist wasn't there so instead I spoke to a registrar. The registrar questioned why I was there and said that I needed to be seen by a specialist congenital heart consultants.
29. I was then sent to the specialist unit at Queen Elizabeth Hospital ("QEH") Birmingham and I was immediately signed off work until I had seen the specialist. I saw the specialist 6 months later and she took me off the heart medication that had been prescribed and gave me more appropriate medication. She said that I was born with an irregular heartbeat and that the medication I had been given was for adults who had acquired a heart problem. She arranged for an angiogram in 6 months hence.
30. It was explained to me that during my heart operation in 1972, the surgeon had used Teflon to repair the hole in my heart. They said that this was good and effective, however it had the unintended consequence of increasing pressure on the valves.
31. Soon after seeing the heart specialist at QEH, I was admitted by ambulance to Telford hospital. I saw a respiratory consultant. The respiratory consultants suggested that indigestion could be the cause of my chest pains, which I found ridiculous. I phoned the specialist at QEH who arranged for an ambulance to pick me up from Telford hospital and took me straight to QEH.
32. After a number of investigations, I was found to have respiratory and heart failure. I spent two weeks in ITU and it was really touch and go whether I would survive. 'Do not resuscitate' considerations were ongoing and I was on a ventilator for between 17 and 18 hours a day. My Sats scores were in the low 70s and I was diagnosed with type 2 respiratory failure.

33. I was in QEH for a total of 8 weeks. Before all of this I was on sick leave for nearly a year and, prior to being admitted, I had just applied for medical retirement. The manager phoned up the unit when I was in hospital, after which he said that he would push my medical retirement and I was formally medically retired in February 2004.
34. Between 2004 and 2008 there was no indication whatsoever that I had HCV. I was adapting to a new way of life after being forced into early retirement by my health. I applied for disability living allowance and I was volunteering for a local charity.
35. In 2008 I attended the theatre and experienced bad sciatica. I went to see my GP who prescribed me with co-codamol. Dr GRO-B then said that he should do blood tests as he hadn't seen me for a while. Late, the night before I had the blood test, I drank a miniature bottle of whisky, to ease my sciatica and help me to sleep. The blood tests were early the following morning.
36. The results came in a few days later and the GP phoned me and told me to come and see him. He explained that my liver function scores were sky-high. He asked me if I drink alcohol and I explained about the whisky the night before the test.
37. Dr GRO-B then proceeded to ask me about my background. In the course of doing so, Dr GRO-B asked me if I had ever had a blood transfusion. I explained that I had open-heart surgery in 1972 and I believe this had involved me receiving blood. After hearing this, the doctor said that he would do an HCV blood test.
38. I was called back to see Dr GRO-B when the results came in. Dr GRO-B said that I had tested positive for HCV. He initially wanted to refer me to Shrewsbury Hospital but I put my foot down and insisted that I was treated at QEH where my other consultants were based. I think, on reflection, that the whisky from the night before my blood test had raised

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my liver function scores and if I had not had it, the HCV would not have subsequently been diagnosed.

39. I didn't know anything about HCV when I was diagnosed. It wasn't really explained to me either. All the GP said was that it affected the liver, and even this was more inferred than explained.

40. I was duly referred to the hepatology department at QEH where I was seen by the consultant, Dr Freshwater. Dr Freshwater said that he would take a blood test and I was to return in 2 weeks to go through the results with him. I had 15 samples taken from my arm, which was blue by the end of this. The friend who was accompanying me at the appointment nearly passed out at the sight of all the blood being removed from my arm.

41. When I returned two weeks later, Dr Freshwater asked me if I wanted the good news or the bad news. He said that the good news is I don't have AIDS and the bad news is that I have HCV genotype 2b, which he explained is one of the worst types to treat. I had not been told that I was being tested for AIDS.

42. Dr Freshwater said genotype 2b was most prevalent in North America and so the fact that I had such an invasive procedure in New York in 1972, led him to believe that this was the most likely cause of my HCV infection. He also said that it could be treated and this would involve a 48 week course of interferon and ribavirin.

43. There was an ongoing clinical trial of telaprevir at the time, though Dr Freshwater stated his belief that I should not be a part of it as it would be a waste of time putting someone with so many health problems in a control group. He gave me a leaflet and said he would leave it with me, whether to take the interferon treatment.

44. I had a liver biopsy at QEH in 2008, the results of which were inconclusive. The biopsy itself was extremely painful and a horrible experience. It was performed using what I would describe as an apple



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corer and I had it done whilst on the ward. I was kept in overnight before being discharged. The biopsy revealed nothing but a subsequent fibroscan of my liver showed that there was some scarring.

45. I went back to the hepatology department in the spring of 2010 where I was offered a 48 week course of interferon and ribavirin. It was explained to me that it had a 35% success rate. Dr Freshwater said that given my medical background and history, he was confident that I would be able to cope with and persevere with the treatment. He said that most people give up with the treatment soon after starting and he thought I would be able to deal with it.

46. I began this treatment in August 2010. I received an injection of pegylated interferon once a week and took 2 tablets of ribavirin twice daily.

47. The specialist nurses in the hepatology department explained the treatment and showed me how to inject the interferon. I was warned that the treatment would make me feel ill and it would be difficult. They also privately warned my friend about this. I should say that to this point I had not experienced any HCV symptoms, though things like fatigue may have been masked by my other health issues.

48. After injecting me with the first dose there and then, I was warned that it would hit me in 4 hours or so. A week later I self-administered the interferon in front of the nurses. This was intimidating at first as I was very needle-phobic at the time, which was made worse by having to inject it into myself. However, I soon got into a routine and used to doing it.

49. On the day that I had been diagnosed with HCV, I bumped into my cardiologist Dr Sarah Thorne, in the hospital. I explained about the HCV treatment and she arranged an appointment to see her. As a result I went for weekly ECGs at QEH during the first few months of the treatment until they were satisfied that it was stable (See Para 69 below).

50. I also went to QEH for regular blood tests at the hepatology department. These were weekly at first and later fortnightly. The results of these tests showed that my viral load was going down.

51. After completing the 48 week course of pegylated interferon and ribavirin, I was found to be clear of HCV. This was finally confirmed in January 2012 after subsequent tests. I have also had liver function tests at QEH and these have shown my liver to be functioning normally.

52. After finishing the treatment, I suffered withdrawal effects from not injecting interferon, for about 4 weeks afterwards (See para 63 below).

### **Section 3. Other Infections**

53. I do not believe that I received any other infections as a result of my blood being contaminated.

### **Section 4. Consent**

54. I consented to being tested for HCV although I was not aware that I was being tested for HIV/AIDS and so could not consent to that.

55. I signed forms consenting to receiving the pegylated interferon and ribavirin treatment.

56. I consented to being part of the HCV Research UK study, signing the consent form in 2013. This involved taking a blood test from me which they would store for 10 years. In a letter from the HCVRUK study, it was explained to me that the study 'is concerned with identifying reasons why some patients are able to clear infection spontaneously, whilst in others the infection becomes chronic, and also why some patients respond well to therapy but others do not. In order to answer these questions, the study plans to look at the genetic make-up of a large number of patients

who have ever been infected with HCV.' The study has another 2 years to go but I have heard nothing about it since.

### **Section 5. Impact**

57. The greatest impact of my HCV infection was undoubtedly the side-effects of the treatment. I can remember the nurses at the hepatology department saying that they were making me ill to make me better. Prior to starting the treatment, I was asymptomatic.
58. Throughout the treatment I had a high temperature and fever-like symptoms. I remember my temperature being as high as 41 degrees Celsius some nights. I was unable to sleep and felt generally very unwell. Thankfully I was medically retired and didn't have to juggle this with working at the same time.
59. The effects of the treatment were worse for the first month, then after that it became cyclical. I injected the interferon on a Tuesday and 4 hours after the injection I felt rough. This continued until Thursday and by Friday I started to feel better. I managed to do a few things over the weekend before having to self-inject the interferon again on Tuesday, starting the cycle all over again.
60. I suffered from bad eczema during the treatment for which I was referred to a dermatologist. I also had terrible mouth ulcers. My mood was all over the place and I was noticeably short-tempered.
61. At some stage within the first 6 months of treatment, my brother had a lot of mental health issues that my mother was struggling to deal with. These pressures, coupled with the effects of the treatment, led me to struggle and I began to experience dark thoughts.
62. I remember saying to one of the nurses at QEH that 'I don't think it's worth carrying on.' The nurse didn't really comment but afterwards she

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phoned my friend. I had begun to feel like I didn't want to carry on with life. I was isolated and depressed. On a scale of 1-10, I would say I was between 3-4 in terms of thinking about taking my own life. It hadn't yet become so severe that I was planning to but I was definitely heading that way.

63. After the call from the liver nurse, my close friend and confidant suggested that I speak to my GP about my difficulties. She arranged an appointment for me to see Dr. GRO-B. Dr. GRO-B was very kind and helpful and he gave me a few pointers. He said that his door is always open and he knew how difficult the treatment was so if I ever needed a chat I could reach out to him. He was very good to me at this time when I was struggling.

64. After completing the treatment I had withdrawal symptoms from the interferon injections. My body was anticipating the next interferon injection and it felt like I needed it. The withdrawal from the interferon lasted for 4 weeks and was worse at times than during the treatment. Whereas before, during the treatment as I explained, the worse parts were related to a couple of days after the injection. The withdrawal effects were all the time for about four weeks. I don't really know why I was not gradually taken off the medication.

65. The nurse explained that this 'cold turkey' is quite common and they didn't warn me about it because I had enough on my plate. In fact this was one of the worse aspects of the treatment.

66. Back in 1997 I applied for a mortgage to buy a property. I had to get life insurance to do so and, when completing the form, I ticked 'yes' in response to a question asking whether I had ever received a blood transfusion outside the UK.

67. This answer led to another form, this time focussing on AIDS, to which I had to reply 'yes' in that I had received an operation abroad. I responded 'no' to all other questions. In response to this, I knew that my premium

would be extortionate and I was forced to find a mortgage without life insurance, which thankfully a mortgage broker arranged for me. This was years before I had unwittingly been given an HIV/AIDS test.

**Section 6. Treatment/Care/Support**

68. I have not faced any difficulties or obstacles in obtaining treatment, care or support in consequence of my infection with HCV.

69. In that past, I had observed from my extensive number of appointments with different hospitals and departments that they were not always 'joined up' with one another. They didn't liaise about my various health issues. That said they are much better now,

70. One example of this was when I bumped into my cardiologist outside QEH straight after my HCV diagnosis. My cardiologist was concerned and asked if I was ok. I explained about my HCV diagnosis and the treatment I had been offered. It was this chance conversation that led my cardiologist to consider the potential implications of interferon on my heart condition and consequently she arranged for me to have ECGs during the first few weeks of the treatment. Had I not bumped into my cardiologist on that day, I question whether this would have been picked up on.

71. I have noticed that the various consultants have started to copy each other in to letters regarding my general treatment now, which can only be a good thing but it has taken a long time.

72. I have received counselling in relation to my diagnosis with, and treatment for, HCV, although this was not offered to me by QEH. After my diagnosis I was not offered counselling or psychological support. I heard about a counsellor connected to the hepatology unit at QEH Birmingham. I enquired about speaking to her but I was told that she was very busy and only there if I really needed it.

73. It wasn't a matter of course that people were offered counselling at QEH. They said it was a pity that I didn't live in the Birmingham area because they could have referred me to a local counselling service. I think it would have been beneficial to have someone to talk to at the hepatology unit at QEH.
74. After my diagnosis, the respiratory community nurse got in touch and suggested that I may need some help. She offered to refer me for counselling and within 2 weeks I was speaking to a counsellor at Shrewsbury Hospital. She was a counsellor who normally dealt with cancer patients. I felt very lucky because she understood me and we had a good relationship.
75. This counselling was for 1 hour every week for 9-10 weeks, which I believe was probably more than my allocated number of sessions. I found the counselling helpful and it prepared me to deal with the upcoming treatment. I felt like a stronger person afterwards.
76. My GP was helpful and supportive when I spoke to him 6 months into my treatment. He said he was always there to talk to and he put me on a list for the local counselling service. However, I didn't hear anything back from them until a year or so later, by which time I had finished the treatment and cleared the HCV. That was when I needed it, during my treatment and not afterwards.

## **Section 7. Financial Assistance**

77. Dr Freshwater, the consultant hepatologist at QEH, informed me about the Skipton Fund and supported me with my application. I filled in the form and then Dr Freshwater completed a lot of the relevant sections. My application was submitted to the Skipton Fund in 2008.
78. In the course of submitting my application to the Skipton Fund, Dr Freshwater advised me to get my GP records. I phoned up and arranged

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an appointment to see Dr **GRO-B** who had booked a double appointment. We went through all the letters together and he showed me which ones to copy. Dr **GRO-B** said that the GP practice normally charges for this service but he would not do so in my case.

79. I received a letter in response to my application from Nicholas Fish a few weeks later on 29 September 2008 (enclosed as exhibit **WITN4292002**). Nicholas Fish explained that my application had been declined due to the fact that the likely source of my infection was the probable blood transfusion received in the USA in 1972. Although my consultant had endorsed the application by saying that it was possible that I could have contracted HCV through subsequent NHS procedures if sterilisation had been inadequate, Nicholas Fish said that the Skipton Fund are only able to make payments where the infection is thought to have arisen through treatment with NHS blood or blood products. I understand this now but at the end of this letter, Mr Fish informed me that as my case did not fall within the terms of the Skipton Fund, there may be a similar scheme in the USA to which I could apply to. I have not done this because I don't feel it is worthwhile. Also, Nicholas Fish gave me no clear directions or even indicated whether any such scheme existed.

### **Section 8. Other Issues**

80. I have nothing else to add.

### **Statement of Truth**

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

Signed

**GRO-B**

Dated

8/12/2021