Witness Name: Karen Fox
Statement No.: WITN2012001
Exhibits: WITN2012002 – WITN2012019
Dated: 16 March 2020

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF KAREN FOX

Section 1. Introduction

1. My name is Karen Fox. My date of birth is GRO-C 1963 and my address is known to the Inquiry.

2. I live in London and have one adult son, Ashley.

Section 2. How Infected

3. On GRO-C 1989, when I was pregnant with my son Ashley, I went to the GP for a regular antenatal appointment with my auntie. My GP noticed that my legs were swollen with fluid, and told me to go to hospital, so I went to University College Hospital.

4. While at hospital I was told I had pre-eclampsia, and I was given medication to induce labour. During the birth I haemorrhaged, and the doctors had to cut me open to get Ashley out because his head was too large. The student nurse

assisting with the birth pulled on the umbilical cord and it snapped, leaving the placenta inside me, so I was taken to the operating theatre and the placenta was removed, while Ashley was taken to an incubator because he was having trouble breathing.

5. The next day the doctors brought Ashley to see me, but I was too weak to care for him. I was told that my haemoglobin was very low and that I would need a blood transfusion. I was then given a transfusion of 4 units of blood. I was not given any information about the risks of receiving a transfusion or given a choice of whether I wanted to receive one.

6. I was discharged from hospital about a week later. However, I did not feel any better. I felt sick like I had the flu, and was having serious nose bleeds with blood clots coming out of my nose. I told my GP of my symptoms but he said I probably had a cold.

7. I then went to the Royal Free Hospital to tell them I was feeling ill, and brought my father. My son's father, Roger Walker, had advised that I go to hospital because I felt so ill, I was too weak to stand and couldn't eat, and he agreed to look after Ashley so I could go. The doctors did some tests and then told my father that my kidneys were failing. They told him that it was lucky I had come in, because if I hadn't, I might not still be alive. They then told him that I needed a kidney transplant GRO-C

8. Sometime between 7 December 1989 and 13 December 1989 I had a plasma exchange at the Royal Free Hospital as part of an effort to clean my blood and improve my kidney function. I understand that I could have been infected from either this or the blood transfusion. The plasma exchange was not successful in improving my kidney function.

9. I then went on dialysis for a short while, and then received a transplant GRO-C GRO-C kidney in 1990.

10. Sometime after the transplant, it became clear that my new kidney was not functioning properly. It began to fail, and I went back on dialysis.

11. After one of my dialysis appointments I ran into my transplant surgeon, whose name was Rosemary (I do not remember her last name) in the corridor of the hospital and she said to me, casually: "GRO-C hasn't got hepatitis, where did you get it from?" I was incredibly confused, because I didn't know what hepatitis was, or that I had it. It turned out that my they had found out I had HCV after the transplant procedure and had assumed I had gotten it from GRO-C GRO-C so decided to test him for it.

12. When I said I didn't know anything about it, Rosemary asked me if I had been taking drugs, and what my childhood was like. She did not provide me any information about what HCV would mean for me, or what I should do next. Later, Rosemary even asked my brother Peter what my childhood was like, if I had had a bad upbringing, if my parents had divorced early and if I was affected by this, as a way of trying to investigate how I had contracted HCV.

13. I believe my diagnosis occurred in late 1992, as there was a note in my records from 6 October 1992 that confirms I had tested positive for HCV antibodies **(WITN2012002).**

14. I was sent to see a nurse about the HCV, who explained that the virus was spread through blood, and explained that the doctors would be taking precautions to avoid infection, such as putting all of my dialysis needles into a special yellow bag, and having me dialyse in a separate room away from the other dialysis patients. The nurse also told me that I could spread the virus by kissing or drinking from the same cup as someone, which made me extremely worried as I didn't know anything about the virus and was concerned about infecting my son Ashley.

15. I then went to see a more senior nurse, who explained the risk factors for HCV and asked me again if I did drugs. I confirmed I did not, and he told me I had likely contracted it due to my blood transfusion. I was frustrated that I had

already been asked by three people if I had done drugs, when it was surely in my records that I had had a blood transfusion. I did not have anything to do with any kind of drugs. I felt unclean, dirty, confused and hopeless.

16. From then on, I had to dialyse in a separate room. Sometimes I was by myself, and sometimes with one other patient who was also infected either with hepatitis or HIV.

17. I would have liked to receive leaflets with more information in them about the seriousness of HCV, how I had been infected and what the future would hold for me. I think this information should have been provided to me at the time of my diagnosis, and that I should have been taken into a private room to speak with a doctor about it.

18. Instead, I was told in passing that my dad had been tested for HCV but didn't have it, so they were not sure where I had got it from, and that I would need to have dialysis separately from now on. I had no context for this, and was told in a busy corridor with lots of people around, and no privacy. I was embarrassed, and while I was informed about the impact that HCV would have on my dialysis, I was not given any information about the seriousness of the condition itself.

19. I also do not understand why I was persistently asked by medical professionals if I had used drugs or had a 'bad upbringing'. By that point it should have been in my records that my either the blood transfusion or the plasma exchange were the main cause of the HCV infection, as I did not take any form of drugs or participate in any other risky activities from which I could have contracted the virus.

20. Although I was told about the precautions to be taken during my dialysis, I was not given any information about how to avoid infecting Ashley or other family members. I therefore became very concerned about infecting him and having him tested regularly. I bought Ashley a whole new set of cups, towels – everything he might need to use in the house – and told him they were

presents and he was not to use anything I had touched. When he was about five, I phoned the British Liver Trust and asked them if I could transmit the infection to him by sharing household items, and they told me I couldn't, but I was still terrified I would and became very vigilant around this.

21. Shortly after my diagnosis Rosemary retired, and my care was taken over by renal specialist Dr Davenport. Dr Davenport did explain to me what could happen as a result of my HCV, and gave me leaflets about how it can be contracted and how many people in the UK have it, which I was grateful for. He took scans of my liver and blood tests.

22. I remember feeling so scared about the future, and worried about going through life with this death sentence hanging over my head. I felt very depressed, very low in myself, wondered why this was happening to me when all I wanted was to have my baby and a happy life. It all seemed too much for me.

Section 3. Other Infections

23. I was infected with HCV only. I was tested for Hepatitis B at the same time as my HCV test and this came back negative. I also was tested for HIV and this came back negative.

24. I was so very lucky that I was not given these two viruses as well. It was bad enough receiving HCV and having to cope with that alongside my other health issues. I can't imagine where I would be if I had caught HIV too.

25. I also received a letter in 1999 stating that all patients on the kidney failure programme should be vaccinated against Hepatitis B, so I have done that **(WITN2012003).**

Section 4. Consent

26. I do not think I have been treated without my consent because I have always signed a consent form before any procedure..

Section 5. Impact

27. Right after my transfusion, I began to develop flu like symptoms. I felt weak, shivery, had the shakes, and was vomiting. I had blurred vision because of my high blood pressure, and had blood clots coming out of my nose. These symptoms improved when I went on dialysis after the first transplant failed. I understand that this is because dialysis filters toxins out of your blood, so it can temporarily improve your results on liver function tests.

28. During the periods I wasn't receiving dialysis, I continued to feel tired and have headaches, but I didn't recognise this as symptomatic of my HCV because I had some similar symptoms from my renal failure.

29. Over the years I have had the following physical symptoms relating to my HCV: nose bleeds, bleeding and bruising easily, severe fatigue, jaundiced skin and eyes, itchy skin, poor appetite, weight loss, confusion, drowsiness, slurred speech, spider blood vessels on legs, ulcers on legs and hands, easily broken skin, blisters on my backside, dry skin, hair loss, muscle aches, joint pain, stomach cramps, cataracts, nausea and fever, dark urine, diarrhoea, vascular calcification, high blood pressure, among other conditions.

30. Both my kidney failure and the HCV arose out of the birth of my son; the kidney failure as a result of the pre-eclampsia and the HCV as a result of the blood transfusion. However, I am not blaming my son for anything; nothing was his fault. I wanted my son and I am a proud mother. I will never know if the HCV had some part in causing my kidneys to fail, as they happened at the same time.

31. However, having HCV has caused significant difficulties in managing my kidney disease over the years. I have had three failed kidney transplants, in 1990 GRO-C, 1994 GRO-C and 2000 (from a deceased patient). I understand that the HCV may be in part responsible for some of these failures. My current kidney was transplanted in 2013 from a 71 year old patient, so while it has not failed yet I must keep having it checked as it is now old enough that it may start developing issues naturally. Some of the medications which have been suggested to manage my kidney failure have not been given to me because they were contraindicated with my HCV.

32. Dr Davenport, my renal consultant at the Royal Free Hospital, eventually referred me to Dr Dusheiko, Consultant Hepatologist, for my HCV-related investigations. However, it seemed there was initially some confusion as to the status of my HCV infection, and failure of the doctors for a period of years to take it seriously and investigate treatment options. In 2000, there is a letter in my records from Dr Dusheiko to my GP which says "*From a liver point of view, things remain completely stable with no evidence of any active hepatitis from her blood picture. She continues with dialysis three times a week and I don't think there is any need for us to have any more input in her care other than just to keep an eye on things. There is certainly no indication for treatment at present.*" **(WITN2012004).**

33. Because the dialysis kept my liver function results down and my symptoms down, I think this may be why doctors did not consider treatment for me as I appeared to not be suffering many effects of the virus. However after I had my kidney transplant, the medication I was put on to prevent rejection of the transplant decreased my immunity, which made the virus much stronger than it had been when I was on dialysis.

34. In 2004 I was diagnosed with diabetes, which I believe is the result of both the HCV and the medication I was on to prevent the rejection of my kidney. I also started to develop vascular calcification, which caused my circulation to

worsen until blood stopped flowing to my left leg and it developed gangrene. The medication that I was meant to receive to contain this infection was contraindicated with HCV, so the infection could not be contained and my leg had to be amputated above the knee.

35. Because of anti-coagulant medication I am taking, it is very hard for wounds to heal, so the wound from my amputation in 2017 has still not healed and has developed an ulcer. I therefore cannot use the prosthetic leg that was given to me because my amputation wound is still too painful and irritated, so I must use a wheelchair. My arm muscles are not strong enough to use a manual wheelchair, because I have had four fistulas on one arm and two on the other from my dialysis, which have decreased my strength. I must use a motorised wheelchair, and have had to move to an adapted property. Coming to terms with my new limited mobility has been a struggle, as I have had to re-learn my physical limitations at an older age and plan how to transport myself to hospital, to the shop, and occasionally to family gatherings.

36. Even considering all of the above, I would say that the main effect of the HCV on my life has been the damage it has done to my mental health. I have suffered from severe depression at times. My life has become very isolated, due to the complications that having HCV has brought to my already compromised health. I have very low mobility and rarely leave my house except to go to the shop or to the hospital, which leaves me feeling depressed and lonely. I have really struggled with having dialysis in a separate room, because dialysis takes 4 hours, several times a week and I am made to sit there by myself, when there are people just next door who are allowed to socialise to pass the time.

37. In about 2002 I started having suicidal thoughts and sought help from the crisis team at my local mental health service. I was assessed by the team as follows **(WITN2012005):**

> *"For many years Karen coped with her serious medical problems. However she presented in 2000 linked to destroyed expectations of her third kidney transplant and associated medical complications with decreased quality of life. Karen now has much contact with the hospital, her care falls under a number of different medical teams and her mobility is poor, which gives her little freedom to get on with everyday living. Karen previously had suicidal ideas, although I do not think she has ever represented an active suicidal risk as she cares deeply for the welfare of her son. '*

38. I also struggle with the stigma of having HCV, and constantly fear that someone will judge me or assume I have contracted it through taking drugs, or that I will infect someone. Even after clearing the virus, I worry that it will come back, that I am not entirely clean, and that I still have to disclose it. My psychology report in 2002 refers to this as well, noting, "*Having hepatitis C and the associated stigma and real rejection she has experienced from other people have led her to be increasingly secretive*" **(WITN2012005).**

39. In 2004 it was noted that the Royal Free did not have a health psychology service, but that that kind of service would have been beneficial for me because I had already been assessed by the clinical psychology team twice and no longer met their criteria for further assistance, but I required further input regarding my anxiety around health conditions **(WITN2012006).**

40. I was not able to have treatment for my HCV for many years after my diagnosis. My doctors were concerned about the effect of the drugs on my kidney, when it was not failing, and/or on my dialysis.

41. I was given about 6 weeks of treatment with methotrexate and a very small amount of interferon in 2000, but this was not to treat the HCV. This was used to treat skin lesions on my arm and leg, and was injected directly into the affected sites. **(WITN2012007).** The skin lesions had come about because I

was given an MRI scan with gadolinium (a contrast dye) which was not meant to be used on kidney patients, and which resulted in skin lesions and vascular calcification. I am not aware of what other effects might have been caused by this dye due to the fact that I was infected with HCV.

42. After this, Dr Dusheiko remarked repeatedly, in 2006 and 2007, that he was waiting for less aggressive HCV treatment to be approved so that I could try it without the risk to my kidneys. **(WITN2012008).**

43. In 2010, I was offered a course of pegylated interferon and ribavirin. However, I had to stop this treatment after 12 weeks as I developed pancytopenia. **(WITN2012009).**

44. There was a miscommunication between the HCV nurses and the doctors managing the treatment during this time, resulting in me suffering from the pancytopenia and severely low haemoglobin for a period of time before the doctors realised the effect that the treatment was having and asked that I stop the treatment. The nurses had sent emails to the treatment team saying that my haemoglobin was very low and they needed to increase my dose of EPO, which was medicine I was taking to bring up my blood count, so that I would be able to tolerate the interferon treatment. However, the doctors on the treatment team failed to read these emails and didn't increase my EPO dose enough, so my blood count went down rapidly and I was unable to tolerate the treatment.

45. When the doctors finally read the nurses' emails properly and realised that they should have increased my EPO dose more, the nurses said it was good that the miscommunication was resolved in time because it could have killed me, and they could not believe my haemoglobin was that low and I was still walking around. The doctors then had to put me through a vast amount of tests which would not have been necessary if they had increased my EPO dose when they were asked to.

46. I believe that if the doctors had increased my EPO dose to the amount that was requested by the nurses at the time that it was requested, I would have

been able to tolerate the full course of interferon treatment and could have cleared the virus then.

47. In addition to my low haemoglobin, I had other side effects while taking this treatment. I felt very ill, itchy, lost my appetite, lost a significant amount of weight, felt very tired and dizzy, and began sleeping most of the time.

48. During this treatment I also had to delay having investigations for other health issues as these couldn't be performed while I was taking interferon and ribavirin. **(WITN2012010).**

49. After the treatment failed, I was told I would need to wait for direct acting antivirals to become available. **(WITN2012011).**

50. In August 2016, I was approved for a 12 week course of Harvoni treatment. I took this and cleared the virus, with SVR achieved in April 2017. I had serious side effects while I was on Harvoni treatment as well, but I felt taken care of a lot more than when I was taking the interferon. I felt the doctors were monitoring what was going on and if I was feeling well, and I was given numbers to call if I felt unwell.

51. I was told by the doctor managing my Harvoni treatment that I still have chronic liver disease but it did not develop into cirrhosis. I was told that there could be a little bit of the virus left behind in my body. I therefore must still receive 6 monthly scans to monitor the progression of the liver disease and make sure that the virus has not come back.

52. Although I have cleared the virus, I am still afraid there are remnants of it hiding somewhere in my body and that it will come back.

53. I believe that there were unnecessary delays in me accessing treatment. I was not approved for Harvoni treatment until it had been tested on patients with kidney failure. When it first came out, they only conducted trials on people with no other pre-existing health conditions. My doctors had to go to a lot of meetings about my case before the go-ahead was given for treatment. After a

while I was then approved for Harvoni treatment, but then had to wait two more years to start treatment because of funding issues. In the meantime, while I was waiting, I felt so upset, so dirty, so angry, so depressed, so alone, and so disappointed with what was going on. I did not want to live on this earth anymore. I thought that the government were trying to fob me off. I thought, how the hell can they delay treating me for the virus after they gave it to me in the first place. Along with the dialysis and transplants, it was all getting too much for me.

54. I understand that there were other direct acting antivirals that I could have taken earlier if Harvoni was not available for kidney patients yet, but Harvoni was the drug funded by the NHS so it was the only option provided.

55. The biggest issue I have had with accessing medical care due to my HCV is the requirement that I have dialysis in a separate room to other patients. This makes me feel extremely isolated and deprives me of the ability to talk to other patients going through the same treatment to pass the time. It also upsets me because the other patients can see me going into the separate room and they often ask me what's wrong with me or why I can't be with them, which I find embarrassing. Sometimes there is one other person in the private room with me because they are also infected with either hepatitis or HIV, and often through drug use. It upsets me to be lumped together with people like that and kept away from everyone else having dialysis. There were also rumours going around the dialysis unit about me and the other patients who had to dialyse separately. People thought that we were passing it on to other patients through the gloves the nurses wore when treating us, but if this was the case it was because the nurses were not changing their gloves between patients, which was not our fault.

56. At some point I asked if I could have dialysis at night instead of during the day, because then I could use the private room without having to walk past all of the other people having dialysis and endure their stares and questions. I was given the opportunity to do this, which has worked better for me, although I still get

lonely and miss the ability to socialise with other patients. Having to dialyse separately really still made me feel dirty inside and out. I could never really come to terms with it all. I tried my very best to live with it because I had to, but even given the opportunity to dialyse at night did not make me feel any better.

57. I have found it difficult to find a dentist who will treat me due to my infection, as is evidenced in my records. **(WITN2012012).** My local dentist would not treat me, so I had to be referred to a specialist dentist who extracts teeth for people with hepatitis. **(WITN2012013).** In the referral letter the dentist describes me as a "potential drug user". At some point Dr Davenport referred me to a dentist at the Royal Free Hospital which was also a specialist dentist, but this has closed down.

58. Accessing dental care has been very important to me because of the long term effects of the HCV and the treatments on my teeth. After taking the interferon treatment I started to develop abscesses on some of my teeth and some of my teeth started snapping off and had to be removed. At this point I only have three teeth left of my own and wear dentures on my top teeth.

59. In the early years after having Ashley, I was struggling to cope with my health issues while raising him as a single mother and keeping him safe. I became obsessed with trying to protect him from my infection, and I told him not to tell anybody because of the stigma.

60. Because of my fear of the stigma I became more and more isolated. I was too afraid to tell men who were interested in me about the infection because of the stigma, and didn't want to form relationships anyway in case I might infect them. I told a few friends about it but was very careful who I told, and even the close friends I told initially thought that they could get the virus from using the same cup as me or holding the same pen. Even when I told them they couldn't, some of them were reluctant to believe me.

61. Since Ashley has moved away from home I rarely go out. I feel that even my family sometimes don't invite me places, or sometimes I don't feel like going

out. They don't visit me; they might phone, but they never come over or take me out. I was embarrassed to tell my family about the HCV because I didn't know how they would receive it. I am still afraid when people find out that they will assume I have done drugs and be afraid to come near me.

62. I have not had any trouble with my regular treating doctors, but whenever I have had interactions with doctors or nurses who do not regularly treat me, I found that they were not aware of what precautions they did or didn't need to take around me and acted afraid to touch or operate on me due to their lack of knowledge about HCV. I have found that doctors still assume I contracted HCV through drug use, even though it is in my notes that I received a blood transfusion. At heart check-ups, the doctors sometimes seem afraid to ask me questions about it due to the perception that the way I got it must be embarrassing to talk about. I always ask them directly if they have read my notes and let them know that it was from a blood transfusion, and that they can't catch it from me, and they sometimes seem reassured by that, as if they hadn't thought or learned about it before.

63. As a result of this lack of awareness, I am very reluctant to see doctors now who are not regular doctors treating my liver or kidney issues. I am also reluctant to have a blood transfusion even though I have been told that there is no risk of infection anymore. However my haemoglobin dropped again when my leg was amputated and I did receive a transfusion then.

64. Before I had Ashley, I was working full time as a telemarketer. After he was born, I tried to go back to work with a childminder looking after Ashley, but there was an issue when the childminder started contacting Ashley's father (whom I did not have a good relationship with) instead of me when something went wrong, and I felt I was losing control of the situation and losing my relationship with Ashley. When Ashley started calling the childminder 'mummy', that was the last straw. I also found it difficult to manage my health issues and still work. I felt like I was on my own.

65. I stopped working after that, and claimed DLA, which has now changed to PIP. When I was on DLA I had to re-apply every three years, which was very hard for me as I cannot write properly and had to get help to fill in the form. When DLA changed to PIP, the people who assessed my PIP claim didn't read my form properly and said I was well enough to work. I had to take the case to court.

66. Ironically, I could not even walk to the court; Ash had to help me every step of the way. When I went to the hearing the judge said "Why are you here? You shouldn't have had to come this far" and confirmed that there was a mistake and I should definitely be eligible for the benefit based on my paperwork. I now receive PIP on a permanent basis every 3 years, although the DWP can look at my case at any time.

67. I am very grateful that I have been able to access the assistance I need now. However, at times when the assistance has been reduced, I have had to go to a food bank with Ashley as I had no money for food. I would regularly cook him one big meal to eat every night for dinner for a week, as it was all I could afford.

68. I did try to get work at times when I felt I could manage it, when my kidneys were working, but when I mentioned to employers that I had hepatitis they would not hire me. At other times, I was too ill to work. I wish I could have worked, so that me and my son could have had our own home, and could have lived much better. I feel like the virus has taken the best part of my life away by preventing me from working.

69. I am dependent on the council for housing. While I have a suitable flat now which is adapted for my wheelchair, I had trouble several years ago when I was desperate to move flat and the council would not take my requests seriously. I had been burgled three times, felt extremely vulnerable on my own and wanted to move out of the area, but they wouldn't listen until my physical mobility requirements changed. I couldn't even get insurance to protect my

possessions from burglary because insurance companies wouldn't cover someone with HCV **(WITN2012014).**

70. I feel that if I had not been infected, my financial situation would be significantly different as I would have been able to go back to work. Ashley and I could have had a house, and I wouldn't have been dependent on the council for my housing and income. However, the stigma of the hepatitis really stopped me from living my life to the fullest.

71. I also feel that if I had been able to clear the virus earlier, either by finishing my full course of interferon and ribavirin treatment in 2010, or by receiving Harvoni treatment earlier, I wouldn't have deteriorated to this extent and Ashley and I would have been able to live a more normal life.

72. For the entire time that I have had the virus, it has ruined me and Ashley's lives. I have never been able to move on with my life. However hard I have tried to put it at the back of my mind, I could not; it was always there, affecting me physically and mentally. I remember when Ashley was younger, I was so weak that I had to sit on the curb and rest while waiting for to pick him up from school. When he came out, he would hold me up so I could walk home. Once, he helped me walk to the McDonalds to get some food for us. I sat down and rested while he went and got our food and a tea for me, but I then fell right onto the middle of the table, into the food. Ashley helped me up, and the manager or staff were so helpful, bringing us more food and tea. We were there for about an hour before I was strong enough to walk home. That's not what kind of life my son deserved. He looked after me the best way that he could, helping me walk, and laying with me on the sofa at home or going to his room. I was so wiped out because of the dialysis, the HCV and all the other health issues that I have endured because of the HCV, that I could not do any of the normal tasks a mother would do, like picking up my son from school, let alone doing anything engaging or fun. If I hadn't had HCV I would have been able to spend time with my son, whereas we could not have fun together because I was too

ill. I feel the government wasted my life and my son's life, and I could not give him the best parts of life, such as going out and holidays.

73. I did try to make our lives better, I just could not give him what a parent should have been giving him. When people went on holiday, I felt so bad. No one ever asked us to go with them, and I didn't have enough money to go anyway. He had days out with his school, but there were also days when he had to stay behind crying because I did not have the money to pay for him to go on the trip. Because of this HCV and how it took a hold of my and his life. I just did not have enough money for us.

74. Over the years my illness has seriously affected Ashley's mental health, as he was my only child and sole carer. He had to grow up quickly and learn to manage my health issues and speak to doctors for me. This led him into depression. He felt guilty that he couldn't help me as much as he wanted to, and I think he also blamed himself for contributing to my illness as I contracted it after his birth. I still have to remind him that it's nothing to do with him, and I think he still feels that way. He made me think he was okay but I know he was not, even to this day. I know he still carries my health and problems on his shoulders. He saw me go through all of my health problems and thought that it was his fault, but it was not, it was someone else's fault. I adore my son.

75. Some part of the guilt Ashley carries is due to the fact that my father did blame Ashley to some degree for my illness, which is horrible. He has passed away now and I never had the chance to talk to him about this, so I wasn't aware until after he died that he had blamed Ashley and made him feel bad for infecting me.

76. I thought my life would be a better one, not close to the way it is now – now I feel I have achieved nothing. Without my beautiful son I don't know where I would be. He is the brave one out of all this. What he has had to live with for all of his life, it was so unfair on him.

77. I also feel that some of my family members have been resentful that both my dad and uncle gave their kidneys for me, and that both transplants ended up failing in part due to the HCV.

Section 6. Treatment/Care/Support

78. I have had counselling, mainly when I was assessed by psychiatrists during my inpatient stay when I had suicidal thoughts. I did discuss my infection during these sessions and found it did help me feel much better, but there was only so much that counselling could do as it couldn't cure the HCV, which is what would make my and Ashley's lives so much better.

79. I was never offered any counselling at the time of diagnosis or during treatment; it wasn't until I was really at crisis point that this was offered.

80. Ashley has not had any counselling, and continues to blame himself for my illness, which is not his fault. I told Ashley not to carry this blame, because I wanted to give birth to him and am proud of him, but it is hard for him to let go of that.

81. At one point Ashley was asked to join me for a form of counselling, but he did not want to do this. I could understand why, but I was really worried about him. During the counselling I had to work through all of both of our feelings and actions by myself, which made me feel depressed and emotional. My health started to go downwards.

82. At one point I also went on a 6 week support group programme for people with a long term health condition. I found that very helpful as I had the opportunity to speak with other people with serious conditions and discuss how to manage them and when/how to inform others about them.

Section 7. Financial Assistance

83. At some point in the mid-2000s I wrote to my MP, Glenda Jackson, to ask for support with the heating in my house, as it was freezing and my attempts to contact the council to resolve this had not been productive. I explained that I feel the cold a lot because I have hepatitis. She responded by speaking to the head of housing at the council and succeeded in getting me a new boiler and radiators. She also told me that due to my hepatitis I could be eligible for assistance from the Skipton Fund.

84. I then made a Stage One application to the Skipton Fund and received the £20,000 payment.

85. I found the process of applying daunting because I had to write to my doctors to get evidence that I had been given the blood transfusion **(WITN2012015)**, have two kidney doctors sign the application, and have a liver biopsy, which required me to come off the anti-coagulant medication I was taking for my heart first. Due to my other health conditions it was a long complicated process, but my doctor did confirm I had contracted HCV from my blood transfusion. **(WITN2012016).**

86. I later on applied for a Special Category Mechanism payment, supported by a letter from my consultant **(WITN2012017)** and detailed supplementary information from him regarding the impact of my infection on me **(WITN2012018).** However, my application was refused because the Skipton Fund said my income was too high because my son was under the age of 18 and I got extra money because I was living on my own.

87. I thought that everyone who applied for the Special Category Mechanism was successful as long as they had one of the required health conditions as a result of hepatitis. Now my health has gotten even worse, with the amputation of my leg. I can't walk due to the scabs on my stump, which inhibits my movement so I can't go out. My friends don't call round and I don't have any carers because

they are too expensive and I am already in debt with Camden Council because of unpaid care hours. I cannot see why I would not qualify for this compensation, and I very much need it.

Section 8. Other Issues

88. I have not been involved in any campaigning on this issue.

89. I consulted a solicitor about a potential clinical negligence claim against University College Hospital pertaining to the complications arising out of my pregnancy in 1989, because I wanted to find out why my kidneys had failed and I had contracted HCV. **(WITN2012019).** I did not take the case very far because I was told by my solicitor that I might not want to bring a claim against the NHS if I continued to require their services to manage my conditions. I did obtain an expert report saying that I had contracted the HCV from a blood transfusion for the purposes of this claim, but I am not sure where the report is.

90. In terms of my expectations of the Inquiry, I would like to see an apology from the responsible parties for what they've done. I don't understand what has led them to do this. I can't see what they have achieved by it. I've gotten rid of the HCV, but it's already done its worst to me. It's caused liver damage and contributed to my amputation. If I hadn't been infected, I would have lived better than I have lived.

91. In terms of compensation, I have really struggled for many years and I would like to be living a little better than I am living now. I am owed the years that I have lost between me and my son. I know I can't get those years back, but what I am owed is compensation for the years that I lost – the best years of my life.

92. I am concerned that I haven't been able to obtain medical records from University College Hospital from the time of my transfusion. I am told that the records from that time no longer exist and they only have more recent records.

I was also told by the Royal Free and my GP that they only have part of my health records, and a great deal of the important records are lost, although I understand my solicitors have accessed these. I can't remember a lot of what I have been through so it is important to me to have a record.

Statement of Truth

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

Signed **GRO-C**

Dated ……16 March 2020………