

Witness Name: Sharon Moore

Statement No.: WITN2222001

Exhibits: WITN2222002-003.

Dated: 1<sup>st</sup> May 2019

## INFECTED BLOOD INQUIRY

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### FIRST WRITTEN STATEMENT OF SHARON MOORE

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I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated the 5<sup>th</sup> November 2018.

I, Sharon Moore, will say as follows: -

#### Section 1. Introduction

1. My name is Sharon Moore. My date of birth is the GRO-C 1959. My address is known to the Inquiry. I am not working due to having chronic arthritis, COPD and asthma. I intend to speak about my infection of hepatitis C. In particular, the nature of my illness, how the illness affected me, the treatment received and the impact it had on my life. As a result of the hepatitis C, I have then developed breast cancer which is linked to hepatitis C and was cited by Penrose in his report, it was a large tumour and it led to me requiring a right side mastectomy in 1994, removal of my lymph node glands. Subsequently I have reduced mobility in my upper quadrant, because they had to take out my trapezius muscle out to make a breast for me, which my body went onto reject. The hepatitis C has exacerbated my ulcerative colitis resulting in my bowel bursting and leaving me with the need for a permanent open-end ileostomy. I do not wish to be anonymous for this statement.

## Section 2. How Infected

2. On the 10th June 1987, I was admitted to Luton and Dunstable Hospital, due to severe anaemia, caused by ulcerative colitis. I was under the care of Dr Jain, Dr Davies and Dr Simmons. When I had to go to the toilet, I was losing a lot of blood and it was making me very weak. I had an urgent blood transfusion and I was given four units of blood. The batch number for the infected blood was revealed during my 2010 Judicial Review, *Moore, R (on the application of) V Skipton Fund Ltd & Anor* by my legal team at Irwin Mitchell and is recorded. I exhibit this under WITN2222002. I do not personally know the batch number now though. One of those units was HCV positive, I was not aware of the transfusion itself, until a look back exercise was conducted in 1995; even after this look back exercise was completed, I was still not told about my infection until 1998. Indeed, the Blood Transfusion Service wrote to Dr Jain when this look back exercise took place in 1995. When I tried to sue Luton and Dunstable Hospital, I was told that the case had time barred as I only had 3 years to put a case forward. They waited 11 years to tell me I had this infection and I am disgusted that I have never been given the proper opportunity to obtain the compensation I deserve. My QC was Rabinder Singh from Matrix Law; my barrister was Vikram Sachdeva from 39 Essex Street, curiously the same law firm as the Department of Health and my lawyer Andrew Lockley head partner at Irwin Mitchell who now heads the Legal Aid board.
  
3. I remember, after I had the transfusion that I was extremely ill. It felt like a drop of ink in a glass of water was how Professor Dusheiko described it during my Judicial Review in 2010. Originally, it took me months to recover from the transfusion in 1987. I was skeletal; I had a normal frame but I was losing a dramatic amount of weight during this period, at one point I plummeted down to seven and a half stone. My hair was falling out; I had itchy patches and pain in my ribs that is how ill I was. The fatigue was extreme; I was zapped along with these unexplained rashes, I really believed I was going to die. Slowly I managed to get my weight back up again and the hospital decided that it must have all been due to my anaemia. They did not do any further investigations in 1987.

4. My GP at the time of my infection on the 10<sup>th</sup> June 1987 was Doctor Khakoo based at Houghton Regis Medical Centre, Peel Street, Houghton, Regis, Bedfordshire LU5 5EZ. I have been with this GP practice since 1977. I was notified of my infected unit of blood in 1998, my GP was Dr Bhalla at the same surgery. My GP now is Dr Joy Jinmi, who has been my GP for the past 11 or 12 years. My consultant who treated me for the ulcerative colitis was Dr Jain Ashen. Dr Rothwell Jackson an eminent surgeon conducted my ileostomy operation at Luton and Dunstable Hospital in August/September 1991.
  
5. When I found out that I had had hepatitis in 1998, I received a little card/letter in the post that said, "*Please contact the Blood Transfusion Service to come in for testing, we are doing a look back exercise and we believe that you have received contaminated blood*". I went straight there and was tested. Luton & Dunstable Hospital explained to me that the infection had occurred in 1987 and they had no idea what hepatitis C even was in 1987. I believe this is nonsense, I believe they kept my infection quiet, they must have known. I was told that while I had tested positive for hepatitis C, my body had naturally cleared it. The Blood Transfusion Service did warn me though that the hepatitis C could come back later maybe 20 years in the future, which is now. They also warned me that I could still develop cirrhosis of the liver and cancer because of it. HCV affects every organ in your body. The natural clearer argument is a lot of nonsense. I have not beaten it fully if I still have these risks from it. My position is, how dare you give me this blood in the first place. What about my life? My relationship with my partner at the time broke down because of the stress this put on us. My family relationship broke down as well. I remember I was treated like a leper, I would meet my cousins and they would tell me not to kiss the baby in our family, "*just in case*". Everyone was questioning if they could catch it from me and this was after I was told I had spontaneously cleared it.
  
6. I had 4 units of blood in 1987, I had a further 4 units in August 1991, when I had the colectomy. My son then passed away in the womb, in September 1991. I had another 2 units of blood then and in 1994 when I had treatment for the breast cancer, I had another 4 units of blood. The Blood Transfusion Service

tell me it is only the one unit of blood that was contaminated out of these transfusions and this was in June 1987.

7. When I was told about the existence of hepatitis, I was not initially told that it could come back. There are a number of strains of hepatitis; the hospital gave me the bare minimum of information. They stonewalled me with no explanation as to why it took so long from 1987 until 1998 to tell me. They have never explained why they did not start to test the blood until 1991. The lookback was 1995, but still, I wasn't told until 1998. Information has never been properly provided. I could have died in those 11 years.
8. I should have been informed earlier than 11 years after the point of infection. I should have been given the full care and support. There was no treatment of course because I have spontaneously cleared it, however I feel I was denied treatment because no one told me for 11 years, but this is the argument they use to deny me the financial support. They don't know when I cleared the virus and they don't know if it will come back, but the powers that be have decided that I am not worthy of the support. I have had 30 years of this, I was a young woman when this all started. I am an old woman now. They cannot prove when I spontaneously cleared it, not even the month; no blood test was done in December 1987, which would have been their criteria to clear it, which is 6 months. They took no bloods because they did not know I had it in the first place.
9. I remember when I was told I had hepatitis, it was done very clinically. There was no empathy or apologies, no redress, the hospital just decided to pass the blame onto the Blood Transfusion Service. I do not buy this, how did the hospital not know about the blood? I remember Dr Davies at Luton & Dunstable Hospital when she told me in 1998 saying, "*At least you didn't catch HIV as well as HCV*". I stood up out of my chair when she said this and shouted, "*Are you for real? You are sitting there telling me at least I didn't get two of these diseases when there is no bloody business giving me one in the first place!*" It was a disgraceful thing to say to me. "*Don't worry it's not AIDS or anything, it is just showing you have had hepatitis and we have identified the donor*". That

is the only reason my name came to light, because the donor was identified in the lookback. Some people have received all the viruses. I have never received compensation, I was denied legal aid and I was put into a corner to fight this. I took it as far as I could until 2010 when I had an excellent legal team, with Irwin Mitchell, but every step of the way I had to fight. It was an unsuccessful judicial review; as referenced above, therefore, the matter remains unresolved. There was no test in December 1987 and PCR was not done until 1998 because PCR was not discovered until 1995. They have tried to baffle and bamboozle me and squash me when the fault lies with them. They had no business of giving me hepatitis in the first place. That is the bottom line. NHS patients in an NHS hospital being given contaminated blood, the Government and the NHS have a moral and financial obligation to us all. This is what I quote time and time again on any media interview over the years. The NHS have been absolved of wrong doing. What about the managers on six figure salaries? All the clinical directors responsible for my wellbeing. They all failed me. It was a catastrophic failure all the way down the line.

10. As the information I was given was very clinical, I only found out about the risks through my own reading. I was given no information about the potential risks with my ex-partner.

### **Section 3. Other Infections**

11. I have been told that there is a chance that I could be infected with vCJD, otherwise known as mad cow disease. The Blood Transfusion Service in Luton told me that there is no test in existence that can confirm this, which means any test has to be done post mortem, as they have to take brain tissue. A female manager at the Blood Transfusion Service told me that it was very likely that about half the population of the UK are walking around with VCJD and don't know it, that is because people were infected through the use of surgical instruments as well as blood. Therefore, I have that worry as well. I have also developed COPD and severe arthritis. The most appropriate treatment for the arthritis in my knee at one point was knee replacement surgery however because of the VCJD risk; it was deemed that surgery would not be the most

appropriate course of action for me. I feel like wearing a bell round my neck and crying out "I'm clean! I'm clean!", it truly is a leper's disease. I feel like a social pariah, people are not interested in how I got it, that it was from a transfusion. The same questions come up continuously. Have you done drugs? Unprotected sex? Even with my partner, we used protection, but the whole relationship broke down after we found out about hepatitis. He would always question it; he would question how hepatitis could be passed on, in the blood. In the end, we drifted apart. I have to put the vCJD risk and HCV on every legal form I fill in. Travel insurance is also a fortune. My core morbidity is above five now. I am on a whole cocktail of drugs. I have had operations denied to me, specifically a knee replacement due to comorbidity, HCV & my VCJD risk. It was the same with my knee operation. I was told that I would need to have both knees replaced at some point, but now because I have hypertension, COPD, the risk of having had hepatitis C, a risk of VCJD as well which is undiagnosed; it all means the risk is too high to operate. It is all too much; the risks go against me you see. I certainly attribute the very chronic arthritis, depression, chronic fatigue, kidney cysts, low immunity and cancer from having had hepatitis. The depression is really bad. There are some days I feel helpless with it all, and I question why has this happened to me? There is nobody that wants to redress it, no apology, no compensation, not even token compensation, not even a one off Skipton payment, which was allowed to so many others. It feels malicious.

#### **Section 4. Consent**

12. I do not know if I have been treated without giving my consent. I find it hard to get my head around being under the care of 3 Consultants, Dr Jain, Dr Davies and Dr Simmons at Luton and Dunstable Hospital in 1987; having blood tests done virtually every day at one point and they still claim they didn't know I was infected. I do think they did know, but I cannot prove it. In 1987, hepatitis C was known as non- A, non-B hepatitis. Many of my medical records are now lost, I don't know what has happened to them. I can't remember every blood test that has been done to me through time so I don't know if I have been tested without my knowledge is the honest answer. It is the blood test records that I

am looking for. These are the records that are unavailable, Mr Dusheiko's comments during my 2010 Judicial Review, were, "*There was very little by the way of test results all those years ago*". My barrister, Vikram Sachdeva cited that the criteria of the Skipton Fund was illogical, based on this reasoning, illogical and too narrowly drawn. However, onus of proof is bared on the claimant, which is again wrong and to force someone to prove medical results is illogical and illegal. How can I? How can a claimant, a member of the general public, be expected to dig out all these results when the institution who has caused this, has destroyed them?

13. I can't prove I have been tested against my consent, but I believe that yes that has occurred. I don't know what the tests they did on me were through the years, there were a lot, but I simply can't know if they did things without my consent for sure.

14. How would I know if I had been used for research? Am I part of a bigger picture? As an NHS patient in an NHS hospital, receiving NHS treatment, I should have trust in my clinician. I put my trust and life in the clinicians and this is what happened. Luton and Dunstable Hospital are part of a teaching hospital so it is possible. All trust with the medical profession are let down with incidents this.

## **Section 5. Impact**

15. The mental impact has been huge. There was no counselling or anything offered after my diagnosis, I was just given this bombshell and left. I cried for days. I already had a severely compromised immune system at that point, which resulted in the death of my son, Ryan in 1991 when I was pregnant with him. Since 1987 my ulcerative colitis had been getting progressively worse, leading to my bowel bursting in August 1991. I had to have an emergency complete colectomy which is an ileostomy. I was nearly 5 months pregnant at the time, and in September 1991, Ryan died. It was so sudden. I was in Luton & Dunstable Hospital at the time when it happened but I was in a surgical ward, not a maternity ward, because I had so many problems with the ileostomy at

that point due to having a weak immune system. The hospital didn't know I was in labour with him and ultimately, he died. I was infertile after this. There was the option of undergoing fertility treatment but I was too frightened that I could pass the hepatitis C onto another child, so I chose not to have any more children. In 1994, I developed breast cancer, stage 3. I had sharp pains in my right breast, I thought I had strained myself so I went to my General Practitioner and they examined me. Once they did, they felt a lump and sent me straight to hospital. I have had a mastectomy now, the doctors took muscle from my back, to recycle and create a replacement small breast. My whole body's immune system was thrown into orbit by this. My body rejected the breast 3 times, before I gave up. Now I just use a prosthetic breast by Amorena from the Breast Clinic. Breast cancer is linked to hepatitis C but still it took them until 1998 to tell me about the existence of the hepatitis C. I am 25 years "clear" now, but I still go for mammograms every 5 years and will do for the rest of my life. All because of the hepatitis. The cancer could come back in my bones or be secondary, it could kill me. Now when my blood is tested what it shows is that I am antibody positive but PCR negative.

16. When I was younger I used to excel in swimming, I used to be a model and now because of this, my walking is so bad I have to walk with a walking aid and both my legs are bowed as I have chronic arthritis in my spine and both my knees. I have also been diagnosed with fibromyalgia, which is arthritis all over my body. That in itself shows that something severe is happening to have it all over your body. I also have a kidney cyst often linked to HCV. One of my kidneys is damaged and is smaller than the other. I also have high blood pressure now.

17. My ulcerative colitis in August 1991 was aggravated after the HCV infected blood in 1987. I think one of the factors that helped me beat HCV was being on predsol enemas and prednisolone. After the ileostomy in 1991, I developed an infection in my stitches; I remember being on metronidazole a strong antibiotic. Interestingly I was also on metronidazole in 1987 as well when I was in hospital as I remember having a fever and someone in the hospital saying to me that it was probably some sort of bug in my stomach. I believe, it was

HCV the whole time. I could not eat, I felt so sick my joints ached; I had peculiar rashes as well which the doctors told me were probably a reaction to a prednisone steroid. I had debilitating fatigue which the doctors at hospital said was "just anaemia", yet I had the 4 units of blood. It is a contradiction and they fobbed me off every time. Of course in 1987 there was no such thing as hepatitis C, it was known as non-A, non-B hepatitis. The Government knew as far back as 1975 as the World Health Organisation told them of contaminated blood and still, I was given this transfusion.

18. In 1991, my bowel burst due to ulcerative colitis which led to a complete ileostomy. A month after that took place in August 1991, in September 1991, I was pregnant and I lost my child as well. I was 5 and a half months into term which was devastating. Subsequently I have gone on to get breast cancer for which there is a link between this and hepatitis C. The tumour was so big, I had to have a right hand side mastectomy, removal of lymph glands and re-siting of the trapezius muscles, that's how bad it was. Many women fortunately get the lumpectomy where they get rid of a little lump. However, mine was a complete right sided mastectomy with rebuild because the tumour was so big. I had to have chemotherapy, radiotherapy, all of it, it was terrible. That was in 1994.

19. I have developed asthma on my lungs which has subsequently turned into COPD. There are links between this and hepatitis C as well. I have to take inhalers to manage this as well and it is one of the reasons I have been on benefits for a very long time. I have problems with lesions on my skin, as well. Last year, one of these caused me so much concern, that Luton and Dunstable hospital Dermatology froze it under aseptic conditions. I did not have any of these problems prior to HCV. The marks on my face look like liver spots to be honest. I have never been given a liver scan or a fibro scan. The HCV also left me with a kidney cyst and one of my kidneys is smaller than the other. I collapsed in May 2017 and was hospitalized with acute kidney failure as well after simple gastroenteritis. My compromised immune system is so weak, I get every infection going round so I am careful with what I eat, hygiene and staying away from people with infections. After the HCV, I caught chicken pox twice

and mumps both sides of my face. These are childhood diseases that I had never had before. Needless to say infections like this would knock me flat but these illnesses didn't, before the HCV.

20. I have not undergone treatment for the hepatitis C. I was not afforded the option because I was not told for many years. I spontaneously cleared it, but I do not know when and I do not know how long I had the virus for. This is my argument, because I cannot prove it was longer than 6 months and I cannot produce all my medical records to prove my case, I am entitled to nothing. All the further medical complications I attribute to the hepatitis C as well. I am a clean living person, I do not understand how this was not discovered before 1995 and then no attempt was made to tell me until 1998.

21. I was technically denied treatment. The interferon and ribavirin was denied to me because no one told me I was infected. I am aware that many people have died from this infection. I know that there by the grace of God, go I. They did not have the right not to tell me though. I have lived in the same house for over 29 years and there was no attempt to contact me before 1998. It is a very real frightening thing for me, because I have now lost so many dear friends in the same situation as me. These are people who have cleared hepatitis C and have then gone on to die of liver cancer and cirrhosis of the liver. That is what the hospital consultant confirmed could happen to me in 20 years and that information was given to me 20 years ago. You are living with a death sentence and it is of no real comfort to be told that I have beaten it and to be quoted studies that indicate very few problems for other people who have spontaneously cleared it. It may be that the studies show very few problems but that is because these people received their tests 6 months after infection. No body tested me after I was infected 6 months later. I do not value the beat it in 6 months' nonsense. I do believe it went on for longer, but what can I do, how can I prove this? I would like the Inquiry to look at this, to examine the moral and legal justification on what has been done to me.

22. If I have to have a procedure like a dental extraction, it has to be in hospital. Even though I am not a haemophiliac, if I get a cut, it takes a long time for it to

clot. The last operation I had, it took a long time for me to come around, about 2 hours. Now, I am mainly treated as others are. When I have blood tests, no one gowns up or anything, however I remember a point when my kidneys failed and I ended up in hospital in 2017 with my notes saying, "*Hepatitis C carrier*", even though I had naturally 'cleared it' according to the hospital. I am still under the care of Luton & Dunstable Hospital now because there is no point transferring to another hospital; they are all as bad as each other. I had to take Luton & Dunstable hospital to court in either 1998 or 1999 for factual inaccuracies within a medical report I had done. They had put in my report that I had a left hand mastectomy when it was the right side. I met with the hospital solicitors and amendments were made in the notes. The hospital is known for factual errors; I do not have a great deal of confidence in anything they do. Their administration procedures are much improved now I must add, but back in the 1980s and 1990s, it was very bad. This is the thing, when I was arguing with them about where my blood test results were, they told me that the records would be destroyed after a certain period of time. My question is, why? They are my records!

23. I remember I needed to have a nose operation due to continuous nosebleeds. That was only to remove cartilage, a day procedure. Even then, the doctors gowned up as if I was something that was quite diseased. If I have any dental operations, I have to go into a separate theatre at hospital. I remember I had to have two extractions done to my wisdom teeth; my dentist would not do it. She told me that they did not have the facility to treat 'high risk' patients. At that point, I had to have it done in Luton & Dunstable Hospital in a special theatre for people with infectious conditions. I was in extreme pain, so I did not care who did the procedure, but when I was there, I had many problems with regaining consciousness after the operation and there was a lot of bleeding as well. I should have been in and out in 2 hours, but I ended up being admitted for over 5 hours.
24. My family have kept their distance from me. They do not want anything to do with me. There is a lot of suspicion, no sympathy and a whole load of questions about hepatitis C. They would ask how would they would catch it, they

confused it with HIV at one point because the initials are HCV. All my relationships have fizzled out, so I do not bother trying now. I am 60 years old now; I have four Chihuahuas and a big staffie dog that keeps me busy. I have two brothers, Stephen Watts and David Amir Malik that live in Canada; they have nothing to do with me. My step-dad died a complete arsehole; he announced that I had a disease of a needle-sharing addict. We never got on; I was devastated when he said that. I have never done drugs in my life, I am terrified of needles, and even a blood test reduces me to almost fainting. In the last 10 years of my mum's life, I was not able to see her; I could not even go to her funeral. My mum, Shirley Watts and my Step-Dad, Farakh Zia Ahmed Malik lived in Pakistan as my step-dad worked for the embassy. Mum was never keen on me visiting because of the hepatitis C. I was in the papers all over the place you see. I spoke out every chance I could get. I have been featured in every medium of news reporting possible which made Mum nervous about me visiting. My husband died many years ago before my HCV infection in 1987. My second partner left me when he found out about the hepatitis C. He could not cope with it.

25. I have been on benefits continuously since 2001. After I fell seriously ill in the 1990s working became very difficult. Now I physically cannot cope with any work because of my physical disabilities and debilitating conditions. I am on Employment Support Allowance, in the support group and PIP in the standard group. I have had a very hard time because of the developing medical conditions over the years before everything started to be linked to the hepatitis C.

26. I worked in London in 1978 for a few months before I was a victim in an IRA bomb blast. I fled London and came to Bedfordshire as I have family there and worked at Lipton tea in quality control. Later on, I was discovered as a fashion/calendar/car and yacht show model. I went into modelling because it was not every day work; my husband liked me to be a housewife and care for the house and didn't mind me modelling as well. Since my ill health has taken hold, I have been unable to work and I have had to go on benefits. I live in my overdraft now. I live to survive only. When bills come in, I borrow from Peter to

pay Paul. If I had had an ex-gratia payment of £20,000 that would have helped with my quality of life. I could have a nice holiday, a car or central heating, which works, but I am left to struggle on benefits. Everything I have is second hand or bought cheaply. If I need anything, I would have to ask the DWP or a bank for a loan. If anything happens, it is a very tight existence.

27. After I was diagnosed, the stigma was huge and it made it impossible to break into anything. I applied to join the police in 2000 for example. This was not really a big goal of mine, but my forte is investigations and that was hard to be knocked back for. I remember applying and in the interview, all the interviewer focused on was the fact I had had hepatitis C and how I had been infected. He rolled his eyes when I told him I had received the infected blood from a blood transfusion, it was as if he was saying, 'a likely tale', he treated me as if I was a recovering addict. I have never touched drugs in my life. I had even passed all the written tests before I reached the interview stage because I was graduate fast-tracked. I have been denied immigration to Australia because of the infection. I have been denied life insurance, I have been denied a mortgage, apart from what I already had prior to my infection, I also did a lot of modelling in my career prior to 2001, but ultimately my ailing health meant I had no choice but to stop working.

## **Section 6. Treatment/Care/Support**

28. I have never had outside support really. I recently heard about the Red Cross counselling that is available. I am in a different category because I was able to spontaneously clear, but it has destroyed my life the same as everyone else. I should be paid as well, I have to declare the same things as all those who are infected with HIV and hepatitis C on every official document. If I did not declare it, it's an offence, and if it came out later on, I would be in a lot of trouble, liable to prosecution. I have no partner, no money and I am living with a day-to-day existence. They did this to me and who is to say that the virus is not lying dormant elsewhere? It affects every major organ in your body. I may have "cleared" it but the ramifications of it have been with me for years.

## Section 7. Financial Assistance

29. When I applied for support I was classed by the Skipton Fund as a spontaneous natural clearer, which means I allegedly beat it within 6 months after infection, however Polymerase chain reaction tests were not available until 1998. This test only proves that the virus was there and that is it. There were no blood tests done in December 1987 to prove that I had beaten it. The hospital alleges I cleared the virus within 6 months but there is no evidence to support this. It is a way to avoid paying me the support I am entitled to. There was no blood test conducted in December 1987 to accurately confirm that I had cleared the infection of hepatitis C. I know this for sure because I was not in Luton. It was December, it was Christmas time, I had gone to my Uncle, John Watts' house and his partner Katherine Watts in Orpington Kent. I was there throughout December. No blood test was ever done. Even when Professor G M Dusheiko prepared my medical report. I exhibit this under **WITN2222003**. He said in it, there was very little by the way, of evidence of tests to prove the existence of hepatitis C; bear in mind I had been in hospital in June 1987 for 2 weeks and I probably had blood tests conducted every day. Where are these blood tests now? I want to know; why did they not pick up on this? There was definitely no blood test done in December 1987 because why would they do a test in the first place when they had no idea about the existence of hepatitis in the first place at that point? This is what I am up against with the Skipton Fund. No one, none of the agencies can give me a month or a year confirming the date I beat hepatitis, yet they still deny me help. The judge, Mr Justice Kenneth Parker went along with all of this nonsense during my judicial review and ruled against me, I was incandescent with rage when I left that court room.

30. The Skipton Fund, the EIBSS and the Government have used this argument to not pay me the money I am owed. The EIBSS is in collusion with the Skipton Fund and the Government, I believe. I find this disappointing because they are supposed to be independent. Even more worrying is Professor Dusheiko who wrote my medical report; he is now one of the medical board members on the Skipton Fund, so there is a conflict of interest!

31. Ireland paid everyone and Scotland are getting better support than England.

The balance is completely uneven. I am not eligible because I am unable to prove that I have been infected for longer than 6 months. I submitted my application to the Skipton Fund on the 26<sup>th</sup> July 2004 but was rejected. I applied again on the 11<sup>th</sup> January 2005 but was again rejected. I appealed this decision and this appeal was rejected on the 9<sup>th</sup> June 2009 on the basis that I was unable to satisfy the panel that the length of my infection was probable, more than just possible, that it was more than 6 months in length. There was a judicial review in 2010 for which I had a fantastic legal team, but my legal aid was stopped and I couldn't query the review. The EIBSS denied me any help and I am also denied any help from the Caxton Foundation as well, even discretionary help. Where they consider that the infection was probable from contaminated blood, you are entitled to a one off payment, that option has been denied to me. The Caxton Foundation have discretionary funds to help with winter fuel costs etc that was also denied to me. For assistance with maintaining my house, say for example your washing machine breaks down and you need to buy another one, that support was denied to me as well. A big no all the way down the line. The schemes are not fit for purpose. The Government have allegedly set up these trusts to help people, but then the schemes look for a hundred different ways to not pay people. It's a hypocrisy. How can Skipton, Caxton, EIBSS be independent and all of them deny me help?

32. I am classed as a stage 1; they do not like me because I ask the awkward questions. Their position is that most spontaneous clearers cleared in 6 months from infection. My response is *you* are saying that but where is the proof? There were no blood tests in December 1987. I was a glamour model, I had a very good figure and I went from that, to looking extremely ill. There is no way I beat it in 6 months. The Government set up these trusts and funds to give the image that they are helping people but then look to deny you help in any way possible.

33. I would like to remind the Inquiry that the initial claimants, before the funds were set up brought forward a claim and were awarded compensation for being given HCV via blood. *A and Others and The National Blood authority and Others*, on Monday 26<sup>th</sup> March 2001. There after the Department of Health brought in the trusts and the ex gratia scheme of £20,000. I believe this scheme is not fit for purpose. Some people who were infected got this as a one off payment. On top of this they have added the yearly payments, plus their DWP and DWP PIP enhanced rate for many; the Skipton fund top ups and Caxton Fund. There has been a great deal of abuse to the Caxton Fund and ultimately I am someone who has been infected with HCV and I am left living on the breadline, in a small 2-bedroom house, driving an old 15-year-old car and surviving solely on DWP. It is outrageous. I have been left high and dry with not a penny from the Government by way of ex gratia, and not a penny from even the hospital as a good will gesture, but the CEO is on a 6-figure salary. The Government should give me the £100,000 sum originally given to the 6 claimants in the very first HCV contaminated blood legal action. £20,000 is an insulting sum anyway, but to be denied even that on top of everything that has happened along the way, is a very bitter pill indeed.

34. The Government has saved millions with these payments and showed no redress and no remorse for people like me pigeon holed into one of their illogical and too narrowly drawn criteria with heavy onus on the victim to prove eligibility when to date they *cannot* tell me when I beat HCV. It is entirely possible that my recovery period went over the 6-month criteria, as I was very ill for at least a year afterwards.

35. The whole scheme is not fit for purpose; it is full of holes. The Government have put in so many obstacles and barriers, it becomes completely illogical. There have been 187 individuals who have spontaneously cleared; many of the dependants and parents of children who were infected/affected have also received no support. Professor Dusheiko was paid to give his medical opinion on me in 2010; he now sits against me on the Skipton Fund and draws a £70,000 fee every year. Isn't it strange that we have the good Professor Dusheiko who did my medical report for me, citing illogical criteria to enable

my barrister and QC to come up with the illogical statement. Now the good professor sits on the Skipton board. There are eye-opening conflicts of interest throughout the whole process. I queried if Professor Dusheiko had anything to do with my case when it was considered by Skipton and Nick Fish, administrator, said he could not possibly answer that. They do not like it because I ask the difficult questions. There was one other woman from St Albans who was also Professor Dusheiko's patient who was also classified as a spontaneous natural clearer, she was also denied and she like me, went onto to develop connected illnesses. There is no accountability, no redress no apology not even from the hospital. It is a catastrophic failure from the Government downwards.

36. Considering I have supposedly been all fine and merry after being contaminated with HCV, with no side effects as reported by the Skipton Fund criteria, how is it, that the day after receiving the contaminated blood, I have and continue to suffer from chronic fatigue and still have problems with peculiar rashes and skin lesions on my arms and face, yet I am entitled to no support that the other infected patients receive?

37. I would like the Government to at least consider me for at least the one off payments, to reflect what I have been put through. To be allowed to join the schemes the others are on. The widows have been recognised, they didn't receive the infected blood but are allowed to join the schemes. It is a dreadful thing what has happened to the widows as well and like them, I would like to be recognised as well, it would be something. The Government recognised the terrible distress and loss experienced by the widows and even though they did not receive a single drop of contaminated blood themselves, the Government have seen it fit to see that they are given ex- gratia payments and support. Perhaps people in my situation, could be offered that kind of support as well. My life too has been destroyed. There should be a one off payment to everyone in compensation terms. I am completely incensed that the EIBSS are allowing additional payments for stage 1 people now. I am denied it because if you have been denied support by the Skipton fund and EIBSS, I cannot get access to the additional payment, which has been granted to all the other stage 1 people.

## **Section 8. Other Issues**

38. I was not a drug user, there was no grey area, there was no promiscuity. When I quizzed the hospital about why they did not test me for hepatitis C, they said that just because a patient comes into hospital with a ferocious headache, we don't automatically assume it is a brain tumour. They said to me that I was a clean living woman, catholic and in a stable relationship for 9 years, I do not do drugs, I do not drink, I do not even smoke. I was not what they called a "typical" hepatitis C patient. That was what the hospital told me and for that I am penalised. When I found out, I could not sue them because I had gone beyond time bar, I questioned the doctors including one of the medical directors and they turned round and said all that. They should have tested me earlier, I was their responsibility and they failed me. It is a catastrophic failure. How could they have not have known? The moment you are infected, you are infected. I had a blood transfusion that was supposed to make me better but instead of making me better it made me worse and they still did not think to test me. It costs a lot to be disabled, the Government is morally bankrupt, and they have a moral and financial obligation to us all.
39. Thompsons Solicitors have recovered my medical records and I have been given an opportunity to review these in full.

**Statement of Truth**

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

Signed

GRO-C

Dated

26 May 2019.