Witness Name: Caren Nadeau
Statement No: W4216001
Exhibits: WITN4216002-10
Dated: 14/12/20

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF CAREN NADEAU

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 17 July 2020.

I, Caren Nadeau, will say as follows: -

Section 1: Introduction

1. My name is Caren Nadeau. I was born in Liverpool, and my date of birth is GRO-C **1965**. I reside in GRO-C, and my full address is known to the Inquiry. I am married and I have two daughters. I am currently a homemaker.

2. I intend to speak about my infection with Hepatitis C ("HCV") after having received, I believe, blood plasma during an operation to correct an intussusception in 1966, when I was five months old. In particular, the nature of how I learnt about my infection, how the illness has affected myself and my family, the treatment I have received, and the impact it has had on my life.

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 am not seeking anonymity 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 without access to my earlier medical records which have either been misplaced or destroyed. I have confirmation of destruction of my records only from Alder Hey Hospital. I do have some records that relate to my medical history but with many gaps throughout the years.

Section 2: How infected

7. In my early years I resided with my parents in GRO-C Merseyside. In 1966, when I was around five months old, my mother had noticed that I had started crying with discomfort and vomiting on more occasions than would be normal for a baby. My mother alerted my father to this, and apparently, he became frantic, wondering what could have caused my health to deteriorate. It seems he may have thought that I had swallowed an object accidentally. The family doctor, Dr Altman was called. They decided to keep a close eye on me from that point forward.

8. After three to four days, my health had not improved and I had become listless so the doctor contacted a paediatrician at Alder Hey Children's Hospital for advice. Upon hearing my symptoms, they were told to take me immediately to the Children's Hospital in Liverpool where initially, they suspected I had meningitis. However, on further examination my condition was diagnosed as 'intussusception.' (**See Exhibit WITN4216002**). This is a condition where one segment of the intestine 'telescopes' inside of another, forming a complete bowel obstruction. This would explain why I was vomiting, as this was the only way for my body to reject liquids or solids. Due to the severity of my condition, it was decided that I required an operation.

9. I am not sure how long my procedure took or how long I was in hospital after I had undergone my operation in 1966. Obviously, I cannot provide exact facts around this time as I was only five months old. My mother Averel Sutton is willing to provide a statement which will deal with this period. (**See WITN4676001**) Please refer to my mother's statement for context on this issue. My mother was with me both prior to and post my operation taking place

10. When I have since asked my mother about this period of time and how she felt, she has always stated that it was one of the most horrendous chapters in her life, as she had to witness her own daughter going through such an abhorrent and painful procedure. My hands were constantly tied down to the hospital bed by my side, so as to ensure I would not be able to touch or interfere with the tubes which were attached to my forehead.

11. In retrospect, you could say that this operation I had undergone was a blessing in disguise, as if I had not, then I do not believe I would still be alive today. I have since learnt that if this condition is left untreated, then it can cause serious damage to the intestines as the blood supply can become cut off. My mother has always said that I was at death's door when I was admitted to the hospital, and it was only having the operation itself that saved my life.

12. On the other hand, it could be suggested that my surgery was the worst thing to happen to me. When I asked my mother about the operation, she had stated that I was given plasma. I have a letter from my mother that outlines what took place. (**See Exhibit WITN4126003**) I believe this plasma transfusion contained contaminated blood, and therefore, was the cause of my subsequent HCV infection.

13. I was only five months old when I received this plasma transfusion during the operation in 1966. I am aware that no information or advice surrounding the associated risk of being exposed to infection was provided to either my mother or my father beforehand due to the time period.

14. In the run up to my HCV diagnosis on 14 March 2017, I had not noticed any persistent symptoms which would have otherwise indicated that there was something not quite right regarding my health.

15. However, in hindsight, I may have suffered from a number of the most common HCV symptoms, but, I had previously explained these away through alternative means. For instance, whilst I had commonly experienced unusual tiredness and fatigue when I was growing up, I had always put that down to everyday life stresses. Between the late 1970s and the early 1980s I had undergone numerous blood tests to ascertain the cause of my fatigue, and at one stage it was suspected that I had glandular fever but I tested negative for this. Since clearing the virus, the increase in my energy levels has

been amazing. I'm in my mid-fifties and have more energy now than I ever had and this has had a positive knock on effect as to how I cope with life in general.

16. Furthermore, I had also suffered, particularly after exercise from an all over body ache. It was non -specific, more a general malaise that would happen especially at night and affected my neck and shoulders mainly but ran down through my whole body at times. It was something that I thought I would just have to learn to live with. Again, since my treatment finished I have noticed that this ache – a pain I thought would be perennial – has gone completely.

17. In addition to the above symptoms, I do believe that my HCV may have had an impact on the treatment I have received throughout my life. As I was growing up, I had always experienced colds which would persist for longer periods than everyone else around me. They would often progress to Sinusitis and I would lose my sense of taste and smell. I believe that this could have been caused by my HCV having had an effect on my immune system. Additionally, when I have been given antibiotics as treatment for any reason, they have never really worked as well as intended.

18. There are other conditions such as contact dermatitis that I have experienced on and off over the years as well. Additionally, I was prone to migraines, normally caused by exposure to very bright light. I would get zig-zag lines across my vision which would only clear after time in a darkened room and taking Ibuprofen. Thankfully, this is another possible symptom that seems to have vanished over the past few years.

19. I did and still do suffer from IBS. It seems to run in the family. I used to experience a pain that ran up my right side that I associated with the IBS. However, since I cleared the infection this has also subsided. Finally, I have always had very sensitive gums and regularly bled whilst flossing. This has improved considerably of late and in fact my dentist recently commented on how healthy my gums are now.

20. In December 2016, I had a persistent and horrible cough which would not clear. I left a period of around six to eight weeks before seeking medical assistance to determine if my cough would clear on its own accord. By early February 2017, my cough was still incessant so I took the decision to visit my GP at the Riverside surgery in GRO-C to gain medical assistance. I think I saw a locum as my GP, Dr Oxenham was not available. To determine the cause of my cough I underwent a full range of blood tests.

21. Within a week or so, I then had a consultation with Dr Oxenham. I was told that the results of my liver function test had come back as abnormal. He thought it may be fatty liver (NAFLD). As a result, it was suggested that I should undergo an ultrasound, as this may give a conclusive reason for my abnormal test result. I had private health care which I used to attend Nuffield Health Exeter Hospital, Exeter where my scan took place. The result of this returned as normal. The cause of my cough had not been determined, but I don't recall any further blood tests at that time being carried out by Dr Oxenham or anyone else.

22. I later attended a further face to face consultation with Dr Oxenham, where much to my dismay, I was told that I had tested positive for the presence of HCV during my recent blood tests. He then conducted a further blood test to confirm the presence of the infection which it subsequently did. I was devastated by this news and I can't begin to describe the feeling of dread that came over me. How could I possibly have contracted such a disease?

23. I was provided with a leaflet from the internet that gave basic information about the condition. Dr Oxenham was sympathetic and said if there was anything he could do he would and he obtained an appointment with the liver nurse very quickly on my behalf in order that I could have a fibro-scan.

24. When I was diagnosed, Dr Oxenham had tried to assure me that my HCV could not easily be transferred to other individuals. However, he was not effective at convincing me of this fact. I was constantly worried about passing my infection on to my friends and family through the simplest of means such as touching them or even through food preparation.

25. There was a period after I was diagnosed with HCV in March 2017, where I did not know how to tell my mother about my infection. In the end, I decided to telephone her once I knew the children and my husband had been tested and the result was negative and I had been to see the liver nurse and knew there was no damage to my liver. I felt completely numb and had burst into tears at the thought of putting my news into words. When I divulged that I had tested positive for HCV, she immediately started crying. It was at this point that I discovered that I had been given plasma. I was so emotionally compromised by this call that I only recall two instances of what we had spoken about during this conversation; The fact I had contracted HCV and that I asked her to undergo a test as I knew she went through a major operation herself when she was 15 years of

age and I was worried she may have been infected then and passed it on to me. She was tested and it was negative.

26. I would like to say that I am happily married. I do not have any tattoos, I have never taken intravenous drugs or drugs of any kind. I have had medical and dental treatment outside of the United Kingdom. In 1993, I had a D&C whilst resident in GRO-C in France. I did not have any blood products during this procedure. In 2000 I had a couple of fillings whilst resident in New York State.

27. Whilst there are other areas of concern with regards to the cause of my HCV infection, they are extremely minimal or obsolete. For instance, I did have my ears pierced, but only one set. This was conducted with sterilised equipment. As I was growing up, beside my intussusception in 1966, I did undergo a number of other operations. However, as far as I am aware, I did not receive a blood transfusion as treatment during these operations. By the time I was diagnosed with HCV, I had also given birth to two daughters and on both occasions, I had haemorrhaged during birth but I was not given blood in either setting. I have also suffered two miscarriages where dilation and curettage (D&C) procedures were performed but again without the need for a transfusion.

28. When I asked my mother where she believed my HCV infection could have stemmed from, she had mentioned that the cause could have been plasma. I have considered my dental treatment. Can you ever be sure of how dental equipment was sterilised in the past? But it was a reputable practice. No, through a process of elimination, the only potential cause of my HCV diagnosis was the plasma transfusion I had received during an operation for my intussusception in 1966.

29. After I was diagnosed with HCV in March 2017, Dr Oxenham had, as mentioned referred me to the liver nurse very quickly. By April 2017, I had an appointment with Laura Strang, the liver specialist at The Royal Devon and Exeter hospital. Here, I was questioned about the details of my case. I had stated that I had an operation for my intussusception at around the age of eighteen months old, of which, she didn't know whether this could have been the cause of my HCV. It wasn't until a few weeks later, after finally telling my mother about my HCV diagnosis that I discovered I was in fact only five months old when the operation took place in 1966.

Section 3: Other Infections

30. I do not believe that I have received any infection other than HCV as a result of being given infected blood. I have tested negative for both HIV and HBV.

31. I would like to add here that although I cannot be certain, I wonder if the infection with HCV affected my tolerance to certain medications. Over the years I have had difficulty with a number of prescribed drugs, including antibiotics and even over the counter measures such as Canesten. I can experience reactions from pain to nausea with all the attendant difficulties this causes in sourcing effective treatments.

Section 4: Consent

32. As I was only five months old when I believe I was infected with HCV in 1966, it was my mother and father who would have provided consent for my treatment and tests. Therefore, I believe that they would have given fully informed consent on my behalf.

33. When I was diagnosed with HCV in March 2017, I was fifty-one years old. As a result, I know that I would have provided consent to all tests and treatment I was subject to and made aware of around this period.

34. However, you could say that I was unaware that a full blood was test carried out to determine the cause of my persistent cough in March 2017. I was not made aware that this would be used to determine the presence or not of HCV.

35. Since my HCV diagnosis, I have found out that it is apparently a standard practice across the board for tests to be carried out for the presence of HIV and HCV in all circumstances, where the symptoms of these infections are apparent. However, that should not deflect from the fact that people are entitled to know what is being tested for even if only in layman's terms.

Section 5: Impact

Mental/Physical Impact

36. From the point of my HCV diagnosis in March 2017, until I was cleared in November 2017, my mental state declined rapidly to the point at which I developed depression. I could not bear the thought of having contracted this infection, so initially, I shut myself off from the world and began failing to function as I normally would have done. I was in such a dark and difficult place, that every day, I thought about taking my own life. Looking back now, I wonder how I could have possibly contemplated leaving my friends and family behind, or how I could have developed these thoughts. My family are everything to me. However, this just goes to show what effect HCV had on my outlook on life, and how it changed me into a person whom I did not recognise.

37. I look at the presence mental health has now and the effects it has on nearly every household in the United Kingdom. I can understand how desperate these people are to get better. I have always said that during my suicidal period of 2017, I had surrounded myself with so many people that had loved and supported me dearly, but, even this was not enough for me at one point. I cannot even begin to fathom how some individuals may be feeling in this world if they do not have this support mechanism around them which I was so lucky to have.

38. As previously explained, during my HCV diagnosis in March 2017, Dr Oxenham had unsuccessfully tried to convince me that HCV was not easily passed on to other individuals. Therefore, I have always constantly worried that I could transfer my infection to my friends and family through simple means such as touching them or preparing their food. This anxiety was only furthered by the fact that I had OCD, which I believe started during my early years. It is from this point that my heightened anxiety started to affect me as a person. My anxiety had become so extreme that I had started to stay away from my friends and withdrew from society in general.

39. Since November 2017 when I was cleared of HCV, I have not experienced any further psychological problems, certainly nothing to this extent.

40. As previously stated, between the point in which I believe I contracted HCV in 1966 and when I was cleared of this infection in 2017, I had not fully recognised the physical impact my HCV had on my body. I had previously explained my symptoms away as

having stemmed from everyday life stresses. Looking back, I realise that my HCV had caused me to experience extreme tiredness and fatigue on a daily basis.

Treatment

41. In the months following my diagnosis in March 2017, I had set up a face to face consultation with Dr Christie at the Nuffield Health Exeter Hospital. At this appointment, I had asked him every possible question regarding the treatments which were available and suitable for me to commence for my HCV. This appointment also confirmed my infection and genotype which was 1A. (**See Exhibit WITN4126004**)

42. I also had a phone appointment with Sister Fiona Fry where again I was told that only the most seriously affected patients were being seen and that there would be a waiting period before I was treated. I was told that there were only two patients who could be treated within the Clinical Commissioning Groups ("CCG") in any one month, so there would be a very long waiting list of around nine months approximately to wait until treatment could become available for me. As my liver was not compromised there was no urgency in providing me with treatment. I was therefore effectively told I would have to join the back of the queue, where I would have to wait until the funding for treatment became available. (**See Exhibit WITN4126005**)

43. Between April and July 2017, my psychological health had started to deteriorate quickly to the point at which I had developed suicidal thoughts. I was finding it increasingly difficult to function within the normal environment. In desperation, I thought that if I would write a letter to my local MP, they may be able to examine the treatment available to those suffering from HCV. However, the letter I was provided with in response was not the result I was expecting. My MP had simply stated that the guidelines in place had been followed. As a result, they were unable to bring about any action to help me with my treatment.

44. In the face of adversity, I was desperate. I remember sitting down with my husband and we both weighed up my options with regards to obtaining treatment, and the benefits and advantages of each options. During this process, I had a face to face consultation booked with Dr Christie. Here, I explained that I did not want wait for funding to become available due to my mental state. Dr Christie was very welcoming and understood my frustrations surrounding the length of the waiting list for funding. He had stated that he had previously tried to speed up the process, but, he was not

successful. His hands were tied but he did agree to explore potential costs. (**See Exhibit WITN4126006**)

45. Dr Christie was adamant that it would be beneficial for me to wait for treatment through the National Health Service ("NHS") however, I did not know how long this would take as it could be much longer than the estimated nine months. The mental anguish that I was experiencing on a daily basis was unbearable and the thought of it continuing, untenable. Treatment asap was a must - whatever the cost.

46. Therefore, in spite of his recommendation that I wait, I made it clear to Dr Christie that I wished to obtain treatment through private health care to accelerate the process of me clearing my HCV. By June 2017, I had spoken to AVIVA Healthcare to ascertain whether my private health care insurance would cover my treatment for HCV. It did not. I was stunned to discover that whereas it would cover the cost of in-patient treatment, for instance an operation, it did not cover the cost of drugs purchased as part of an out-patient course of medication. Now I had the further stress of the potential cost and incurring debt if I wanted to access rapid treatment for my condition.

47. Pierre and I researched purchasing anti-viral drugs from across the world. Due to my risk-adverse outlook on life and on the recommendation of Dr Christie we decided not to procure generic drugs from overseas which can be purchased at a fraction of the price.

48. In the end, we had decided to purchase a treatment called Maviret. The reasons behind this decision were twofold. The drug carried the least amount of side effects and was of high efficacy, around 96%. My treatment cost in excess £25,000 for the drug itself, and there was an additional 10% handing fee placed by the NHS on top of this cost. This had meant that my total charge was £28,586.06. (**See Exhibit WIT4126007**)

49. Now aware of the cost of the treatment my husband and I took out a loan from the bank for £30,000 over seven years. However, we were in the fortunate position that our finances allowed us to clear it in 2019. It is a lot of money but what are we without our health and I shudder to think what the consequences may have been had I not been able to have the treatment at such an early stage. I am eternally grateful that we had the financial wherewithal to go down the road we did. So many others suffer as they don't have that option.

50. I did complain about this handling fee of over £2,500. I felt it was an extortionate amount in the context of my treatment. When I had made an enquiry about purchasing my private treatment drug at NHS prices (their cost was £12-13,000), it was explained to me that could be seen as "profiteering". How can this fee not be considered as profiteering from my misfortune? I would like to point out that by paying for this expensive treatment I reduced the burden on NHS England and yet I was still penalised.

51. For support during this process, I had a conversation with Paul Desmond from the Hepatitis B Trust who talked about his experiences with HCV in the1980s. He discussed the fact that there were talks ongoing on obtaining generic treatment drugs from elsewhere in the world such as India.

52. My treatment was purchased in September 2017. By the begining of October 2017, I had started my treatment which was due to last for a term of eight weeks. Around two weeks into my treatment, I underwent a blood test to determine the HCV levels in my blood, and how my body was reacting to the treatment. Astonishingly, in November 2017, my test results had returned as negative for the presence of HCV. I was then tested every few months beyond this point, and then subsequently, every six months. I was cleared, I could not believe it. After jumping through so many hoops to obtain the best treatment possible so that I could clear my HCV as quick as I could, I had done it. I could not be any happier.

53. During the course of my treatment, I could feel the change in me taking place. I had a complete change in my mood. I can only describe this feeling as if the dark cloud which had previously been hanging over my head since I was diagnosed, had been removed. I no longer felt constantly tired and lethargic. As I've already said, it was as if I had more energy in my mid 50's than when I was in my 20s. When you have been tired your whole life, you learn to live with it.

54. I do believe that there were treatments which I consider should have been made available to me at any earlier point in time, but I was not prepared to wait over nine months for funding for my treatment to be approved by the NHS. I do not honestly think that I could have survived such a wait and in fact, I am sure it would likely have been longer. My mental health was in such a decline that I hate to think of what I may have done or where I may have ended up.

Impact

55. I do not believe that my infected status had impacted upon my treatment, medical or dental care for any other conditions. I have not been refused treatment in either setting, and I have not been treated differently following my HCV diagnosis. It was such a short period between my diagnosis and clearance that I had not noticed any difference in my treatment within this time.

56. As I have mentioned previously, I had developed severe anxiety as a result of my HCV diagnosis. I had always been a little anxious but never to this extent. This impacted me on immeasurable levels, to the point at which it had stopped my daily life. For example, I have a great love of music but I could not even bear listening to it. I play the piano but even this was too much for me. I shut myself away and I avoided all social settings until I was cleared of HCV. I even stopped my daily swim at the local health club as I was paranoid that I could pass the infection on in the water. My HCV had not caused me to lose any friends as such, but instead, due to my anxiety and depression, it did stop me socialising. This was particularly difficult, as myself and my family are very sociable people and have always had people over for dinner but I worried too much about the risk in food preparation and close contact.

57. I did not know how to tell my friends about my HCV, so after I was cleared, I took the opportunity to tell them the reason behind why I had stayed away from them for such a long period. They were totally shocked that I had kept this news from them.

58. Naturally, my family were the closest individuals to me, so they witnessed the true impact of my HCV diagnosis in its entirety. My husband works away a lot for extended periods of time due to his job, but when he was home, it was tough for him to see me in a way where I was unrecognisable. It must have been stressful for him with the worry about my condition on top of his workload.

59. My two daughters were also affected by my HCV. My oldest daughter lived with us throughout my diagnosis and my treatment, where it impacted on her a lot. She was engaged in the preparation for her University finals between the March and May and had the added worry of my condition to cope with. She had to witness me turn from the mother she once knew who was happy and bubbly, into a person who would break down in tears on a regular basis due to her fragile mental state.

60. When I talk to my youngest daughter about how she felt when I was diagnosed with HCV, she said that she could not cope with the fact that I did not wish to carry on with my life. On hearing this, she had become extremely upset and angry and did not understand why I would have ever considered leaving her and the family as I was her rock.

61. The feeling of blame has impacted my mother the most throughout this process. She was devastated by my diagnosis because we believe that I was given the plasma transfusion which contained contaminated blood, whilst undergoing the operation for my intussusception.

62. I have always felt that with the majority of people in society, when they hear that a person has been diagnosed with HCV, they automatically associate this as having been contracted through prostitution or the use of intravenous drugs. I believe this could be described as the stigmatisation surrounding HCV.

63. This stigma can be demonstrated perfectly when at the suggestion of my daughter we attended the Sexual Health Clinic in Torquay in March/April 2017. This was because an earlier Hep. C test she had undergone had been mislaid, either by the local surgery or the laboratory. I was really worried about the impact on her and this is why she suggested the clinic. When we went in she was refused the test because it was a sexual health clinic and the potential infection was not from sexual contact. A member of the staff then questioned me about how I had contracted the disease and she asked if I had taken intravenous drugs or had tattoos. She refused to believe my explanation that I had contracted the infection as a baby, especially when I mentioned my liver function was within normal parameters.

64. Whilst I did obtain treatment for my HCV through private means, I was very lucky in the respect that we are financially in a good place to be able to afford this. My treatment did not cause financial hardship so we felt really privileged. However, I was disappointed that my private health insurance did not pay for the medicine itself. There are plenty of individuals out there who are not in the financial position we are in. They should not have to fight every day to obtain treatment for their infection.

Section 6. Treatment/Care/Support

65. Since I was diagnosed in March 2017, I had faced difficulties in obtaining treatment for my HCV through the NHS due to the length of time individuals are told to wait for funding. Previously, when I had placed my name on the waiting list for funding, it was approximated that I would have to wait a minimum of six to nine months until it would become available. However, due to the rapid deterioration in my psychological state at the time; whereby my depression and anxiety levels had heighted to the extent of paranoia, I was unable to wait for this length of time. This obstacle is the reason why, as previously stated, I had sought treatment through private health care at the Royal Devon and Exeter NHS Foundation Trust to accelerate the process of clearing from HCV. I commenced treatment with Maviret in October 2017. By the end of November 2017, I had achieved a sustained virological response and had cleared my HCV.

66. When I was diagnosed with HCV in March 2017, I was offered counselling by Dr Oxenham. However, similar to the treatment itself, at the time there was a very long waiting list before I could be seen professionally. Due to the length of time to wait I decided to see if I could cope before I would seek counselling assistance. As time crept slowly past, I came to realise that need for psychological help.

67. In June 2017 when I had spoken to AVIVA Healthcare about obtaining treatment through private health care, a member of staff realising that I was so upset had recommended that I book an appointment to see a psychologist. She had thought this would help me cope with the experiences I was currently going through with HCV at the time. On the 4th of July 2017, I began private psychological counselling with Dr Marie Mills. We discussed my HCV which had exacerbated my anxiety and led to my depression. Her counselling was invaluable to me including throughout the treatment process. She also supported my contention that early treatment would benefit my mental well-being. (**See Exhibit WITN4216008**)

Section 7. Financial Assistance

68. In March/April 2017, while I attended the appointment with Laura Strang the liver specialist she had mentioned that that I may be able to obtain financial assistance for my HCV if I were to make an application to the Skipton Fund. I took this suggestion on board and decided to carry out research both online and by telephone. When I had phoned Skipton, I had asked a member of staff what I would need by way of evidence

to put forward my case. It was stated that I would need written evidence of my blood transfusion having taken place during my operation in 1966, and that this fact had to be supported by a medical professional in charge of my care. I explained that I did not have access to my medical records as they had been destroyed, and they replied that I should just submit any evidence I had to demonstrate the facts.

69. On 15 June 2017, I had asked Dr Christie to aid in completing my application form for the Skipton Fund. I had reaffirmed with him that I believed I had received contaminated plasma during my intussusception at the age of five months. My application form was sent to Skipton on that same day. (**See Exhibit WITN4126009**)

70. On 05 July 2017, I had received a letter from the Skipton Fund in reply to my application. This letter had explained that my claim for financial compensation had been refused. This was based on the grounds that there was no supporting evidence that I had received a plasma transfusion during the procedure of 1966 I had mentioned. My doctor had submitted one handwritten note which he had discovered in my medical records relating to my intussusception which did not demonstrate the facts. All other evidence was missing or destroyed. I could not therefore prove that the plasma transfusion mentioned was the cause of my HCV infection.

71. In July 2017, I made the decision to appeal against my original Skipton Fund judgement. To support my claim, I had submitted photos of the scar caused by my operation, and the letter that I referred to earlier, from my mother as additional evidence.

72. However, not dissimilar to my first application, I was unsuccessful. I received a letter from the Fund on 24 July 2017 which stated that there was no evidence of a transfusion and in any case, it was unlikely that the operation I underwent would cause bleeding sufficient enough to require one. It went on to say it was likely any fluids supplied were for dehydration. (**See Exhibit WITN4216010**). This contradicted the facts I set out to establish and is insulting towards my mother's recollection of events – events I am sure are seared into her memory through the trauma she experienced.

73. I feel that the burden of proof set out by the Skipton Fund is too high for anyone to be able to substantiate in order to gain assistance. This is particularly exacerbated by the fact that my medical records had been destroyed by the very NHS that I believe caused my infection and which made it impossible to try and find written evidence to support

my application. Surely those administering the Fund are aware of the time limits on retention of records yet they place such store on their production as proof. I can imagine the same frustrations have materialised with a number of other applicants. In reality, if I had not been in a lucky position whereby I am a little more financially privileged than other people, I would have been a lot more disappointed about my dismissal for financial assistance.

74. I have not applied to any other Funds for financial assistance. I have also not been involved in any litigation proceedings surrounding my HCV.

Section 8: Other Issues

75. Since clearing my HCV in November 2017, I had taken the decision to almost put this period behind me and lock it away in a box so that I did not have to think about it or relive it on a day to day basis. You could say that providing this witness statement has reopened that box and released my 'demons'. I have felt that same pain and heartache I previously experienced by telling my story, but I know now that I am doing this for all the right reasons. The public have a right to know about what being infected means. – the Government and the NHS **need** to know. Once this is all over, I hope I can just carry on with my life as normal and look to the future.

76. Throughout this process, I have felt extremely let down by the NHS. I feel that HCV has been put to the bottom of the file of issues with regards to their order of priority surrounding funding for treatment. I feel that the majority of current patients are possibly on the fringes of society without a voice and it suits the powers that be that HCV is, for the majority of the public, associated with drugs use and therefore the level of funding available can be supressed. If this was a cancer related infection for instance, I wonder how much more funding would be available? However, as the Infected Blood Inquiry gains more publicity, this perception about HCV might change and more advancements may be made.

77. I find it particularly upsetting that the Infected Blood Inquiry witnesses were not included within the initial vulnerable persons category under the coronavirus ("Covid-19") shielding programme. If I had not been in the position I am in at the moment where my liver is functioning well, I would have been more worried. However, there are plenty of people who have HCV who would need to shield and should have been granted this

status. After all, HCV is an infection which affects the liver and the immune system and I am surprised by this gamble with people's health.

Statement of Truth

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

Signed GRO-C

Dated 14th December 2020

Table of Exhibits:

Date	**Notes/ Description**	**Exhibit number**
10/07/17	Letter re Intussusception	WITN4216002
06/17	Letter from Averel Sutton	WITN4216003
16/06/17	Letter from Dr Christie	WITN4216004
23/06/17	Letter from Sister Fry	WITN4216005
10/08/17	Letter from Dr Christie re funding	WITN4216006
20/09/17	Invoice	WITN4216007
28/08/17	Letter from Marie Mills	WITN4216008
15/06/17	Skipton Application	WITN4216009
24/07/17	Skipton Appeal Decision	WITN4216010