Witness Name: Michael John Clark

Statement No; WITN4750001

Exhibits; WITN4750002-12

DATED 7-9-21

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF MICHAEL JOHN CLARK

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 14 April 2021.

I, Michael John Clark, will say as follows: -

Section 1. Introduction

1. My name is Michael John Clark. My date of birth is GRO-C 1967 and my address is known to the Inquiry. I live in York and I am married to Anna. We have 2 sons together, Isaac who is 20 years old and GRO-C who is 16 years old. I work as a welder/fabricator.

2. I intend to speak about my infection with Hepatitis C (HCV). In particular, the nature of my illness, how the illness affected me, the treatment I received and the impact it had on myself and my family, and our lives together.

3. I can confirm that I am not legally represented. I am aware of the provisions regarding anonymity and I am happy for my story to be in the public domain. I also understand that where I may make a criticism of any medical professional then they may have a right of reply.

Section 2. How Infected

4. When I was 9 years old, I used to go to a judo class with a boy I was friends with. I don't think my mum was aware that I would go to this class, but it was something I would do with my friend each week. The class was held at the Railway Institute building in York.

5. On 23 June 1977, I had gone to the class alone that day as my friend couldn't come with me. I was walking back home from the class along the York Bar walls when I fell off the wall, landing on the ground and hitting the right side of my head.

6. The fall off the wall would have been about a 12-foot drop and I know that I started to bleed heavily on impact with the ground. I was surrounded by passers-by who rushed over to help and they carried me to the railway offices (which is now The Grand Hotel, York). I know that an ambulance was called but I can't remember how quickly it arrived.

7. After the ambulance arrived, I don't remember much else. I know I was taken to York District Hospital. I'm not sure if I was given something to make me unconscious or if I was unconscious due to the accident, but I don't remember waking up until the next morning.

8. When I woke up in the hospital after the accident, I can remember that my mother was there. I also remember being told I had suffered a concussion and lost a lot of blood, which meant I had required a blood transfusion.

9. My mother had also been told the same and she clearly recalls being told I had required a transfusion, as at the time she had been very concerned about my blood loss. I also had a large number of stitches to close the laceration on the right side of my head, and had been observed overnight due to the head injury. My mother has never indicated to me that she was asked for consent or given any warning of possible risks relating to my blood transfusion.

10. I still remember the t-shirt I was wearing on the day of the accident as it was one of my favourites and it had a tiger on the front. I remember that I had been bleeding so much from my head that the t-shirt was absolutely soaked in blood, and I never got it back after going into hospital. I assume it had to be thrown away.

11. I have always been aware that I had a blood transfusion as a result of this accident, and it was something I had told Anna not long after we had first met when she asked about my scar. She can still recall this conversation. I still have a significant scar on the right side of my forehead from this accident, although it has faded over the years.

12. A few months after the accident when I was still very young, I recall not feeling very well and visiting my GP with my mum a few times in relation to this. However, I could not quite put my finger on what I was feeling and did not really think too much about this afterwards and thought it was the residual effects of the accident.

13. I rarely went to the GP after my childhood and I remember when I did finally go to my GP sometime when I was in my 30s, they mentioned that I hadn't been for an appointment in a very long time. I just got on with life but I often felt quite fatigued, although I put it down to getting older and being busy with work and our sons.

14. When our son GRO-C was born in 2004 at York Hospital, he was unwell and he had an issue with his platelets. He was kept in an incubator for some time and the doctors ran various tests on him to diagnose the problem. The nurse looking after GRO-C also asked my wife and I to provide blood samples, which at the time we did feel was quite strange. We had no idea why we needed to do this or what we were being tested for and no real explanation was given. We simply complied as any parent would when it came to their child's well-being.

15. My wife and I both remember the nurse looking after GRO-C telling us that we should not try and have any more children. At the time we did not really take it seriously and jokingly said we were definitely not going to have any more children due to the stress we had undergone with GRO-C being so unwell.

16. Looking back, this was a very strange experience and such an odd thing for the nurse to say to us with no context provided. We were never told exactly what was

wrong with GRO-C nor was there ever a reason given as to why she had said that. Thankfully, GRO-C was okay in the end and is now 6'5 and a healthy 16-year-old.

17. As the years passed, I started to feel more and more drained and the fatigue became more acute, and I just did not feel like myself. I could not exactly put my finger on what was wrong, but I did not feel well at all. It is just something you know that within yourself you are not right. I even went to a walk-in centre in relation to this, but they were unable to tell me what was wrong.

18. Sometime around December 2012, I went to see my GP Dr Khan at the Priory Medical Group - Tang Hall Lane Surgery. I explained to him how I was feeling, and I also believe at that stage I was having some issues with vomiting a dark coloured substance, which I later learned to be old blood caused by oesophageal varices.

19. I think I had also mentioned to Dr Khan that my alcohol tolerance had become extremely low, and I could not even drink 2 beers without feeling quite drunk. I had also been suffering nose bleeds around this time which was unusual for me. I remember that I had one set of blood tests and then Dr Khan asked me to come in for another set of blood tests sometime later, but he did not tell me what exactly he was testing me for.

20. Sometime after I had these blood tests, I was driving back home after a family holiday away in June 2013 when I got a call from Dr Khan. The call came up over the car's sound system, and he told me that I tested positive for HCV with

genotype 1A - although I don't think what this genotype meant was explained to me at the time. **(See Exhibit W4750002)**

21. At the time, I really did not know much about HCV and thought it was something that you could catch through water. I was not aware of the serious nature of the infection. I was also really confused about this as I thought I had been vaccinated for some form of hepatitis before going on a previous holiday to Turkey.

22. After informing me that I had tested positive for HCV, Dr Khan asked me whether I engaged in gay sex which of course I told him I do not. He also asked me if had ever had sex with prostitutes. I jokingly said that I had been to Thailand but had not slept with any prostitutes and I remember him saying something like, "Mr Clark, you're not taking this seriously". He also told me I would have to be tested for HIV, which was a shock and definitely raised my level of concern at the time. I was surprised and annoyed that this sort of diagnosis was imparted over the phone. My children were in the car and heard it all, including the questions asked. As it happens I am fairly open with them but that is not the point; Such potentially very distressing news should really be delivered face to face.

23. Dr Khan asked me to come in for a face to face appointment with him. At this appointment he asked me whether I had ever had a blood transfusion, and immediately the accident where I fell off the Bar walls came to mind, and I told him that I had received a transfusion in 1977. From our conversation, he seemed to believe this was the route of transmission of the HCV.

24. Looking back, there is no other possible route of HCV infection aside from the blood transfusion in 1977. Although I have one tattoo, this was done safely at a

proper tattoo studio. I have never been an intravenous drug or engaged in any high- risk activities for HCV. I have never been medically treated abroad and am happily married.

25. Other than this accident, as far as I am aware I have not received a blood transfusion on any other occasion. The only other medical procedure I believe I have had prior to my HCV diagnosis was for an umbilical hernia as an infant, and this would not have necessitated a transfusion. My son GRO-C had the same procedure done without needing a transfusion and it is a minor procedure. Therefore, I am sure the blood I was given after my accident is the route of my HCV transmission.

Section 3. Other Infection

26. I do not believe that I was infected with any other infections as a result of the blood transfusion. I believe I have been tested for HIV, but as I was never told I had tested positive, I assume the outcome was negative.

Section 4. Consent

27. I was not asked to consent to an HCV test that was conducted by my GP Dr Khan. I was not even aware that he was testing me for HCV at the time.

28. Although I was offered an HCV treatment called AbbVie D HCV that was part of a drug trial, I do not believe that I was offered this treatment for the purposes of

research. St James' Hospital applied for me to have this treatment on compassionate grounds.

Section 5. Impact

29. Finding out I was infected with HCV was extremely confusing, as initially I had no real idea about what this meant. At the time I really did not know that it was a serious infection at all, and I think I thought it was similar to the other forms of hepatitis.

30. Since learning more about HCV, I can definitely see that I had symptoms of the disease for a long time before I was diagnosed. I put things like fatigue down to growing older and being busy with work and family commitments, but now that I have cleared the HCV I feel better than I did 10-15 years ago, which to my mind shows it was a symptom of the HCV.

31. I also struggled with mood swings and not feeling myself, which I now can attribute to the HCV. I did not gain much weight over the years either nor did I have a big appetite which changed post-transplant, and I also had an unusually low tolerance to alcohol; As mentioned, I would feel quite drunk after just a few beers which is strange for someone my size.

32. Nearer to the time when I went to see Dr Khan in December 2012, I struggled with vomiting old, darkish blood and nose bleeds, which I later learned was due

to Oesophageal varices that can happen occur when you have HCV. With hindsight, I think these were the symptoms that led Dr Khan to test me for HCV.

33. Although I have always been very open with my family about the HCV and my health issues, it was not ideal to receive the news of my diagnosis over the car's speaker system while driving with my children, especially given the questions Dr Khan proceeded to ask me about my sexual history and personal life. Thankfully, I had nothing to hide and was able to answer honestly, although there was an element of embarrassment involved.

34. At the face to face appointment I had with Dr Khan after my diagnosis, as mentioned above, he did ask me further questions about a possible route of transmission and I had no real risk factors in my life other than the blood transfusion I had received at 9 years old.

35. At this appointment, Dr Khan provided me with absolutely no information about HCV or what it meant to have been diagnosed with it, either for myself or my family going forward. I was not advised about any precautions I should take to avoid infecting others, and at this stage I really knew nothing about how serious the infection I had was. I was not advised that my wife and children should be tested for HCV.

36. I think Dr Khan suspected I had HCV and how serious it was when he saw me, as one of my symptoms was vomiting blood and this would have indicated I had been infected quite some time ago. However, he made no mention of this at the time. He obviously saw my symptoms as symptoms of HCV in order to test me

for it in the first place, but he never let on how bad he suspected my health actually was.

37. Dr Khan told me that he would refer me for an appointment with Dr Millson, an HCV and liver specialist at York Hospital, and I received that appointment a month or so later, in July 2013. I can't remember what tests I underwent prior to this appointment.

38. I recall that when I was waiting at the hospital to see Dr Millson, I got chatting to a young doctor. I told her that I had HCV and my wife and I both remember her saying something like "HCV is something that we have given people" and that it is "a nasty little infection". At the time, I didn't really understand what she meant by this but looking back, it was a very strange thing for a doctor to tell a patient. On consideration, she was indirectly admitting something was wrong with the blood given to patients.

39. At my appointment with Dr Millson, I remember that he said that I would need to undergo some tests to evaluate the damage to my liver. He also mentioned the possibility of me needing a liver transplant at some stage, and I remember being really shocked by this. Until this point I really had no idea how serious an infection HCV was or of the potential consequences. No one had pointed them out to me.

40. At this initial appointment with Dr Millson, he said that considering my blood test results and current health, he felt that I had been living with HCV for over 35 years. This meant that the timeline of being infected when I was 9 years old made sense. It was a shock that I could have been living with this infection for

such a long time without being aware of it, but the symptoms came on so gradually that you just don't realise what is happening until it's too late. Being infected at such a young age means that you probably are not so aware of the symptoms as you compensate with youthful energy and then they creep up on you as you get older.

41. Dr Millson told me that I would be referred to Dr Mark Aldersley, a liver specialist at St James' Hospital in Leeds. Dr Millson also seemed to imply that there was a bit of a postcode lottery when it came to how quickly you received HCV treatment, and that I might be in a better position being treated at Leeds.

42. At this appointment with Dr Millson, he was quite non-committal about how bad my health was and just posed the need for a transplant very loosely as a possibility; it did not seem from his tone something that I was likely to need. It was only when we read his referral email to Dr Aldersley that we saw that in fact my liver was extremely damaged and I had cirrhosis of the liver. **(See Email chain; Exhibit WITN4750003)**

43. As this had not been made clear to my wife and I before, we were of course stunned to see this. I was angry at how this dealt with, more so for my wife. It is devastating news to learn of in such a manner. Dr Millson apologised over email that he had not made it clear during the appointment that my liver was cirrhotic. He said that he thought he had made it clear that transplant and HCV treatment were often successful, but following our appointment with him we didn't even realise that a transplant was something I would need. **(See Email chain; Exhibit WITN4750003)**

44. After my appointment with Dr Millson, I received an appointment to see Dr Mark Aldersly at St James' Hospital in September 2013, almost 2 months later. I had been told by Dr Millson I would need treatment fairly quickly, and it was concerning and worrying to have to wait this long for an appointment.

45. Anna emailed Dr Millson about this delay to receiving an appointment and inquiring about starting HCV medication, as I was really suffering with fatigue, vagueness, confusion and mood swings. I was also struggling to sleep and this together with my feelings of anger were fuelling a descent into depression over my situation. She was increasingly worried about how I was going to cope until this appointment with Dr Aldersly.

46. Dr Millson's reply to my Anna's email was very curt and basically seemed to imply he had already spent more than enough time dealing with us and to contact the Leeds Liver Unit instead **(See Email chain; Exhibit WITN4750003)**. He just seemed to lack empathy for the situation that we had found ourselves in, through no fault of our own.

47. Prior to my appointment with Dr Aldersly, I can't remember exactly what tests I underwent, but I had further evaluation of the condition of my liver. I may have had a liver biopsy around this time too.

48. At this appointment in September 2013, I asked Dr Aldersly if I may have to undergo a liver transplant at some point. His attitude was completely different to Dr Millson and he said something along the lines of, "it's not a question of IF you will need a transplant, you will definitely require a liver transplant at some point in order to make a recovery".

49. Hearing this from Dr Aldersly was a massive shock for myself and Anna. For the first time, we both really understood how really serious the situation was. Dr Aldersly recommended that I start a course of HCV treatment when it became available, and that I undergo an evaluation to see whether I would be suitable for transplant.

50. Following this appointment, I did in fact undergo an evaluation for a liver transplant. This was done at St James' Hospital and I was put up in a hotel overnight which was opposite the hospital. It felt like the doctors were interviewing me in order to decide about whether they wanted to give me the transplant or not. This included a psychological evaluation. After this was complete, I was told on the same day that I was a suitable candidate for a liver transplant and that I would be put on the list. It is not a pleasant feeling being under the spotlight knowing that how you answer and react will determine how the rest of your life plays out.

51. I was offered a course of HCV treatment in October 2013. This consisted of Interferon injections and ribavirin tablets. I think the course was meant to be about 6 months long. Initially, these injections were in pen form, but as I was having issues with my platelet count, I was switched to proper syringe type injections, as I think they were adjusting the doses I would receive.

52. The side effects of this course of treatment were absolutely horrendous. I became so fatigued I could barely do anything at all. It was so debilitating that I sometimes slept the whole day. I could not get out of bed at all for about 48 hours after an injection.

53. I remember that on a number of occasions Anna had to come home from work early to check on me as she couldn't get in touch with me, and it was because I hadn't even gotten out of bed yet by the afternoon. My mother also came over to check on me regularly, and was very worried about how unwell I was.

54. I continued to have the symptoms that I had suffered with previously with the HCV but even more intensely. This included mood swings, feeling depressed, anger and lethargy. I was so weak that at times I was unable to feed myself.

55. I needed to use the toilet more often than usual and I was unable to hold my urine. I couldn't leave the house for very long, and even doing things like walking the dog became impossible. I was even unable to make it to the toilet in time on a few occasions.

56. During the Interferon and Ribavirin treatment I developed cysts on my eyelids which I struggled with for quite some time, even after I stopped taking the medication. They were a very worrying side effect. I even had a biopsy performed on the cysts, although I was never given the results for this.

57. Although I was meant to stay on the treatment for much longer, by early December 2013 the Interferon and Ribavirin were having a significant effect on my platelet count and varices. I was vomiting blood and my stools were black. It was clear that I was not able to tolerate the treatment and my blood test results indicated that my body was failing to produce red and white blood cells properly as a result of this treatment. Consequently, it was stopped.

58. From around February 2013, I had been having issues with my workplace as I had been unwell and having to attend various medical appointments. They even wrote to Dr Khan in order to find out what was going on with me. I believe they had put a clause into my contract stating that I had to provide them with my medical records, which I did not want to do. Eventually this led to my dismissal. I was outraged by the way I was treated and decided to fight my corner.

59. From this point I was only going into work for internal meetings about my dismissal, but eventually this matter was taken to the employment tribunal and I was awarded a payment from my employer. This was not an easy path to take and caused a lot of additional stress on top of my continuing physical ill health.

60. Losing my job was a difficult thing to go through while being unwell, and we were forced to live off my wife's income and our savings for quite some time. We had just moved house and taken on a bigger mortgage, which was a big worry. We felt we couldn't treat the children to all the things they wanted which was difficult, and I was too unwell to find a new job during this time.

61. When I started the HCV treatment in October 2013, I applied for Personal Independence Payments ("PIP"), as I was so unwell. However, I was considered fit enough to work following the PIP health assessment, which made absolutely no sense at all. This made things a lot harder for us. Here I was; far too ill to work but not considered ill enough to receive financial support from the state. It was so disheartening I had always been in employment and paid my way yet when I needed assistance it wasn't there.

62. While waiting for a liver to become available for my transplant, my health was deteriorating rapidly. I continued to vomit blood daily and my bowels problems were becoming worse. My mother continued to come and check on me when I was at home and Anna started working shorter days as she was worried about leaving me for too long as I was so confused and unwell. I also continued to suffer with mood swings and bouts of angry about the condition I was in and this made Anna fearful of my state of mind and what I may do.

63. Towards the end of March 2014, I spent time in York Hospital as I was becoming so unwell due to the varices, and I required these to be banded. Anna struggled to communicate with doctors at St James' Hospital about my admission at York, and it was a stressful time for her as well.

64. I think I was so unwell and in such a state of confusion that I was a bit out of it, but my wife really picked up on the attitude shown towards me by hospital staff as a result of the HCV. There was always an assumption made that I was a drug user, or that my infection was self-inflicted and I was treated differently and looked down upon as a result of this.

65. When Anna and my sons came to visit me in hospital in York, the doctors and nurses always seemed shocked that I was a family man. They always seemed to link infection with HCV to being a druggy living on the streets, they did not expect me to have a normal home life. I had not experienced any of this stigma with Dr Aldersly or Dr Milson, but I think that is because they were aware I had contracted HCV through a transfusion as opposed to drug use.

66. About 2 weeks after spending time in York Hospital due to the varices, I got a call on 07/04/2014 to say that I had been matched with a liver. I was asked to come into St James' Hospital to discuss whether I wanted to take this liver and proceed with the transplant.

67. When I arrived at the hospital at about 4pm on 07 April 2014, I was told that the liver that I had been matched with had Hepatitis B (HBV), but it was still a good option for me. I had previously been told that I might just get a portion of a healthy liver for transplant, but I was not told that I might get an HBV infected liver.

68. Although I was concerned about getting an HBV infected liver, I did feel some pressure to take this liver. I think it was a junior doctor who spoke to Anna and I about this and although I was given the option to turn it down, it was made clear by this doctor that this might be my only chance to get a transplant before my condition deteriorated further and I became unsuitable for a transplant. He made quite clear that my next varices bleed could be my last.

69. Although I was concerned about whether this liver would work as well as a completely healthy liver, I decided to go ahead with this transplant in the hope that it would make me well again. I felt like this was my only option in the circumstances given and I didn't want to lose out on the opportunity and then regret it later.

70. Anna was told she did not need to stay with me as my operation would be sometime the next morning. She did not want to leave me but she was told she would be called with an update as soon as I came out of surgery. I was worried

about the prospect of such a major operation but I tried to not to think too much about it and just think of it as an opportunity to get well and get my life back on track.

71. The liver transplant was performed in the morning of 08 April 2014. After the operation I was taken to the Intensive Care Unit ("ICU") and eventually to a ward. Anna had been anxiously waiting for a call from the hospital as she was told not to call the hospital and to wait for them to call her.

72. By 4pm, Anna had heard nothing and was so worried about me that she called the hospital to get an update. She was told I had been out of surgery and in a corridor waiting for an ICU bed since noon, until I had been moved to the ICU when a bed had become available. She could have known the surgery had been successful by 12pm but had to wait 4 more stressful hours due to the hospital's carelessness and lack of thought.

73. Anna was extremely upset that she had not been given an update about me, and my mother and the boys were also worried and upset. By the time Anna had called the hospital and heard I was out of surgery, visiting hours were over and they had missed their opportunity to come and see me. However, the sister on my ward was understanding about what had happened and told Anna she would make an exception to her and the boys visiting outside of the normal hours.

74. Another day while I was recovering in hospital after the transplant, Anna and my mother came to visit during visiting hours, but I had been taken down for a scan. Normally patients are not taken for tests during visiting hours as family and

friends can travel long distances to visit patients, so I'm not sure why I was taken at this time.

75. When Anna complained to the sister on the ward that I wasn't there to visit, she said that I should have called Anna to tell her I was going down for a scan. It seemed ridiculous that she was putting the responsibility on me who had just had a liver transplant and was completely out of it to keep my family updated at all times.

76. Anna felt that once again a lot of the doctors and nurses treating me had an attitude problem and probably thought I was a drug user and living on the streets. When I felt ready to go home after just a week in the hospital, the staff kept asking who would look after me if I left the hospital. They seemed completely unaware that I lived in a house with my family, and appeared to think I was going onto the streets. I went home on 15 April 2014. On the transplant discharge form, I noted that they had not made it clear I received a Hepatitis B infected liver. **(See Exhibit WITN4750004)**

77. I recovered fairly quickly from the liver transplant and made sure to keep on top of all the medication I had to take, including Adaport which is an anti-rejection drug. I was told I would require regular monitoring and appointments, but after coming out of hospital I did not get sent an appointment letter, something which I expected to receive fairly quickly.

78. When I called the liver unit at St James' Hospital about this sometime later, it was clear there had been an error made. I should have already had a follow up appointment. They asked me to attend the clinic first thing the next day, and then

when I got there they asked me why I didn't have an appointment and kept me waiting around! I was dumbfounded. I eventually was seen by a doctor, but it was frustrating and everything seemed mismanaged, considering the magnitude of the procedure I had undergone.

79. 3 to 4 months after the transplant, my ALT liver function test was still reading on the high side. The doctors were not sure why this was, and initially they were concerned that my body might be rejecting the liver. Fortunately, this was not the case. I was still seeing Dr Aldersly at St James' Hospital as well as Dr Phaedra Tachtatzis on some occasions.

80. Anna remembers asking Dr Tachtatzis whether her and our sons should be tested for HCV and vaccinated against HBV, as she knew I had been given an HBV infected liver. Dr Tachtatzis laughed and asked why that would be necessary, as the HBV in my liver was dormant.

81. GRO-C

She also insisted that her and the boys were vaccinated against HBV by our GP, as she was concerned about this. Again, this was all done of her own back. The boys have never been tested for HCV.

82. I was able to find a job and start working again about 3 months after the transplant. Thankfully, my employer has been really supportive and understanding about my health and the fact that I do have to attend regular appointments.

83. At my follow up and monitoring appointments, I was often seen by Kirsty Miles, one of the specialist nurses in the liver unit at Leeds. I had explained that I would

prefer appointments at a certain time due to work commitments, but I was often given appointments at very inconvenient times and she seemed reluctant to change them. I felt there was an assumption that people being treated for HCV and having had a liver transplant wouldn't be working, but that was very different to my situation.

84. In April 2015, I was offered a course of AbbVie D HCV medication on compassionate grounds, after an application was made by the hospital on my behalf. I was told that this was a trial drug that had been previously used in the USA successfully.

85. I took this course of treatment for 24 weeks, and it was a completely different experience to the Interferon and Ribavirin. I did not have any serious side effects and by July 2015 at my week 4 PCR test, I was testing negative for the virus which was very encouraging.

86. By the end of the treatment I was told my levels looked good and that the treatment appeared to have been successful. In April 2016 my HCV levels were undetectable and by June 2016, I was given the all clear for Hepatitis C.

87. Despite the fact that I had received the all clear for HCV and had received a new liver, in around 2017/2018 I started feeling quite unwell again. Again, I just didn't feel myself and I informed my doctors about this. This included Dr Driver who I saw at York Hospital.

88. How I was feeling was just brushed off or put down to my weight gain which had resulted post-transplant. It felt to me like they were always pointing the finger at me as having done something wrong rather than trying to find out what was

actually the problem. I even saw a dietician who advised me to lose weight and exercise more frequently, even though I wasn't significantly overweight and I'm sure there are far heavier people who had received transplants.

89. One thing that is really quite baffling is that in a letter by GRO-D to Dr Driver, she said that I had mentioned I drink more than the recommended amount of alcohol, and this might be the cause of my abnormal liver function results. This is something I had never said to her as I very rarely drank, but it bolstered my suspicion that they were continually trying to find ways to blame me without actually getting to the root cause of what was wrong with me. **(See Exhibit WITN4750005)**

90. My wife has always felt that this nurse in question, GRO-D, was also quite rude and accusatory towards me. It always felt like she wanted to put the blame on me for everything. In another letter from Dr Ramu Chimakurthi to Dr Fisher **(See Exhibit WITN4650006)** it says that I do not smoke and rarely drink alcohol, which is an accurate representation of my situation as opposed to what Kirsty said in 2019.

91. In December 2018, my ALT levels were still showing an increase, which was concerning as it just wasn't clear what the reason for this was. In July 2019, I had a liver biopsy which showed non-specific inflammation, and I was treated with increased immunosuppressants. I believe Dr Driver thought this inflammation was a result of my body rejecting the liver.

92. Despite taking increased doses of immunosuppressants, I was still feeling unwell. Finally, in December 2019, Dr Driver did further tests which indicated I had tested

positive for Hepatitis B. This was called a 'resistant mutation' and my medication was changed to Tenofovir.

93. I believe I was informed about the Hepatitis B through a letter from Dr Millson. He said that they had noticed my liver was not functioning normally, and I had tested positive for Hepatitis B. He said I would need blood tests to see if my immune system was able to fight the Hepatitis B, and that they have medication available that can easily suppress Hepatitis B.

94. Dr Millson also informed me that he had been contacted by Public Health, as Hepatitis B is a condition that is recorded on the Public Health Register. He said that "You will also remember that your liver transplant had been exposed to hepatitis B prior to being grafted into you and there is the small risk in such cases that the virus is transmitted". **(See Exhibit WITN4750007)**. Yes, sure I was aware of that but no one had ever explained the odds of it happening or what the symptoms were to watch out for. Obviously, it was not something they expected to happen either, otherwise I would have been tested for it much earlier.

95. I have also seen a letter from Dr Millson which was written to my GP Dr Fisher at Park View Surgery, asking him to check whether I had regularly been picking up my Lamivudine prescription, which I was taking to prevent Hepatitis B infection. In this letter, he also said he would check with the team at Leeds about this, and was insinuating that it was my fault that the Hepatitis B had reactivated, despite taking my medication carefully every day. It always felt like the blame was shifted onto me at any opportunity, when I had done nothing wrong **(See Exhibit WITN4750008)**

96. When I saw Dr Millson at an appointment, I told him that I don't understand how the Hepatitis B was missed all this time, despite the fact that I had been given a Hepatitis B infected liver. My ALT levels were raised enough to be of concern for over a year before anyone twigged. How can that be in the circumstances? He completely avoided the conversation and instead praised Dr Driver for identifying the Hepatitis B, saying he was a good doctor. To me, it seemed that he knew I had been treated negligently and was trying to avoid discussing it.

97. Since all my doctors knew I had been given a liver infected with Hepatitis B and that I had been given Lamivudine post-transplant to manage Hepatitis B, I just don't understand how this was never monitored or considered a possibility for how I was feeling and for my raised ALT levels and inflammation. It was something they either never considered or worse, completely missed and gives a strong appearance of negligence. Even if there was a "small risk" as Dr Millson mentioned, this should have been tested regularly.

98. In another letter, Dr Driver says 'Unfortunately, in August he did not have an up to date hepatitis B viral load or an up to date tacrolimus level". However, since the transplant, I was never tested for Hepatitis B at any stage and when my wife asked about the risk to the family of getting Hepatitis B, she was laughed at by Dr Tachtatzis. That was really shocking at the time and even more so in retrospect. **(See Exhibit WITN4750009)**

99. After I found out about the Hepatitis B diagnosis, I called Kirsty Miles at St James' Hospital in order to inform her about this. I remember she asked me to hold on and spoke to someone else before coming back on the line with me. I think she was checking what she should say to me.

100. After this conversation, I was also asked to attend an appointment at St James' Hospital with Dr Tachtatzis to discuss this. I believe she came to the clinic specially to see me, as it was only after I checked in with the receptionist that she came down to the clinic. Although it was clear that the Hepatitis B was a reactivation from the infected liver I had received, there was still an implication that the Hepatitis B could be from another source.

101. After this appointment, Dr Aldersly wrote to Dr Millson in relation to the Hepatitis B diagnosis I had received at York Hospital. He said that it indicates a reactivation of Hepatitis B from within my donor liver which had been Hepatitis B anti-core positive. He said this was unusual if I had been compliant with Lamivudine, which I always had been.

102. Since being treated for Hepatitis B I do feel better, but it is worrying that I was living with an infectious disease like Hepatitis B with absolutely no knowledge of its "live" presence and thus not taking any measures to prevent passing it on. I am thankful my wife pushed to have her and our sons vaccinated for Hepatitis B, as I could have infected them unknowingly.

103. I have continued taking Tenofovir and I am told I am close to having completely cleared the virus. They continue to put down my slightly elevated ALTs to weight gain, but given they put down all symptoms of the Hepatitis B to weight gain previously, I am not very trusting of this opinion.

104. Dr Millson and Dr Driver are trying to reduce my medication now that my Hepatitis B is under control. However, they wish to do a liver biopsy before doing this as 2 years ago my latest biopsy had indicated some inflammation.

105. Dr Millson wrote to Dr Tachtatzis in April 2021 and asked whether the biopsy could be done at York with the specimen sent to Leeds for analysis. However, I am still waiting to hear about when this biopsy will be, as I believe Dr Millson has not received a response from Dr Tachtatzis yet. As of 11th of August that is still the case.

106. My wife is very angry with how I have been treated and feels that we should pursue legal action against the hospital. Although it is clear I have been treated negligently, I have always been reluctant to pursue any legal action or complaints as I felt that the doctors were the reason I am still alive. However, this is something we are now considering going forward.

107. Following my diagnosis with HCV, Anna was of course initially concerned with how I had come to be infected. I am sure she may have had some suspicions. However, as she put it, I haven't left her side since we got together and it was clear from the beginning that this was caused by the blood transfusion. She has been extremely supportive of me and pushed for my care at all times. I feel it has brought us closer together as a family.

108. I am close to my sons Isaac and GRO-C, and I have always been open with them about what is going on with the HCV. As mentioned above, they were in the car when I got the call from Dr Khan with my HCV diagnosis, so they have always known what is going on with regards to my health.

109. Isaac had a few issues in school not long after my diagnosis and I'm not sure if it was linked to my health issues and what was happening at home, but moving him to a different form was helpful for him and he felt much better after this.

110. When GRO-C was in primary school, there were some parents who did not want him to play with their children due to my HCV. Other than this issue, we did not face a lot of stigma from family and friends as a result of the HCV and as I have said, we were always very open about my diagnosis, mainly because we did not know much about HCV when I was first diagnosed. Possibly, with hindsight I may have kept a bit more back if I had been fully aware of the perception some people have of the infection.

111. Sadly, we faced more stigma from medical professionals than anywhere else. When they learned about my HCV diagnosis, it always felt like I was put in the same boat as a drug user, and it was hard to go through a difficult time medically with mostly, unsupportive doctors and nurses.

112. As a family we suffered financially as I was unable to work for a long time but was considered ineligible for PIP. Now that I am in a job where they are understanding about my health issues and allow me some flexibility to attend appointments, I think I would find it very difficult to move to a different employer, even if I was to be better off financially.

113. I worry that if I change jobs in the future, I may not be allowed the same flexibility to attend the medical appointments I will continue to have to attend for a long time. As a result, this could impact my career going forward and force me to turn down better career opportunities in the future.

Section 6. Treatment/Care/Support

114. As described above, I have faced difficulties with the treatment I received as a result of the HCV. Although treatment has always been made available to me, my wife and I have often had to chase follow up appointments and have faced a considerable amount of rudeness from some of the medical staff treating me.

115. During my time in hospital, as I have already outlined, I have often been made to feel like I am a drug user, and have not been treated with kindness and respect. As I was so unwell for large parts of my time in hospital I think a lot of this has gone over my head personally, but it is something that has upset and troubled my wife a great deal.

116. Prior to my liver transplant I was assigned a social worker who was meant to support me through the process, but I found him unhelpful when I got in touch with him about claiming disability benefits when I was unable to work. Although in theory there was a mechanism in place for support, it didn't really help in practice.

117. Although I received a psychological analysis prior to my transplant, my family and I were not offered additional support, despite the stress and hardship we were experiencing. I know that my wife felt like she had to push and argue on my behalf for the care that I required, and this was difficult for her.

118. In relation to my diagnosis with HCV there was no offer of psychological support or counselling for either myself or the family.

119. As I detailed above, I felt pressure to accept a Hepatitis B infected liver for transplant, and then when the Hepatitis B reactivated, I received no monitoring for this whatsoever and my weight was continuously blamed for my abnormal liver function test results. Kirsty Miles even said it was linked to drinking too much, when in fact I drank very little - it was very demeaning.

120. I have also struggled with obtaining appointments at suitable times, despite the nursing team knowing that I work. It has always felt like a struggle to organise the care I need, and on occasions there have even been complications with picking up medications that I have been prescribed and needing doctors to reconfirm with the pharmacy that this is medication that I actually need, as it is so expensive.

121. I do feel that I have faced a lack of support from the various doctors and nurses treating me. Although I have felt less inclined to complain about this aspect, it is something that my wife remains very upset about and wants to pursue further. It as it has made the overall experience much harder for us.

Section 7. Financial Assistance

122. After our initial meeting with Dr Millson in July 2013, he mentioned that a fund called the Skipton Fund existed and it had the purpose of providing financial assistance to those who had been infected with HCV as a result of a blood transfusion or through the use of blood products.

123. Dr Millson told us that as he knew my wife and I were respectable people and that the source of my HCV was the transfusion I had received when I was 9 years old, he would recommend me for financial assistance to the Skipton Fund.

124. Dr Milson told us that he would access my medical records on my behalf, and complete the Skipton forms for us. When he received the records, he wrote to me and said that the records relating to my accident in 1977 did not include mention of a blood transfusion. However, he did say that the notes were very difficult to decipher. The notes just said that I had a concussion and required some sutures, they did not detail how serious the accident was. **(See Exhibit WITN4750010)**

125. In order to support the application to the Skipton Fund, I wrote a letter describing the accident as I remember it **(See Exhibit WITN4750011)** and my mother Judith Hall also wrote a letter to the Skipton Fund, however, she put 1976 as the year but it was 1977.

126. In her letter to the Skipton Fund, **(See Exhibit WITN4750012)** she explained that the medical notes do not reflect how serious the accident was. She definitely knew I had been given a blood transfusion due to significant blood loss and she was also told that I had been unconscious for 12 hours following the accident.

127. Other than writing the supporting letter to the Skipton Fund, I did not have much involvement with the paperwork side of the initial Skipton application, as that was all dealt with by Dr Millson. The application was submitted in September

2013.

128. In October 2013, The Skipton Fund wrote to me and asked me to provide further medical records as evidence of my blood transfusion, as the records that had been submitted by Dr Millson did not confirm that I had received a transfusion.

129. Although I tried to get further records from my GP, the information they held about the accident was extremely limited and did not detail the treatment I received, including the transfusion. It just mentioned that I had suffered a concussion and required sutures **(See Exhibit WITN4750010)**. As a result, the Skipton Fund rejected my claim on the basis that I could not provide proof of receiving a transfusion in 1977.

130. This rejection from the Skipton Fund seemed unfair, as the fact that the hospital notes were so limited was completely out of my control. Even Dr Millson had said that the notes had been difficult to decipher so it was not even clear what these notes said. I also had no other risk factors for HCV.

131. I decided to appeal this decision in June 2014. In October 2014, my appeal was rejected by the Fund's Appeal Panel, on the basis that a laceration to the head like the one I had suffered would not warrant a blood transfusion. I'm not sure how this conclusion was reached. How can they know what happened? It is well known that not everything is recorded in hospitals and certainly not back

then. It all seemed very black and white.

132. Although it was frustrating to hear this news as my mother and I were both aware about how much blood I had lost following the accident, I just accepted the fact that the decision was final and did not make any effort to pursue the fund any further. It was money we were not expecting to receive, so I tried to avoid seeing it as a loss.

133. If I had been given financial assistance by the Skipton Fund, it would have made our lives more comfortable, especially during the time when I was unable to work due to my ill health and had been denied PIP. We did use our savings to manage during this time, and we felt like we could not treat the boys in the way that we would have been able to otherwise.

134. My wife feels that now that I am better, I push myself to work extra hours in order to save money for the family. This is something that I do because I want to make sure my family will be able to manage without me if my health deteriorates again. If we had obtained financial support from the Skipton Fund, we would have had more financial security and I would have less concerns about this.

Section 8. Other Issues

135. I hope through this statement I am able to raise awareness of the experiences of HCV patients and the difficulties and stigma we have to face, even from the medical professionals who should be understanding of our situations.

136. I have never been a blood donor.

137. The events I have described have shaken my faith in the NHS. I tend to quiz doctors now a lot more thoroughly and I don't think it is too harsh to say I have feelings of distrust at times. Recently, over a month ago, I underwent some blood tests – regular testing is important in my condition - and was expecting the results to be communicated to me as I was told they would be. I have heard nothing. I then accessed my medical record on-line thinking I would find them there but again nothing. What does that say? I am grateful for all the treatment I have received but my health was put at serious risk by the NHS in the first place and I think I am entitled to peace of mind.

138. I would like to add that recently I have received a copy of my Skipton application and having read through it, I am disappointed in the response provided by Dr Millson. He did not answer, in my view, the most important question at Section 4B "….is it probable that the infected person's HCV infection was acquired in consequence of NHS treatment received before 01 September 1991" he simply provided a letter dated 02 October 2013. In it he outlined the basic facts and provided copies of my medical records from the accident, which I can understand, but there was no mention of the opinion he expressed to Anna and I that the state of my liver was consistent with the fact that I had been infected since childhood. An opinion such as his at the time may have made a difference to the decision to refuse taken by the Skipton Fund.

Statement of Truth

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

Signed GRO-C

Dated 7-9-21