Witness Name: Susan Mayze
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INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF SUSAN MAYZE

Section 1. Introduction

1. My name is Susan Mayze. My date of birth is GRO-C 1955. My address is known to the Inquiry.

2. I live with my husband Allan and we have a son Robert.

Section 2. How Infected

3. I was born with several bladder issues, these got much worse after my son was born. I would have little or no prior warning of needing to go to the toilet and in the night barely had enough time to get out of bed. I tried to take tablets but because I also suffer from epilepsy I had to be careful with what I took. Eventually I was referred to a specialist at St Thomas' Hospital and had several procedures to try to rectify the problems.

4. The first operation I had was in August 1979 at St Thomas' Hospital, it was a Marshall Marshetti repair which turned out to be the wrong operation but they said that they did not know until they had opened me up. There was no improvement in my symptoms. Then in July of 1980 I had a Stamey repair of the neck of my bladder, this improved my symptoms for a while. However in 1981 I had a cystoscopy during which one of the stitches on the Stamey sling was cut. After this my symptoms became worse again. I had another cystoscopy in 1981 during which they found a piece of Dacron (the material used for the Stamey repair) embedded in the neck of my bladder. This was removed.

5. In October 1983 I underwent a bladder neck tightening operation. It was during this operation I was given contaminated blood. There was some kind of complication and I was in theatre for over five hours. I found out later that I had been given a blood transfusion during the procedure. My records indicate that I was given 2 units of blood during the operation. When I came round I saw that I was hooked up to a bag of blood, I believe that I was given four bags of blood in total. They told me that there had been a little problem during surgery, they mentioned it in passing and brushed it off. All they said was that they had had to give me some blood while I was in theatre because I was bleeding.

6. No one ever mentioned that I might need blood. All I remember is being told to sign the form; I do not remember anyone explaining the possibility of a transfusion. I was never told of the possible risk of infection from contaminated blood.

7. My weak bladder was not life threatening, it was a nuisance. In fact, the surgery in 1983 did not even resolve the problem. I would have refused the operation if I had been told that there was a chance that I would have to be given blood, and that they could not guarantee that the blood was safe.

8. In around 2008 I started going to see my GP with all sorts of complaints. I had been struggling at work and thought that I was depressed. I had various tests to rule out certain things, no one ever mentioned Hep C to me.

9. My GP had noticed that my liver levels were rising and sent me to Medway hospital for a liver scan in February 2010. I was told that I had a fatty liver, they told me that this can just happen, that some people suffer from it and others do not. I even asked if there was anything I should or shouldn't do to improve the situation, but I was told no.

10. My GP continued to keep an eye on my liver levels, they continued to rise year on year. In late December 2013 I went to the gastroenterology clinic at Maidstone Hospital where I had a general chat with a consultant about my symptoms and he took a sample of my blood. At that point I just thought it was a general blood test and I don't recall Hep C being mentioned at all.

11. In early January 2014 my GP called the house but I was at work, he left a message with Allan asking me to call him back straight away. I think I must have rung the GP from work; he asked me whether I had received a letter from Maidstone yet, I said no. He went silent and then he said "I am sorry to have to tell you that you have got hepatitis C". I remember very clearly that I was standing on the landing at work, one of the girls that I was working with came out, my legs just went and I grabbed the barrier. I don't know why I reacted like that because I did not really know anything about hepatitis C at that point. My GP said that he did not want me to worry about it, he asked me to come in with Allan later that day and he said that he would explain everything.

12. Allan and I went to see the GP later that day. I did my best to hold it together in the car. When we arrived the GP explained that I had tested positive for hepatitis C and said that this is why my liver function levels had been raised. He said that he would refer me to Maidstone for the treatment and that in the meantime I should not worry too much about it until all of the tests had been done. He did not explain much about the treatments, as a GP he did not know too much about the trial drugs. He said that they may be able to cure me of it

but that until I had more tests he could not say. He said that Maidstone would be able to tell me more and to offer me treatment.

13. The GP knew about the blood transfusions that I had in 1983, it must have been somewhere on my notes. He told me that this transfusion had saved my life at the time. He knew me and Allan, he had a good understanding of our medical history. The GP saw how shocked I was, I don't think he wanted to say too much more because he could see how worried I was. He did say that I had been lucky because I had not got AIDS or HIV, Allan said that he did not see how this was lucky.

14. The GP told me about the risks of passing the infection through intercourse, by sharing needles, and if you do drugs and that sort of thing. He also said do not share toothbrushes or nail scissors.

15. The GP was as helpful as he possibly could be, he knew a bit about the liver because he had done some of his training on a liver ward. However he was not an expert. I came out of the surgery and I just broke down.

16. We were quite well armed by the time we had the appointment with Dr Bird at Maidstone Hospital a few weeks later. We had thought about what the GP had said and we had questions at the ready. Mr Bird went into more detail than the GP had done. He asked me how many sexual partners I had had, if I had any tattoos or piercings, how much alcohol I drank and if I had ever used recreational drugs. I felt like I was being treated as though I was a person of low morals who also had drink and drug problems. None of which was true. I was given enough information to understand the severity of the infection and how I could endanger everyone around me. I felt like a Leper, terrified to kiss my loved ones and had constant thoughts of whether I had ever had so much as a paper cut that could have infected anyone else. Nobody tells you how to deal with the mental torture of being contaminated.

17. I do not think it should have been up to the GP to tell me about the hepatitis C. Hepatitis C is an everyday occurrence for a hospital, it is not for an individual GP. I understand that the NHS only has a certain amount of

resources and time but I believe I should have been called back by the hospital and given the diagnosis and all of the information and advice about the infection straight away.

Section 3 – other infections

18. As far as I know I have not received any infection other than Hep C through contaminated blood.

Section 4 – Consent

19. Between being given contaminated blood in 1983 and my hepatitis C diagnosis I had five operations. I don't know how the hep C could not have been picked up over all of these occasions. It just doesn't ring true. Before every operation I have had, I have always had pre-op checks which included blood tests. I recall being asked on several occasions whether I would mind being tested for HIV and AIDS. I agreed and even said they could test for anything they needed to. I do not know why they did not test for hep C at the same time. From the point of view of the nurses and doctors, surely they would want to know whenever they were dealing with a patient from whom they could pick up an infection so that they could take the necessary precautions. I dread to think of all of the health workers that have been put at risk.

20. In 2002 I had my gall bladder removed at Lewisham Hospital. Just before the operation they said that I would be last in because I had tested positive for MRSA. I then developed an MRSA infection in my belly button wound and had to go back to the hospital several times for them to try and clear the infection, all to no avail. After having the open infected wound for a year, I had to have another operation to remove the belly button so they could clear the infection.

21. We moved to Kent in 2004 and since then I have had three more bladder procedures at Medway Hospital. After the last operation I was readmitted to hospital a few days later due to severe bleeding as a result of an internal stich

coming loose. I was passing huge clots of blood and had to be given a bag of plasma because I had been left bleeding in A&E for 6-7 hours and my vision had started to deteriorate due to the amount of blood I had lost.

22. The last of these operations at Medway took place in December 2013, a few weeks before my Hep C diagnosis. When I went to see the surgeon for follow up I told him that I had recently been diagnosed with Hepatitis C. He was totally expressionless; he did not write anything down and made no comment. He did not even really acknowledge what I had said. His reaction was so odd that I felt as if he already knew.

Section 5 - Impact

23. Before we moved to Kent we lived and worked in London. For the last 5 years that we were there I was really struggling at work. I and other members of my team were being asked to do things that we had not been trained to do and there were lots of arguments between us and senior management. It was an exceptionally stressful time, by the end I was working until 11 o clock at night and was crying at work every day. We finally decided to leave London and we moved down here in December 2004.

24. I started working full time as a customer services operative in 2005. After a few years I started to find the job really hard. I could not retain information, I could no longer do tasks that I used to be able to do really quickly. I did not understand why.

25. I started to bring work home again because it was taking me so long to do things at the office. I was in my 50s and had a wealth of office experience since the age of 15. The more I worried about work and my lack of ability to do things, the worse I felt. Why couldn't I concentrate or cope with things? I felt inadequate even though I was working harder and harder. I couldn't relax and felt worn out and found it difficult to sleep.

26. They started to monitor people at work, this meant even more pressure. My manager had his computer linked to mine so that he could see what I was doing. I just kept questioning myself and wondering what was wrong with me, I was surrounded by young people who just knew what to do straightaway. After what had happened in London I thought perhaps it was me and perhaps it was just work. In London I had often cried on the way to work and would sometimes have to rush to the ladies to blub, I thought that I was having another time like that again.

27. I tried to tell myself just to do a bit at a time, just one job at a time. But then someone would come in and give me something else to do or the phone would go, or a customer would come in. I always felt as if I was like a bomb about to go off.

28. I could not cope with anything; I could not see an escape route and had several morose periods during that time. I found it very difficult to sleep; my mind would be racing about what I should have done that day and what I had to do the following day. The only time I could relax was when I went out to see family, when I was somewhere with other things going on and when for that period of time I could forget about everything else.

29. If Allan or our son were short with me I could not cope with that at all, I would feel as if they were picking on me and there would be more tears. Al got fed up with it; he tried to be sympathetic but can be wearing when someone is constantly all doom and gloom. I found it difficult to see the positives I suppose. Before that time it was normally Al that was the pessimist, out of the two of us I have always been the optimist.

30. I went to the GP because I thought I had depression. The GP suggested taking tablets but I have never really been a fan of taking medication. If I had been suicidal I may have thought about taking anti-depressants, but I thought at the time that I just needed to pull myself out of it. It's better for me to talk about things, that's the kind of person I am.

31. I now believe that the confusion, stress and depression during this time and maybe even when I was in London were all related to the hepatitis C.

32. The main physical symptom from the Hep C was fatigue; before I was diagnosed I just put it all down to the fact that I was depressed. That's what I thought it must be, that I was working full time and taking work home with me and that's why I was tired. I did not put it down to me being ill. Apart from feeling down and unable to cope, feeling tired and finding it difficult to do things, in my body I felt ok. I did not have aches and pain. Previously I had been fairly healthy, I had one cold per year and that was it.

33. There are other physical symptoms that I had at that time but which I do not know whether are linked or not. I do not like to think that everything was linked to the hep c but when you look back you do wonder. You just don't know whether everything is part and parcel of the condition.

34. For example my calves and ankles became very swollen. But around the time of the Hep C diagnosis they were severely swollen and getting bigger and bigger by the day. Dr Bird prescribed Furosemide, a diuretic of 200mgs a day. When I asked my GP for a repeat prescription he said the dose should have been 20mg not 200mg. I wonder if this caused me harm but never really got an answer.

35. For a few years I had grey marks on my face and neck that looked like bruises. They were really dark and then they would fade down.

36. Following my diagnosis in January 2014, I had a liver biopsy and was told that I had liver cirrhosis. Mr Bird informed me that there was a trial of a new drug but that I had missed the deadline for the trial. He said that they could offer me Interferon and Ribavirin. I was told that some people complained of being sick on the treatment but the side effects were brushed over. I received a letter stating that the treatment "*may cause some side effects along the way*" **[WITN19320002]**. No one told us what to expect or forewarned us of what was to come.

37. In August 2014 I started the treatment. I took interferon injections once per week and then Ribavirin tablets. This period is very vague for me, I became very confused and disorientated. Allan has told me that I was like a different person. This is when the encephalopathy really kicked in. I was becoming very tearful and had terrible mood swings. I became unable to make my body do what it needed to do. Allan would help me into the shower and I would just stand and stare at the ceiling and then would stare at the dial on the shower. I kept getting in and out of the shower thinking that if I started the process again I would be able to turn on the shower. It would often take me hours to get into bed; again my brain just would not tell my body how to get into bed. I would just stand there, in my head I was desperately trying to will myself to move my legs and to lie down on the bed. Eventually Allan would just pick me up and throw me onto the bed.

38. In October 2014 I was admitted to Maidstone Hospital three times for encephalopathy, water infections, ascites, seizures and low sodium levels. All of it was linked to the hepatitis C and the treatment. I kept being discharged and then I would have to return a few days later in an ambulance. All of this was making me more and more confused; I was not myself, I was talking nonsense on the ward and was sometimes refusing to eat and to take my medication. This time is very foggy for me, I do not remember much at all. Allan says this was the hardest time because the encephalopathy got so bad.

39. I do remember that I tried to escape from the hospital. I had been told that I would probably be going home the following day but that I would need to wait until the medicines had been issued by the pharmacy. I waited until dark and thought that I had waited long enough; I thought that I would go along to the pharmacy myself. I did not get dressed but just got out of bed. Without telling anyone where I was going I left the ward. There was no one by the desk, I remember walking past. I knew the way that everyone came in, I had walked in the corridors quite a lot prior to being admitted. By then it was 10pm, they found me wandering the corridors and rang Allan straight away. In the end Allan had to take me to the pharmacy to show me that it was shut.

40. On 16 October 2014 Mr Bird made the decision to stop the Interferon and Ribavirin because it was thought that this was the cause of my symptoms.

41. On 26 October 2014 I was admitted to Maidstone for the third time that month. On that occasion it was the hospital who asked me to come back in. Al got a phone call from the pathology department, they said that they had my recent blood test results and that some of my levels were off, they had called for an ambulance to collect me. We found out later that my platelet level was so low that I was in danger of going into a coma.

42. It was decided that I should be transferred to Kings College Hospital (Kings), I moved on 12 November 2014. I do not really remember much about being in Kings, the encephalopathy was so bad at that time. The day after I was admitted, Al visited me and was there when I was talking to the doctors. He had to tell them that what I was telling them was not true. I was not in my right mind at all. I could not hold a pen or a knife or fork because my hands shook so badly and I would have to have my food cut up or even fed to me. The doctors there kept telling me that I was a unique case. They said that my symptoms were not wholly typical of encephalopathy but they did not know what else was going on. Al was worried that the confusion was related to my epilepsy but the doctors did not agree. To start with they thought that I had sudden onset dementia and I was seen by a psychiatrist.

43. When I was in hospital I had several different night terrors. I thought I had been attacked by one of the male nurses so much so that I ran through the hospital shouting that I had been attacked. I pressed the button for the alarm, I truly believed that I had been assaulted. On another occasion I believed that I had been left in a room on the floor. I did not like being in a room on my own. I had recurrent dreams that all of my family were killed in a plane crash. There had been a plane accident reported on the news, the one that went down in the sea and was never found. I would have this dream again and again, like groundhog day. When I woke up I knew that they were dreams but I was frightened to go to sleep.

44. I was discharged from Kings on 2 January 2015. My symptoms had improved while I had been in hospital. When I got home although I had the drugs I was still very unwell and I was still not myself. From our point of view it was worse being at home and doing our own thing without having any support from anyone. To be honest I am surprised that Al and I are still together, it was not a pleasant time for any of us including our son and it proved exceptionally difficult.

45. Allan really did not know what to do with me. It was a bit like someone who has dementia and is in the middle stage where people outside can see a difference in that person but the person themselves is not aware of it and still feels like the same person. I had been a very independent person and was in charge of organising so many things for us like the shopping and all of our paperwork. Suddenly I was being told what I could and could not do and I did not understand why I was being treated like a child. I made my voice heard, we had lots of arguments. I thought that Al and our son had a plot to put me in a home but I could not explain that to them. These thoughts made sense to me in my mind but my brain was not capable of finding the words to explain to them what I was doing and why I was doing it. All this time they were despairing and were finding it difficult to cope with me as I was suddenly a different person. I couldn't be left alone for fear of what I might do, so we all felt trapped and couldn't see an end to this terrible nightmare.

46. For months I was behaving strangely and definitely out of character. From the outside I seemed ok but my family knew that things weren't right. Three occasions come to mind. On one I went to a jeweller to buy rings for me and Allan to celebrate our 40th wedding anniversary. I went with my son who saw a watch in the window which he commented on as we went into the shop. The watch was £500 and I went and bought it for him. I would never usually have spent this amount of money on a watch. This caused a furore and my son said that he did not want it and would never wear it, I guess that he thought that it would always remind him of me being ill.

47. On another occasion I had to have an X-ray on my foot. Allan took me to the hospital and said that he would be back in an hour because there were some errands that he had to run. I was seen quite quickly but then had to wait for my results. I had time to wander into the tiny chemist that was attached to the hospital and I managed to spend £700. I always used to think ahead about Christmas and so in my head it all seemed logical. It was only because I couldn't carry it all that I did not leave the shop with it. Allan arrived and I remember seeing the look of despair in his eyes. He had to explain to the pharmacist what was wrong, once he had looked up the condition he said that he was happy to take the goods back but said that he would have to charge us the 2.5% credit card fee.

48. Another time I went to the local supermarket which is only a tiny shop. I ended up spending £800. Again in my head this made sense because Al hates shopping and I was thinking that I was doing the right thing because he would not have to buy any food for months. It was done with the best intentions but it caused another row. The food I bought I could not eat anyway because of the salt content, in the end it all had to be given or thrown away. It was just nonsensical, it was not what a person in their right mind would do.

49. Following my discharge from Kings I continued to have regular follow up appointments with Dr Agarwal. He asked us why I had been put on the Interferon treatment and not on the new trial drugs. When we told him Mr Bird had said we had missed the trial date, Dr Agarwal appeared to be surprised, but made no comment. Dr Agarwal said he would put me on the new trial drugs as soon as I was a bit fitter.

50. Before I started the second treatment I had an appointment with Dr GRO-D. Al and I explained to her that I had been trying to do more and more for myself, that I had been trying to keep track of taking all of my medication but that on occasion I was doing it wrong. She did not let us finish explaining that we now had a system which had rectified the problem. Instead she interrupted me and spoke to me as if I was a bit of a pain. She started umming and ahing about

putting me on the trial, when I said that I had already been accepted she told me that she did not think I was "worthy". I became very angry and told her that I was only there because of the NHS and the government and the mistake that they had made. She said that the treatment was very expensive and that she did not think that I would be able to take the drugs properly. I started to cry out of frustration and I said that I did not care how much they were. Then Al tried to defend me and she started shouting at him too. We were both dumbstruck with her unprofessional and uncaring attitude.

51. I just wanted to be treated like a human being instead of an inconvenience. We later told another doctor in Dr Agarwal's team that we never wanted to see Dr GRO-D again.

52. In May 2015 I started my second treatment, of Harvoni and Ribavirin. This was very different from the first treatment, there were no injections, just tablets. The side effects were joint pain and muscle weakness, severe tiredness, loss of appetite and sickness. I was told after 12 weeks of being on the treatment that I had cleared the Hep C.

53. Dr Agarwal was surprised when he saw me after I had completed the trials and said I was unrecognisable from the person he had seen 9 months previous when I was an inpatient. He again said I was a "unique" case and that I had been an "extremely sick woman". When he told me I had cleared the virus I burst into tears, but this time it was tears of joy. The relief I felt was immense, for so long I had felt like a Leper, always afraid I might infect someone else.

54. While I was in Kings I kept getting toothache, I mentioned it to the doctors but they were more worried about everything else. When I was discharged I went to see a dentist, I told her that I had hep C, she said that she was happy to examine and Xray me. She told me that I needed the back tooth out, but she did not want to do anything there because my platelets were so low. The dentist said that she would not do it because she did not have the facilities to treat me if something did happen and said that I would have to have it taken

out at hospital. I think this was more about the bleeding than it was about the hep C. She wrote to the hospital but I did not have the tooth taken out for a year, it took a year for them to get round to arranging an appointment for me.

55. Prior to and after I was discharged from Kings I was doubly incontinent for a while because of the combination of drugs they were giving me. I was lucky if I made it to the toilet in time. It was all to do with trying to stop the encephalopathy. A community nurse came to see me and asked me what I wanted, I did not know, I had not ever been in this situation before. She made suggestions about three different types of pads, bed pad, knickers, lotions and potions for legs and itchy skin. My legs were very swollen at that time and the skin often broke so they had to be bandaged.

56. In November 2017 I was diagnosed with liver cancer. I received treatment for this in 2018. Fortunately, the tumour had been found quite early and was small. I had TACE and Microwave Ablation treatment direct to the tumour. I only had some tiredness for a few days with the TACE treatment and some localised discomfort and minimal bruising with the Ablation. A few months later after an MRI scan I was given the all clear.

57. I was clear for almost two years, but in November 2019 they found another tumour on my liver. I went in for treatment in January 2020. This time I had microwave ablation rather than TACE. I have had a scan since and it came back ok. Before the pandemic I was having an MRI scan and blood tests every three months. But during 2020 I had two scans rather than four scans. I have recently been told that although there is no sign of cancer, my bilirubin levels are high. I am concerned about this, but due to the pandemic I have not had an appointment with my liver consultant. I have been liaising with my cancer nurse from time to time and so have had to rely on her for information and support.

58. The week leading up to any consultant appointment is always an anxious time for us both. Having the liver problems is never far from our thoughts and trying

to lead a normal life isn't always as easy as it should be. Even planning something as simple as a meal out has to be carefully considered because of my low salt diet.

59. In the early stages my illness affected everything: what I drank, ate, my mobility, everything. The doctors told me that I could only have 1 litre of water a day because of my high sodium levels. I remember being constantly thirsty and I used to argue with Al about this. Because of my anatomy I am always going to be susceptible to getting water infections. When I started drinking less liquid this is when the water infections started again. I was on a low salt diet and so had to be very careful with what I ate. I could not walk anywhere and definitely could not do stairs, my legs were so huge and I did not have the strength to lift them as I had lost so much of the muscle. Hep C impacts on every facet of your life, we are restricted on everything that we do.

60. All of this was thrown at us; I had been a relatively well person but do not have the same quality of life now. It has changed our lives forever. It's a cruel disease, I used to have my own freedom to do what I wanted to do, now even if I was well enough to go away I can't get affordable insurance to cover me. We have always had Great Danes but after I had my diagnosis our plan to get a replacement Dane had to be forgotten because we had so many hospital appointments it wouldn't be right to leave a dog alone all day. Travelling to Kings can be an almost all day event depending on traffic and appointment type and times.

61. We had so many rows, it was an everyday occurrence. Al would get frustrated because I could not explain myself and I thought that he and Robert were ganging up on me. I thought that they wanted to put me in a home so that they could get on with normal life. Because of the encephalopathy it seemed to me that whatever I did was wrong, if I was watching TV, reading or whatever I felt that I was being scrutinised. I had a diary and I just used to write good day or bad day. Some days I just felt like screaming or running away.

62. We have never been the kind of people to go out to big social events. I used to drag Al to places but since I have been ill even this has stopped. I am used to having people around, I had five brothers, but Al was an only child until he was 11. Al likes his own company and I have learnt to like mine.

63. Our son was very angry when I was ill. He hates hospitals with a passion. To give Al a break I would sometimes ask Robert to take me to hospital, he would be agitated for the whole time that we were there. He rarely visited me whilst I was in Kings. He said that he did not like seeing me like this; he said that he was frightened of what he was going to say to the doctors because they did not seem to be doing anything. One of the doctors said to him "your mum is really lucky". This really wound him up. I am his mum and he was worried about me, I had turned into someone that he did not know, I was not in my right mind and he didn't know what he could do to help me.

64. I think in some ways it has taken more of a toll on Allan than it has on me, most days I feel relatively well and there are lots of periods of being ill that I do not remember at all. Allan had to watch it all unfold and it was very traumatic for him and Robert. I think that most people will have trauma in their life which they get over or they don't, but most people usually only have one at a time. The trauma that we have been through is constant and is ongoing, albeit that I'm not as bad as I was with the encephalopathy.

65. Al is the kind of person who will question everything. As far as I could see the doctors were almost like gods and their expertise was not to be questioned. This whole thing has made me stand up for myself a bit more, I have changed and I know I have changed. I am less tolerant about people giving me rubbish, I am more outspoken: I do not go out to look for a row but particularly with doctors I am more cautious of what they are telling me and if I don't understand I will ask. I know I am not the same person that I was; it is difficult to explain to someone in words.

66. I have lost confidence and independence. I used to be able to go out to Spain on my own to visit my brothers, getting to the airport and waiting round by myself did not bother me. Now I would not go somewhere new unless I was with a relative or close friend I could trust, which I find really frustrating.

67. We were told by Dr Bird and by our GP of the risks of passing the infection through intercourse. I have known Allan since I was 15, he had not shown any sign that he had any problems but then for most of my life neither had I. Then I started worrying about him, then I started worrying about little things like having a paper cut. The question whirls round in your head: have I ever infected anyone?

68. The first person I told was Allan's cousin Jackie. I felt that we had to tell her because we spent quite a lot of time with her little ones and I was worried that she would not want me to be around them. To be honest Jackie was initially relieved when I said I had Hep C, she had thought that we were going to come back from the hospital saying that I had cancer. This was before we realised how serious the Hep C would be.

69. For the best part of a year I did not tell anyone apart from Jackie and our son. I felt very vulnerable, I felt so unwell and had been told that I had something that could potentially kill me, I did not want to make my life more difficult than it already was by telling everyone else. But then I thought no it's not my fault, and I told the rest of my family. Everyone was very understanding. I asked my brothers not tell their children, they were much younger and I did not think they would understand.

70. My brothers were a bit annoyed when they found out that I had kept it from them for so long. My brother Jed lived in Spain, he was being treated for cancer and had a huge operation around the time that I was diagnosed. He died a few years later. I could not go to visit him because I knew that I was infectious, he was not expected to survive the operation but he eventually had another two years. Even during the extra time he had, I could not go out to see him because I was terrified of passing anything on to him. They had told me that I could only pass it through blood but I could not take that chance. I

never saw him again, I could not even go to his funeral. I felt that I had let him down. It has taken me a long time to come to terms with not being well enough to go and see him when he needed his family most. He didn't know I was unwell, as I didn't want to make him worry about me when he had enough trouble of his own. I can only hope that he didn't think badly of me and think I didn't care.

71. My sister-in-law was also in hospital with cancer and again I felt bad that I wasn't there for her. She has been like a sister to me from the age of 10 and we are a very close family. We were also unable to help with the care of my mother-in-law who had vascular dementia and this was particularly upsetting for Allan. She had been like a second mother to me and we were great friends. Her last few years could have been made easier if we had been able to help Allan's sister with her care.

72. My eldest brother, Peter had the same condition as Jed, he also lived out in Spain with his wife. He sadly died in early 2020. When he was alive I couldn't really have a normal conversation with him on the phone because although he could talk he had to whisper and started coughing if he talked too long. He came to see me when I was at Kings, at times like that you want the support of your family even if it is just a half hour visit. I couldn't visit Peter as often as I would have liked because even when I was no longer infectious, the insurance was so expensive. I used to have travel insurance with Barclays bank which covered me for my epilepsy. Since I have told them about the hepatitis C they will not insure me for either condition. I did manage to go out and see him just before he died, but the insurance cost me more than the flight.

73. When I was a child I wanted everyone to like me, I had my first epileptic fit when I was 7 years old. I felt that I always had to make a joke of it to make friends and to avoid being one of those kids that was picked on. I have always had the ability to make fun of myself. But with the hepatitis C it made me feel dirty, I suppose it is because some people view alcoholics or drug addicts as weak people. I did not want people to think badly of me, I was very cross

when the hospital asked me if I had had lots of sexual partners, they may as well have asked me if I had been a prostitute, that is how is made me feel.

74. I am not as worried about what people think of me now, I have got to an age where I think you either like me or you don't. If I tell people now that I have cirrhosis, the first thing that people say is "big drinker?" At the hospital they asked me how much alcohol I drink, but since my diagnosis I don't drink at all. There are still narrow minded people but it is ignorance that makes people think the way that they do and things like HIV and AIDS are much more talked about now. Sometimes I get the feeling that people are judging me, but now I make it my mission to enlighten people as much as possible about hepatitis C and the ways you can get it.

75. I tried to continue to work after I was diagnosed. Although they didn't know what was wrong with me, my employer could see I was struggling more and more and just couldn't do what I used to. My boss suggested maybe I should leave and get myself better and then I could return afterward. But I couldn't afford to be without the money I earnt. But things got steadily worse in the next 5 months and I was made redundant.

76. Since then I have not returned to work because I have not felt able to do so. More recently I have begun to feel quite well in myself. Jackie runs a wedding venue and suggested that I could do some work for her. She contacted her insurers to check the position and they said that they could not have someone like me working for them as I would be too much of a liability in case I cut myself whilst working with people or visitors/guests; or injure myself or someone else if I fell or got dizzy.

77. I did apply for PIP payments and ESA but the assessments you have to go through make you feel as if you are begging for money. You can only tell them how you feel on that day. I don't understand why we have to go through it when we have the letters from the doctors which state our condition; chances are it is only going to get worse. I believe that if you have a long term

condition you should not have to go through the same assessment as someone with a back problem or a broken leg.

Section 6 – Treatment/ Care/ Support

78. I was referred to a counsellor by my GP. I was on the waiting list for a while before I got to go and see someone. I finally got an appointment to see someone in Faversham. I knew the bus route and I knew where the building was but when Allan and I drove we got so confused. We must have taken a wrong turning somewhere. After we parked we walked and walked and by the time we found the place the woman said that I was too late for the appointment and that I would have to rebook. When we left the building we must have taken a wrong turn again, it was winter and it started to snow, we walked for such a long time to find the car. I was freezing cold and so tired by then that when we did eventually find the car I burst into tears and couldn't stop. Having the encephalopathy made me very confused and extremely emotional and dealing with this type of situation only exacerbated the problem.

79. Some months later I was again referred by my GP to see a counsellor in Sittingbourne. I had one session with her during which she said she thought I might need CBT. However on the mornings of the next two appointments I unfortunately had epileptic seizures and was not in any fit state to go. Allan phoned on each occasion to let them know why I couldn't attend, but then I received a letter informing me that because I had missed two appointments, and in line with their policy, I had been discharged and would need to go back to my GP to ask for another referral. I went into panic mode and burst into tears yet again. I couldn't believe that people could be so insensitive. Far from all the help I had been promised when I was discharged from the hospital, it seemed that everyone was doing their utmost to make my situation as difficult as possible. It felt like a conspiracy against us as everywhere we turned there seemed to be an obstacle of some kind. We were both exhausted and couldn't jump through any more hoops just to get some help.

80. We gave up on the idea of trying to get the CBT as the counsellor had suggested. I am sure that I would have dealt with the problems much sooner if I had been given the help. Instead my husband had to deal with me on a daily basis either crying uncontrollably, shouting and swearing at him (even in public!) for no real reason other than frustration and not being able to control my emotions. I put him through sheer hell for months and months and nobody wanted to help. I don't know how he survived having to watch me, this stranger 24/7, in case I did anything irrational or bizarre. He had found out the hard way that at that time I couldn't be trusted to be left anywhere on my own whether I was out or even just in another room at home. The only advise he had been given when I was discharged from Kings was "if she gives you any trouble, give her one of these" and he was given Haloperidol an anti-psychotic.

Section 7 – Financial Assistance

81. As soon as Jackie found out that I had hepatitis C she started doing lots of research. She found out about the Skipton Fund and printed all of the forms from the internet. The doctors at Maidstone did eventually tell us about it but by then we had started filling out the forms.

82. When we first sent the application off we explained on the form that I had received a blood transfusion in around 1983 at St Thomas' but we did not send any evidence. The application was rejected by Skipton who said that we needed to supply proof. I rang to request my records from St Thomas' Hospital. I was told that my records had been destroyed.

83. By strange coincidence my nephew had a temporary job at D.O.H in the late 1990s, his role had been to transfer old records to microfilm. At that time he had picked up my notes and had recognised my surname as it is quite unusual. He had copied them to microfilm. Once we knew this, we asked the GP to request the records, miraculously the records turned up. Once we had

the relevant information the first stage payment came through approx. 6 months after applying. I don't know what we would have done if we had not been able to get the records. I could not work and I was too ill to be left by myself, which meant that Al who was self employed could not work either. Without the money from the Skipton Fund how could we have survived?

84. However when it came to claim the second stage payment it took four attempts. The first two had apparently been lost by the hospital, the third form was my fault, as I had tried to help speed up the process by putting some of the information in myself, in the hope that the doctor would just sign his part and I could get it sent for payment. We kept telling the doctors that our savings had all but gone and we were continually told that the form had not yet been signed as "he was very busy". What with general household bills, and the added costs of £40-50 travelling to London for each hospital appointment, we were struggling to keep our heads above water. After approximately 6 months I was told the form had been done and sent to the Skipton Fund. I was rather sceptical as to whether this was actually the case, so I rang and spoke to Nick and he said they had received two completed forms in the same envelope, but dated differently! He said it would get it actioned asap and we did eventually receive the second stage payment.

85. I am now in receipt of monthly payments from EIBSS and receive the winter fuel allowance.

86. I wasn't aware of signing a clause stating that I would not make a claim in relation to contaminated blood. The government were not making any admissions of liability but offered this money as a kind of charity which you have to accept because you will not be able to survive without it.

87. I find it strange that across the UK there are different payments made to people infected. I assumed that everyone got the same amount until I found out that there is a discrepancy in payments made to those infected with HIV compared to those infected with hepatitis C. They now think that hepatitis C has just as much of an impact on people as HIV. If that is the case what is the difference? It is a different infection but the same cause, the bottom line is that

we were given contaminated products which resulted in illness and so we should be treated the same. You would think that it would be much simpler to pay everyone the same amount anyway.

Section 8 – other issues

88. In an ideal world I would like the Inquiry to find out the whole truth to be told no matter whether good, bad or indifferent. It is time that those responsible held their hands up. I am a great one for justice, none of us are perfect and we all do things that maybe in a different setting you might not do. This scandal is not down to one person, it is down to a committee of people. Someone or several people have gone through the process of deciding whether to tell everyone or to keep it all a secret. I would like to know the reasoning behind the decision to keep it a secret.

89. I would like the Inquiry to ask why more wasn't done to let people know sooner that they may be infected. If all hospitals have to keep a list of those who received a blood transfusion, there is nothing to stop the government or the Department of Health writing to each hospital to identify the patients that might have been given contaminated blood. Then the GPs of all those on the list could ask their patients to come in and have a blood test. Most people have a GP and so they probably would get round to telling most people. At least they would have been seen to be doing something about it, as far as I can see all they have been trying to do is hide it.

90. Until more recently I certainly never saw anything in the paper or on the TV saying that if you had a blood transfusion during a certain period that you should see your GP. Even now not many people know about what happened. By not informing people they have taken away their rights as human beings and have made the situation far worse than it ought to have been. I had no idea that I was posing a risk to Allan and others before I was diagnosed.

91. No matter what we are told we will always question whether we have the full story. I think there will always be more questions to be asked. No matter how hard people try to uncover the truth there will be those who try just as hard to keep things quiet. There was a time where they could have said that they were only just aware of the risk and at that point they could have advised everyone to get tested. Instead they allowed documents to be destroyed and swept everything under the carpet to save a few pounds and to avoid the embarrassment. As a result it has and will continue to cost them a fortune.

Statement of Truth

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

Signed . GRO-C ....

Dated …18 march 2021................