

ANONYMOUS

Witness Name: GRO-B

Statement No: WITN5855001

Exhibits: Nil

Dated:

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF GRO-B

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 7<sup>th</sup> October 2021.

I, GRO-B will say as follows: -

**Section 1. Introduction**

1. My name is GRO-B and I am 68 years old. I live in GRO-B and my full address is known to the Inquiry. I have lived here for 38 years. I married my wife in GRO-B and we have two children. We also have three grandchildren. I took early retirement from my role as a haulage (HGV) driver in 2003, having worked for over 40 years in the industry.
2. I intend to speak about my infection with Hepatitis C ("HCV") after 1969/1972. In particular, I will speak about the nature of how I learnt about my infection, how my illness had affected me and my family thereafter, and the financial assistance I have received. Further, I will also provide detail on the impact that my illness had on my brother's life, as well.

3. I can confirm that I have chosen not to have legal representation and that the Inquiry Investigator has explained the anonymity process to me.
4. The Inquiry Investigator has explained to me the 'Right to Reply' procedure, and I understand that if I am critical of a medical professional or organisation, they will have the right to reply to that criticism.
5. I wish to acknowledge that naturally as time passes, memories can fade. I have been able to provide approximate timeframes for matters based on life events. However, these timeframes should be accepted as 'near to' rather than precise dates.
6. I have constructed this statement with access to my medical records.

## **Section 2. How Infected**

### *Blood Transfusion History*

7. I cannot be certain on the point in time or the procedure through which I became infected with HCV. Since 1969, I have received three separate blood transfusions - one in each of 1969, 1972 and 1997. I will briefly explain the circumstances of each transfusion below.
8. The first instance in which I required a blood transfusion was in 1969 at which point I was 15. At the time I was a trainee salesman at a firm called GRO-B. GRO-B I suffered an issue with my duodenum which I discovered through my stools as they were exceptionally dark in colour. I also began feeling very weak and generally unwell which led to me collapsing in my hallway and throwing up blood.
9. Consequently, I was taken to GRO-B Hospital and, as stated, I was treated for an issue with my duodenum. I was treated in an adult ward

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and remained in hospital for two weeks undergoing some invasive treatment, although I am not sure specifically what this was. During this stay, I was given a blood transfusion. I am uncertain on how much blood was transfused, but I remember thinking it was a significant amount. After this, I seemingly made a full recovery and returned to what I believed was a full bill of health.

10. Then, in 1972, I had to return to the hospital when I noticed my stools had become exceptionally dark in colour again. It was clear that I had suffered a similar problem with my duodenum/stomach as the symptoms were exactly the same as before. I was again taken to GRO-B Hospital and, again, was in receipt of a blood transfusion. I am uncertain about the amount of blood transfused. I proceeded to make another full recovery.

11. Later, in 1997, I suffered a third episode of the above symptoms. I had been out cycling and my chain broke which meant I was forced to walk up a steep hill. I proceeded to take my bike round to a friend's house as he was able to fix it. It was at this point that I began feeling extremely weak and, when I returned home, I noticed my stools were very dark in colour again.

12. My brother, GRO-B then took me to hospital and I was immediately admitted on specific request of the A & E doctor with serious stomach ulcers. This occasion of hospitalisation was the worst as I felt particularly weak, to the extent that I was unable to stand. My stools and vomit were made up mostly of blood (haematemesis). During this episode, I was in and out of consciousness and, therefore, I cannot be certain of the treatment which I was given. That being said, I recall being given another blood transfusion in order to boost my Haemoglobin levels. I do not recall the exact amount transfused.

13. At no point during any of the above instances of hospitalisation were the risks of blood transfusions explained to me, even though my wife remained very concerned that I had received blood. Neither myself, nor my wife, were ever provided with any information or advice with respect to blood transfusions and

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the associated risks. We were most certainly not told anything about the possibility of exposure to serious infections.

14. My recovery from the 1997 episode was not similar to my recoveries to the previous two episodes. Instead, during the weeks immediately after, I suffered with extreme tiredness and, on many days, I was forced to remain in bed all day, as I felt like all I was able to do was sleep. The tiredness subsided, but I was then faced with a general ache all over my body.

15. As is clear, I received blood transfusions on multiple occasions, however, I cannot be sure on which occasion it was that I was infected with HCV.

### *HCV Diagnosis*

16. I did not actually discover my HCV infection until 2001. In 2001, my late brother, GRO-B, suffered a serious illness and urgently required a bone marrow transplant. As a blood relative, I underwent bone marrow compatibility tests to discern whether I could feasibly be a bone marrow donor for my brother. I desperately wanted to be a match so that I could save GRO-B's life.

17. I underwent these compatibility tests at Addenbrookes Hospital in Cambridge. I was treated by Dr Alexander at Addenbrookes on the request of Dr Beatty from Addenbrookes Hospital. These tests were initially positive and for a while it was believed that I was a compatible donor for my brother. I was ecstatic with the thought that I may be able to save my brother's life. However, it was as a consequence of further tests that my HCV infection was discovered.

18. Dr Beatty communicated my positive HCV infection status over the phone. This was followed up by an in-person appointment with Dr Beatty for further discussions. I remember being in complete shock at this diagnosis. Because of the situation with GRO-B there was still great urgency, but I was left reeling from this horrifying diagnosis. During the consultation, Dr Beatty explained

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that HCV is a virus that attacks the liver. She also explained that I could have been infected with HCV through any of the blood transfusions which I had previously received. This initiated the start of an exceptionally difficult period of my life. For a long time I remember feeling numb as I struggled greatly to come to terms with what had happened.

19. I was forced to deal with my diagnosis concurrently with my brother's illness. I felt totally useless as I was unable to help [GRO-B] and this had a hugely detrimental impact on my physical and mental health. I suffered from serious depression and anxiety over the fact that I was unable to assist [GRO-B]. Later, these mental health issues developed into dark, and often suicidal, thoughts.

20. Unfortunately [GRO-B] passed away at [GRO-B] in [GRO-B] in 2002. We were unable to locate a compatible donor to save his life and he passed away at [GRO-B]. I was totally devastated. *(Please see below for further discussion on the impact this had)*

21. After the diagnosis in 2001, I became frustrated with the uncertainty over which transfusion engendered my HCV infection. I was repeatedly told that it could have been through any one of the transfusions in 1969, 1972 and 1997. It made the situation more difficult to deal with and I struggled with this.

### *Experience with Clinician*

22. I recall an instance in 2001 during which I encountered a particularly dismissive and unsympathetic clinician at the Blood Transfusion Service (BTS). Having previously been told by Dr Beatty that my HCV infection may have originated from any one of my blood transfusions, I was very surprised by the BTS clinician's statement that it was most certainly not from the 1997 transfusion. I questioned her on this and her responses were dismissive and lacking in care and she was insistent that my infection was not from the

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treatment in 1997. I felt as if she lacked empathy for my circumstances and did not understand my position.

23. This culminated in the clinician conducting further investigations into the sources of blood for my 1997 transfusion. In effect, during this transfusion, I was transfused with seven separate blood donations of which six were quickly confirmed to be non-infectious. Unfortunately, there was a delay in obtaining the infectivity status of the last remaining donation. Throughout this delay the BTS clinician remained convinced that my 1997 transfusion was not the source of my infection, even though there was no confirmation of the status of the last donation.

24. In February 2003, the last donation was finally confirmed to be HCV negative, which ultimately verified the BTS clinician's position. Even though it was useful to confirm that the 1997 transfusion was not the source of my infection, I remained extremely disappointed with how I had been treated by this particular clinician.

### *Referral to HCV Clinic's*

25. After my diagnosis in 2001, Dr Beatty immediately transferred my care to a HCV clinic at Addenbrookes hospital. It was from here that my treatment for my HCV diagnosis began. *(Please see below for discussion on the treatment that I have received)*

26. At this point, I was provided with extensive information on HCV and the health related issues that the infection presents. I underwent 2 liver biopsies. The first biopsy failed as the doctors were unable to extract any of my liver, partially because my liver had already been damaged through my HCV infection. This was an extremely uncomfortable experience.

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27. On the second occasion, an ultrasound was used to assist in obtaining the liver biopsy. This procedure was a success and the doctors were able to extract a piece of my liver for testing. Again, this was an uncomfortable experience to undergo. The biopsy was tested and it was confirmed that my liver was cirrhotic, as I had been told to expect.

28. At the HCV clinic's I was looked after by a nurse named Tracey who I got on with very well and grew very fond of. Tracey made clear how I should change my lifestyle by avoiding cigarettes and alcohol consumption. She also encouraged me to increase my exercise as well as improving my general physical health. I was very receptive to Tracey's advice and the care that she provided with respect to my HCV infection. I believed she was a highly competent nurse and that she cared about my health, even though she took a hardline approach with me.

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

29. I can confirm that I was not infected with any other infections as a consequence of my medical treatment.

### **Section 4. Consent**

30. I was aware of my need for a blood transfusion during all three instances of my hospitalisation. I consented to having blood transfused due to my immediate need at the time. However, at no stage was I notified of the associated risks with blood transfusions and the possibility of any sort of infection being transmitted through the treatment. With hindsight, I firmly believe that I was not provided with adequate information on the risks of blood transfusion and I, therefore, do not believe my consent was fully informed at the time.

31. I was involved in a research project at Addenbrookes Hospital after I had my diagnosis confirmed. I happily consented to being involved in this project because I am of the belief that, if it could help someone else, then it is worthwhile. I was asked to give further blood than would usually be asked for, for the purposes of the research.

## **Section 5. Impact.**

### *Mental/Physical Impact*

32. The HCV diagnosis had a hugely detrimental impact on my mental health, mostly due to the shock and immediacy of the situation. I struggled to come to terms with my infection and the causes of it and, most significantly, I struggled with the reality that my infection prevented me from saving my brother's life. I would like to reinforce the severe impact that this had on my health.

33. As explained above, I had passed several compatibility tests in order to be a bone marrow donor for [GRO-B]. However, my positive HCV infection status totally obstructed my ability to help him. This facet of my story is the most difficult factor that I have had to deal with; I was present at his death, where I sat with him holding his hand and that is when I realised that I couldn't save him.

34. In the years after [GRO-B]'s passing, my mental health significantly worsened because of the reality that, had it not been for my infection, I may have been able to save my brother. I felt useless because I was unable to help [GRO-B]. The loss of [GRO-B] and the circumstances around his death, was truly devastating for both myself and my family.

35. I recall an evening shortly before [GRO-B] passed away. I went to visit him at the hospice and [GRO-B] said to me "...I don't want to die..". This was completely



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heartbreaking and it was made more difficult by the situation surrounding my own diagnosis. I remember questioning why the doctors could not use my bone marrow, even with the HCV infection, as it would still save GRO-B's life albeit whilst risking the transmission of HCV.

36. I continued to suffer from depression for a long time after GRO-B's passing. This had a profound impact on myself and my family. I generally felt distant and I am certain that this would have impacted on my wife and children. I struggled to remedy the situation because of the depression I was suffering.

37. With respect to my physical health, the infection took less of a toll. I took up cycling as a hobby from 1993. This meant that I had maintained a good level of general physical health from then. Having said that, there were some inevitable knock-on effects on my physical health from the struggles with my mental health.

38. As stated above, my liver had become damaged as a consequence of my HCV infection. This initially meant that I had to have regular check ups, which were conducted at Addenbrookes Hospital. At one stage, I was required to visit Addenbrookes once a week which usually came at great inconvenience given the distance and time it took to travel to/from. I am still required, to this day, to visit Addenbrookes to have my liver checked twice annually even though my liver damage has stabilised. My visits are also used to take a blood test to test HCV viral count on a similar bi-annual basis.

### *Treatment*

39. I was not immediately provided with treatment, and it initially took a number of clinic visits in order to obtain this. I have been in receipt of multiple different rounds of treatment for my HCV infection using a variety of medicines.

40. For the first treatment round, I was working as a lorry driver through an Agency. The treatment consisted of two separate medicines in Interferon and Ribavirin. The Interferon was administered through a weekly injection and the Ribavirin was taken orally in tablet form daily. Initially, I spent a weekend in hospital to be taught how to administer the injection. I then was allowed to give the injection to myself at home which was much more convenient.
41. Usually, for the two days after the injection, I would really struggle with energy levels and would feel extremely tired. I remember really struggling with this initial treatment round. For this reason, as well as the fact that my haemoglobin was too low, I was taken off this treatment after approximately three to four months.
42. There was approximately one to two years between my first and second round of treatment. I found the second round of treatment to be equally challenging. The combination of medication remained the same (Interferon and Ribavirin), but it just consisted of different doses. During this treatment round, I experienced severe side effects which included headaches, nausea and vomiting. In addition to this, I felt very weak which often meant I felt unable to stand up long enough to have a shower. This contributed greatly to my feeling of being unable to participate in family life as I felt too unwell to do so.
43. Similarly, for my third round of treatment, I was offered the same medication, but again, with different doses. For all that I was aware of, the treatment was a failure and the side effects were just as burdensome as they had been previously. I really struggled with this treatment and in particular with this combination of drugs. It took a massive toll on all aspects of my life.
44. The last round of treatment which I underwent came a few years after the third round. The medication which I was offered was called Harvoni and it was administered orally in tablet form. I had to wait quite a while after being told

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about this treatment because there was a limited supply of this drug. I became frustrated with the system in the UK when I became aware of others, in Australia for example, gaining access to the treatment faster than I was able to.

45. The Harvoni drug treatment was a success in my case. It seemed to work in a matter of months and continued to help deal with my infection for a long time after.

46. At one stage, I was offered counselling and received invitations to attend group sessions for people who had also been infected with HCV. I opted against attending these sessions because, at the time, I could not see the benefit and I do not like talking about my infection.

### *Impact*

47. During the treatment, my social life was non-existent because of the side effects. I felt constantly tired and often this was accompanied by a feeling of nausea. This made me feel lonely as I no longer felt able to socialise with friends as I once enjoyed doing.

48. To my knowledge, I do not believe that I ever suffered any stigma stemming from my HCV infection. I never felt as if I had been treated differently to others because of my infection, and this was most likely because I chose not to tell very many people about it.

49. I chose to only tell immediate family members about my infection and not friends. As stated, I do not like talking about my infection and so I felt more content telling fewer people. I did ask the doctors about whether I had a duty to tell anyone from a health perspective, but they confirmed this was not necessary and so I opted against it.

50. I can confirm that I have experienced no major financial impacts as a result of my HCV infection. I was, and continue to be, intent on not letting this infection get the better of me, so I worked as much as I could to ensure that I was out of the house and active.

51. I would like to reiterate that the most difficult aspect of my HCV infection has been my inability to save my brother. As mentioned, this has had a profound impact on myself and my family and to this day is still something that I find difficult to talk about.

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

52. Aside from a delay with obtaining the Harvoni treatment, I never faced any obstacles in getting access to treatment. Tracey, the nurse at the HCV clinic, was very caring and worked well with me and this meant that I was always engaged with my treatment plan.

#### **Section 7. Financial Assistance**

53. In 2002, Tracey stated that I may be eligible for a £20,000 lump sum payment from the Skipton Fund. Tracey was very useful in obtaining this lump sum payment as she helped me fill out the forms and process the documentation. I ended up receiving an initial £20,000 lump sum payment and, a few years later, I received a further lump sum payment of £45,000. Then, a few years after that, I received a third lump sum payment of £25,000 again after being notified of it through Tracey.

54. Since then, I have been in receipt of monthly payments of around £2390. These were initially from the Skipton Fund, but are now from the England Infected Blood Support Scheme (EIBSS). This has meant that the HCV infection has caused me no real financial burden.

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55. I do not recall any difficulty in obtaining financial assistance. My applications were made less stressful as I had Tracey for support who was always able to send my documents to the correct doctors so that I was granted access to the financial support.

56. I do not recall signing up to any scheme or any pre condition. Tracey was usually the person who would direct me to these payments and I trusted her guidance and direction.

### Section 8. Other Issues

57. As a child, I was taught that people in positions of power, such as doctors and politicians, can be trusted. However, this scandal has meant that I have totally lost faith in these professions. I feel as if I have been lied to and deceived and I am extremely disappointed to have been badly let down by certain individuals and organisations. I believe it is only fair that the full truth is established and those who are responsible are identified and held to account.

### Statement of Truth

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

Signed \_\_\_\_\_  
Dated 21/02/2022

GRO-B