Witness Name: Lesley McEvoy
Statement No.: WITN1934001
Exhibits: WITN1934002
Dated: 1 February 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF LESLEY MCEVOY

Section 1. Introduction

I, Lesley McEvoy, will say as follows: -

1. My date of birth and address are known to the Inquiry.

2. I live with my partner in Cheshire, having moved here from Yorkshire to live together. I have two children, aged 33 and 29, who both live away from home and are settled. I am divorced from my husband at the time of my illness and treatment. I have been self-employed for 30 odd years but can no longer work full time because of my health.

3. On the 8th April 2017, I changed my name by Deed Poll in order to revert back to my maiden name of McEvoy.

Section 2. How Infected

4. When I was 26 I had my first son. We were living in GRO-C Yorkshire, so the local hospital was Staincliffe Maternity Hospital in Dewsbury. The baby was due on 26 November 1985, but on GRO-C November I was admitted because I had pain and was generally unwell. On GRO-C November the membranes ruptured and my waters were leaking so they decided to induce the labour. At 06.10 on GRO-C after a 15 hour labour my son was born. The labour had lasted across a few shift changes, and apparently I had been haemorrhaging blood, but because it was quite a slow, steady trickle they had not realised how much blood I had lost. I became really very ill and was so weak I could not lift my head off the pillow. They kept chivvying me along, saying 'come along you've got to bath your baby and get on'. I think they thought I had postpartum blues. My arms and legs felt like lead and I couldn't lift my baby. They took blood and a couple of days went by. I think it was over a weekend because the lab was shut and they were waiting for the results. I remember the doctor coming to me on 24 or 25 November and expressing alarm at my low blood count. He said it was at 8.4 and that any lower than 8 and I could suffer a heart attack. They said I needed a blood transfusion because they hadn't realised I had lost so much blood which was the explanation for the lethargy (letter from Staincliffe Hospital dated 29 November 1985 summarising birth and noting blood transfusion, **WITN1934002**).

5. At that time, in the 1980s, there were adverts for HIV on television. HIV had just been discovered and the adverts had big tombstones, and described what a death sentence the disease was. Although it was regarded as a gay man's disease they were saying it was in blood products. I was terrified of contracting AIDS. I told the doctors I didn't want blood because some blood was infected: we knew that much then. They dismissed my concerns and said it was nothing to worry about. I insisted I wouldn't have the transfusion and held off. They began really nagging me and were losing patience. My father was of the same blood group and said he would donate, but they said I would

need a couple of units and that they wouldn't be able to take more than a pint from my father. They said I needed blood from a proper blood bank, which was Seacroft in Leeds. Eventually a consultant came and shouted at me, in front of everyone on the ward, and called me a 'bed blocker'. He said he needed me off the maternity ward because I had had my baby, but said that because I needed a blood transfusion they could not move me because I was too ill. He said that, 'without this blood transfusion you could die'. The consultant told me that there was no risk from blood supplies in relation to HIV. He told me I was at more risk of dying and leaving my baby with no mother. He said my fears were groundless.

6. I was in floods of tears. I felt humiliated. I remember ringing my dad from a payphone on the ward. In the end I caved in. A junior doctor came to me and said that they knew enough to know that if blood is heat treated it kills HIV. He said he would be honest with me and said that not all supplies are heat treated, some are of older stock. He said that if he could guarantee that the blood would be heat treated would that put my mind at rest? I said I supposed so, I thought that was as good as I would get.

7. The next day, the day of the transfusion, the junior doctor showed me the sticker across the blood bags that said they had been heat treated and said, 'you will not get HIV: they are safe'. It was GRO-C, my birthday, and on that morning at 10.30am I received the blood transfusion. That was the exact date and time I was infected with contaminated blood. I was transfused with two units of blood, following which my haemoglobin levels improved to a score of 12.

8. I used to be a blood donor. I could not donate when I was pregnant, but I went back to giving blood when I could after the birth of my first son. I gave plasma too. I carried on giving blood for around three years until I fell pregnant with my second son in 1989. After the birth of my second son I never managed to

get back into donating, but for those few years between children I did. I have to live with the guilt that I unknowingly put infected blood back into the system.

9. I was given no information or advice about the risk of being exposed to infection before the transfusion. In fact, as explained above, when I expressed my concerns in relation to HIV I was told the blood was safe and that my fears were 'groundless'. The hospital admitted that there were blood stocks which were not heat treated which were still in use. If I had not been vociferous it is likely I would have received untreated blood and the results would probably have been far worse.

10. As a result of being given the blood transfusion, I was infected with HCV. I had the worst, most aggressive strain, Genotype 1A, which is the most resistant to treatment. Genotype 1 came to Britain from the United States. I know now that you only need a drop of blood to get infected. I got two whole units, a massive dose. When I was discharged I was very ill for a few weeks, but it was my first baby and I didn't know what to expect. My viral load at diagnosis was millions of units, so they could tell I had probably received a massive dose at the point of transmission.

11. My path to diagnosis was not straightforward. I found out I was infected with HCV as follows. Twenty years later, in around 2004, I started getting really ill. My eldest son was at university, my youngest doing his A-Levels. I was getting joint pain, crashing fatigue, stomach upsets, high blood pressure. I was going to my GP with a variety of different things which could all be symptoms of others illnesses. The GP tested for all the usual stuff, but the HCV test was not routine.

12. The crashing fatigue was the thing that was the worst for me. I was self-employed so I just had to keep going. I was travelling around the UK and abroad doing speaking engagements and delivering training. It used to get to 3pm and I would be dead on my feet. I would have to stop at a service station

on the way home and sleep for a few hours. The fatigue was getting harder and harder to cope with. I went to the GP and said I had something badly wrong. I thought I had cancer. The GP even ordered a brain scan but they couldn't find anything.

13. In the end, towards the end of 2006, I went back to the doctor yet again. It was a young doctor. She did not even look at me, she read the screen in front of her, I told her how I was feeling and she said, 'I think you are depressed, I think this is all in your head'. I told her I am a psychotherapist and that is not what this is. She said she could offer anti-depressants or nothing. I left with nothing. After I left the surgery I sat in my car and rang my husband. He said we'd shelve the business and pay privately for more tests and try to get to the bottom of it, as the NHS were obviously not going to diagnose whatever it was.

14. In February 2007, as I got into my car I put the radio on. It was Anita Roddick, talking about the fact she had just been diagnosed with HCV from a blood transfusion in 1985 when her daughter was born. That was the first time I knew that blood had been infected with HCV. My blood transfusion had been in 1985. I listened to all her symptoms and I sat and cried as I thought, 'this is me'.

15. I rang the doctor and was met with the same cynicism as before. I asked for a HCV test and the doctor asked why as I had never been a drug user, had had no medical or dental treatment overseas, had no piercings, no tattoos, no risk factors. I said I had had a blood transfusion in 1985. The doctor said it was not in my medical records. It turned out that it was not on the computer based records. He said it must be on the paper records and that those records had never been transferred to their computer systems.

16. The GP did the test, but to save money did not do the full PCR (polymerase chain reaction) test as this around costs £60. The antibody test only costs £3 and there is then a wait of ten days. I was told that if that test came back

positive then the GP would do the full PCR test. I had the antibody test and had to wait the ten days. By then I was doing my own research and I knew that the result would be positive: it was a dreadful wait. Eight or nine days after the test I remember I was making the tea and the receptionist at the GP surgery called me to say that the antibody test had come back, and she said the GP had asked her to ring me to make another appointment. She didn't know what she was saying and she told me the antibody test was positive. I asked whether she knew what she had just told me. She said no, she didn't, and I should just come back in for the PCR test. I told her that what she had just said had imploded my life.

17. I went in for my appointment with the GP. The GP was apologetic, he said I had no risk factors for HCV and he said the NHS has given you this. He then did the PCR test and I had to wait two weeks for the result. He gave me a handful of leaflets and said that, being honest with me, he did not have any other patients with this and could not advise me a great deal. He said as soon as the results came back he would get me referred to a hepatologist and that they would be the best source of information rather than the GP.

18. I was referred to Dr Morea at Bradford Royal Infirmary. **Not Relevant** **Not Relevant** **Not Relevant** That appointment was when the sort of treatment you can get with this disease started. Dr Morea didn't know how to handle me at all. I attended the appointment with my husband and whenever I asked a question Dr Morea would answer my husband. In the end my husband asked him to talk to me, not to him. I pointed out that he did not seem used to women asking intelligent questions. When I asked about my treatment and symptoms, he would say, 'you don't need to know that yet'. He infuriated me so much I said I had no trust in him. Anita Roddick had progressed to cirrhosis by the time she found out she had HCV and she was too ill to treat. I thought I was probably cirrhotic at that point, as I had Genotype 1 and had been infected for over 20 years, so

it seemed highly likely that my disease would have progressed to cirrhosis. I told Dr Morea I wanted to know who the best treating doctor was. Dr Morea told me to get an appointment with Charles Millson at St James University Hospital, Leeds. He said Dr Millson was the best person in this part of England but he explained that my funding was in Bradford, so Leeds would not pay. I told him that I would worry about that.

19. The battle to survive began then when I realised that I would have to become my own best advocate. Given what I know now about my treatment journey and that my only hope eventually came from an experimental drug trial, I believe that if I had stayed at Bradford Royal Infirmary for my treatment I would now be dead. **Not Relevant**

Not Relevant

20. Charles Millson was due to come to Huddersfield to do a talk about two weeks later, 'My Liver and Me', and it was open to the public. The talk was about the liver, alcohol and hepatitis. I bought tickets and during the break I collared him and said, 'you don't me but you are going to. Dr Morea says you are best and I want the best so I want you to treat me.'

21. That first meeting with him probably changed my outcome. In general, the medical profession were very sympathetic to those who had contracted HCV through blood transfusions and were sorry that the NHS had created the problem. I was viewed as one of the innocent victims. It should not be like that but you soon learn there is a stigma attached to how you got the infection. Charles Millson said my major crime had been to have a baby and that is not how it should be. He fought to have my funding transferred to The University Hospital in Leeds, which was, and still is, a centre of excellence.

22. That was my personal experience of what information you are given and how that information is communicated to you, and it embedded the mentality, for

me at least, that you have to fight your own corner. Charles Millson was great at putting me on to resources that were vital. He put me in touch with The Hepatitis C Trust which was a turning point for me as I ended up working with them. As St James University Hospital is a teaching hospital, information about upcoming drug trials crossed Charles Millson's desk and he knew about upcoming studies. He also knew I was voracious about information about the condition and that I wanted to learn everything I could about the disease and any new studies that were underway and he would clue me in on that. Most patients would not want that, but I did. It was through him that I found out about the drug trial that saved my life.

23. Once my care was transferred to Charles Millson, I did get adequate information to help me understand and manage the infection, but I had to fight to get there. Prior to meeting with him I feel I did not get adequate information.

24. I am not sure whether information should have been provided to me earlier. This is because all the GP could do was to hand me a few leaflets as that is all he had. Up to that point we had not known what I had. I'd like to say at this point that my GP at the time was excellent, once my diagnosis had been made – so I have no criticism of my GP practice after that point.

25. I also strongly believe that receptionists must be very careful about how the results of tests are communicated to patients. When the GP receptionist told me the antibody test was positive she had no idea what she was communicating to me. What she told me absolutely devastated me.

26. As for what information I was given about the risks of other being infected as a result of my infection, when I went to see the hepatologists, both Dr Morea and Charles Millson's first piece of advice was for the family to be tested. The disease is not sexually transmitted in normal sexual practice; it is transmitted blood to blood. Despite being told this by my treating doctors and the clinic nurses, my husband at the time was so terrified of becoming infected, that he

did not come near me for the first six months. I was not too bothered about sex as I was so ill. But we had been married 16 years and just to have been close during that time would have helped me so much, but he wouldn't even hug me for quite a few weeks after the initial diagnosis. He didn't take having to be tested very well either. When his result came back negative, despite reassurances from the doctors that it would be (as he had no signs of infection), he broke down in tears and I realised then just how terrified he was of this. He did begin to hug me later and was affectionate in general, but I think that was the start of him distancing himself from me.

27. Worse than any of that was the children. From the research I had done I knew the infection could not transfer in uterus, but it could do so at the point of birth, so the prognosis for my first son was better, as I had the transfusion after he was born. I also knew the infection could not be transmitted through breast milk, so I was fairly sure he would be ok. I was more fearful for my second son. I became pregnant with him four years after the transfusion. I rang my eldest boy at university and talked about it over the phone. He said not to worry and that he would be tested. He rang me back to tell me he was fine and his test was clear. My second son was doing his A-Levels at the time. I took him to the GP and told them not to mess about with antibody tests but to do the PCR test from the get go. They were accommodating by then and did the test. We had to wait two weeks for the results of the PCR test and they were the worst two weeks of my life. It was bad enough that I had the infection, but I couldn't have lived with having given it to him. I remember making deals with a god I no longer believed in, asking him to give me the worst form of hepatitis if he could just spare my son. The result came back clear and he was ok. It was just me.

28. I also had to ring the father of my children to tell him and suggest he too get tested. That was a difficult conversation.

29. Charles Millson was good at helping me understand the virus. He confirmed it could not be passed on through breastmilk, nor in utero. There is little information available and people on the Facebook Groups were very worried about how it could be passed on and, more importantly, whether it can ever come back once it's cleared on treatment. A lot of information is missing. The disease is not like HIV, although there are many similarities there are also a lot of differences.

30. Charles Millson sent me for a HIV test, as the blood was cross-contaminated. I went to see the HIV specialist and broke into a sweat. He sat me down and said, 'I can guarantee you haven't got it. If you had had it untreated for 20 years you would be dead by now. But I will do the test.' He said that HIV wards are closing down now as no one is dying from the disease in this country any more. He said that if you have HIV you can probably live a natural life span with the medication we have available now, but if you have HCV your prognosis is far worse. He told me that he knew I was thinking HIV was my worst nightmare, but it is not. Coming away from that appointment I knew things were bad if I was thinking I would have been lucky to have HIV and not HCV. Thankfully my family did not have to be tested for HIV.

31. I am in the process of applying for access to my medical records. I have not encountered any difficulties as yet, though I know that the Staincliffe Hospital has shut down. There will be no records from the drug trial as these are not available. I would like to have the opportunity to provide a second statement if necessary once my records are made available.

Section 3. Other Infections

32. I do not believe I have received any infection other than HCV as a result of being given infected blood.

Section 4. Consent

33. I do not believe I have been treated or tested without my knowledge or consent, or without being given adequate or full information, or for the purposes of research.

Section 5. Impact

34. The physical effects of HCV were numerous and debilitating. For about four years before diagnosis I started having symptoms that were too vague to pin down, but had a dramatic effect on my life. I suffered with crashing fatigue, which was the worst symptom overall. The joint pain became so bad that it is difficult to describe: I would wake in the morning and feel I had been beaten with a bat, I would get up and you could hear the bones in my feet cracking. I couldn't unclaw my hands, it was like crippling arthritis. I had to wrap my hands around a cup of tea, so that the warmth would help them unstiffen, and it would take an hour or so to unclaw them. I would take pain relief in bed and it would take an hour before they kicked in and I could get out of bed. I suffered gastrointestinal problems. I was diagnosed with all sorts of things, including IBS (irritable bowel syndrome). I had high blood pressure which the GP gave me medication for, and it was put down to being a business person with a busy and stressful job. They thought I was having TIAs (transient ischaemic attacks) at one point and a diagnosis of ME was even discussed. I had pain under my ribs which was thought to be gall stones or kidney stones. But on further testing and my insistence that I wouldn't 'buy in' to any of these diagnoses unless they were proven beyond doubt, none of these were proven to be the cause of my symptoms.

35. I kept going back to the GP about my symptoms and they would ask me what I wanted, a sick note? After four years you do start to doubt yourself. And that is when the doctor said she thought I was depressed. In some ways it was bittersweet when I got the diagnosis, because at least I was vindicated – it

wasn't in my imagination. They were very humble, but it explained everything. That is why it is such a difficult disease to diagnose.

36. The mental effects of the infection were the isolation, fear and stigma. I wasn't depressed, not really then, that came later when my family fell apart. As a middle class English person I knew no one who had the disease. As I told my friends and family about it I was faced with educating them, at the same time as not wanting to scare them to death. Most thought there was surely a vaccine for it. They thought it came from dirty water. You don't want to say it but it is almost like HIV. That is the only thing you can liken it to. I felt totally isolated. It was only when I got in touch with the Hepatitis C Trust that I realised there were other people out there. Most are drug users, a good 60% is through drug use, or someone infected by another drug user. The most sympathetic and supportive group that I came across was the prison cohort of HCV sufferers because they live with this stigma, day in, day out. They have a community around them who understand it and a peer group who know about it. There were no support groups I could go to. I didn't want to go to a drug rehab group and I couldn't sit in an NA meeting and 'fit'. I didn't seem to belong. There was no community for me, apart from the Hepatitis C Trust helpline.

37. The further medical complications and conditions which have resulted from the infection were summarised by my GP on the EIBSS SCM form, as follows:

> '*Diagnosed with Hep* C *antibody 16.03.2007. Contracted as a result of blood transfusion in childbirth. Typical history of medically unexplained symptoms for few years prior to diagnosis. Referred to hepatologist, Genotype 1a and biopsy showed Stage 1 fibrosis. Symptoms and lack of explanation caused reactive depression which worsened with diagnosis. After failed treatment this became severe. She has been treated with Citalopram, Fluoxetine and psychological therapies. Trazoclone has also been used. The condition has become chronic and recurrent […].*

Chronic fatigue was a major symptom prior to formal diagnosis and has been persistent since. It has affected cognitive function, ability to work and contributed to exacerbations of depression. It has also prevented regular exercise with resulting negative impact on wellbeing. There is no effective curative therapy for this and the condition remains ongoing and chronic.
Clinical assessment: The severe depression, chronic fatigue, [illegible] and gastrointestinal problems all combine to affect daily living. In particular the impact on higher cognitive function has lead to inability to continue in original professional role as management support consultant and has had lengthy periods of unemployment.'

38. The standard treatment at that time was 48 weeks of pegylated Interferon and Ribavirin. For those with Genotype 1A there was a 40% chance of success as it is the most resistant form of HCV to treat. When I started treatment there were more than six million units of the virus in my blood. I received treatment in 2007 and 2008. The treatment failed. By the time I finished the first round of treatment the viral load was down to a couple of thousand units. I asked Charles Millson if I could do it again because I thought we could probably knock it on the head whilst the viral load was so low kick it whilst it was down. Charles Millson explained that I could not because NHS protocol says the virus develops a resistance to the Interferon and also mutates so treatment becomes even less effective. With a second round of treatment for relapsed Genotype 1 you have less than a 20% chance of success. As a result, and because of the cost involved, NICE would not approve it. I was not sick enough. Illogically, I would have to wait for a year, for my viral load to get really high, to put my case forward again.

39. After the standard treatment failed I asked what would happen if I did nothing. I was told that the virus could get a spurt and replicate more quickly. I was told my prognosis was between five and seven years during which time it would continue to damage my liver, could progress to cirrhosis, and the probable progression would be liver cancer. My husband and I talked about it. I felt

physically and emotionally wrecked by the treatment I had already had and said I was at peace with the prognosis. Once treatment ends you feel comparatively well. I wanted to enjoy the time I had left with my husband. But my husband said he didn't want me to die and we needed to look around for alternatives.

40. Charles Millson knew of a drug trial at St Mary's Hospital, London. The only difficulty was that the trial would only take people under the care of St Mary's because, if anything happened, you needed to get to that hospital quickly. I would need to attend that hospital for everything, even routine blood tests. Charles Millson said that of all of the trials running he believed this to be the best one. I rang St Mary's and talked my way on to the trial. I went to London and stayed with someone from the Hepatitis C Trust for a week and passed the initial screening on the understanding that every week on a Monday I would have to go down to London for the injections and to collect the medication.

41. The trial piggy-backed Interferon and Ribavirin, which is what I wanted the NHS to give me, and it was a double blind trial so I had a two thirds chance of getting the trial drug and a one third chance of getting the placebo. I thought it was a risk worth taking as my viral load was so low that Interferon and Ribavirin may have helped on their own, even without the trial drug. I finished the drug trial at the beginning of 2010 and on 16 July 2010 they rang me to say the drug had been successful, that I did get the trial drug and that I was clear of the virus. I had undergone three years of treatment more or less back to back.

42. It had been a very tough trial. It was a global trial and every week the numbers of people taking part would drop. We were never told explicitly, but we believed that some people died. Of the people in England there were about 16 of us at the beginning. I can't be sure of exact numbers because the information was confidential, but by the end only two of us were left. You were

never told why the numbers dropped. Some people pulled out because the side effects became too intolerable. I heard that some died, but we were never told directly as it was all anonymous and double-blind. One of the things I am most proud of was the work that we all did as part of that trial. Instead of people with Genotype 1 having to do 48 weeks of treatment with Interferon and Ribavirin, they developed an oral pill, with no Interferon, for 12 weeks only, a 'Mono Therapy'. When the drug trial ended the drug company, Jansen, asked me to assist with the publicity to help get the new drug licensed, so I did it. Jansen flew me around the world, speaking to drug companies and virologists. NICE later approved the drug for use in the UK.

43. During the drug trial I had to go to London every Monday and I had to cover the expenses. I had to travel on a Monday at peak time and it could cost me £300 for a day return from Yorkshire. My husband could not come with me as we could not afford two train fares and there was no official funding for travel or accommodation. Friends helped us out and when I was too ill to travel I would stay with friends in Peterborough, and they would put me on the train to London. I travelled to and from London for a year during the trial.

44. Eventually, when the team at St Mary's realised how expensive my travel was, they started making my appointments during off-peak hours whenever possible, so it reduced my fare to between £100-£300 per week. The consultant in London realised what we were having to do. St Mary's has a travel fund for people in the area who are struggling to help with travel expenses, like the tube, etc. So every now and again they would put my expenses through for me, a £100 or so here or there: they stuck their neck out and bent the rules to help me and I was very grateful to them for that. Financing travel expenses during the drug trial was a major obstacle and none of the charitable schemes (see below) would cover any of that.

45. The mental and physical effects of the treatment were as follows. It was known that the trial drug and not the placebo would cause depression. One of

the trial criteria was a willingness to take prophylactic antidepressants, because of the risk of depression. Another was to keep a journal of any physical and particularly any mental issues during the trial. My therapist (who I had found and funded privately) helped me a great deal and saw me regularly and supervised the filling in of the journal. Ribavirin can cause 'Ribarage', it is like PMT on steroids and you can behave like Jekyll and Hyde. I worked really hard to make sure I never suffered in this way and my therapist is witness to this. Psychologically I weathered the treatment very well and it didn't get me down, I accepted what I would be going through.

46. Physically, I was in bed a lot of the time or at St Mary's in London. Often I was too sick to walk down the train carriage to go to the loo or get a cup of tea. The train staff came to know me as a regular traveller and they knew I was having chemo of some kind, so they would bring me tea, a newspaper and a bun. Sometimes when I was having a really bad day, they would get a wheelchair to help me off the train. They were brilliant.

47. The drug trial was initially interested in studying me because I had already undertaken 48 weeks of Interferon and Ribavirin combination. They wanted 'relapsers' or 'non responders' to traditional treatment, for the trial subjects. The trial involved a further 48 weeks of the same combination of drugs, meaning I have had 96 weeks in total. I don't know of anyone else who has had treatment with those drugs for that length of time almost continuously. They said they would be interested in studying someone who had had such a long period of almost back to back treatment because it was so unusual.

48. Ribavirin is very hard on your stomach and you therefore need to take a high content of fat when having the drug. I am left with a hiatus hernia and acid reflux. I also suffer from oesophagitis and gastroenteritis. This is ongoing and I am on medication for life. I attribute this to 96 weeks of taking drugs that have such a history of adverse affects on the stomach.

49. A lot of people who have had hepatitis C treatment have been left with polymyalgia or fibromyalgia. Since the drug trial I have been diagnosed with fibromyalgia, which produces chronic fatigue and chronic muscle and joint pain, attributed to the treatment I have had. My mobility is really affected, for example, I don't find it easy to shop at the supermarket and either go with someone or have my shopping delivered as I struggle with lifting heavy shopping. We have also had to take on a cleaner as I cannot kneel on the floor and clean. We used to enjoy hill walking, but I can't walk for long now and certainly not over rough ground due to pain in my feet and knees. I feel much older than my years and my body feels like that of a much older person with aches and pains – arthritis and joint pain that I didn't imagine getting until I was much older.

50. Interferon is a type of chemotherapy and it is believed that it can affect heart function. During the drug trial they did a heart trace every week before commencing treatment. The drug affected my heart and I had to sign to say I understood it might leave me with heart problems. I have got left ventricular regurgitation as my left heart valve is weakened as a result of the prolonged Interferon.

51. My infected status has not impacted on my dental treatment, as my dentist has been very good, but it has impacted upon my medical treatment on occasion. Some of the worst treatment I have received was from medical professionals, which I assumed would not be the case. When I went for my liver biopsy, I opted to go through Bupa as we had private health insurance at that time, and I was admitted to the Capio Yorkshire Clinic, a private hospital. This was my first encounter with the sort of stigma you are exposed to with HCV and it was a shock. They knew I had Hepatitis C and my medical notes had yellow and black tape over them and a skull and cross bones. I do understand the need for caution but it makes you feel like a plague victim. The nurse noted I was there for a liver biopsy and asked whether I was a drinker. I said I had had a blood transfusion but she looked at me sceptically, and said 'no drug use at uni

back in the day then?'. I told her I had never taken drugs. She replied, 'that is what they all say'. When she left the room I cried. She came back into my room some time later and I told her she had made me feel like a pariah. She said, 'you are newly diagnosed, you will get used to it'. She came every half an hour throughout the night to carry out observations and made a huge show of putting on an apron and double-gloving. I said, 'you are a nurse and you should know this can only be passed on through blood to blood transmission'. She said, 'believe you me I am taking no chances with you'. In the morning the consultant asked her to remove my cannula and she flatly refused. The consultant had to do it. My husband was incensed by the treatment and wanted to make a complaint, but I felt I had too much to deal with to do that. I have to say, at the BUPA hospital, it was just this one member of staff. Everyone else was very kind – but one person treating you like that is one too many – especially from a medical professional who should have known better. The way you are treated when you have HCV can be appalling and that is why, at the time, I had to have the support from a psychotherapist.

52. To this day, whenever I have to go for surgical treatment, I am treated differently. Although I am now clear and my blood is clean, because I am antibody positive the hospital always put me to the end of the list, and I am the last one in theatre. If I am booked in for 7am, and am nil by mouth, I can still be there at 9pm at night, so they can sterilise the theatre after my surgery. That is not right. It makes me feel like a leper and is stigmatising.

53. HCV impacted on my working, family, private and social life in many ways, as follows.

54. When I was still able to work, in the first three or four months of my treatment, I had a regular client which was a factory. I informed the management of my diagnosis, but the workers did not know. I did a lot of work with the client, both on the factory floor and in the training room. I turned up one day and the union representative stood up in front of everyone and said, 'we understand you

have got Hepatitis C. No one here wants you in the staff kitchen. You cannot use our cups and saucers and we are boycotting your training.' They didn't even want me using the toilets. There was no point trying to explain you cannot catch the virus like that. The management tried to do so, but the contract was over. It became common for people to ask me to keep my cutlery and crockery in different cupboards.

55. The impact of HCV on my social life was unexpected. The reaction of certain people in our social circle shocked me. My husband and I lost friends as a result of the virus. People just faded away – they didn't know how to 'be' around me – what to say or how to behave. Because they couldn't handle it, they just disappeared. On one occasion we were staying with friends for a dinner party , and one or two people knew about the virus, but I didn't make it public. As they were passing the plates down the table at the end of the meal, a woman said, 'I don't think your plate and knife and fork should go in the dishwasher with everyone else's'. Another time, friends said that if I was present they didn't want to attend dinner parties because they were scared of catching the virus. When we went to stay with friends one weekend we told them about my diagnosis over dinner. We stayed the night and were later told by other friends that they had burned the sheets after we left.

56. The impact of the virus on our children was lessened by our decision, as a family, not to tell our children's school. My oldest son was at university and my youngest doing his A-Levels when I was diagnosed. I had heard horror stories about other parents saying their kids could not play with other kids and things like that. There was no reason for the school to know, so we told no one. I hope the children were spared some of the stigma by this decision.

57. The impact of my infection on my parents was more difficult. Thankfully, my father had passed away a few years before I was diagnosed and he never knew. My mother was still alive and in her eighties when I was diagnosed. Some years earlier she had made me promise not to put her in a home but to look after her in her own home in her old age. During the time I was diagnosed

she was living at home and had carers four times a day. I would go in regularly and do the other things the carers would not do. She had worked for the police as a police matron, so she knew what HCV was, and her younger brother had died of liver cancer a few years before, though this was not connected to HCV. When I told her my diagnosis, my mother looked me in the eye and told me that dying of liver disease was the most horrible way to go. She said she wouldn't want her grandsons to see that and told me the best thing I could do for myself and my children was to kill myself. She said my husband, my soul mate and best friend, would not want to live with me like this, that he did not sign up for it and he would leave me. And that was my mother. I couldn't believe it.

58. The impact of the infection on my family life turned out to be the worst of all. It destroyed my marriage. My husband had supported me through the first round of treatment. He had talked me into the drug trial as he said it was our best chance of clearing the virus and that once we were free of it, we could live our lives out together. In total I went through three years of treatment and got the all clear in July 2010. Then, in October 2011, he got up, told me he loved me, kissed me goodbye and went to work. He never came back home after that day. I never saw him again except in court when he sued for divorce. He had been having an affair throughout that year unbeknown to me and that day he left for somebody else. He said the treatment and the drug trial had been too much for him, that he had turned into a carer and not a husband, that he had cleaned up my vomit and nursed me, and that he no longer saw me as a lover and a wife but as a disease.

59. He filed for divorce and wanted an immediate sale of the house so he could afford the deposit on a new home GRO-D He cited unreasonable behaviour, saying Ribavirin had made me present with Jekyll and Hyde symptoms. He knew the hospital had warned us about this in the drug trial. I knew I had not suffered with this and my psychotherapist throughout the drug trial knew I hadn't either. GRO-D

GRO-D

60. I had no money left as the illness and treatment had used up all of our financial resources. Before beginning my first round of treatment, I had cashed in all my personal endowment policies and all my investments, as I knew I wouldn't be able to run the business. I was planning on using that money to cover my loss of earnings as no financial schemes would offer assistance for treatment. I believed then I was covering finances for a 48 week treatment period. Little did I know it would turn into almost 3 years and take all my financial resources. I could not afford the court and legal fees and friends clubbed together to help me pay my legal bills. I cross-petitioned on grounds of adultery and produced my diaries from the time of the drug trial which my therapist had supervised. That journal really helped because I could document I had not suffered Ribarage or mental aberration as a result of the drug trial.

61. The judge said that he could not accept an illness and its subsequent treatment were the cause of unreasonable behaviour. The judge's decision was that, because of my infection with HCV, which was no fault of my own but through the contaminated blood scandal, if he ordered an immediate sale of the house there would be very little equity in it and I would not be able to afford to buy anything else. He refused to order a sale and gave me our home for three years, during which time, if I could earn enough money to remortgage the house or sell it to release my husband from his mortgage obligation I would get to keep 100% of the house. If not, I would have to sell it and he would get 40% and I would get 60%. Over the next three years I did manage to rebuild my business enough to remortgage the house a few months short of the court deadline.

62. Until that time I had managed to deal with it all, but I found I couldn't deal with the loss of my marriage. I felt as if I had gone through it all for nothing because I lost the person who had meant the most to me in the world apart

from my children. The loss was incalculable and that tipped me over the edge. I fell into a complete depression and had a nervous breakdown. I remembered what my mother had said right at the beginning and thought maybe she had been right, cruel as I thought she was being at the time, and that it would have been preferable if I hadn't survived the illness or the treatment.

Section 6. Treatment/Care/Support

63. I did face difficulties obtaining treatment in consequence of being infected with HCV. The first was when I decided I couldn't give my care over to Dr Morea in Bradford and that I wanted to be cared for by Charles Millson. The difficulty was the changeover in funding. Thankfully, there was not too much of a delay in the changeover as Charles Millson helped facilitate it.

64. The second difficulty I faced was when I was told I could not repeat the treatment after the first round had failed, as set out above. This seemed counterintuitive; I had to get sicker before they would help me. It was frustrating because it was cost based, rather than success versus risk based.

65. Counselling or psychological support was not made available to me in consequence of being infected. My GP did not offer any at the point of diagnosis. If I hadn't done the job I do as a psychotherapist I wouldn't have got any support at all. All psychotherapists have supervisors to make sure our mental health does not suffer as a result of what we encounter in our work. When I got diagnosed I was completely shocked and devastated. I went to my supervisor and said the standard NHS treatment would last 12 months. I said I would need help to get through it. My supervisor kindly gave me monthly sessions free of charge, but it is something I had to source myself.

66. Then, when I finished the drug trial in January 2009 I started working for the Hepatitis C Trust in March 2009. I had to wait six months to see whether the trial was successful and the Trust paid for me to see a therapist for ten

sessions, so I went back to my original supervisor. This was around the time my marriage was failing and I could not handle the disease destroying my family. My husband's desertion and the court case unravelled me totally. Had I not worked for the Trust I would not have got this assistance. My GP at this time *did* offer a referral for counselling, but it was connected to my breakdown when my husband left. I refused it, as there was a waiting list of more than six months and by then I had sourced therapy from my supervisor – plus the Hepatitis C Trust was funding my sessions – so I didn't want to be put on an NHS waiting list.

Section 7. Financial Assistance

67. I found out about the Skipton Fund because as soon as I was diagnosed by my GP he pushed a sheet of paper over to me about the Fund. He told me to apply straight away and said he would support my application. He put a lot of time into it and went through my original records and found the evidence about the blood transfusion. I received a Stage 1 payment of £20,000 from the Skipton Fund in around April 2007. The application was quite straightforward because my GP provided a letter in support and there was no other route to infection. There were preconditions imposed on the making of the application for financial assistance. I think at the time there was a form attached which said something along the lines of this being an ex-gratia payment and you cannot sue anybody. I no longer have it but I remember looking up what the ex gratia criteria meant.

68. My observations about the financial assistance offered by the various Trusts and Funds are as follows. The financial assistance is not enough and is totally inadequate. Although £20,000 sounds like a lot you cannot live on it for long. I remember looking at the Stage 2 payment of £50,000 and thinking how much I needed that money – but to get it, you had to be at death's door.

69. The lack of financial assistance was a huge stress. I was self-employed running a limited company delivering personal development psychological training with around 20 trainers on the books. Although they were freelance I had to pay them as and when they did the work. In December 2006, before I was diagnosed, I was struggling to work due to my ill-health. I did a lot of 'stand and deliver' work where I would deliver training on my feet all day and travel all over the world. I found I simply couldn't do it any longer and my income was starting to drop. I decided to buy out another company who only delivered health and safety training, the thinking being that health and safety was a statutory requirement and not a 'soft skill' like my company which could easily be dispensed with. It was also not my area of specialism so I would not be able to deliver the training but instead could work behind the scenes to keep things running. I remortgaged £30,000 from the house to buy the new company, and it kept a bit of money coming in, but I underestimated the difficulties I would experience in that first year of treatment. Not only could I not stand and deliver, but I could not even go into the office to keep the company going. The treatment left me with crippling fatigue and cognitive impairment which made running such a complex business impossible. When it became apparent that I couldn't work, we started to struggle, and then my husband at the time lost his job. He was sacked, not made redundant, so because of the sacking he could not claim any benefits for six months.

70. My mother died in April 2008. I am an only child and my parents had worked hard to own their own house. I sold her house and we lived on the equity as we had no assistance from anywhere else and I had cashed in all my policies, endowments and savings. The £20,000 from the Skipton fund went straight against the mortgage as we were realigning our finances to deal with the year of treatment. I had thought I would only have to support us through the 12 months of treatment, but I found I was too ill to work and my then husband lost his job. My inheritance literally paid the bills and bought the food and that was all we had. We cut back on everything but essentials. I cancelled my pension and now have a depleted pension pot, which is now not enough to enable me

to retire. Whenever I got notices through from other Trusts they were means tested and we never seemed to meet the criteria: we were too badly off not to need it, but not bad enough to qualify because we owned our own property and were not claiming benefits. If my mother had not died we would have ended up selling our house and probably going into social housing.

71. The staff at the hospital said we could apply for Disability Living Allowance and the Hepatitis C Trust put me onto a benefits advisor to help me. We applied for everything and got turned down for everything. Even my consultant put in a letter on appeal. The answer was that it was not a long term disability. I ticked a lot of boxes: I couldn't walk 40 yards, I couldn't climb stairs, I spent time in bed, I couldn't always cook meals or look after myself, but they said it was the treatment causing the symptoms and there would be an end point to that.

72. There is a great disparity between the HCV and HIV schemes. When I saw the HIV consultant he made a telling comment. He said I would find out as I went through this process that those contaminated with HIV would get more money and financial assistance than those with HCV. There were other disparities too: those infected or co-infected with HIV would get fast-tracked through the benefits system and didn't have to jump through hoops.

73. I have recently sold my home in Yorkshire that I struggled so hard to keep and now live with my partner in a house that he has built, so there is no mortgage. I own nothing. The only regular income I have is £1,500 a month from EIBSS. I work part time, occasionally seeing private therapy clients, but it's not regular income. If I didn't have the EIBSS payment I would not be able to live. I want to buy a small property but I do not know if a mortgage lender would accept the EIBSS payment as reliable income. I cannot get life insurance or travel insurance. I have nothing to leave my children except any savings I can build up going forward.

Section 8. Other Issues

74. Through my work with the Hepatitis C Trust and talking to the people I have met, including those in prison who I've worked with through running harm reduction schemes for vulnerable people the overwhelming feeling is that successive governments have kicked this issue into the long grass for over forty years now. GRO-D GRO-D GRO-D Even since this Inquiry opened how many people have died?

75. There are two issues that I hope the Inquiry will address above all others. First, who is culpable and how did it happen? What did the Government know and when, and could it have been prevented? I remember Lord Owen, former Labour health minister, told me that the minute he knew, in around 1983/4, he ordered the imports of blood to stop, and was mortified when he later discovered the imports had continued. He had issued a memo, but when he asked for that document to be produced, it had been destroyed. If that is the case then obviously it must be looked at by the Inquiry.

76. The second issue I want the Inquiry to cover is financial recognition for those infected and affected. I was infected with this disease when I was 26 years old and it has robbed me of good health and life. I have now had more life with this disease than without it and it has affected me and my family. Someone going to prison for what happened would not change my life at all, but financial recognition would. I want the Inquiry to pursue financial recognition that goes some way to putting right what we have lost. I will never get back to where I was before I was diagnosed and went through treatment. I will never recover financially. I have worked all of my life and I have nothing to show for it and nothing to leave my children. If it was not for the EIBSS payment I would not be able to live. I would become dependent on others. For the worst disaster in the history of the NHS we deserve financial equality. It may seem shallow to

say that financial recompense would make more difference than some politician going to jail, but in our society, money equals security, and the one thing this disaster robbed the victims of was security. Security of a healthy old age. Security that everything they worked so hard for and built up over a lifetime can be there to give them a comfortable retirement. Security that we have something to leave our children. That we can access financial products – mortgages, life insurance, health insurance. In my case it robbed me of the financial independence I had been proud to work towards all my life. That needs to be restored for all those who have suffered through no fault of their own in this nightmare.

77. I have carefully considered the question of anonymity for this Inquiry. I have chosen not to be anonymous despite the continuing stigma associated with this disease. I think it is extremely important that the Inquiry understand the impact this disease has on people's lives. This disease puts a shadow on your life and the lives of those you care about forever.

Statement of Truth

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

Signed

GRO-C

Dated 1 February 2019