

# ANONYMOUS

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Witness Name: GRO-B

Statement No.: WITN4212001

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 14 September 2020.

I, GRO-B will say as follows: -

### Section 1. Introduction

1. My name is GRO-B. My date of birth is GRO-B 1962 and my address is known to the Inquiry. I was born in GRO-B Surrey and grew up in London. I intend to speak about my infection with hepatitis C (HCV) from a suspected blood transfusion following a road traffic accident. In particular, the nature of my illness, the treatment I have received and the impact that it has had on my life.
2. When I was 17, I set up a successful GRO-B business and have subsequently established several other companies, most of which have been in the environmental and sustainability sector.
3. I can confirm that I am not legally represented and the anonymity provisions have been explained to me and I **would** like to be

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anonymous. Running my own business, there is a significant chance of reputational damage if I my name is disclosed.

### Section 2. How Infected

4. One evening in [GRO-B] 1986, I was on a night out with some friends in [GRO-B] where my mother was living at the time. I can remember the specific date because it was the same day the [GRO-B] [GRO-B] 1986.
5. Towards the end of the night, someone suggested that we go back to my house for a few more drinks. We all piled into a car, with me and two other friends in the back. As we were approaching [GRO-B] in central [GRO-B] we hit black ice. The car went straight through an electricity pylon and into the basement of a flat belonging to an old lady.
6. Everyone was quite seriously injured – the driver broke his jaw, the front passenger had bad cuts to his face, as did one of those in the back with me. The other person in the back broke both their arms. My injury, however, was the most significant of all; a serious frontal lobe injury.
7. I was taken to the Royal United Hospitals in Bath, where I was in a three-day coma. This was not an induced coma - the impact of the crash had knocked me clean out. I had a blood transfusion at some point during this period. My sister specifically recalls me having one and I remember the doctor telling me that I had been transfused. When I woke up, I had lots of drips connected to me and there was definitely a blood bag there. I can also remember a doctor informing me that the lacerations to my head caused an unusually high amount of blood loss.
8. When I was discharged from the hospital, I went to stay with my mother in [GRO-B] for a while. I was in serious need of an extended period of

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recuperation. I wasn't able to work – I had to liquidate all of my assets and I found a cottage near GRO-B in Somerset.

9. I stayed here for about three years, gradually recovering from my injury. From a young age, I have always had a great interest in nature and the environment and I was really able to nurture this over my period of recovery. I would spend my time sat in trees, meditating and reflecting on life. I had a long period of contemplation that most people don't get until towards the end of their life.
10. During this time, I was seeing a wonderful head injury specialist at GRO-B in Oxford, but I am unfortunately unable to recall his name now. I also regularly attended GRO-B Hospital in Bristol for checks ups that allowed doctors to rule out more serious consequences of my injury.
11. Almost three years after the accident, in 1988, I was still recuperating and was sat out in a tree. I got up, walked away and suddenly the penny dropped. I realised I was fine. It was time to get on with life. Before, my recovery had been slow and incremental, but it just came to me, I realised I had fully recovered.
12. 90% of people that have an injury like mine suffer from some sort of impairment to their cognitive capacity. I, however, have a strange feeling that I am in the miniscule minority that actually get a little sharper. Having made a full recovery, I was still in my early twenties, with a new lease on life and feeling on top of the world.
13. I had no observable symptoms over this period of my life, or afterwards for that matter. I was tired at times, but I led a very busy life. There was no indication that I was suffering from any disease or infection. I have never used drugs, had any tattoos or medical treatment abroad and generally have a very clean lifestyle. Over the course of my life, I have had five or six monogamous relationships and have never been

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promiscuous. Other than the treatment following my accident, I have never needed a blood transfusion.

14. Then, in 2004, I was having quite a rough time; I was going through a very stressful period with my business, my relationship was falling apart and my dog had just died. I was feeling very down. I went to see my GP, Dr [GRO-B] in [GRO-B] I'm not sure exactly why, but she wanted to run a blood test. She then asked me if I had been drinking a lot recently, as my ALT levels indicated high alcohol consumption.
15. When I told her I hadn't, she ran some further tests and then confirmed that I had tested positive for hepatitis C. Together we ran through the possible routes of transmission and tried to work out how I had become infected. By deduction, we concluded that the only possible cause of my HCV was a blood transfusion. I had no other risk factors.
16. We had a conversation about managing the condition, covering the low risk of sexual transmission, the need to use contraception as a precaution anyway, the importance of minimising blood to blood contact and the need to be careful around others with toothbrushes and razors etc.

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

17. To my knowledge, I have not been infected with or exposed to any infection other than hepatitis C. I believe I was tested for HIV but this was negative.

### **Section 4. Consent**

18. As previously noted, I was not conscious at the time of receiving a blood transfusion. As I was not aware of being given such treatment, I, by implication, was not able to consent to it.
19. I was aware that I was being tested for hepatitis C and provided my consent for this test to be conducted.

**Section 5. Treatment/Care/Support**

20. After the initial conversation with Dr GRO-B following my diagnosis, I was referred to the Royal Free Hospital in London. Here I was under the care of Professor Dusheiko initially, before soon getting moved onto Dr Patch.
21. I had a liver biopsy with Dr Patch, which found mild scarring. I had another biopsy towards the end of my treatment as well and both were truly awful experiences. It is a very invasive procedure and painful even though I had lots of pain killers. I wouldn't wish it on my worst enemy. It really was horrible.
22. About eight months after my diagnosis, in 2005, my treatment began. It consisted of weekly Interferon injections into my stomach and daily Ribavirin tablets. I think it lasted for three months, I can't recall exactly. Dr Patch told me that it wasn't a particularly reliable or effective treatment, but it was all that they had. Around this time, I was told that I was genotype 3.
23. The doctors told me that if my ALT levels didn't come down, then it wasn't worth continuing. It was a really gruelling experience. I will go into further detail on the impact of the treatment below, in Section 6.
24. The treatment was unsuccessful. I was determined to keep going and carry on with the treatment, but Dr Patch insisted that I stop. This really upset me, as I just wanted to get the whole thing out of the way and get back to my life.
25. I had a second round of treatment a few years later, in 2007. I asked to have another go at the treatment – the doctors, however, were more

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cautious and asked me if I was certain. It would be the exact same treatment and there was no indication that there would be any difference in the results. Rarely do you try again with the same medication if it failed the first time. But I made a big fuss and insisted that we give it another shot. The desire to have my HCV cured was my paramount concern.

26. So, I had another three months of awful, debilitating treatment. People asked me why I was putting myself through it all over again. But the tiny chance that it may have some positive effect was enough for me. The reputation of the disease, the associated stigma, the progression of the potential damage to my liver – it was all enough to make me willing to try anything. I was also acutely aware that it could be life-limiting and this was a big factor, as well.
27. Dr Patch soon told me that it had failed again. By this point, I had started to get annoyed with him and I was not at all happy with the treatment. But, realistically, I know that this was because the treatment was failing and I was getting frustrated about the lack of progress.
28. After this second round of treatment failed, Dr Patch referred me back to Professor Dusheiko, who wanted to put me forward for a trial. He told me that there were new drugs becoming available and, knowing that I was desperate to have another go at treatment, recommended that I be involved in the clinical trials.
29. The first offer came in 2009, from the pharmaceutical company Gilead. They were trialling a new combination therapy; Interferon and Ribavirin again, but with the addition of a third drug, the name of which I cannot recall. I had the injections again, but there were two pills to take this time. I remember walking back to my flat in GRO-B when I received a call from Dusheiko with more bad news. This treatment was also ineffective.

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30. Professor Dusheiko advised me that more trials would be coming up and invited me to come in and meet his colleague, Professor Rosenberg. Around 2010, Professor Rosenberg became my main consultant and we actually remain good friends to this day.
31. Another trial came around soon after this, I believe with Gilead again. It was carried out at University College Hospital and consisted of a drug called Sofosforin, or something like that. As far as I can remember, it was just tablets, without any injections. This did make it much easier to take. I was working in Los Angeles quite a lot at the time and I remember having to go through customs with all the medication and drug certificates etc.
32. It was an early generation drug and came with considerable side effects, but they weren't as bad as those that accompanied the combination therapy I had previously been on. The drug caused a drop in my ALT levels and my viral load was undetectable at the end of the treatment. I can't recall the duration of the course of medication but I had to wait three months for them to remain low before it could be confirmed that the treatment was successful.
33. Unfortunately, this didn't happen. Three months later, I went in for tests and Professor Rosenberg soon confirmed that my ALT levels and viral load were back up. Another huge disappointment, but it came with a small silver lining; my involvement was proving to be very useful for trial purposes as my genotype seemed to refuse otherwise effective treatments. This would help refine the drug and Professor Rosenberg assured me that another trial would come along soon.
34. I was invited to further clinical trials intermittently, all of which were ineffective. By 2014, I had been through five treatments, all of which had been horrendously debilitating and not at all successful. I was starting to become concerned about end of life issues and was devastated by my inability to have a meaningful relationship which I attributed to my desire to be clear of the virus before making such a

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commitment. On top of this, I was having a dreadful time trying to apply for compensation from the Skipton Fund, but I will cover this in further detail in Section 7, below.

35. Luckily, I had good people around throughout this time, particularly Professors Dusheiko and Rosenberg. I am naturally an optimist so I was hopeful that they would find something that would work for me. Professor Rosenberg gave me excellent support over this period and nurtured the hope in me that a treatment would come along. This really bolstered my positive outlook on life.
36. Despite the wonderful support offered by my consultants, I was not offered any psychological assistance or counselling following my diagnosis or over the course of my treatment. I requested some Cognitive Behaviour Therapy (CBT) in 2012, but it was completely useless. I will go into more detail on the impact that the treatment had on my mental health in Section 6.
37. Around 2016 or 2017, I received a called from Professor Rosenberg. He told me there was a drug that was becoming available. It wasn't a trial this time, but a treatment available to all on the NHS. As I had put myself through so many trials in the past, the doctors made sure that I was prioritised for the treatment.
38. If I remember correctly, it was for three months again and consisted of a single pill, once a day. I would go to the Royal Free to pick up the prescriptions. It felt good to know that there was a drug helping others that had been improved because of my involvement in trials. The big question, for me at least, was whether it would finally be the treatment that worked for me.
39. And, sure enough, my ALT levels began slowly decreasing. Having been disappointed so many times before, I tried not to get my hopes up. But three months later, my test results indicated that they were staying down. Another three months went by and they were still down.



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The provisional all clear came six months later. And finally, as of about six or seven months ago, I was completely discharged with my final all-clear.

40. It still feels so incredibly good to be able to say that I am clear. It really is an absolutely wonderful feeling to think that I have come through this awful period of my life having beaten the virus. It is a privilege, despite the pain and disappointments along the way, to have been involved in the development of the drug as well. On top of all this, I have come out of it with a lifelong friend in Professor Rosenberg, who really is an absolutely brilliant man. I now feel back to my old self; I have a number of huge projects on the go and am working in an area that I love.
41. I have had some dental work over the course of my treatment, but I don't think that my infection has had any great impact on this. I informed them of my hepatitis and I needed to have a consultation about it, but I haven't noticed any change in the treatment that I have received. I don't know if it is worth mentioning, but this was all carried out at a private dental practice.

### **Section 6. Impact**

42. The impact of my HCV infection and the subsequent treatment has been severe and wide-ranging. Having not known about my infection for so many years or suffered any significant symptoms prior to my diagnosis, the biggest impact on my life has come from the multiple rounds of treatment that I underwent. In order to provide a comprehensive account of the impact, this section will be divided into the following sections; a) physical health, b) mental health, c) work and financial life and d) family, social and personal life.

#### ***Physical health***

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43. Every round of treatment I went through was hugely debilitating. The side effects were devastating and had tremendous impact on my life. I had awful fatigue; a persistent tiredness that was very difficult to fight.
44. I had outbreaks of skin rashes and experienced drastic weight loss. I also had the constant sleep problems that often come along with hepatitis infection. I'd spend endless nights lying awake in bed worrying about the future. I also developed a strange sensitivity to light, which I have since heard can be a symptom of HCV.
45. There isn't much more to add in terms of the impact on my physical health, other than to emphasise again how truly horrible the treatments made me feel. I went through so many rounds of treatment that it is difficult to distinguish the particular effects of each, but they were all pernicious and punishingly harsh.

### ***Mental health***

46. Being informed that I was infected with HCV had a huge impact on my mental wellbeing. Knowing that I had been suffering with it all this time, with it damaging my liver without me knowing, definitely added to the stress of it all. It just kept playing on my mind – how is this going to unfold?
47. I was on anti-depressants for a short while after my diagnosis. As previously mentioned, it was a traumatic time for me even before my diagnosis and finding out I was infected really pushed me over the edge. It was a strange feeling, knowing that I had recovered from my initial injury all those years ago, to then find out that I had been infected with this virus by the very same treatment meant to heal me. I had fought so hard and resolved that battle, now this one had come along. It felt like an iron girder crashing through my home, it was so invasive.
48. Then there was the disappointment of failure after failure when it came to my treatment. Every time that I got the bad news that the medication

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had not been effective, I felt my determination to beat the disease diminish. Luckily, I was stubborn and insistent when it came to my treatment and I was in the care of people that were determined to find a medication that would work for me. But, without them, the devastation of putting myself through gruelling treatment that provided no benefit may have been too much for me to continue with.

49. I will cover this in more detail under Section 7, below, but my experience of applying for financial assistance has also had a considerable impact on my mental health and proved to be a very traumatic time.

### ***Work and financial life***

50. Another aspect of the impact I have felt has been on my business and my ability to work and earn a living. Running my own companies means that I need to be constantly on top of my game and my business was severely impacted when my diagnosis caused me to take my eye off the ball. The brain-fog often associated with HCV has a detrimental effect on an entrepreneur trying to get ahead; you need razor sharp focus. Mental acuity is paramount and having my health to worry about, on top of all the stresses of work, meant that my focus just wasn't where it needed to be.
51. The impact of treatment was even more damaging to my ability to further my business pursuits. I was able to carry on with my business during treatment, but I was lucky enough to be working on my own terms. If I wasn't working for myself with the flexibility that allows and following my own passion, then I wouldn't have been able to function.
52. But it's like running a marathon with a tiny stone in your shoe. You might finish the race, but without that stone, how much faster might you have been? It is very difficult to quantify the loss of earnings, but they

would have been substantial – easily millions of pounds. My  
**GRO-B** work is currently charged at £2000 a day,  
so the debilitating effect of my treatment has certainly caused me to  
lose a considerable sum in loss of earnings.

53. I have had no problems obtaining mortgages or anything like that. I haven't protected myself with pensions, however, so I do sometimes worry about my future finances. I can't remember being asked about my condition when applying for travel insurance.

***Family, social and personal life***

54. The impact on my relationships has also been monumental; I'd say this is probably the most pernicious consequence I have experienced. When I received my diagnosis, I was already in the middle of a break up. I don't want to overstate it – the relationship was coming to an end after ten years and it wasn't my diagnosis that actually caused us to separate. But it was a final straw on an already broken back. We went out for dinner and I told her about my diagnosis. It wasn't causative, but it probably expedited the separation.
55. Since then, there has been a persistent strain hanging over all of my relationships. Each time something seemed to be starting up with someone, I'd have this unbearable moral dilemma tearing me apart – when is it appropriate to tell them about my HCV? When do we have the conversation? It really is the least romantic thing to discuss, with the power to end a relationship before it has even begun. It pervades every relationship and, no matter how well you think it's going, there is never a good time to bring it up. Over time, I have learnt that honesty is always the best policy.
56. I met my current partner after my HCV was finally cleared and, when I felt we were at the right point in our relationship, it felt amazing to tell her that 'I used to have HCV'. She is very understanding of my experience.

57. The infection has definitely got in the way of my desire to get married and start a family. I would love to have children, but I'm 58 now and feel like I've lost the 20 years of my life that would have been the right time to have done so. So much of what could have been has now slipped through my fingers.
58. My family are all aware of my diagnosis and they are understanding of it, but it is a horrible thing to have in the background of family gatherings. The events following my application to the Skipton Fund have also had an impact on my relationships with relatives, which I will detail further in Section 7, below.
59. Finally, there has been an impact on my social life, with very few of my friends knowing about my HCV. It's been a bit of a dark secret within my social circle. During my illness and treatment, I was not able to engage with my friends. I became so introspective and withdrawn. I was very gregarious and outgoing prior to my initial injury and then introverted during my recovery, so I had already experienced both sides of it. My general tiredness and low mood made it very hard to motivate myself to socialise. I didn't drink at all during my treatment and I now am only a light drinker.
60. One of my friends actually got hepatitis themselves and opened up to me about it. I was still so worried about the stigma of it myself that I didn't tell him about my own infection. About six months into his treatment, I decided to tell him that I, too, had HCV in the past. He was actually really pissed off that I hadn't discussed it with him sooner but that's what the fear of the stigma attached to the infection does – makes you keep it secret.

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

61. At some point over the course of my treatment, I can't remember exactly when, Dr Patch advised me to apply for compensation from the

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Skipton Fund. Because of my dyslexia, my sister helped me complete the application forms. I remember it being relatively straightforward. I asked my GP at the time, Dr. GRO-B for my medical records and these were provided to go along with the application. I am aware now that this application was submitted in 2007 but was returned as further information was required.

62. I am aware from the Inquiry staff that I later submitted my discharge records from the Royal United Hospitals in Bath, (dated 04/03/86) where I was treated following my injury. I recall that these were scant, containing very little information and making no mention of a blood transfusion. I have also been made aware that there was also a confirmation of destruction letter from the Royal United Hospitals, (dated 14/04/08) stating that a lot of my medical records had been destroyed because I hadn't attended the Hospital for a number of years.
63. I received a rejection letter soon after, (dated 04/03/10, I am informed) stating that I had provided no proof that I had ever received a transfusion and that the injury I had sustained was unlikely to have required one. I can so clearly remember being told I had a transfusion, I thought that they must have made a mistake – so I submitted an appeal straight away. I informed them that my search for records had returned very few results and my sister provided a letter in support of my appeal. Professor Rosenberg endorsed my appeal application to the effect that he believed there was a 'high probability' that I received a transfusion at the time of my accident.
64. In June 2010, almost three years to the day after my initial application was sent, my appeal was rejected. (I am aware that the letter is dated 24/06/10). Again, they stated that my inability to provide records proving I had received a transfusion made me ineligible. I couldn't believe it. I always assumed that I would get it, it just felt so unfair. It seems, to me, to be perfectly normal that they wouldn't have recorded

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a blood transfusion. Isn't it a fairly routine procedure? I don't understand how they can reject me on that basis. The records weren't available, so on what basis can they conclude that a transfusion was unlikely? How can they be so certain without any records that it did not take place?

65. It felt like I was being denied compensation because I forgot to fill in a certain box on an insurance claim form, like they were able to get away with not giving me assistance on a technicality. A delay of three years is also outrageous, negligent even. I was left with a sword of Damocles hanging over me, waiting for years for some unknown body to judge me. This unacceptable wait definitely added a significant strain that I really didn't need.
66. To go through the health and financial impacts of the infection itself and to then be turned down for compensation, it is like a sucker punch. It just added insult to injury and felt like someone had made a judgement on my credibility. This did not help with the psychological impact of the whole thing. I felt like I was being punished for an error - and not even one made by me, that was miniscule in comparison to the errors that led to the whole scandal.
67. As I have mentioned previously, the rejection from the Skipton Fund had a profound impact on my relationships with my family. Essentially, being rejected by Skipton made them doubt that I was infected with HCV via a blood transfusion. It was like a black mark against my name. It isolated me within the family as they all began to question whether I was being truthful about how I been infected. Members of my wider family, in particular, such as nieces and nephews, really backed off after the rejection from Skipton; it caused a big family rift. It was almost like the outside world had looked in and judged me as unworthy, damning me to the disapproval of my own family. I'm sure this wasn't the intention of the Fund, but it has been the net effect. It has damned me.

68. It was a similar story with my girlfriend at the time. We had just got to the point in our relationship where we were having *that* conversation and then the rejection from the Skipton Fund sowed the seeds of doubt in her head too.
69. I had great hope that this would provide some help and that's why I had told my family about it. The reality of it, however, was the very antithesis of the help that I had envisaged. I thought that Skipton would be the sort of organisation that would have appreciated the distinction between those infected with hepatitis through tainted blood and those infected through other means. But, in the end, their rejection made me feel just as stigmatised as the original infection did.

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

70. I have always had a tremendous faith in the NHS. Nye Bevan came up with this wonderful idea to help Britain out of its post-war bankruptcy. For that to be tainted with this neo-liberal view of insurance and compensation destroys all of that and casts doubt on the functioning of the whole system. It really is terribly sad.
71. To find out that those with hepatitis weren't on the Covid-19 shielding list is typical of an attitude that I have come across over the course of my treatment. I remember Professor Rosenberg telling me about the government being reluctant to cough up the money for some of the drugs that were proving to be effective. It was almost as if they were saying, 'Why should we be giving money to those dirty hepatitis sufferers, they don't deserve our protection.' I think the absence of hepatitis sufferers being on the shielding list comes from the same milieu. It's all about the money at the end of the day.
72. A terrible black mark now hangs over the National Health Service as a result of this scandal – and scandal is the correct word. Not only were



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these original mistakes made, but the handling of the whole affair going forward has been terrible. My experience is evidence of that.

### Statement of Truth

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

GRO-B

Dated

4/02/2021