

Witness Name: Carl Harvey  
Statement No.: WITN3862001  
Exhibits; Nil  
Dated; 18.02.22

## INFECTED BLOOD INQUIRY

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### WRITTEN STATEMENT OF CARL HARVEY

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I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 06 March 2020.

I, Carl Harvey, will say as follows: -

#### **Section 1. Introduction**

1. My name is Carl Harvey and my date of birth is GRO-C 1964. My address is known to the Inquiry. I intend to speak about my infection with hepatitis C (HCV). In particular, the origin of my infection, the treatment I have received and the subsequent impact on my personal, work and family life.
2. I currently run a child-care business with my wife, though in the past I had a career in the music industry, running my own music production company.
3. I can confirm that the anonymity provisions have been explained to me; I do **not** wish to be anonymous.

4. I make this statement with the benefit of an incomplete set of medical records (see Section 8 for more detail).

## **Section 2. How Infected**

5. I have had a number of health conditions over the course of my life and have undergone several surgical procedures as a result. Most notably, I suffer with Irritable-Bowel-Syndrome (IBS). Around 1987 I needed to have an operation on my sphincter to remove warts.
6. I had this operation at University College Hospital (UCH) in King's Cross, London. I remember bleeding profusely for a considerable time afterwards and I know that there are a lot of blood vessels in this area of the body. I still suffer with bleeding to this day.
7. Looking back, I believe this operation to be the cause of my infection with hepatitis C. I do not have a specific memory of needing a blood transfusion or being informed of having had one, but it is likely that the amount of blood I lost would have warranted a transfusion and/or blood products.
8. As previously noted, I have had a small number of other minor surgeries, but there is no suggestion that I had a blood transfusion during these operations.
9. I have had very little exposure to other risk factors; I did experiment with drugs when I was younger (smoked a cannabis cigarette), but I have never used any drugs intravenously and haven't used any illicit drugs at all since the early 1980s.
10. I have never been treated for any medical condition abroad or any place that would be considered high risk. I have one tattoo that I got from a recognised parlour in 1979. I have several friends that have also

been tattooed at this parlour, one of whom at the same time without issue.

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

11. I do not believe that I have been infected with or exposed to any infection other than HCV. I believe I was tested for HIV and this came back negative.

### **Section 4. Consent**

12. As previously noted, if I did receive a blood transfusion during any of my operations, I was not aware of having received such treatment. I, therefore, did not have the opportunity to consent to it. Similarly, I was not aware that my blood was being tested for the presence of HCV when the infection was diagnosed.

### **Section 5. Diagnosis**

13. In the early 1990s, I went to see my GP as I was getting hangovers that were much worse than I would expect to get. After just one pint I would get a terrible hangover that would last for two days.
14. I remember him saying that this was probably just a result of me getting older, but I was only about 28 years old at the time. The hangovers were most certainly a result of my liver damage, but this was of course unknown at the time and no further tests were conducted.
15. This symptom continued and gradually worsened over the subsequent years and there were others. I would get terrible sweats at night to the extent that the bedsheets would be soaking wet and, if I had a drink, I would feel like I had been poisoned or had malaria, such was the kind of fever I would experience.

16. I had a busy social life at the time; I had moved to London and was in a band. I just dealt with these symptoms and didn't think too much of it.
17. At some point towards the late 1990s, I was rushed to the Whittington Hospital in North London. I had suffered a really bad bleed as a result of Irritable-Bowel-Syndrome (IBS) and the doctors were worried that I may have bowel cancer.
18. I had experienced these symptoms of IBS before, so I was not overly worried myself, but I was also used to doctors being concerned about my condition.
19. As a result of this admission to hospital, I had some blood tests. Sometime afterwards, I was invited to go for some more blood tests and these confirmed that I was HCV positive.
20. I was called into the Whittington Hospital and informed of the results. I remember sitting in the room and the nurse's face as she told me, but I do not remember anything that was actually said.
21. She was very solemn as she broke the news. All I really remember was being very shocked and completely taken aback by the diagnosis. I couldn't understand how I had managed to contract such an infection.

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

22. The nurse that informed me of my diagnosis was very nice and she offered to get me treated at the Royal Free Hospital in Hampstead. I remember her saying that the treatment at the Whittington was very good, but that she was moving to the Royal Free under Professor Neil McIntyre. He was apparently an expert in the treatment of hepatitis and she got me in for treatment there.

23. I don't remember the exact timescale, but I recall that my appointments at the Royal Free Hospital began fairly quickly; it was within a number of months.
24. At some point, I was informed of my genotype which I am aware is genotype 3.
25. The first consultant I was placed with retired before long and I was then placed under the care of Professor Geoffrey Dusheiko. He informed me that NICE would not be funding my treatment because I wasn't in the right postcode (at the time, I was living in Crouch End).
26. Professor Dusheiko was livid – he told me that they wanted put me on a course of Ribavirin and Interferon, but couldn't do so without the necessary funding. This made me quite depressed; you are offered help and then suddenly told that they aren't willing to pay for it. I thought about the damage being done to my body by any delay and it angered me.
27. I told my mum about this and she wrote to the local MP, Barbara Roche. Within a few weeks, I received notification from the Royal Free that I had been given a place on a combination therapy trial.
28. As far as I can remember, all of my periods of treatment took the form of trials for pharmaceutical companies. The NHS have never funded any of them. It felt like I had to beg for my treatment from the corporations.
29. As I have said, I am uncertain of the exact timescale for all of this, but I believe that this first trial began around 2002. I had definitely been diagnosed for a number of years by the time it began.
30. The treatment lasted for six months and consisted of Interferon injections twice weekly into my stomach accompanied by daily ribavirin tablets.

31. As far as I remember, I was monitored monthly over the course of this treatment, but I am not certain of this.
32. The treatment itself, as well as subsequent rounds of treatment, had a wide variety of severe impacts on my mental and physical health, my personality and my social and work life. I describe this in more detail in Section 7, below.
33. I was devastated when Professor Dusheiko told me that this treatment had not been successful. To endure the horrible side-effects of the drugs only to find out that it was all for nothing was difficult.
34. I can remember mentioning to one of the hepatitis nurses that my partner and I were planning to have children and her telling me that I should wait for at least a year after the end of the treatment before trying to conceive. I had been informed of the small risk of sexual transmission of HCV prior to this, but I believe there was an additional risk of potential birth defects arising from the drugs themselves.
35. Sometime around the conclusion of my first treatment, I had a liver biopsy at the Royal Free. Of the records I have seen, this procedure is the first instance of severe scarring to my liver being noted and I believe that it was in late 1999. My most recent Fibro scans confirm that my liver is cirrhotic and the readings are generally at the higher end of the scale.
36. The biopsy was by far the most painful, draconian procedure that I can imagine. I am genuinely unable to believe that they ever pursued this procedure.
37. I still remember the look of pure terror on the face of the young doctor as he conducted the biopsy. He was not being supervised by a senior doctor and he fumbled his way through it. I had a second liver biopsy a few years later and insisted that it was not a junior doctor that performed it.

38. A few years down the line, I was again enrolled on another clinical trial for treatment. I had been regularly monitored in the interim and in the mid-2000s, the pharmaceutical company Roche were trialling a 12-month course of the same drugs I had previously had which I presume was an enhanced derivative.
39. As far as I can remember, the Interferon was administered differently, using a piece of equipment similar to an EpiPen.
40. So, I underwent another year of torturous treatment, the impacts of which are detailed below at Section 7. Again, the treatment failed. I was apparently in remission over the course of the 12 months, but my viral load shot up within the space of two monthly appointments once I stopped taking the treatment.
41. I was monitored at the Royal Free throughout this period of treatment. I believe that this was undertaken by a specific team attached to the trial, rather than my usual consultants.
42. Roughly ten years later, in 2015, I was at a routine check-up with Professor Dusheiko and he said that it had been far too long since we had tried to treat my HCV. He advised me that a new treatment was being developed and asked if I'd like to be enrolled on other trial.
43. Prior to this, I had sort of given up on treatment. Now that there had been advances, Professor Dusheiko and I agreed that it made sense to have another go. Even after the previous failures, I have great admiration for and trust in the doctors at the Royal Free Hospital.
44. I was enrolled on a four-week trial of a drug developed by Gilead pharmaceutical company called Sofosbuvir. It just consisted of tablets this time, one a day if I remember correctly.
45. It was almost an instant cure. Four weeks after my first tablet, I had an HCV test and it was gone. I carried on taking it for three months afterwards. Eventually, they advised that it could increase the risk of

cancer, but kept monitoring me regularly and everything to date seems to be ok in this regard.

46. One complication has arisen from this treatment – over the past decade or so, I have noticed that nurses sometimes have trouble taking my blood. It is a condition called polycythaemia, which means that my blood becomes very thick and over-coagulated.
47. I believe that this may have been as a result of my HCV infection because of the constant need to take my blood for tests. The treatment I now receive for this over-coagulation is for a pint of my blood to be taken regularly, which is done at the Royal Free.

## **Section 7. Impact**

48. The impact of my HCV infection and the subsequent treatment has been extensive and wide-ranging. The infection itself has had a considerable impact on my life, but the real consequences have been felt after my diagnosis and as a result of the multiple rounds of treatment that I underwent. In order to provide a comprehensive account of the impacts, 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***

49. Since the mid to late 1990s, I don't think that I have ever felt 'well'. The most notable impact has been on my ability to focus. I am simply unable to think straight and focus my attention on anything. I have a malaise, and am tired and suffer from what is often called 'brain fog'.
50. It is difficult to determine whether this general feeling of malaise and inability to focus is a result of the HCV itself, the depression that I developed, the treatment that I subsequently received or a combination



of all three. What I do know is that none of it was present prior to my operation in the 1980s.

51. This has had a huge impact on my work life, which I describe in greater detail below.
52. I also remember some very specific physical effects of the HCV. Sometime in the early 2000s, I think it was 2003, I went on a holiday to Barcelona.
53. I was unable to leave the hotel room. I had, for some reason, developed extreme photosensitivity and the sun felt overpowering. My eyes would stream and I couldn't open them. It was completely blinding, like waking up with a bright light in your face.
54. I informed my GP of this upon my return and later the hospital, but none of the doctors I have discussed this with have been able to explain it.
55. I generally haven't had an issue with my sleep, but I often get terrible night sweats. Sometimes, you could wring my sheets out, they were that soaked in the morning.

### ***Mental health***

56. Over the years since my diagnosis, there has been a devastating impact on my mental health. If I had been invited to give this statement about a year ago, I would have been an absolute wreck during the interview – in fact I doubt that I would have agreed to it.
57. The diagnosis itself flipped my whole life on its head, but the real impact on my mental health began when I commenced treatment.
58. I can remember reading the packaging of the drugs I was taking for my first round of treatment and noticing that it causes a drop in serotonin. The treatment really did make me very depressed.

59. I was on a bus once reading the newspaper and suddenly just burst into tears. I was racked with this constant feeling of terrible sadness, like someone had just told me my mother had died.
60. Many of my days started with me waking up with a feeling of dread. My hands would be clammy and I would be sweating – just like when you had an important job interview. In fact, I would go as far as to say I was often felt too terrified to leave my bed.
61. I don't think I have ever fully recovered from this. As I have said, it is only really in the past 18 months that I feel like I have returned to the 'normal' part of the spectrum in terms of my mental health.
62. During this period, I was prescribed anti-depressants by my GP. They made me feel so weird and ill, I decided to come off them. I know that this is can be a normal trade off with anti-depressants, but I decided to just persevere with my problems.
63. I think the impact of the second round of treatment was even more extreme than the first. I actually seem to have forgotten a lot of this time; the depression had really set in and was so deep rooted at this time.
64. I essentially had a complete personality change – I used to be the hub of many social interactions, the life and soul of the party. But I became a really miserable person to be around. I describe this impact on my social and family life in more detail below.
65. I have never been offered any psychological help. Throughout my HCV treatment, I begged for some help with my mental health, but was never given anything. Not at the time of diagnosis nor at any stage later prior to my cure.
66. My depression actually got worse after the successful treatment cleared my HCV. The drug 'cured' me of the disease, but the ravages

of HCV and the treatment I underwent have left underlying scars that still cause me problems.

67. There have been times when I have felt suicidal and had feelings of being completely worthless. I could be overcome with feelings of dread and despair. There was one occasion when I drove to Birmingham to visit my Nan's grave and did not expect to return. However, I do now feel like I am in a better place than I have been.
68. Up until about two years ago, I was constantly asking my GP to refer me to someone for help with my mental health issues. I eventually did get an appointment at the local psychiatric unit and they concluded that I had some form of adult ADHD, which really doesn't add up to me.
69. I also was once referred to see a 'shrink' in Crouch End, but he was awful. He just made me feel worse.
70. I have given up on the mental health services in this country. They are useless; any help you are eventually able to get is terrible.
71. I feel about as good as I ever have now. Depression doesn't rear its ugly head like it used to, but there are still many things that cause me great worry and anxiety.

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

72. The physical and mental impacts of HCV and my various treatments have had a detrimental effect on my work life and the trajectory of my career.
73. In the year or so before my diagnosis, I had finally started to make some good money and be successful in my professional endeavours. I had set up a small production company. I had a particular talent for visualising the whole thing when I heard a band play – I could clearly see the whole arrangement and this put me in really good stead.

74. Then I suddenly found that things I was usually very good were really hard to focus on. I just could not seem to think straight; my decision making and clarity of thought were completely out the window. This had a detrimental effect on my business as you needed to be at the top of your game to survive and my company slowly fizzled out.
75. At the time of my diagnosis, around 1996, I was working at a small business in Camden Town that sold equipment to recording studios.
76. I decided I should inform my employers as I would regularly need to take time off for hospital visits and treatment etc.
77. They seemed to be fine about it all initially, but before long I noticed that something in their attitude towards me had changed. There was a different atmosphere – it's hard to put my finger on precisely, what but something was different.
78. My colleagues would make weird jokes about me being infectious and not coming near me. It was always in jest, but I eventually decided to look for something else. It was deflating and although I didn't feel forced out, it was just not where I wanted to be anymore.
79. The next job I took was more of the same. I thought it was best to tell my boss as I'd often need to take time off. I think he believed I got it from taking drugs or prostitutes.
80. I always believed it was best to be honest when going to interviews and starting new jobs, but I found I was unable to get a job at the level for which I was qualified.
81. Eventually, I stopped telling my employers. When I made this decision, I started to get the jobs that I was really qualified for. But then I would be hiding it from my colleagues and employers and this simply made things worse; I was constantly anxious about people at work finding out about my infection.

82. As my mental health suffered as a result of my treatment, so too did my ability to work. In 2010, I had a job with Lloyds of London as an audio-visual specialist. I was making videos for them and had a lot of responsibility for a lot of important people's time.
83. I was just about able to pull this off for a time, but it was a monumental struggle. I couldn't do things first time around and I'd have to keep doing them, over and over, until I got them right. Tasks I had always completed with ease suddenly became really difficult. My concentration and recall just wasn't there any longer to the degree that I required.
84. I was eventually made redundant from this position. By the end, I was literally falling apart. I'd suddenly collapse into tears and have full on breakdowns in both work and social situations.
85. Another example is a job that I had in 2017. I was essentially a personal assistant, but my main responsibility was to transfer lots of information from paper onto a digital system.
86. I couldn't copy a single sentence. I'd look at what I had just typed and it would be so wrong that I simply couldn't understand how I had got so confused. I really couldn't get my head around how my thought process had been so drastically interrupted.
87. Not being able to copy a sentence from a piece of paper made my very anxious and it still does. Eventually, they asked me to leave. I couldn't blame them. I found a position stacking shelves in Sainsbury's but I couldn't manage it. The dread of not being able to work on my own terms made me quit.
88. I think I was doing really well when I broke into the music industry. I think I could have progressed quite far and made a good living doing the thing I loved. My education wasn't great, but my early careers suggest I was on a good trajectory.

89. But as soon as a taste of success came along, so did my HCV. It stopped my career in its tracks and, even though I am now clear of the virus, I know it won't pick up again. I feel an intense anxiety about returning to the workplace, being amongst others. It's hard to explain how terrified the thought makes me.
90. My wife and I now run our business together and we get on. We don't earn a lot and we get by on a shoestring, but not too badly. I can find it hard to get up for work in the morning, but this doesn't happen often and being in control of it all is a huge help.
91. I try not to think about the loss of earnings that I have suffered. I know for certain that I would have earned enough to move out of the country – an ambition I have always harboured, if I hadn't been infected.
92. I can't remember exactly when, but not long after my diagnosis, I applied for financial help through the benefits system. I underwent a fitness to work benefits assessment. Whilst suffering from the physical and mental effects of hepatitis and the subsequent treatments, I scored one out of ten in terms of how ill I was. No help whatsoever was made available to me.
93. Some of the worst bouts of depression I have suffered have followed from interactions with the Department for Work and Pensions (DWP) or the Job Centre etc. I refuse to go on interviews with the DWP now; they make you feel so small and inadequate. I would rather die of starvation than go through the trauma of asking the government for help.
94. I've always had a natural need to care for other people. It's so heart-breaking when you need the same help and it just isn't there.
95. I have generally managed to get by with help from partners etc. I would probably be homeless if it wasn't for the help of others. That dependence makes me feel terrible. I want to earn money for my family, to take my wife on holiday and so on. But I can't.

96. I have faced some difficulties in getting loans and I wouldn't even bother to apply for life insurance. The mother of my kids got some PPI repayments relating to our mortgage. I tried to claim and realised that they wouldn't even have given me PPI because of my HCV.

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

97. The infection and treatment I have undergone have had a huge impact on my social life, particularly my relationships with those close to me.
98. As I previously stated, I was extremely sociable in my early life. I was the centre of my social circle and all my friends knew each other through me.
99. But when I was diagnosed with HCV, I became a very angry and humourless man. I was just really miserable, not the sort of person anyone wanted to be around.
100. I didn't speak to my mum for many years. I became so argumentative and my social skills just disappeared. Communication was difficult. My whole attitude was 'fuck you all, you don't know what it's like, etc.' I felt so lonely that I started to push those closest to me away. There's only so much people can take when you treat them like that.
101. At the time of my diagnosis, I was in a relationship. She was absolutely devastated when I told her about my HCV. She got tested herself and was negative. I don't think this test was offered to her, she had to seek it herself.
102. We have two kids together, who were both born in the early 2000s. Over the course of my various treatments, she found it really difficult to cope with my moods whilst dealing with the kids and all the household necessities. I wasn't any help as I was consumed by my condition.
103. We split up around 2010. Within the space of a few weeks, I was made redundant from my job at Lloyds of London and my relationship fell

apart. It was all amicable; I told her she can stay with the kids in our house and I will move out and rent somewhere.

104. I thought that I'd be fine – I would rent somewhere for a few weeks, get my own business back on its feet and everything will be alright. But it wasn't like that at all. It was a very difficult time for me.
105. If I had not been infected with hepatitis, I have every reason to think that I'd still be with the mother of my kids and that's a source of guilt. I put her through a lot. I don't think that my infection has had much of a direct impact on my children. They know about it, but are understandably not too interested in the details.
106. I am currently married; I don't think I'd be here today if it wasn't for my wife, as well as my kids. My wife and I met around 2012 and she has been my rock. She has helped me to let go of a lot of my anger and stop thinking that the world owes me something.
107. She can struggle with my depression, but she is very understanding of my situation.
108. I also lost a significant person in my life because of how my diagnosis affected me. I had a close friend called Claire. She was the sister of an ex-girlfriend and for quite some time we were inseparable.
109. I loved her deeply, not in a romantic way, but we were like brother and sister. One time, when I was deep in a bout of depression, I got very angry at her about something trivial and she has not spoken to me since.
110. I think it was just one remark too many. I still think about how much I regret that, and all the other times that I hurt the people close to me.
111. Nowadays, I am completely terrified of letting people down. It is very hard to explain to others what I've been through and this is all self-reinforcing. To feel lonely in a crowded place with lots of people that



you know love you is a really horrible feeling. Luckily, a lot of those people are still in my life.

- 112. It has also gotten in the way of a lot of my personal ambitions. I have always wanted to do scuba-diving, but the one time I tried it, I started hyper-ventilating as soon as my head went under the water. My brain got caught in some strange anxiety loop, telling me that being under the water was bad.
- 113. I very rarely do any music now, even though it is the love of my life. I simply can't do it. I started a little project recently but I really struggle to keep my focus on these things.
- 114. As for the future, I still really struggle to envisage what it holds for me. I have no goals, no objective, no real ambition. It takes all of that purpose from you. You stop even wanting to do something, let alone actually doing it. It's taken away most of my life – what I've managed to retain I cherish but it's not that much.

## **Section 8. Financial Assistance**

- 115. I have applied to the English Infected Blood Support Scheme. That was in September 2019 but they returned my forms saying that there wasn't enough detail. I couldn't face replying to them as I had sent all the information that I had and I simply thought that as I had no proof of the blood transfusion or any further facts to provide that there was not much point.
- 116. The Hepatitis C Trust may have mentioned possible financial recompense but I can't be certain of this. I have attempted to get hold of my medical records in order to confirm whether I received a blood transfusion. When I mentioned to the Hepatitis C Trust that I had an operation at UCH that involved me losing a lot of blood, the woman I was speaking to reacted as though this was notable. She mentioned

that a lot of infections caused by transfusion appear to have come from that hospital.

117. I obtained my medical records which are extensive even going back to when I was a child but there seems to be no record of that operation in 1987. These were provided by my GP Dr Oliver at the Freshwell Practice in Finchingfield, Essex. I telephoned around a few other places, Chase Farm hospital and the Royal Free Trust, and they confirmed that some of my older hospital records have been destroyed.
118. About six months ago, I was at a regular appointment with my consultant at the Royal Free, Paul Trembling. I mentioned that I was considering seeking compensation and told him about the missing record. He asked me if it was at UCH and had a look through my records. He said 'here it is', and his file had a record of the operation. I assume he would have told me if it had any mention of a transfusion on there, but he didn't say anything to this effect.
119. I have no idea how he was able to find a record of the surgery, when it was completely absent from the records I was sent. The relevant record appears to also be the only one that was missing from the records I was provided with. Why is that the case?
120. I don't have any hard evidence for the cause of my infection, so why would I bother to apply again for financial assistance? Without the ability to prove it, it just seems to me that it would be a lot of effort to be turned down.

## **Section 9. Other Issues**

121. I remember reading about the 'silent killer' in the Sun, or some other tabloid newspaper. Other than this, and my experiences at work, stigma isn't really something I've come across. Then again, I do tend to mix in circles where it is less likely.

122. I have disclosed to all of my dentists that I have HCV and have perceived no notable change in the treatment provided to me.
123. When it turned out that NICE had decline to fund my treatment, the whole postcode lottery really disillusioned me and I lost a lot of faith in the NHS. It took me a little while, but my trust in the Royal Free and the doctors there is really solid. Everywhere else I have been for treatment, I have had no trust in them at all. I think the NHS generally is really messed up and I have very little faith in the organisation as a whole. Even the Royal Free is part of the postcode lottery system, but I'm grateful that I've been lucky enough to get my treatment there.
124. I find it very odd that anyone would look to buy blood from the US – they must have known where it was coming from and who was donating it? If you are going to buy medical products, you don't get it from a drug addict in prison, do you? To this day, I am completely baffled by this. I have allowed myself to get very angry about this terrible oversight throughout my life. If I think too deeply about it, makes my blood boil.
125. Mistakes are always made, but the real test is how you deal with your mistakes. What makes me confused and angry is the cover up, the denial of responsibility. In general, this country doesn't stand up to the test of correcting its mistakes.
126. When I had my liver biopsy, there was a guy next to me in the hospital. He was dying of hepatitis C that he had got from a transfusion. Now I live with a constant thought at the back of my mind: when will that be me?
127. There is simply no support network for people like him and me. Nothing is provided for us and that's like denying it ever happened. I think if there had been something there, just something to give a bit of help, I wouldn't have suffered nearly as much. Even if it was measures that aren't necessarily health related – a bit of employment benefit, for

example – it would have been the biggest help. Too often from diagnosis, during treatments and beyond it just made me feel like I was fighting on all fronts.

**Statement of Truth**

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

Signed \_\_\_\_\_

Dated \_\_\_\_\_

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

Signed

GRO-C

Dated

18/02/22