Witness Name: John Simon Hockaday

Statement No: WITN6010001 Exhibits: WITN6010002-3

Dated: 20 January 2022

INFECTED BLOOD INQUIRY	
WRITTEN STATEMENT OF JOHN SIMON HOCKADAY	

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

I, John Simon Hockaday, will say as follows: -

### Section 1. Introduction

1.	My name is John Simon Hockaday. I prefer to be called Simon. My date of				
	birth is GRO-C 1943. I reside at GRO-C				
	GRO-C I met my wife Gill in 1962, and we married in				
	1966. We have two children and four grandchildren together. I am currently				
retired, having formerly been employed as a Stock Broker, a Dealer, a Mark					
	Maker, and a member of the London Stock Exchange.				

2. I intend to speak about my infection with Hepatitis C ("HCV") after receiving a blood transfusion in May 1980 at St Thomas' Hospital, following a spinal lower lumbar lateral mass fusion operation. In particular, I wish to discuss the nature of how I had learnt about my infection, how my illness had affected me and our family thereafter, and the financial assistance I have received.

- 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. I do not wish to be anonymous as I wish for my story to be known in full.
- 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 limited access to my medical records.
- 7. My wife, Gill was present in the room during the process of drafting my witness statement. She has assisted me with my memory surrounding some important dates.

### Section 2. How Infected

- 8. In 1961, I took up a role as a Stock Broker in London. I then worked my way up the ladder as a young man under the London Stock Exchange. I became a dealer, a Market Maker, and eventually, a member of the London Stock Exchange.
- 9. In 1962, I met Gill, and we married in 1966. In 1989 I decided to leave the Stock Market life and we purchased a smallholding in Devon, where we remained for nine years. The smallholding became too much for me to handle and we moved to Cornwall. Put simply I didn't have the energy to manage the livestock and everything else that goes with running a smallholding. Gill was from Newquay, which is where we have ended up.

- 10. In the 1970's, I experienced a significant amount of pain in my back, whereby I attended various hospitals in and around London. The pain was particularly difficult as when you work in the Stock Market, it is rare to sit down as it was considered lazy. This did not help the condition of my back. I was told by a doctor that I had a possible prolapsed disk in my spine, so I was able to undergo corrective surgery.
- 11. In May 1980, when I was aged around thirty-seven years old, I attended St Thomas' Hospital ("St Thomas"), Westminster Bridge Road, London. SE1 7EH. I underwent a spinal lower lumbar lateral mass fusion operation. As a result of this operation I was given a blood transfusion as treatment. I was in hospital for about three weeks.
- 12. At no point, was I provided with information or advice beforehand, surrounding the associated risks of being exposed to bloodborne infection as a result of receiving a blood transfusion.
- 13. Around 1984, I attended my local doctor's surgery with my General Practitioner ("GP") for a general health check-up appointment, where I provided a sample of my blood to be tested. The result of this blood test had shown that there were abnormalities in my blood, namely that 'it was noted in 1984 that his liver enzymes were abnormal' As far as I can remember, I was not informed of this fact by my GP at the time. (See Exhibit WITN6010002)
- 14. The first time I became aware that there was something wrong with my blood was in 1997 when I decided to donate blood for the first time. This is discussed further in **Section 6** of my witness statement.
- 15. In April 1997, when I was aged around fifty-six years old, my wife had stated that she wanted to donate blood as a token of goodwill, as she had previously received blood during the birthing process of our two sons. She had asked me whether I wanted to donate blood alongside her. At first, I was hesitant as I was worried about the risk of dirty needles. However, I soon changed my

mind. My wife and I presented ourselves at the village hall in Highampton, Devon, where I donated blood for the first time.

16. Out of the blue, on 07 April 1997, I received a letter from Dr N Anderson, Consultant Haematologist, Bristol Centre, Midlands and South West Zone, National Blood Service, which had stated that my blood donation had been screened, and that the test performed had indicated that I may have been exposed to HCV. The letter states as follows:

"Thank you for giving blood at a recent donation session. You will be aware that we carry out a screening test for Hepatitis C. The test performed on your donation indicates that you may have been exposed to this virus in the past. We need to confirm this result with some further blood samples and get some medical details from you, as well as answering any questions you might have. I am enclosing a copy of our booklet "Testing your Blood — We'd Just Like to Check," which contains some basic information. I would like to reassure you that this has nothing to do with AIDS."

- 17. When I read the letter, I was in shock. My wife and I were speechless and the diagnosis had really knocked us for six. I was not fully aware of what HCV was (as an infection), other than that it was spoken about with the same breath as HIV. Therefore, I knew it was within that category. The aforementioned letter was very much to the point. It did not contain any advice on where to go for help or support, it was devastating.
- 18. I do not believe that I was ever told about the risks to others being infected as a result of my HCV. That was, until I received a follow-up letter in 1997 which stated that my wife Gill could be at risk of having contracted HCV, so she would need to undergo a blood test. This had highlighted to me that HCV could be transmitted sexually and through normal day to day contact, such as blood spills etc.

- 19.1 was referred to my GP by the National Blood Service, to undergo confirmatory tests. I immediately contacted my GP Dr Asad Al-Doori, Blake House, Black Torrington, Beaworthy, Devon, EX21 5QE, where I had undergone further testing which confirmed my HCV diagnosis. As far as I can recall, Dr Al-Doori took my diagnosis as a matter of fact. There was not particularly any sympathy, but he was as friendly as he could be.
- 20. Thereafter, I was referred to the Haematology Department at my local hospital, North Devon District Hospital ("North Devon"), Raleigh Heights, Barnstaple, EX31 4JB. I cannot remember what they did after this length of time.
- 21. During my early HCV diagnosis, as far as I am aware, I was not provided with any information on HCV as an infection, or information, which would have allowed me to adequately understand and manage my infection. At no point did anyone ever sit us down and discuss my HCV with my wife or I. We were left completely in the dark.
- 22. Gill and I discussed telling the boys about my infection, and decided at the time that they did not need to know. We were just very careful around them. It was several years later in 2004 that I decided to tell them. Looking back I didn't want to worry them and was being protective, I underplayed my diagnosis and they did not appear to be that concerned.
- 23. It was not until at a later point in time, when I attended a clinic at the Derriford Hospital ("Plymouth"), Derriford Road, Plymouth, PL6 8DH, where I was able to see Professor Matthew E Cramp, the leading Hepatology Consultant in the area, that I was provided with much more information on HCV. I was provided a leaflet, which explained a lot, this is dated 2003. I remember one of the nurses, Amanda Clements talking me through the implications of being infected with HCV. She was very efficient and had a nice manner about her. Prior to that I had felt a bit like a leper but through her I realised there were a lot of other people in the same position as myself.

- 24. When I was told I had HCV, I immediately gave up alcohol. I was not told to do this by the medical profession, but I believed it would help me with regards to my physical state of health. Before this, I was not a regular drinker of alcohol.
- 25. I believe there to be only one cause of my HCV infection. This being the blood transfusion I received in May 1980 at St Thomas Hospital.
- 26. I do not believe there to be any other possible causes of my infection. I do not have tattoos, and have never been an intravenous drug user. Although I had undergone acupuncture for my back between 1976 and 1980, I could not see how this would have been the cause of my infection. They would have likely used disposable needles, and if there was an HCV outbreak, I believe that I would have been notified of this fact.

### Section 3. Other Infections.

- 27. Other than HCV, I do not believe that I have contracted any other bloodborne infection as a result of receiving contaminated blood in May 1980 at St Thomas'.
- 28. As far as I am aware, I do not believe that I have been tested for the presence of any other bloodborne infection. I do not recall having been told that they were going to test me for anything else.

### Section 4. Consent

- 29. Apart from the National Blood Service screening the donations, I do not believe that I have been tested or treated without my prior consent having been obtained, without my knowledge, or without having been given adequate or full information, or, for the purposes of research.
- 30. With regards to my spine operation in May 1980 at St Thomas, I believe that I would have provided consent to this having taken place, as well as receiving

blood transfusions that I would need blood for the benefit of my health. They may have asked me to provide consent to having blood if it was needed, and I would have given my consent. It was my belief that if I did not consent, I would not have been given this treatment.

- 31. Whilst I consented to the blood transfusion, I had no understanding of the potential associated risk of contracting a bloodborne infection as a result. If the medical profession had notified me that on one hand there was a potential risk, but if I did not receive this blood it could be life threatening, then I would have been able to have made an informed decision on whether to proceed. This was never explained to me.
- 32. As previously stated, following my HCV diagnosis, I received a follow-up letter which had stated that my wife should undergo a blood test. Thereafter, Gill had undergone a blood test, to which when the result had returned, she was told that she had tested negative for the presence of HCV.

# Section 5. Impact.

### Mental/Physical Impact

- 33. When I was eventually provided with information surrounding my HCV infection, I had asked for information on the main symptoms. When I had gone through the list of symptoms, I saw fatigue, headaches, and body aches.
- 34. This was a realisation moment for me, I had been suffering from headaches and fatigue after 1980, the worst being from the mid 1980's onwards. I now believe that my fatigue and headaches were as a result of the HCV.
- 35. My wife has stated that she had noticed the difference in my physical health from the 1980's, which would coincide with the point at which I believe I contracted HCV. When I worked at the London Stock Exchange, I began to fall asleep on the train home, which was unusual for me. Gill would have to drive a number of stops further down the train route to pick me up after I had

- woken up. However, at the time, I did not put anything down to this specifically, I just thought I was getting older.
- 36. In the late 1990's, I had undergone a number of invasive liver biopsies which were very painful at the North Devon. My wife and I had moved to Devon at this point in time. I was told that the condition of my general health was not great.
- 37. In addition, I have undergone a number of Fibroscans at the Derriford. I was told that this would allow the doctor to become aware of the condition of my liver, and how or if my liver was deteriorating.
- 38. Within a letter, dated 29 May 2013, from South West Liver Unit, Derriford Hospital, to Dr M Dowling, Neetside Surgery, Methodist Church Halls, Leven Road, Bude, EX23 8LA, I was told that I had mild to moderate fibrosis on the basis of my Fibroscan score. The letter states as follows:

"Mr Hockaday attended for review on the 15 May. He has been under our care for many years now with his chronic hepatitis C' virus infection. Liver biopsy in 2004 showed no significant fibrosis and only mild inflammation, but on the basis of a more recent FibroScan he is now starting to fibrose the liver, and is probably staged at around F2 out of 4 currently. Clearly with relatively slowly progressive disease in an older patient the risks vs benefits of complicated anti-viral therapy need to be weighed up carefully, and Mr Hockaday has given this considerable thought. He is understandably concerned about the side effects of Peg-interferon and Ribavirin and the impact they may have on his current quality of life. We have had a discussion today about this and also the advent of newer oral anti-viral treatments which are very likely to work for his unusual genotype infection, but will not be available outside of clinical trials for the next two to three years at the minimum. I have discussed the treatment strategies of either doing nothing, or potentially having a trial of Peginterferon and Ribavirin to see how well he tolerates it, looking to assess his virological response after four and twelve weeks of therapy.

To assist with this decision I have sent off his IL28B genetic testing today. which would give us a better indication of the likelihood of him achieving a good response to interferon based anti-viral therapy should he chose to go down that route. I hope to be able to append the blood result to this letter and will copy it into Mr Hockaday so that he can let us know if he would wish to trial a period of interferon therapy. If he does go for this option then the journey to and from Bude he finds quite difficult, and it would be helpful for us to potentially undertake some of his haematological monitoring locally as long as we can see his full blood count reliably.

If we reach this stage I would be happy to liaise with you about how best to coordinate this. For now I have provisionally arranged to see him again in the nurse led clinic in a few months' time when we will repeat his FibroScan."

- 39. To date, I have had no further complications. I regularly attend the Derriford for 6-month check-ups, where they check on the condition of my liver. I have been told that my liver has not reached the stage where I am in need of a transplant or any further treatment, but it is slowly deteriorating.
- 40. As far as I am concerned at the moment, the physical state of my health is not particularly good. I still feel a little fatigue and I have to pace myself throughout the day. My headaches have mainly gone, that said, I still take regular painkillers for my back. As with any medication these can sometimes have known side effects.
- 41. Following my HCV diagnosis, I have had a number of further operations; these have included a shoulder operation, two prostrate procedures and a further back operation in 2008.
- 42. Whilst I do not believe that my HCV has had a significant impact on my mental state of health, on occasion I experience lapses in my concentration, and my memory has deteriorated. However, I do not know whether this is

attributable to my HCV, the treatment I have received to eradicate my infection, or old age.

#### Treatment

- 43. In May 2013 I received a letter from Professor Cramp, which stated that there were two possible courses of treatment I could take to treat my HCV infection, but they had serious side effects. This included a course of treatment with Peg-interferon and Ribavirin. I had asked how bad my health was, to which they had told me that the condition of my physical and mental health was okay, but it would be an issue when I got older.
- 44.1 decided to wait a little while until treatment had advanced, so that the associated side effects would hopefully be lessened. I attended the Derriford for regular check-up appointments every six months, to monitor the condition of my liver.
- 45. In the January of 2014, I was told by Professor Cramp at the Derriford, that there was a drug trial in Bristol in which I was invited participate. He explained that I would need to attend the hospital every Monday for three to four months, where I would take a pill and fill in a number of forms. However, as Bristol was more than a day trip away for us to attend, it was not possible logistically and financially to take part in the trial.
- 46. He said they hoped to have a genotype 5 study locally in the coming months and he agreed to keep my name on the list. It was at this point that I was told my genotype 5a had originated from another country. I was also told that they knew from treatment in Canada, which was ten years ahead of the United Kingdom ("UK"), that there would be new trials, which would be introduced.
- 47. In October 2014, Professor Cramp told me about a drug trial, which was taking place at the Derriford. The study title was: 'A phase 3, Multicenter, Randomized, Double-Blind, Placebo-Controlled Study to investigate the Efficacy and safety of Sofosbuvir/GS-5816 Fixed Dose Combination for 12

- weeks in Subjects with Chronic HCV" The Sponsor was Gilead Sciences, Inc. 333 Lakeside Drive, Foster City. CA 94404, USA.
- 48. I was asked whether I would take part. I immediately said yes. He proceeded to tell me that there were five participants, of which one would receive a placebo. I consented to take part in the drug trial, as long as I did not receive the placebo treatment. I didn't want to travel that far only to receive a placebo.
- 49. Prior to the trial I completed an Informed Consent Form, which is dated 13-10-2014. I produce this as my Exhibit **WITN6010003**.
- 50. For a period of around twelve weeks, I attended the Derriford once a week, where I would receive my treatment in tablet form, and fill in a questionnaire. The questionnaire consisted of pages and pages of questions, on topics such as my sexual life, my mental wellbeing and my patience and irritability.
- 51. After twelve weeks, I was tested to see whether my treatment had an effect on my HCV viral load. I was told that my HCV was undetectable. Both Gill and I were elated at this news.

#### **Impact**

- 52. My HCV diagnosis has had quite an impact on me, and it has changed me as a person. When I became aware of the risk that my HCV potentially posed to others, I believe that a switch was flicked in my head which made me distance myself from my family and my relations. My private life and my condition kept me at arms-length from my family and friends, who described me as distant. I am not a sociable person, and I find enjoyment as a lone fisherman.
- 53. I also believe that my HCV diagnosis has had an impact on my family and my matrimonial relationship with my wife. We have been together since 1962 which is almost a life time. We are lucky that my wife and I have a strong relationship, as had we not had this strong bond, we would not have overcome a number of bumps in the road that we have experienced. We are

- aware of how it could have affected us if we were not so strong. My HCV diagnosis has forced our life down a certain road, which we did not foresee.
- 54. My wife Gill has been impacted emotionally. She has had a constant worry that I might not make it very long, and that my life expectancy would be shortened.
- 55. Gill is now no longer able to be a blood donor as a result of my HCV infection.
- 56. Whilst I do not believe that neither my wife or I have experienced the stigma attached to HCV, this is attributable to us keeping my diagnosis close to our chests. We have only told a handful of our closest family, as we were aware that there was definitely a stigma attached. It makes you feel like a second-class dirty citizen.
- 57.1 believe that my HCV infection has had a work-related impact on me, as following my diagnosis, I became easily distracted, as my fatigue and stress levels became overwhelming. I could not figure out why I was so tired and I was going to the GP to find out. I found that my job satisfaction diminished, and caused me to leave my employment early in 1988/9.
- 58. After I was diagnosed, we realised that we had to adjust our finances. I was forced to take an early reduced fixed pension and we turned our farm into a minor holiday/coarse fishing retreat. Whilst this covered our outgoings, it did not afford us a profitable lifestyle. In 1999, due to financial pressures, we were forced to sell our lovely farm and take early retirement that year.
- 59. Due to my back pain, I had asked my GP whether he would sign me off sick, but my request was refused. However, when I was diagnosed with HCV, I was signed off by my GP. From memory I received some form of benefit, I cannot remember the exact details. I am now in receipt of my old age pension, which is £189 per week. I am also in receipt of my work pension which is about £400 per month.

- 60. With hindsight, if the doctors could have told me about the abnormal readings of my liver in 1984, this could have allowed for further investigation; which is discussed in more detail in **Section 6** of my witness statement. Had I known what was wrong with me I would have been able to make better life choices, such as decisions surrounding my work life, finances and pension options.
- 61. That is the niggle in the back of my mind. I could have put in place the mechanisms to change my life. When you look back, my reasons other than my high stressed occupation, were probably confusing my outlook. I do feel very angry about the fact that I was not informed in 1984 that there was something wrong.

## Section 6. Treatment/Care/Support

- 62. For the majority, I do not believe that I have faced any difficulties or obstacles in obtaining treatment, care and support in consequence of being infected with HCV. I have never been refused treatment, but it would always take time to put in place. I was always last in the queue, so that they could clean up after.
- 63.I do however believe that on reflection, there are two areas where I have faced difficulties in the medical setting, surrounding my HCV diagnosis, and the treatment I have received.
- 64. Firstly, around 1984, I had undergone a general health check with my GP, whereby they took a sample of my blood for the purposes of testing. It is as a result of these blood tests, that it was shown that there were abnormalities in my blood. I was not told about this for around thirteen years, until I had discovered this fact within the following letter.
- 65. Within a letter, dated 06 May 1997, from Dr Asad Al-Doori, to Dr A Moran, Consultant Physician, North Devon. District Hospital, Barnstaple (exhibited at **WITN6010002**), it states as follows:

"I wonder if you could kindly see this gentleman who on blood donation was found to be Hepatitis C Positive. I enclose a copy from Dr Anderson and his letter.

Mr Hockaday underwent a number of operations, in particular in 1980, he underwent exploration of the lumbar sacral spine and lateral mass fusion of L 4/5 and 5/1. He did require a blood transfusion then. It was noted in 1984 that his liver enzymes were abnormal. I enclose copy of the appropriate correspondence and the result of the test.

I would be grateful for your investigation and management."

- 66. If the abnormalities surrounding my liver enzymes were investigated in 1984, then it is possible that they could have diagnosed my HCV at an earlier point in time.
- 67. Secondly, In the late 1990's, I had undergone a number of invasive liver biopsies which were very painful at the North Devon. My wife and I had moved to Devon at this point in time. On one occasion, I visited the North Devon Hospital to undergo a liver biopsy, when we were directed to a room in a derelict wing of the hospital.
- 68. When we entered, the room was covered in grime, and filled with old Christmas decorations and unused furniture etc. The condition of the wing was absolutely disgusting. The doctor had said that they did not have enough space in the regular wing to perform the procedure, but considering there was a young man in this wing who was dying from AIDS, I doubt this to be the case.
- 69. To add to the situation, when the doctor had entered the room to perform the procedure, he was accompanied by a young student in tow. The doctor had asked me whether the student nurse could perform the procedure, to which I initially agreed. However, she made a 'pig's ear' out of it, and when she tried

again, I refused. I insisted that the qualified Doctor complete the process which he did.

- 70.1 do believe that my infected status has impacted upon the dental treatment I have received. Every time I had to go to the dentist, I have to self-disclose my infection. I am also always the last on the list. Although I understand that I have to disclose my infection due to the risks posed to the dental staff, it had made me feel as though I was carrying a chip on my shoulder through no fault of my own.
- 55. Neither my wife or I have ever been offered counselling or psychological support as a result of my HCV diagnosis. In my view we should have been.

#### Section 7. Financial Assistance

- 56. In the early 2000's, my wife Gill wrote to Sir Gary Streeter, the Health Secretary at the time, surrounding my HCV diagnosis and the impact it had on myself and our family. Gary Streeter referred us to our local MP, who was quite knowledgeable on the matter.
- 57. Around 2004, I read in the newspaper that the Skipton Fund were providing financial assistance for persons who had contracted HCV as a result of receiving contaminated blood or blood product.
- 58. Within a short period of time, I contacted the Skipton Fund, who had told me that I was potentially eligible to receive financial compensation, and that I would need to provide proof of my HCV through documentation. I had in my possession letters from my doctor and the hospital confirming my HCV status.
- 59. Thereafter, on 13 December 2004, I received a letter from Keith Foster, Scheme Administrator, Skipton Fund, which had stated that they required further information surrounding my HCV.

# "RE: Skipton Fund Ex Gratia Payment (Ref: 5694)

I refer to your recent application for payment through the scheme and I wish to advise you that your application has been returned to the completing medical practitioner as further medical information is required.

At this stage no further action is required on your part. Once the application has been returned to us we shall continue to process your application."

- 60. In 2004, I received confirmation my application for a stage one ex-gratia payment had been accepted.
- 61. On 06 January 2005, I received a stage one ex-gratia payment of £20,000.
- 62. Whilst the payment I received was a lot of money initially, I cannot say that it had much of an impact on my life. It was money which soon depleted.
- 63. At no stage have I ever received a monthly payment from the Skipton fund. On speaking with the Investigator I am now in contact with the EIBSS in order to establish whether I should have in fact been in receipt of a monthly payment. I will let you know the outcome of my conversation with the EIBSS.
- 64. It is my belief that I would have been provided with a further payment of £25,000 from the Skipton Fund in my estate when I died. I had read this information somewhere, but I may have mis-interpreted this information. Again it doesn't help when no one in authority explains the process.

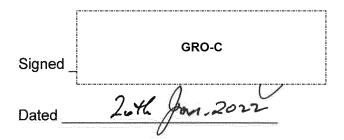
#### Section 8. Other Issues

- 65. On 15 February 2021, I was sent a letter, from Professor Matthew E Cramp, Consultant Hepatologist and Professor of Hepatology, South West Liver Unit, Derriford Hospital, which informed me that as a result of my participation in the Hepatitis C Virus Research Study, my details would be passed onto the Infected blood Inquiry ("IBI").
- 66.I have provided a witness statement to the IBI as I want to help others. The process of providing my witness statement has allowed me to get everything off my chest, albeit it is distasteful bringing up the past. It was such a long time ago, that you learn to live with not talking about what happened.
- 67. I would like the IBI to achieve transparency for the future. Everything must be open from the outside, so that something similar does not happen again. It was a known fact that as there was a short supply of blood in the UK, we sourced blood from America which was not screened. I would like the IBI to gain a better understanding of what happened, and learn lessons for the future. It all stank from the beginning. The people who knew about the Contaminated Blood Scandal ("CBS") made the wrong decisions. It is similar to when you go to war. The fact comes out thirty years later and you realise why everything was done.
- 68. In addition, I would like the IBI to recommend counselling for those infected with HCV and/or HIV.
- 69.1 believe that the stigma attached to HCV needs to be re-educated. In my mind's eye, if I had told my work colleagues about my HCV diagnosis, they would have thought it was associated with HIV.
- 70.I believe that it would have affected my work prospects, and others would have given me a wide birth. It would not have been conducive for my working

relationship to progress. It all boils down to ignorance. People did not understand HCV as an infection.

# **Statement of Truth**

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



### **Table of Exhibits:**

Date	Notes/ Description	Exhibit number
06 May 1997	Letter, from Dr Asad Al-Doori, to Dr A Moran, Consultant Physician, North Devon. District Hospital, Barnstaple.	WITN6010002
13 October 2014	Informed consent form in the name of John Hockaday	WITN6010003