Witness Name: Louise Cannon Statement No: WITN0726001 Exhibits: WITN0726002-25 Dated: 20<sup>++</sup> November 2019

# INFECTED BLOOD INQUIRY

# WRITTEN STATEMENT OF LOUISE AUGUSTA CANNON

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 05 March 2019.

I, Louise Augusta Cannon, will say as follows: -

### Section 1. Introduction

- My name is Louise Augusta Cannon. My date of birth is <u>GRO-C</u> 1952 and my address is <u>GRO-C</u>
  Gloucestershire <u>GRO-C</u> I am a divorced farmer's wife and have two children. I was married for 25 years, but I live on my own and currently suffer with Myalgic Encephalomyelitis (ME).
- 2. I intend to speak about my infection with the Hepatitis C virus (HCV), which I contracted as a result of being given a blood transfusion shortly after childbirth.
- 3. In particular, I intend to discuss the nature of my illness, how the illness affected me, the treatment that I received and the impact it had on my life.

4. I confirm that I have chosen not to be legally represented and that I am happy for the Inquiry team to assist me with my statement. My sister also gives me support.

### Section 2. How Infected

- 5. As a child I was extremely fit and healthy, and never had any illnesses. I was brought up in the countryside and married a farmer at the age of 22. Two and a half years later I fell pregnant with our first child.
- 6. In GRO-C 1977 I was admitted to the Rosie Ward in Addenbrooke's Hospital, for the birth of my first child. I never had any illnesses prior to the birth and was a fit and healthy young lady I did not take any medication and never had anything wrong with me. Throughout the pregnancy I was well, and I recall the nurse saying 'I wish I could have your blood, you have exceptionally good blood'. I will never forget her saying that. I gave birth to our daughter, Sophie on GRO-C at 3.15pm, via emergency caesarean section. I only weighed between 8 9 stone at the time. I later had an X-ray on my pelvis and it showed that my pelvis was too close together to give birth naturally.
- 7. I came out of the operation fine, but was given pain relief because of the metal pins used as part of the procedure, as it was quite painful to get in and out of bed. I was in hospital for approximately ten days – this was standard procedure after a caesarean.
- 8. On GRO-C I remember 3 or 4 doctors and consultants coming round and standing at the end of my bed in their white coats. They were discussing me and left without speaking to me at all. Soon after a nurse came over and said that I needed some blood, to which my reply was that I did not want any. I did not think there was anything wrong I was eating well, sleeping and managing with the baby and I had not lost any blood. I questioned the doctors on their decision, but she insisted that I required

the blood, and I was given two bags of the poison. I did not want the blood and my gut feeling told me that I really did not want it. I felt as though I had no voice.

- 9. Once the nurse had set the equipment up to let the blood flow into me, it was only 10-15 minutes before hives big red lumps started to come out on my arms and at the top of my body. I started to feel unwell and felt frightened. I told the nurse I did not want the second pint, but she explained that the reaction was normal and insisted I had the rest of the blood. I was timid at that age so I did as I was told a second pint of blood was administered. I should have pulled it out and left the hospital but I was not brave enough back then. I was very well behaved, they were strict and it was like being at school.
- 10. I did not feel any benefits from the blood at the time, and if anything I felt pretty rough afterwards. I will always wonder why I needed the blood transfusion, as I did not haemorrhage, I was not giddy and had no abnormal effects after the caesarean. I did have food poisoning in hospital, but this would not warrant a blood transfusion. I certainly could have gone home and was capable of looking after myself. Perhaps they wanted me out of hospital, as they required a bed, but I could have left anyway without the transfusion. I was under the impression blood was expensive and difficult to get hold of at the time.
- 11. When I returned home to the farm to look after the baby, I did not feel very good my whole body was blown up and my face swollen. Before the pregnancy I was slim and petite, very hardworking and capable. I have always been very self-aware, so I knew something was not right. Our doctor at the time insisted such symptoms can occur as a new mother, but I started to become allergic to everything I even had to stop drinking certain drinks, as they would make me poorly. My family kept questioning what had happened to me, and wondered why I was ill all the time.

- 12. Three months after our daughter was born, my husband and I moved to Suffolk to start a dairy farm. I started to become poorly and suffered with giddiness. I had 6 months of terrible anxiety and was not able to sleep. I developed allergies to medication, and could not even take the contraceptive pill. Dr G Mair saw me whilst in the Marketplace, Halesworth, Suffolk and he could not understand why I was so unwell – I was extremely sensible with my diet. After 6 months, the bloating started to go away.
- 13. In 1980 I gave birth to our son Thomas, again via caesarean section, this was booked at Norfolk and Norwich Hospital. He was born bright yellow and kept in an incubator for over a week. The nurse explained there was something wrong with me because there was something showing that I was not very well, but she came back to say they could not work out why and that they would do more blood tests. I was kept in hospital longer to make sure I was ok.
- 14. I could not understand why I could not manage my health after having children. I was always getting something; colds, sickness and a rash developed around my eyes. The dermatologist could not get to the bottom of it for a while, but it was finally diagnosed as the herpes virus. I could no longer wear makeup on my face, and every year I have to take a 3 month course of treatment. I also suffered with ear infections and was given tablets for Meniere's disease. The prescription made me feel terrible; I would fall asleep driving and nearly had an accident. My brother told me to stop taking the tablets. Dr Mair sent me for a brain scan to check if there were any other problems, but nothing was detected.
- 15. At the age of 30, we moved back to Hertfordshire with my husband. More rashes started to develop, and I suffered with further illnesses and lots of infections. I contracted bronchitis at one stage, which developed into pneumonia and I was bed-ridden for 3 weeks. The doctor said he would normally have sent patients like me to hospital, but decided not to because of my circumstances as I had to look after my very young

children. I had terrible pain in my back and could not get out of bed, but I still managed to look after my son. My husband was busy on the farm at this point. I had to try and work around being poorly as nothing was helping the skin problems, tiredness or sickness. I even had to wrap my head up, as the exposure to cold weather would affect me.

- 16. My husband paid for me to see an allergist in Baldock, and the tests revealed I was allergic to pretty much everything on the farm. It did cross my mind whether I had picked up something from the farm, and whether this was making me ill. I used to lie in bed wondering why I had food allergies, medical allergies and sensitive skin. The allergist suggested a soya diet, which I tried.
- 17. Battling constant illness and fatigue as a farmer's wife was very challenging and my husband and I divorced in 2000.
- 18. In 2001-2002 the illnesses carried on, I felt fatigued, and had bouts of feeling extremely tired. I would often question and fight against the tiredness, but it eventually took over and I was unable to do anything. I could only eat little food and when I was able to eat my stomach would bloat easily.
- 19. After 6 months of doctors' appointments, I was taken seriously about being unwell, and further blood tests were taken. By this point I had problems with the lower part of my body, was losing weight, and constantly picking up infections. The testing went on for over a year and my health was deteriorating; I was not able to do anything. My lifestyle completely changed and I became stressed and worried not knowing what was wrong with my body.
- 20. Upon receiving the blood test results, I was sent to see Professor Brown at Gloucestershire Hospital, as something was not right with my liver. He was very judgemental and took the opinion that I was a drug addict and alcoholic. He did not seem to care and had already made up his mind. He

lectured me on alcohol and questioned my drinking habits; I explained I would have a glass of wine at night because of the divorce, but no more. He said I could be sent to Alcoholics Anonymous and that I would need to cut all alcohol out. During this visit he assured me that it was nothing too serious and I did not have HCV – I did not know what it was anyway, and nor did my family when I told them. To be fair to Professor Brown, it could seem as though I was drinking heavily and taking drugs because people like that do not admit they have a problem. However, if he took the time to look at my medical records, background and responsibilities, he would have seen I was not that kind of person. He was quick to judge and I was treated as if I was inadequate and not capable of doing anything.

- 21. During an appointment with Professor Brown, I was diagnosed with HCV, genotype 3A (apparently one of the strains that responded well to treatment). I tested positive for the virus on 11 October 2002. He asked where I had contracted it, but I had no idea and did not know what the virus was. I mentioned the holidays I had abroad but this was dismissed as a way of catching the disease. He explained it was an infection in the liver. At the time there was no evidence of how I contracted the virus and Professor Brown had no time for me at all. He was short, precise, dismissive and not willing to be kind or thoughtful to me as a patient. I was sent home just being told that I had HCV and to think about how I may have contracted it. I had to cope with the news on my own. I recall my mother and sister being very upset when I told them. (WITN0726002-06)
- 22. I later told the specialist nurse, Mike Bunting, whom I was assigned, that I gave birth at Addenbrooke's Hospital and was given a blood transfusion afterwards. He made contact with Addenbrooke's, but they had no records that I had received blood. I explained that my notes would have been taken to Norfolk Hospital for the birth of my second child, as again I had a planned caesarean. This is where my medical records were later found as mentioned in section 5.

23. I have never had any tattoos or taken drugs. I had my ears pierced as a teenager.

### Section 3. Other Infections

- 24. I have suffered with countless illnesses induced by the HCV infection. These include; ear infections, Meniere's disease, skin rashes, pneumonia, gynaecological infections, bloating, herpes, extreme fatigue, tiredness and Myalgic Encephalomyelitis (ME). I had an allergic reaction to all the aspirin family including most painkillers and have suffered anaphylactic shock with these.
- 25. To my knowledge I do not remember being tested for any other virus including HIV. The only test I know that has been carried out was for HCV.

## Section 4. Consent

- 26. I definitely did not give any consent to allow the doctors, consultants or nurses to administer the blood. I cannot recall being asked to sign anything, but if I did then it would have been in connection with the caesarean operation and for the safety of my unborn child. I vaguely recall a nurse coming in, in a hurry because of the situation, saying I needed to sign a bit of paper before theatre for the emergency caesarean. Regarding the blood transfusion, I would never have consented to be given blood unless it was life threatening, which it wasn't.
- 27. I said no to both bags of blood but the nurse said she would carry on giving it to me. They made me have it. I was born at a time when children were seen and not heard so I felt unable to challenge the decision. I did not want the blood; my own blood was very good. I did not want someone else's blood in my body and I knew that it was being drip-fed into my healthy, young, fit body. I had no choice, no voice, not any. I am still very angry. I never took medication; I was always a very holistic person.

- 28. I strongly believe that I was treated as a guinea pig when the blood transfusion was administered. I was fit and healthy at the time and did not haemorrhage and lost no blood during childbirth. There was no reason for giving me the blood.
- 29. After knowing that the blood was contaminated nearly 30 years on, I could not think why they would have transfused a very young, healthy, strong and capable woman who had never haemorrhaged or felt ill in any way. I had never been anaemic in my life.

# Section 5. Impact

- 30. Fortunately, the stress of my divorce and trauma of living on my own brought on the HCV symptoms earlier. Had my body not have gone through this, I could have died and the hospital would not have necessarily known why.
- 31. I was sent for a liver biopsy, and found it the worst hospital procedure I've ever had - I was told not to move or breath for the duration, as it was a very dangerous procedure and they could cut and damage the liver. This could trigger off a bleed in the liver and it would be serious for me as they would be unable to stop the bleed. I was scared, terrified and alone, wondering why I had to go through this and what it was for because I did not understand HCV or my liver problem at the time. I felt claustrophobic and dreaded having to hold my breath whilst they punctured my side with a large needle, like the ones we used to use on the cows to administer magnesium. The biopsy was taken on 4 April 2003 (WITN7268007) and performed by a nurse who seemed unsure of herself, so another nurse came to help who talked to me. I was not sedated for the procedure. I lay still, not breathing and was terrified during the biopsy, which was painful. I was instructed to lie on my side for a couple of hours afterwards, just in case of a bleed. When I felt ok I rested and they kept me in hospital because I lived on my own.

- 32. I was assigned a specialist nurse called Mike Bunting, by Professor Brown and he was put in charge of my HCV treatment. He was a lovely man - very open and honest and all my knowledge came from him. He was my only help and all I had in the three years of being on my own at home. He was based on London Road in Gloucester, which is where the drug addicts are sent. He came to visit me at home to explain about a possible treatment and went through a lot of paperwork. My sister was present for this appointment. He asked if I could think of where I may have been infected and asked if I had ever had a blood transfusion. I could not think at the time, but after a number of weeks I remembered that they had given me a transfusion at Addenbrooke's. He looked into this for me but could find no records because it had been over 25 years and he told me that often they only keep them for 20. As mentioned above my records were later found at Norfolk and Norwich Hospital. Mike managed to obtain all of the data on my blood type, the amount of blood transfused and other relevant information and I have since seen this paperwork.
- 33. I was very thin, not well, tired, and had no appetite. I had days of being yellow in the face. I was just in another world of shock and confusion about myself and where the HCV had come from. I kept questioning why me.
- 34. Once HCV was diagnosed, Professor Brown told me that I was probably too old at the age of 50 to be given the extremely expensive treatment. He explained that there may not be funding and he would have to find out and let me know. He also told me that no alternative treatments would work and not to go down that route. A considerable time later a further appointment was arranged to see Mike Bunting.
- 35. I felt lucky that Gloucestershire Hospital agreed to fund the treatment; as I was made aware how much it would cost, but finally something was being offered to clear the virus. Mike Bunting said that Interferon and Ribavirin can have some side effects for some people and if I was not mentally well

enough I would be unable to start the treatment. In a conversation with my sister he explained that I was seriously ill and if the treatment did not work I would end up bed ridden, waste away and die. He told her that I had a genotype that should respond well, but only if my body was fit enough to take the treatment. This was hard news for her to receive but Mike said we could try the medicine and see how I go. From the outset Professor Brown said there would be a 50/50 chance of success.

- 36. To commence the treatment I had an appointment at London Road. I sat in a sterile room and was given a kit. I had to sign before the medicine was handed over, acknowledging that I had received the drugs and that I was going to administer them myself, that I knew that, that and that the medication would have to stop if my body responded negatively. Mike Bunting explained everything and he gave me the opportunity to decline the treatment before I signed, especially as the drugs were new. I felt as though I had no choice but to pursue the treatment, I had to clear the infection.
- 37. I had a phobia of injections and recall passing out in primary school after immunisations, but I had to overcome the fear to save myself. I experienced a few symptoms every time I injected myself it was difficult knowing I was making myself ill, but I had to look at the bigger picture. I had flu like symptoms, fevers, sickness, painful aches and had no appetite. On some days I would be too unwell to even go to the doctors, I suffered with terrible rashes on my skin and my hair fell out. For 6 months I lived upstairs, and for only 2 hours a day I would be well enough to do anything. I stayed in bed all day on the days of injection, and I just put up with it on the better days. I tried my best to keep going and to get better to stay alive. During this time I remained positive, it seemed as though I was just surviving, and I tried to survive the best way that I could. I was proactive and did not want to wallow in self-pity. I had the support and encouragement of my mother and sister, which helped during this hard time.

- 38. Although I had a specialist nurse, due to funding and the fact that I could not travel to Gloucester, Mike was only really at the end of the phone. The visits allowed were very limited and he could only manage a few visits. He would only ever come to the house for emergencies, as his hands were tied with other work. I was made aware of the situation before starting the treatment.
- I still drove initially whilst on the treatment, because it is part of my nature to do the best I can. I do not drive very often now and have not for 4 years as I have ME.
- 40. Throughout the treatment I could not take any tablets; I am allergic to aspirin and have side affects when taking painkillers. I was accidently given a painkiller at my mother's house, but collapsed in the bedroom and passed out I had an anaphylactic shock. I dragged myself to the bed and ended up staying in my mother's bed for a few days. My doctor explained I was a unusual case and did not know what to do with me.
- 41. The first course of medication did not work and initially Professor Brown was unsure if I could try the new pegylated Interferon – he was unable to offer the new drug to all of his patients (WITN0726008-9). Blood and heart tests were taken to see if my body could handle the medication for a second course of treatment, and I was deemed fit and healthy enough to do so. It was stated that this second course of treatment would have to stop if I showed signs of wanting to commit suicide, or if my blood count dropped too far. It was explained to me that I would be on the medication for another 6 months, but that it would be different to the 'older chemo' and more direct than the first course of treatment, as pegylated Interferon protects the healthy cells. The explanation of the treatment was clear and thorough. I agreed to further treatment because I had no choice, but there was a 6-month gap between the treatments to allow the body time to recover. I spent time holistically trying to get well and to feel better - I ate organic food, did not drink any tap water and carried on with acupuncture. My HCV count was re-tested before the second round of treatment.

- 42. The second round of treatment was horrendous and the worst mental torture you could put anyone through it was deeper than depression. I was like a zombie. I was so mentally ill that I saw demons in my head, they were little creatures with evil faces like the devil, holding mallets banging and chipping away. I can still see them and that image has never left me, they were very evil. After about 3 weeks into the treatment I started to suffer from terrible anxiety. Even when the birds were singing and the sun shining, I could not see the light. Flowers were in bloom and with fragrance in the air, but I could not smell or see I was just a 'nothing', a mass of anxiety and dark, dark days. I would go from that to my bed, where my only comfort was to sleep and sleep again. Some days could be better depending on what I heard, said or what I thought and that could change everything very quickly. Some days I felt able to walk, eat or wash and be a bit human. Most of the time I was in a comatose state sitting and unable to move in the chair.
- 43. During this time I was also trying to care for my 80-year-old mother who was suffering from cancer, but on one occasion she ended up sitting me in the chair and covered me in a blanket. I could not talk and my mind was fixated on one tiny dark anxious thought and until I closed my eyes to sleep it would not go out of my brain.
- 44. My sister travelled down every week from <u>GRO-C</u> to visit, and she thought that one day she would come over and I would not answer the door. I asked Mike Bunting if I could be put into a mental institute with a straight jacket on for security and assistance, but he said nothing could be done. He just mentioned that if I could not handle the medication, they would stop the course of treatment. I knew that if I stopped I would die, so I carried on I do not know how I got through that period. My body was strong enough to continue the treatment but it was a struggle mentally. It later transpired that I should have been put on anti-depressants before starting the treatment and Mike Bunting apologised for this.

- 45. Dr Marlow finally gave me anti-depressants, but I became allergic to them.
- 46. I still get flashbacks of the second round of treatment, because I am such a visual person. It will always affect me, what the chemicals did to my brain.
- 47. Physically I could not even move or talk, so found getting to the toilet extremely difficult, and did not eat for days.
- 48. When they took blood tests at London Road Gloucestershire, they would also check to see if I was suicidal or not. My problem was the isolation that I felt – it was such a low feeling. All of the other skin problems, aches, pains and fevers made me feel as though I did not feel part of anything.
- 49. After finishing the treatment, I waited 8 weeks to see if the HCV had cleared. It was a traumatic time waiting for the result and if I had not cleared the virus, it would have been the end. Thankfully the medication did eradicate the HCV I am very grateful that I was able to take the treatment, as I have met others unable to do so. I am happy to be alive and count myself as blessed. I cleared the virus under the care of nurse specialist Mike Bunting in 2004. (WITN0726010) I continued to be monitored for another year in case it came back.
- 50. I was happy that I cleared the virus and could not wait to get back to normal life, even though Professor Brown and Mike Bunting told me that I had fibroids or fibrosis in my liver. Of course every day I was worried that the HCV virus would come back and no one told me how to look after myself. I remember a hospital appointment in Gloucester Hospital where my heart was checked on an E.C.G machine. The nurse was worried about the very unusual low reading of my heart and asked if I was anorexic or a sports person! She was worried enough to look for another nurse to get a second opinion! I was allowed to go home, but told to monitor any symptoms and to get in touch with them if there were any

changes. I had lots of tests on my body, I was very ill and not able to work. I was officially diagnosed with ME on the 19 February 2018 at Southmead Hospital, Bristol. The specialist explained that my body is tired because of years of fighting the HCV infection, although this link to the HCV virus was not put in writing.

- 51. I had extreme pain with ME and even driving the car would leave me in agony and still does.
- 52. I do not know about the state of my liver, and the extent of the damage caused by HCV. To be honest, I am not sure if I even want to know. There has been no follow up call since I have been discharged from the hospital (WITN0726024).
- 53. Six months after I cleared the virus I was tested, but then everything finished, and there was no further contact leaving me to get over it myself. Even though I have cleared the virus, I constantly wonder if it will come back again and I have no confidence. I fear looking in the mirror and seeing my face having a yellow tinge. I continue to feel unwell.
- 54. A fibroscan of the liver was taken on 15 March 2017 at the Gloucestershire Royal Hospital, as required by the Skipton Fund. I had never heard of a fibroscan before. I arrived early for the appointment thinking that it would be helpful and I went in feeling happy. When I was called in the first thing the fibroscan nurse said to me was, 'don't think that arriving early means that you can jump the queue, as it doesn't.' I was gobsmacked, I thought it would help the flow of appointments, but she assumed that I was trying to queue-jump. She told me that my liver was pretty good and that was it.
- 55. My doctor told me that my liver will always be missing a protein or enzymes or something and can never be normal again. Of course I would love it to be normal but I have been told by medical professionals that I

have fibrosis. I am now confused and I am afraid to know the truth about my body and liver.

- 56. Before the blood transfusion, I was told I had the best blood. I want to be emptied of all the bad blood and have my own blood back I do not even want my body anymore because of it. Whilst it is good I have cleared the virus, the lasting damage is still there and this is what I have to deal with. It is like a trailer full of muck; it can be emptied but the smell is still left behind. I cannot bear the thought of people damaging their bodies through drug abuse, and I have no time for them because of my own experience. It makes me angry to think that the dirty blood from these people was given to me.
- 57. My friend and neighbour of many years with whom I had made a lovely friendship with during my divorce, no longer wanted to see me after I told her I was infected with HCV. I lost that friendship, as she wanted to protect her family because her daughter was pregnant at the time. I managed to cope with all the gossip in the village because of my positive outlook.
- 58. I have been ridiculed and labelled by medical staff because of my HCV infection, and during a nurse appointment at the local surgery, the nurse greeted me by saying 'Oh it's you...I better put my gloves on'. I felt extremely cast aside, worthless, and looked upon as a freak. The doctors' surgery is in such a small area, so I have overheard people whispering about me, and people try to protect themselves against you. It angers me that I have been labelled as a drug addict, when I have been a hard working farmer's wife.
- 59. I was told I did not need to declare my HCV infection to the dentist, but I do recall being treated differently during an appointment with the hygienist.

- 60. My infection with HCV has affected my whole life and there is still a huge impact on the family.
- 61. I was suffering with extreme fatigue at the time and was not coping well. My divorce after 25 years of marriage took its toll on me, especially considering the age of my children. After giving birth to our son, I tried so hard to be to a good wife and mother, but I had no energy at all. I was not able to manage a normal life. I became someone else to the girl he married because I was so unwell. He understands and now realises this too, but we both feel that we have missed out, and agree it is very sad how our marriage was impacted. We divorced in the year 2000, and I came back to live in Gloucestershire on my own. I have been in this house ever since. He is happy that I am now getting the help I deserve through the Inquiry.
- 62. The treatment had a negative impact on both of my children and they could not handle the prospect of me dying. Before I started the second round of treatment my daughter found it difficult seeing me so ill. She was only 23 and living with me at the time. My son and daughter were also having to cope with the marriage break-up, having previously enjoyed family life on the farm. My son found it difficult to handle as he lived 100 miles away. He does not talk about what happened as he finds it too upsetting.
- 63. I am now not well enough and lack the energy to look after my grandchildren. I have not been able to be the granny I imagined I would be, and my grandson only knows me ill.
- 64. After the diagnosis, GRO-C GRO-C GRO-C GRO-C I had HCV when I gave birth to my son, but thank god I had a caesarean – God only knows how people cope when they lose a child, and how they remain strong. I do

have to live with the fact that I could have infected other people, and in all my life that will never go away – it is a terrible thing to know about yourself. My nature is to help people, not to hurt them.

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- 65. My children are very precious to me. My daughter was only 23 years old and my son 20, when I was diagnosed at 50 years old with HCV. This was horrific for them and they have gone through terrible times because of it. They have dealt with the fact that their mum is seriously ill and may not recover in their own separate ways and also had to go through the divorce of their parents at a similar time. My children have never known me as the person I was before contaminated blood was transfused into my healthy body.
- 66. When I first moved back to Gloucestershire, I had a few part time jobs including ironing for a local couple. They eventually asked if I would be their PA, but during this time I was coming home from work feeling ill every day. I expressed concerns about my health, so the lady told me to have a think about it. I was never able to accept the position.
- 67. I was also offered a job on a make-up counter at House of Fraser; the interviewer was so impressed that she offered me the role over the phone. Again due to ill health, I could not accept the offer of employment.
- 68. I later worked in the Orchard Room at Highgrove House, but I had to leave due to being ill. The management were very good and stated they would hold my position for as long as I need, but I am still not well enough to return. (WITN0726025)
- 69. Fortunately I received regular income from my divorce settlement, so I have been able to cope financially whilst out of work, and not resort to selling my house. Initially I received no financial help from anyone, so worked an additional three years at Highgrove. I was finding that my finances were being stretched after all this time of work limitations, or not even being able to work.

- 70. Numerous allergies caused by the infection, meant I had to buy the very best food to keep myself well. Both my sister and mother encouraged me to buy organic and non-processed food as soon as the symptoms of HCV started to flare up.
- 71. I was very close to my parents, and they were very supportive with the children. They would help out often when I was unwell, but eventually I ended up caring for them when they moved to Hertfordshire. Mum was diagnosed with cervical cancer at the age of 65, and Dad did not cope well initially. He passed away in 1999 when Mum was still battling cancer. I found it hard after Dad went as we had a very close bond, but I am pleased I was able to look after him.
- 72. I ended up moving back to Gloucestershire with my Mum after the divorce, but lived on my own. Looking after her was a distraction from my own illness.
- 73. As previously mentioned I ended up developing an allergy to the contraceptive pill, so could easily fall pregnant. During Mum's cancer treatment, I ended up accompanying her into the rooms for her radiation therapy treatment. I was always asked if I was pregnant before entering, and said no, unaware to the fact that I was. I had no choice but to have a termination, as the foetus had been exposed to too much radiation. If I were able to take the pill this would have never happened.
- 74. After Mum passed away, I was very tired and in bed for weeks. I had pain all over my body and felt unwell. I definitely overdid it; once her cancer came back and she had dementia I had no choice but to care for her, although I had not properly recovered from my own illness and was working at Highgrove. Towards the end of her life she had to go into a residential home and I found this all very stressful.

### Section 6. Treatment/Care/Support

- 75. I have never been offered or received any counselling or support as a consequence of being infected with HCV.
- 76. After the second course of treatment and the HCV cleared, I became my mother's carer. Through this I was offered counselling, as the authorities could see I was finding everything difficult.
- 77. Gloucester Hospital provided no support during or after the treatment for HCV. Due to an absence of support my GP started to provide acupuncture. I responded well to the treatment and it has helped me a lot.
- 78. My sister is gobsmacked on how I have been consistently treated by medical staff, and especially by Professor Brown. He was awful and treated me as if I was one of his drug or alcohol patients. I had to drive all the way to Gloucester to be belittled by him. Whilst Mike Bunting was a lovely man, but he could not make home visits regularly and on the whole I have not been treated very nicely. No one has ever shown care or concern, or been polite except Dr Marlow and Dr Xerry. Dr Marlow has supported me throughout, she is retired now but I pay her privately for acupuncture and she talks with me and tries to help me as best she can, both mentally and physically.
- 79. Professor Brown referred me to Cheltenham Hospital in order to sign paper work for the Skipton Fund and I have never been treated so rudely in my life. The consultant, Dr Coral Hollywood was extremely abrupt and was not committed to speaking she made it clear she would not fill out the form and that I was wasting her time. She told me that I was overweight, so she lectured about diet and said I needed to buck myself up. I felt like a naughty schoolgirl and could hardly speak as I was stuttering. Her only words were about fatty livers and my diet and that I should wait and see and said there was nothing wrong with my liver and that it was normal. I felt very confused and this is detailed further in section 7 of my statement. My sister accompanied me to the appointment,

and felt the consultant treated us like we had crawled through a sewer. I do not know how she is in the medical profession – she has no etiquette, care or empathy. At the end of the appointment, she remarked 'anything else?' so we got up and left. Moments later she then ran down the hospital corridor, and complimented me on what I was wearing. I wonder what she had seen in the medical notes that led to the change in attitude towards me.

- 80. I then had a follow up appointment with Dr Hollywood which I attended unaccompanied. She explained I was not ill enough to claim for Stage 2 payments, after which she pretended to smile, and remarked 'that's good news isn't it?' I questioned her on this, to which she replied 'well you're normal', and slammed her book down. It later transpired that I was one level off of cirrhosis, yet I was treated like I was nothing. Dr Hollywood was aware I had ME, and knew my medical history, yet she treated me as though I brought the HCV on myself. She immediately formed a judgement, and I am aware of what it is like for those that self-inflict their illnesses, because of my own experience.
- 81. If I were a drug addict I would have killed myself by now because of the treatment from the NHS. No help is offered and you are labelled.

#### Section 7. Financial Assistance

- 82. Mike Bunting spoke about the Skipton Fund and explained I may be entitled to financial assistance. He managed to retrieve medical notes held at Norfolk Hospital, providing evidence that I received a blood transfusion (WITN0726023), and completed the application forms on my behalf (WITN0726011-18)
- 83. In 2004/5 I received a one-off payment of £20,000 from the Skipton Fund. Up until this point I had no financial help at all, whilst I did not have to pay for the treatment, I had to pay for all of prescriptions and over-the-counter medicine to treat the symptoms relating to eye and skin conditions. I had

to pay for parking and driving to the appointments throughout the treatment and after.

- 84. I had no help in any shape or form from any doctor, GP or specialist and received no further financial assistance after the initial payment of £20,000.
- 85. Since 2016/17 I have received the winter fuel allowance.

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- 86. I never heard anything from the Skipton Fund after the initial payment, until a couple of years ago when I received a random phone call where I was asked if I had liver cancer. I started crying and replied 'I hope not'. The phone operator went on to explain she was from the Skipton Fund, and queried if I had ever received anything from them. I told her about the one off payment, so she sent out further information in the post. I kept the envelope in the draw for a while, but I started to look at the forms when I became ill again and after that phone call.
- 87. The wording on the form stated in bullet points the conditions and requirements to be met in order to attempt to receive further financial assistance. The documents explained I would be entitled to extra help if I had cirrhosis of the liver. My GP signed her part regarding fibrosis and then Dr Xerry completed the relevant section in relation to cirrhosis. Then it was sent to Professor Brown and an appointment was arranged at Cheltenham Hospital for me to see his colleague Dr Hollywood. She explained I was 'one off cirrhosis' and therefore not entitled to the additional payment (WITN0726019-20). I did not know what 'one off cirrhosis' meant and I still do not. Her tone was rude and abrupt and I was given a dressing down of my character - as detailed in section 5. When she had finished telling me off, she asked why I was there and why I thought it was appropriate for me to make that appointment for her to sign the form. I tried to communicate with her but her standoff and belittling stance meant that she had no interest in listening to me. She basically told me that she would not sign the form. I did not know what to say as

she frightened me and did not really want to seem to know about me. She remarked that she did not know what all the fuss was about, that I was perfectly fine, healthy and there was nothing wrong with my liver at all. I was very emotional and felt unable to ask her anything. I felt like I was an abuser and just wasting her time. I left feeling very confused, totally embarrassed, ashamed of myself and deflated. She kept hold of the form and had a huge folder filled with all my notes.

A Special Category Mechanism application to the EIBSS was approved, and from April 2017 I started to receive Stage 1 monthly payments of GRO-B On 27 February 2018 I was notified that the monthly payments would increase to GRO-B a month, and that I was also eligible for the increase backdated to 2 October 2017. The backdated amount totalled GRO-B From April 2018, the monthly payment further increased to GRO-B

#### Section 8. Other Issues

- 89. I attempted to speak with my local MP Geoffrey Clifton-Brown in regard to the contaminated blood scandal. I understand he is a very busy man, but he was not interested. I phoned his office a number of times and asked to speak with him, only to be told to attend one of his surgeries. The next time I phoned I tried to explain that I was too unwell to attend, so his assistant Paul sent out some information and copies of Hansard reports. I received the information on 30 October 2017, and this was the end of communication. (WITN0726022). I felt that it was important to speak to my MP was because I was worried that I had been infected through a blood transfusion and I was not a haemophiliac. I had no one else to ask for help and felt totally alone and isolated.
- 90. I would like to know why I was not tested for HCV as soon as the hospital realised the blood was contaminated. They would have had records of who received blood transfusions during the years in which blood was imported. If that was the case I could have cleared the infection without

any damage to my liver, and I would not have had to deal with all of the associated illnesses.

- Gloucestershire Hospital claim that I was given all my medical records in March 2019 – I have a letter to say they have acknowledged the request. (WITN0726021) I have now received a disc from Gloucestershire Hospital containing further notes.
- 92. I do feel very lucky that I was able to clear the virus, but I am still angry that I have been unwell since the age of 23, and the impact that it has had on my marriage and family. It is unjust and I am in a world I would have never ever entered into.
- 93. A lot of people do not know about the hepatitis virus other than the association with drug addicts an ignorance to be addressed. I understand why people treat you like a leper when you explain you have HCV, because of the connotations of the virus. Even now I am not fully aware of the implications of HCV, but perhaps I do not want to know.
- 94. I feel that I have been treated exceptionally well by the Infected Blood Inquiry and I am so thankful for the help given – finally my voice is being heard. They have been compassionate, kind and have shown true understanding, including Sir Brian. I am willing to provide any assistance to the Inquiry. Throughout my infection with HCV I have had to cope and work everything out myself, and now I want to be of use to other people. I have always been very strong but the Inquiry has helped me physically and mentally.

#### Statement of Truth

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

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Signed	GRO-C			
Dated	20th Novembe	V	20	19

# Exhibits:

Exhibit Number:	Description	Date:
WITN0726002	Letter from Professor	4 December 2002
	Brown to Dr Marlow	
WITN0726003	Copy of letter from	4 December 2002
	Professor Brown to Dr	
	Marlow	
WITN0726004	HCV Test Results	26 November 2002
WITN0726005	HCV Test Results	24 September 2002
WITN0726006	Letter from Professor J	5 February 2003
	Brown to Dr Marlow	
WITN0726007	Letter from Dr S Turner	6 May 2003
	to Dr Marlow	
WITN0726008	Letter from Mike Bunting	15 December 2003
	to Dr Marlow	
WITN0726009	Letter from Mike Bunting	08 March 2004
	to Dr Marlow	
WITN0726010	Letter from Mike Bunting	01 December 2004
	to Dr Marlow	
WITN0726011-18	Application form to the	19 January 2005
	Skipton Fund	
WITN0726019	Letter from Dr C	20 January 2017
	Hollywood to Dr S Weir	
WITN0726020	Letter from Dr C	25 May 2017
	Hollywood to Dr S Weir	
WITN0726021	Letter from	19 February 2019
	Gloucestershire Hospital	
	to L Cannon	

WITN0726022	Note from Paul	30 October 2017
	(assistant to Geoffrey	
	Clifton Brown MP) to L	
	Cannon	
WITN0726023	Letter from Richard	11 August 1977
	Whitmore to Dr	
	Whittaker	
WITN0726024	Letter from Mike Bunting	15 November 2011
	to Dr Marlow	
WITN0726025	Letter from Park	08 July 2016
	Surgery to Dr P Xerry	

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