Witness Name: Michael Murray
Statement No.: WITN1945001
Exhibits: WITN1945002 –
WITN1945020
Dated: 12 November 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF MICHAEL MURRAY

Section 1. Introduction

1. My name is Michael Murray and my date of birth is GRO-C 1964. My address is known to the Inquiry.

2. I live with my mother, who provides me with care and support due to my ill health.

Section 2. How infected

3. I was infected with Hepatitis C ("HCV") by regular blood transfusions from about 1983 to 1991 at Wonford Hospital.

4. I suffer from prune belly syndrome and have always had kidney problems as a result of this. When I was a young adult I went into renal failure and required regular dialysis at the Exeter Renal Unit at Wonford Hospital.

5. I was on dialysis for a short period before I had a kidney transplant in June 1983, which was successful for about 6 months but started to fail again in January 1984. I then was on dialysis again from 1984 to 1988, when I received my second kidney transplant. This worked for a while, but then failed again, requiring dialysis, and I had a third transplant in 1992. During the periods when I was on dialysis I also received monthly blood transfusions to treat low levels of haemoglobin.

6. My medical notes state that I received blood transfusions for several periods of time from 1983 to 1991. There are notes in my GP records of several of the transfusions I received during this period. For example, a note on 24 September 1984 states as follows **(WITN1945002)**:

> *On the 6 July 1984 it was noted that his haemoglobin was only 7.1 and by the 18 July it had dropped to 6.8, therefore he was transfused 3 units....unfortunately by the beginning of September he was noted to be anaemic again and was thus admitted on the 16 September for a further 3 units of packed cells.*

It is then noted that I was transfused 2 units of packed cells on 19 September 1984.

7. Another note from 18 October 1984 notes that I received "a transfusion of 2 units of packed cells" **(WITN1945003).**

8. I was not given any advice or information about the risk of infection during the time of my treatment.

9. I was infected with HCV only.

10. I was told I had HCV by telephone call from my renal consultant, Professor GRO-D in 1995.

11. He had phoned me a few months before then to let me know that he was going to test my blood for HCV. I asked what it was, and if I needed to come into the surgery, but he said that he had blood samples from an earlier appointment and he could use one of those. I believe he said that HCV had something to do with my liver, but he didn't go into detail about what it was or what in my earlier tests had made him decide I needed to be tested for HCV. He said that I shouldn't worry much about the test, as it would probably come back negative.

12. Several months later, he phoned back and said "I'm sorry to tell you, Mike, you have Hepatitis C. I'll get the liver clinic at Exeter to get in touch with you for further testing." He did not give me any information about what HCV was or how I should manage it.

13. When I was first told of my diagnosis I didn't understand it. I didn't know what effect HCV would have on my life. I was expecting a 30 minute conversation in which I would be told what to do, and not to worry. Instead, I had a 5 minute conversation, the door was closed and I left.

14. I thought initially that maybe I was misinterpreting the seriousness of the virus because of how casually it was treated. Knowing nothing about HCV, but having some general knowledge of hepatitis, I thought that maybe it wasn't as bad as Hepatitis A or B. However, this impression changed when I did more research.

15. I understand from my medical records that I tested positive for HCV antibodies on 10 July 1995 **(WITN1945004).** I was then referred for further testing in September 1995 to determine if the virus was still active **(WITN1945005).** The letter requesting this referral stated that "between 17 May 1983 and 19 May 1991 he received 139 units of bloods for his anaemia". It also noted that I was

anxious about having HCV and would require a lot of counselling **(WITN1945006)**.

16. I am not sure whether this reference to counselling refers to discussion with Professor GRO-D himself, or to external psychological support. Professor GRO-D did not provide any information about how to understand and manage the infection, nor did he refer me to a counsellor.

17. Professor GRO-D referred me to a Dr Reuben, Consultant Gastroenterologist, at Wonford Hospital in December 1995 to discuss the results of my testing. I do not remember much about my first meeting with Dr Reuben. His letter to my GP following the meeting says that he spoke to me about the risks of interferon treatment and provided me with leaflets, but I do not think this was the case. I do remember getting some leaflets from the hospital generally but not from him **(WITN1945007).**

18. Dr Reuben eventually decided I should not have a liver biopsy to assess the condition of my liver. He noted that he would *"need to see a reasonably active hepatitis to warrant treatment with interferon in view of the small theoretical risk to the kidney"* and that *"there is no rush regarding this as Hepatitis C when progressive usually progresses over decades rather than years or months"* **(WITN1945008).**

19. I do think that information should have been given to me about how to understand and manage the infection at the time I was informed I had HCV, and that further information should have followed this as it became available in the years to come.

20. I was not given any guidance about the risk of infecting others with HCV.

Section 3. Other Infections

21. I was infected with HCV only.

Section 4. Consent

22. I do not remember specifically giving consent to receive my transfusions but I certainly would have consented to them, as they a necessary part of my treatment at the time.

Section 5. Impact

23. I have constantly aching joints in my limbs, which has been explained to me as the failure of my liver impacting on my dialysis treatment. I also am unable to swallow and digest some acidic foods. I have consistent bouts of belching and dyspepsia. The skin on my arms, hands and legs becomes very deeply bruised on any minor impact. I consistently feel cold throughout my body. I have limited appetite, regular diarrhoea and can experience confusion.

24. In recent years my brain has also felt very exhausted and suppressed. I sometimes can't hold a conversation, recall directions, or make observations throughout a conversation.

25. I continued to be monitored for decline in my liver function and kidney function over the years. The kidney transplant I received in 1992 was successful for some time, and doctors did not seem to feel my liver was deteriorating significantly.

26. In 2001, I met with my consultant Dr George to reassess my condition **(WITN1945009).** I asked him about the risk of transmitting HCV to others, as I was concerned about this and had still never been given any advice about it by any of my consultants. He then asked for a list of all my sexual partners. I He said "You need to find all your partners and tell them." This made me very

nervous, as I had had the virus for some time by then and didn't know how to approach the subject with past partners.

27. Dr George also noted that interferon treatment would pose a significant risk to the continued success of my transplant. He then wrote a letter stating, with regard to my HCV **(WITN1945010)**:

> *I think intervention and the natural history of Hepatitis C in patients with transplantation and on dialysis is difficult. It is clearly not a new disease, but is something we have become more aware of since we have screened for it. We are in fact using a lot less in the way of blood transfusions now than we used to 20 years ago and I don't recall very many patients over that period of time developing end stage liver disease. I presume this is a consequence of the relatively slow progressive nature of this condition and sadly many of these patients die of cardiovascular complications long before liver disease manifests itself as a serious problem.*

28. In 2013, I agreed to participate in a study by HCV Research UK, conducted by a Professor Matthew Cramp. The study was called "Host and viral factors associated with outcomes of infection with hepatitis C virus" and had about 10,000 participants **(WITN1945011).** I do not know what the outcome of this study was. I remember signing the consent form, but I was not told anything about what happened after that. The impression I got was that the doctors didn't care about updating us on the progress of the study we were participating in. I would occasionally ask about the progress when I came into give blood, and they would give vague answers, saying that the study was still ongoing, or thanking me for my participation, but without any update.

29. I received treatment for my HCV through a drug trial of Epclusa (a combination of sofosbuvir and velpatasvir in 2017. I was initially offered the choice of two different treatments: 1) Epclusa, offered by Professor Crump at the Liver Clinic

in Plymouth, and 2) Zepatier, offered by Dr Christie, my gastroenterologist at Exeter.

30. I had many discussions with Professor Crump regarding which medication to choose, especially in light of my renal problems. I also received a leaflet from the liver unit which explained more about Epclusa.

31. I had telephone conversations with Professor Crump on 26 and 29 May 2017 to discuss the Epclusa trial. During these calls, he tried to persuade me to start the treatment on 30 May, but I explained this would not be possible because I was still waiting for the results of diagnostic tests from two other hospitals in relation to my renal issues, and did not want to start treatment until I knew exactly how the treatment could affect my kidneys. I felt he repeatedly dismissed my concerns about this and pressured me to start the trial as soon as possible. In addition, he told me that there was almost no difference between the two drug trial options (Zepatier and Epclusa) and he couldn't advise me on which drug to take. However, I found through my own research that people with HCV genotype 1a, which is my genotype, can show some signs of resistance to Zepatier. I told this to Professor Crump and he said the resistance was minimal. As a result of these discussions I began to lack confidence in Professor Crump.

32. The treatment involved taking tablets for 12 weeks from July to September 2017. This was a clinical trial for people with HCV who were also on dialysis for end stage renal disease. There is information about the trial, its goals and eligibility criteria in my records **(WITN1945012).** This treatment resulted in me clearing the virus. **(WITN1945013).**

33. During the treatment, I had the following side effects: pain in the life side of my stomach, belching and dyspepsia, gas in stool with bad odour, periods of consistent diarrhoea, gastric sickness, difficulty sleeping, low blood count, bouts of giddiness, unsteadiness on my feet, irritability, poor appetite, and headaches. During the treatment had fortnightly reviews by the treatment team. However, I do not feel the severity of my symptoms was taken seriously by the team. Every

time I raised the issue of my side effects with them they said "okay, we'll let the doctor know" but nothing ever came of it. I lost 3-4 kilos at one point, which is not good for my dialysis. When I finally pushed to get to speak to Prof Cramp, he said I probably had a bowel infection or it was something I had eaten. But I had been having diarrhoea for 2 months, had not changed my diet, and had been taking the treatment for the same amount of time. My GP did eventually say it could be the treatment that was causing these symptoms, but my treating doctors at the hospital would not admit this. They said no one else on the treatment had ever had the same problem.

34. On one occasion, after I complained to Professor Cramp, he wrote in a letter to my GP on 5 September 2017 that "generally this combination is very well tolerated and he appears to be largely free of side effects" **(WITN1945014).** I wrote back to him on 3 October reiterating that I had been experiencing severe symptoms and felt he was dismissing my concerns. He then wrote back to me on 17 October explaining that he was not intending to dismiss my symptoms but merely to say that I should still complete the treatment as I had already completed 10 out of 12 weeks **(WITN1945015).**

35. After the treatment was completed, I was called back into the hospital for further tests at certain intervals, with the explanation it was part of the trial to monitor my levels for up to a year after I stopped taking the medication. After a while I refused to go back.

36. Whilst this trial was a success in regards to eliminating the HCV, throughout this period I did not receive any advice from the Liver Unit about how to cope with the side effects of the treatment. This made me entirely self-reliant in sourcing help, making decisions, and finding support from my GP, the staff nurse at the renal unit at Exeter, and the internet. Then after the treatment was finished, Professor Crump persistently called me in to the hospital to have a 'catch-up' about the treatment. The fact that no assistance was offered to me throughout the treatment made me reluctant to listen to anything he had to say afterward. I felt that the team continued to want information from me, and to do

more and more tests on me, but were not willing to provide me any support at all or give me any of the information I asked for. This has sadly left me feeling that I cannot trust some doctors.

37. At this stage, although I have cleared the virus, I still have renal failure and a compromised liver. I have dialysis four times a day, and will need this until I am given another transplant, which is likely to be in a year or so. I still have the brain fog and tiredness due to having HCV for so long.

38. I understand that in 2016, my GP received a letter from Public Health England stating as follows **(WITN1945016):**

> *The above patient has been recently notified to us as being antibody positive for the Hepatitis C virus. An HCV polymerase chain reaction (PCR) test helps determine if this is chronic or past infection, and along with liver function tests can be useful to establish any potential liver damage.*

The letter goes on to say that I should be assessed for treatment, and that I could be a risk to others who are exposed to my blood.

39. I know of this letter because some time after my GP received it, in late 2017, his secretary phoned me asking to book me in for an HCV test. I was shocked. Of course, my GP knew that I had HCV; I was in the process of completing my treatment! But the secretary did not understand this and kept telling me to come in for an appointment to be tested. I shouted at her that I was aware of my HCV already.

40. I do not understand why the Public Health agency was suddenly notified of my status in 2016, 20 years after I was diagnosed, and why the GP surgery didn't, upon receiving that letter, note that I was already in treatment for HCV and decide not to contact me.

41. I do not feel I have encountered any obstacles to accessing treatment other than the main issue of my renal problems. Any medication with an immunosuppressant was contraindicated due to my transplant because it would have made my body reject the transplant. I would rather try and keep as much life in the kidney as possible and not go back on dialysis, than try to cure the HCV. So I had to wait until a better medicine was available that wouldn't affect my immune system in the same way.

42. Even after interferon-free treatment became available, it was determined that I couldn't have ribavirin or Harvoni treatment due to my kidney disease **(WITN1945017).** However, it was also noted that my liver damage was not bad enough that I needed treatment right away.

43. Because of the damage to my liver, I require regular monitoring by the liver specialist. I have to go to the hospital every 6 months and have an endoscopy and sometimes a fibroscan, and there is very little change each time, aside from one or two varices. I struggle with having to repeatedly go in and have these tests, when I already have so much medical intervention in my life due to the daily dialysis. The liver team wants to do a biopsy to determine the exact extent of my liver damage, and I am not prepared to do this. I know I may have to have a liver biopsy before I receive any new kidney transplant, but otherwise I do not want to do it. The fear and worrying about the results is not worth it, when there is little I can do about it. I know the appointments are meant to be helpful and help me keep an eye on my condition, but I find it is hard enough having dialysis 4 times a day. It forms a large part of my daily routine. I just want to concentrate on looking after the dialysis and living with the liver symptoms.

44. Whenever I am required to have x-rays or other investigations in hospital, I always have to disclose that I have HCV and explain the whole situation to the team treating me. On one occasion about 2.5 years ago, I was having routine investigations to see if I could qualify to get on the transplant list. Before one of the scans I had to have an injection in one of my arms, and I let the nurse

performing this know that I had HCV. She seemed surprised, and then when the doctor came in she whispered in his ear that I was infected with HCV. I was upset by this, because whispering about it made me feel like she thought it was shameful to have HCV. I don't understand why someone working for the NHS isn't aware that people do not always have HCV because of dirty needles or sex, but by infected NHS blood. I thought she would be more aware and understanding.

45. I still have so many questions that need answering and I don't have the knowledge or experience to answer them. I remember always asking Dr George what my long term prognosis was and what my choices were for treatment, but he always seemed to tell me as little information as possible. He would say that HCV would not likely affect me for a while, or that I was dealing with it quite well, without giving me any specific details about what I could expect long term. He didn't even tell me about my genotype and the difference that makes to my prognosis. I now understand from my own research that my particular genotype tends to mean that the virus doesn't affect you for 10 to 20 years and then suddenly causes damage. If this information was known by the medical profession at the time, I don't understand why Dr George couldn't tell me that so I knew what to expect.

46. I really want my family to understand how I am feeling and what has happened to me but I do not have the energy to explain everything to them all the time. I can discuss my condition with them, but I don't feel they are intimately aware of what is going on with me and how I'm feeling. They are kind to me, but they have their own families to look after. They help me practically by taking me to hospital, but they won't come in to the appointments with me. I often wish they would take an interest in coming in and listening to what's happening with me. They do listen and take great consideration to understand when I speak to them, but when I want to discuss what's happening with my medication or the Inquiry, I sometimes find it's too technical for them.

47. At the time I was diagnosed there wasn't any facility to talk to about any concerns I had, either at the renal unit or the liver unit. As a result of this I felt isolated and got very depressed, to the point where I just felt empty and unmotivated. I didn't make any plans to do anything; I just sat around looking at the wall.

48. My mother has been stoic, and has really helped me immensely over the years, but I should not burden her with this. I don't want to always relay how I feel to my mother. She is getting older now and it's not fair to give her that stress and concern and worry. So it leaves me vacant.

49. I feel that HCV has stolen my life from me. I can never feel confident in wanting to start a family. The exhaustion of coping with my symptoms leaves no energy for any social commitments or even leaving the house on my own. To consider every aspect of a journey, all needs to be planned. Mentally planning becomes mentally draining and requires someone to assist with those plans as I am incapable of planning alone.

50. I sometimes used to go up to my room when people came over because I wanted to escape; I didn't want people to ask about me. I was so fatigued I could barely summon the energy to have a conversation. The loneliness, stigma and embarrassment of having this condition initially made me 'lock myself away', stop going out on my own, and my social life disappeared. It stopped my whole way of living.

51. I still struggle to ask for support from people sometimes because if people are not aware of my condition, they do not see me as having a disability, as I generally appear normal to most people. This means I don't get any support from professionals. No one asks 'how are you coping?' I constantly have to over-explain parts of my lifestyle, such as parts of my medical, social and family history, to new people and am questioned about them. This has become embarrassing, and made me timid and unsure.

52. Having HCV for so long has also had an effect on my education and career. Before my diagnosis I struggled with the symptoms of HCV at college without knowing what they were. I found it difficult to record information and recall later what my notes were about. I would write a paragraph and then read it later and forget what I was writing about or what should come next.

53. Later when I was working as a hairdresser, I had to take a large number of days off work to attend medical appointments. Because I was tired, I also found my work less fulfilling. I had my own hairdressing business for 30 years, and was very proud of my business. I maintained it through 3 recessions, and was proud that even during my renal failure and multiple transplants that I was able to maintain a business. Unfortunately due to returning to dialysis and the ongoing HCV symptoms, I eventually had to sell my business for very little, close it, and walk away.

54. Over the years I have had to apply for financial assistance from the state due to being unable to work. However, I felt there was a lack of understanding of my situation from benefit agencies, and a lot of forms to fill in that would only lead to more questioning. I remember going to a PIP appointment in Exeter, being made to wait for 2 hours for my appointment, and meeting with a woman who seemed to only be concerned about my physical mobility, such as how far I could walk, rather than the other limitations of my health conditions. I was trying to explain to her that I had problems with urinary incontinence due to my prune belly syndrome, and she said that because I was able stand up to use the toilet I was fine, however this was irrelevant to my incontinence.

55. I find that not only my family members but also my close friends have distanced themselves from understanding my diagnosis and disappear from social commitments now. I did try to explain the situation simply to people initially but at some juncture the commitment required to understand becomes muted and people stop having any desire to understand. My impression is they think they can catch it from me.

Section 6. Treatment/Care/Support

56. I have not received any support while I was going through my treatment in 2017. I asked questions about it but felt I was ignored or fobbed off by my doctors.

57. No counselling or psychological support has ever been made available to me. I understand from my records that my consultant Dr George may have been intended to recommend HCV counselling to me after meeting with me in 2001 **(WITN1945009),** but he never did.

58. I have had more counselling about my renal problems than was ever offered to me for the HCV. The renal nurses will sit and discuss issues with me for half an hour, or an hour on some occasions, but the liver team seem to have no capability or interest in doing so.

Section 7. Financial Assistance

59. I was phoned directly by the Skipton Fund in 2004, after I believe Professor Nicholls informed them about my infection and gave them my phone number.

60. I applied for a Stage One payment in 2004, which was granted.

61. In 2014 I discovered during my online research that I could be eligible for a Stage Two payment.

62. In order to apply for a Stage Two payment I had to have the application form filled in by Dr George, confirming that I had a certain stage of liver disease. He delayed significantly in completing my application, and I had to ring three times that summer and write letters **(WITN1945018)** to remind him to do so. In the end, Sheila, one of his nurses, filled it out and submitted it. Unfortunately, my

most recent fibroscan at that time said I had fibrosis but not cirrhosis, which was not sufficient to prove my eligibility for the payment **(WITN1945019).**

63. About a year later I had another fibroscan, which showed significantly more damage to my liver. I asked Dr George if I could apply again but he said no, I wouldn't qualify.

64. I had to change specialists to a different hospital, in Exeter. The new consultant, Dr Christie, then filled out the application form for me and I was able to qualify for the payment. I do not have a copy of this application but do have a copy of a note given by my new doctor by his team, explaining what he would need to complete on the form. **(WITN1945020.)**

65. My only other thought about the compensation schemes is that while I understand that it is helpful to have a bit of extra money coming in when many of us aren't working, it does seem to make professionals feel as if you're all sorted and taken care of and don't need further support. Doctors and nurses will ask if I've received the payment, and when I say yes, they will say "oh, so you're okay then" as if receiving that money is the end of my problems. I would almost prefer to not have received the money and to have support from medical professionals and the community.

Section 8. Other Issues

66. In terms of what I would expect from the Inquiry, I would hope at the least for the ministers and prime ministers from the past to be prosecuted along with any additional ministers to be found guilty, if it was found that information was withheld from the public or the NHS.

67. I believe justice would be in the form of a suitable financial package for the extreme horrors we have had to cope with.

68. My solicitors have obtained records from my GP, Royal Devon and Exeter, University Hospitals Plymouth, and Torby and South Devon Hospitals. I do not think there are any records which are missing.

69. As I have stated above, I have always found it hard to get out of the doctors what I needed to know. I have found their attitudes to be pandering. When I ask a simple question such as "What were the results of my blood test?" They say, "oh yes they're better" but provide no information about what I was being tested for or how much the results had improved. I now push them for more details, and they do seem to be more willing to give them, but in the early days I found them patronising and unwilling to share necessary information.

70. I want people to appreciate the lack of understanding. I don't work, I don't get income support because I have money from EIBSS, no one understands what it's like. Generally, there doesn't seem to be help.

Statement of Truth

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

Signed GRO-C

Dated 12th November 2019