

Witness Name: Nicola Leahey
Statement No.: WITN022301
Exhibits: WITN0223002 - 14
Dated: 3 December 2018

INFECTED BLOOD INQUIRY

15 JAN 2019

FIRST WRITTEN STATEMENT OF NICOLA MARY LEAHEY

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 12 November 2018. I adopt the paragraph numbering in the Rule 9 request for ease of reference.

I, Nicola Mary Leahey, will say as follows: -

Section 1. Introduction

1. My name is Nicola Mary Leahey. My date of birth and address are known to the inquiry. I am married with three children and I am retired. I used to work in the NHS as a senior manager in clinical governance until I retired due to extreme tiredness in 2006.
2. I intend to speak about my infection with hepatitis C as the result of infected blood. In particular, the nature of my illness, how the illness affected me and my family, the treatment received and the impact it had on me and my family's lives.

Section 2. How Infected

3. I believe that I became infected with hepatitis C through NHS blood transfusions. I had four blood transfusions between 1975 and 1980; I do not know which transfusion(s) caused me to contract hepatitis C. I have my ears pierced but that is it. I do not have tattoos and I have never used intravenous drugs.
4. In 1975 I suffered a miscarriage and was transfused with two units of blood at Billinge hospital.
5. On 6 August 1980 I went into Billinge Hospital for a prolapse repair. I intended to have more children, but the doctor decided that they needed to do a hysterectomy instead of a prolapse repair. This decision happened very quickly and my husband had to consent to me having it.

6. It was decided that I would have a new procedure called a vaginal hysterectomy so that the surgeon wouldn't have to open me up. I believe I was one of the first patients to have this procedure.
7. After the procedure, I felt unwell for several days. I had the surgery on a Thursday; on the Saturday I collapsed and had a cardiac arrest. The doctors worked on me and discovered that I had a pulmonary embolism so they started treating me with heparin, a blood thinner.
8. When my mother (a qualified nurse) visited me in hospital that day she felt something was wrong. That evening she called the hospital to ask them to check my blood pressure. I felt something was wrong, my stomach was blowing up. Another patient on my ward also kept ringing their buzzer because they were worried about me. They examined me and realised I was bleeding internally. The hospital rang my husband and told him to get there quickly because I was seriously ill and might not survive.
9. I was too ill at this point to go back to theatre so the doctors gave me a blood transfusion and stopped the heparin. It transpired that my surgeon hadn't sewn me up properly internally and I had been bleeding from my main artery. I have since read my medical notes and understand that I was very fortunate to survive.
10. I remained in hospital until November of that year. My medical notes record that I had a haematoma in my pelvic cavity and abdomen and had developed abscesses on my kidneys and kidney damage; when I left Billinge hospital in November I was transferred to Wrightington Hospital to be under a kidney specialist. The gynaecology consultant continued to see me at Wrightington and also visited me when I eventually was discharged home in November.
11. In total, I had three blood transfusions between August and November 1980. Two of these were in mid-August when the doctors discovered I had been bleeding internally. The third was in September 1980. I was allowed home from hospital for a weekend as it was my child's birthday; over that weekend I began bleeding heavily. When my husband came to check on me, the mattress was saturated with blood and he thought I was dead at first. He called an ambulance and I was given another transfusion.
12. I have been able to obtain the batch numbers of the blood units that were used for my transfusions, including those which were returned unused. Photographs of these records are exhibited as **WITN0223002 - 7.**

13. No one ever discussed any risk of infection through blood transfusions with me. The blood transfusions were administered as urgent treatment. My husband does not recall ever being told about any risk of infection through blood transfusions either; he had to consent to some of my procedures. In the beginning I was under morphine all the time and bouncing through walls. I was very unwell; I nearly died several times.
14. I found out that I was infected with hepatitis C when I went to my GP about extreme tiredness, bruising and sweating in June 2009. She sent me for blood tests and then asked me to go for a second set of tests. I think they tested my ALT levels on the second round of tests. I think I told a friend who worked in pathology about my ALTs and I remember her encouraging me to go back to the doctor to ask for more blood tests.
15. I was then sent for a liver ultrasound in July 2009 and further blood tests. My blood test results showed something was wrong with my liver. I had figured this out by looking at my ALT results.
16. My GP told me I had hepatitis C on 11 August 2009. The day before she had rung me at home and asked me to come into the surgery the next day as they had results from my blood tests. It sounded ominous. I went to see her alone and she told me I had hepatitis C and I had to see a consultant. She seemed to be in the dark just as much as I was; I was surprised at the lack of information given to me.
17. I didn't realise how serious it was. I had done some research and knew that it was bad for my liver, but I didn't think you could die from hepatitis C. I knew that there was treatment available but I didn't know it was like chemotherapy. I got printouts about hepatitis C and the NICE guidance myself from the internet; I wasn't given any of this information by my doctor.
18. I then saw a consultant privately on 24 August 2009 at Euxton Hospital who examined me and confirmed it was hepatitis C. I went privately for this because it would have been 3-4 months to see him on the NHS. At this appointment he referred me for a liver biopsy on the NHS. The consultant did not really provide me with any information, just confirmed the diagnosis and said I would be seeing him on the NHS at Chorley Hospital. I asked for an HIV test and I asked if the hepatitis C could be related to the gastric bleed I had in May 2007. He didn't answer.
19. I saw him again on 8 September 2009 at Chorley Hospital. I asked him a lot of questions, such as why hadn't the liver results been shown in

previous LFT checks, could they fluctuate? He didn't answer some of my questions and I felt he was very dismissive and that he was passing me over to the specialist nurse. I think it was on this occasion that he asked whether I had had needle stick injuries, tattoos, sex with other partners, piercings – he was asking about how I might have got hepatitis C and I found it insulting and embarrassing. I again asked for an HIV test and asked why it had not shown up in previous LFT checks. In May 2007 I had a gastric bleed and tests run at the time showed an ALT score of 110 (I believe the normal range is 1-41) but no one had done anything regarding my liver. I do not recall him answering me.

20. I had the liver biopsy on 7 October 2009. The biopsy was done by someone I knew from when I had worked in the NHS.
21. On 3 November 2009 I saw the same consultant again to get the results. He told me that I had genotype 3A hepatitis C. Again I felt he did not give me a lot of information – he had quite an evasive nature and I felt he was passing me on to the nurse. I still didn't realise how serious it was.
22. My medical notes record that the biopsy showed I had mild to moderate scattered foci, of spotty necrosis within hepatic lobules. It was mild chronic hepatic hepatitis consistent with chronic hepatitis C infection. The appearance suggested Ishak necron inflammatory scale of 6 (range being 0 to 18); a metavir scale of 1 (range is 0-4). My final diagnosis was liver biopsy consistent with chronic hepatitis C infection with on-going inflammation and minimal fibrosis.
23. The consultant told me I was very lucky – I had never smoked, I didn't drink a lot and I was always very fit. I was told I would receive treatment for 6 months and they also arranged a HIV test. I was also given a hepatitis A vaccine.
24. On 26 November 2009 I saw the hepatitis specialist nurse. She was someone I knew of from when I worked in the NHS, and she also knew who I was. She explained that treatment would start in January 2009, after Christmas, and would take six months. She explained the side effects and appointments to me. I started Pegylated Interferon 100mcg weekly and Ribavirin 1gm daily in January 2009.
25. Once the treatment was completed and the results showed that it had worked, I was discharged from the consultant.
26. Nobody told me what to do regarding minimising the risk of spreading infection. I had to find that information out myself and I was horrified. I made dietary changes, but I made those myself – no one ever told me not to drink alcohol, I decided not to.

27. I do not feel I was given adequate information about what the treatment for hepatitis C would involve. I didn't think for a minute that it would be as bad as this. During the treatment process itself, I said that if I had known it would be this bad, I wouldn't have had it. I had no idea it would take me out for days at a time. I didn't know what to expect.
28. I made lists of questions I wanted to ask the doctors and nurses before each medical appointment. These are exhibited as **WITN0223008 - 13**.

Section 3. Other Infections

29. I do not believe I have contracted any other infection as a result of blood or blood products.
30. I have been tested for HIV at my request and my results were negative. I do not know if I have been tested for any other infections. No one has mentioned anything else to me. I asked for vaccines against hepatitis A and B and was given them.

Section 4. Consent

31. I do not believe that I have been treated or tested without my knowledge or consent or for research purposes.
32. I do think that more information should have been given to me during the diagnosis and treatment of my hepatitis C. I had to find a lot of information out myself, which I was able to do because I had previously worked in the NHS so I understood what NICE guidance was and things like that. Even with doing my own research, I still feel that I did not know enough about what to expect, particularly with regard to treatment of hepatitis C.

Section 5. Impact

33. I still live with the physical impact of hepatitis C even though it is now in remission. In addition to extreme tiredness, I also experience night sweats that are so bad they saturate the sheets and we have to change the bedding; sleep problems as I wake up usually three times in the night; and my metabolism was terrifically affected. I now put on weight very, very easily which was never the case before; I was always very, very fit and used to be a runner, but I gained a couple of stone and now I have to be really careful to maintain my weight.
34. Hepatitis C has changed me, physically and mentally. I struggle with concentration and my memory has been affected. I used to have such a professional life and would be in the limelight a lot; now sometimes I

- can't think of words and I have to say "thing" – that annoys me so much. Sometimes I have to ask my husband for words.
35. It has had a very big impact on my identity. I didn't have the confidence to go back to work – I felt I wasn't all there. I wasn't Nicola anymore; I was Nicola minus.
36. I have some other health issues but I don't know if they are to do with my liver and the damage from hepatitis C; in 2012 I had a DEXA scan which identified that I have osteopenia, which is a bone density issue, and ever since I got ill with hepatitis C I have had eye issues, which I have never had before. During appointments whilst having the treatment a heart murmur was identified; I do not need medication for this but it means I am very conscious of my heart.
37. It has also had a significant impact on my mental health. I suffer with anxiety, guilt and depression.
38. This is a life sentence. When they told me that treatment had been successful, they told me that the hepatitis C will never be gone forever. I am not cured but I am treated; it is in remission. There will always be a trace in my body and they say it could come back. I am tested for hepatitis C every six months. It hangs over me. It is a huge source of anxiety when I wait for those test results, and I also worry for the period in between tests; what is to say that although I was clear on the day I had the blood test, the hepatitis C hasn't come back the next day?
39. If the tests ever came back positive again I don't know what the hell I would do. Right now, I have the fight in me because I'm winning against this – but I think I would be past fighting if it came back.
40. I have blood tests every six months and a hepatitis C test. Whilst I wait for the hepatitis C test to come back, I get my blood test results and I keep track of the levels in a spreadsheet. For example, I know my ALT score was 153 in July 2009; one month into the interferon treatment it was 96; then it dropped as low as 17 or 18 at one point.
41. Recently my ALT score has gone up to 25 and I worry what this means. I have to go for a fibroscan soon to check my liver because of my raised ALT score; if that shows anything questionable they will do another biopsy. Just because my blood tests show no return of the virus does not necessarily mean that there has not been further deterioration of my liver. I now understand that I should not have been discharged and should have continued to have regular check-ups.
42. I have to wait three weeks for the tests to come back. Some of the results are greyed out when they come through to me, so my GP will give me un-redacted printouts of all of my tests because she knows that I get very anxious and need to track my results. We have quite a good

relationship, I feel it has been a learning curve for her, as she didn't know about hepatitis C before, but she has been helpful with my test results and has reminded me to tell the investigators about my symptoms.

43. I used to be a clinical auditor, so I record everything. I think that if I didn't keep my mind busy by tracking the test results, I would feel less in control. It's my coping mechanism. I also track my viral load as well as my ALT.
44. I also have anxiety about what damage the hepatitis C may have done to my liver. I worry about whether I could develop cancer or cirrhosis.
45. What really worried me when I found out that I had hepatitis C was the guilt that I might have infected others without knowing. All **GRO-C** were tested and were clear. **GRO-C** have not been tested as we don't want to put them through that, but it is a question for us.
46. I worry about other people I could have infected without knowing. I had a ten-year break from work to raise our children and during that time I ran a playgroup and I had obviously cut myself at times - could I have infected other people? I have also had moles removed; one time, one of them spurted blood all over the doctor's face - we made a joke about it then, but now I worry whether he could have caught hepatitis C through that incident. I sometimes wonder should I tell people to try and trace it back.
47. Since finding out that I have hepatitis C, I make it a point to tell people. I had another mole removed last year and I told the doctor straight away. They took extra precautions even though I was in remission. When I have bloods taken I have a thing about gloves being worn. One time a phlebotomist said he wouldn't wear gloves, and I kept asking him to put them on for my sake as well as his own. He refused to, so I reported him. He was very arrogant even though I had told him I had hepatitis C. I have blood taken every 6 months and I constantly have to explain. I feel the need to make a joke of it and explain that I got it from a blood transfusion in 1980. I'm embarrassed. I shouldn't be, but I am. I'm not a prostitute, I'm not a prisoner - it was a blood transfusion. I am afraid of being labelled.
48. I was very depressed during the Interferon and Ribavirin treatment, which was very tough. Although that has lifted, I still feel depressed. It's there all the time. I know what it's like to almost die - I almost died several times. It brings death much closer to you; you know how quickly it can happen.
49. I started treatment with interferon in January 2010. I had wanted to start sooner, but the nurse advised that we start after Christmas. My husband and I went to clinic appointments with the specialist nurse,

who taught me how to inject myself with interferon and reviewed my progress.

50. Going to the clinic appointments made me feel extremely stigmatised. The clinic would be full of prisoners and some people who looked like prostitutes. I felt very out of place; it felt like people were looking at me and wondering what I had done wrong. As the weeks went on, I would get more and more dressed up for the appointments because I didn't want to be associated with that. I thought it was awful. People around me looking at me, knowing what I had got. Some people looked like drug addicts. I was frightened to go on my own; my husband came with me.
51. The nurse was quite surprised by me. I don't think she had really dealt with anybody who had become infected through a blood transfusion. She had a very matter of fact approach – no compassion. I felt like she was used to treating a different kind of people. That upset me. It really hit me.
52. She talked to us like we were children. She made a point of telling us how expensive the treatment was – I think she quoted in the region of £5,000 per week – and how much the entire treatment would cost the NHS. I felt that she wasn't encouraging me to have treatment; as if she thought I wouldn't bother. She told me I was lucky to be getting the treatment.
53. She also told me that there would be a predictor of success after 12 weeks of treatment and that if there wasn't any improvement by then, they would stop the treatment. This gave me a lot of anxiety over the first 12 weeks as I worried about what would happen if I hadn't improved. It was clear to me that it would be her decision whether I stopped treatment, not mine. This was an added factor on top of the terrible side effects.
54. I knew the nurse from when I had worked in the NHS. I felt that she did not like that I had been more senior than her. It may also be possible that she didn't tell me as much information because she knew I would do my research; but if I hadn't done my own research, what she provided me with would not have been enough information. I tried to ring her several times with questions and couldn't get hold of her; there was no support mechanism.
55. During the treatment process I worried that the interferon might not work. I asked the nurse about this, and she said that I wouldn't be able to have Interferon and Ribavirin again as the NHS couldn't afford it. She said the PCT (now CCG) wouldn't allow it. I was so cross, because I

thought prisoners are getting it – why couldn't I have it again if it didn't work? It was like I was being told that I had had my chance and that was it.

56. The first week, we met with the nurse and she explained the treatment and went through the process. On the second week I was shown how to inject myself. On the third week the nurse watched me inject myself. There were a few steps to preparing the injection and it was quite fiddly. I didn't feel confident administering the injections myself, but I had to do it. There was no alternative option. I feel the nurse could have been more patient and given me more support so I didn't feel so on my own. If it hadn't been for my husband being there, I don't know what I would have done.
57. For the treatment itself, I would inject myself every Thursday at 4pm and I also took ribavirin tablets every day. It's very hard to inject yourself; you have to grab your fat from around the stomach/waist area. The first time I did it at home I was fine, but the second time I froze and couldn't push the needle in. My husband had to push it in for me. Afterwards the injection site would be red and painful. I still have swelling from the injection site eight years later.
58. I had to keep the interferon in the fridge and take it out a certain amount of time before. One time we had a problem because I hadn't taken the interferon out long enough beforehand, so that one failed on us and we had to go to the nurse.
59. When I would inject myself, I would do so at 4pm. By 8pm that evening I would have terrible headaches, flu-like symptoms, light sensitivity and I would be terribly sick. I would go to bed and spend the next four days lying in bed in a dark room. By Monday I would be out of bed again and back in the living. Everyone knew that after 4pm on Thursday I would be out until Monday.
60. I became very depressed, spending four days a week in bed in the dark. At one point I was suicidal. I thought what the hell. I shouldn't have thought like that, and it annoyed me so much; I had these lovely grandchildren and it really got me – why was I thinking like that when I had them? But I was constantly thinking: what was the point? I had never gone through depression before. People didn't understand. It was constantly there. I didn't attempt suicide, but I had access to a lot of painkillers and it went through my mind. But I felt that was the coward's way out and I am not a coward; I am a strong person.
61. That period of depression lasted for about 12 months. I practically became a recluse during that time. Before I got ill we would go out socially with friends every couple of weeks. That decreased when I

started to get ill, but once I started treatment I didn't go out. By Christmas 2010 I started to feel a bit more normal and we might go for a walk by the lakes. In February 2011 I applied to be hospital governor, and in April 2011 I was successfully elected. This coincided with feeling stronger and having a more positive mood.

62. A friend used to come round and take me to the gym, make me talk to people. She really brought me out of myself. Now I look back and think why didn't I ask for help? Why didn't I shout out please help me? To me, it seemed like the attitude was that I should just accept it. Now I wonder why the family had to suffer, why didn't they have counselling to be able to help me? You only think about this afterwards; you get so used to the idea and self-help.
63. The side effects of the treatment were really bad. I had terrific muscle pain, moods and irritability, depression, itchy skin, persistent cough, loss of libido, nausea, lack of concentration (which is still an issue now) and anxiety. I also lost all of my body hair, including eyebrows and eyelashes, and my hair came out in clumps like chemotherapy. This affected my self-esteem quite a bit, as I have always paid attention to myself and taken personal pride in my appearance. Although my hair began to grow back from about Christmas 2010 however not as thick as it was – my body hair has not returned. I wear false eyelashes and pencil in my eyebrows. I was prescribed Daktacort cream for the skin rash, Metroclopramide for the nausea and cough medicine for the persistent cough. I was sent for a chest x-ray on 11.02.2010 in view of the cough which showed no active disease of the lungs.
64. The side effects would last all week. I was told that the interferon would take 6-12 months to come out of my body. It was a further 8 months on top of that when I started to feel a bit more with it and when my hair started to grow back. It was awful.
65. I have also experienced irritable bowel-like symptoms since the interferon and ribavirin treatment. I can't have garlic, spice, caffeine or alcohol, and I have to take Gaviscon and Buscopan a lot. This means I end up missing out on celebrations as I have to have something else whilst everyone has spicy food and alcohol etc. I made an exception and allowed myself one drink when my son was awarded his MBE, but it was worth the subsequent night sweats.
66. I also have to live with sleep issues. I fall asleep from about 6pm and then I wake up and go to bed at about 9pm. After that, I will wake up several times during the night. For the past few years I have been prescribed Amitriptyline for my sleep, which also helps my anxiety.

67. Another aspect of my illness and treatment is that because I had worked in the NHS for so long, I was treated by people I knew. Both the person who performed the liver biopsy and the specialist consultant were people I knew through work. I found it embarrassing to be treated by people I knew. Sometimes it meant I could get better information from them, but it was embarrassing to be treated by colleagues.
68. Being infected with hepatitis C has affected my family, private and social life significantly. Before I started the interferon treatment I was looking after my grandchildren on a regular basis. I couldn't do that during treatment or for 12 months afterwards, so that had quite a big impact. My daughter had to get a childminder to look after their child and my son with three children moved away because they had relied on me. It was also a shame because at that time, I had a new grandchild.
69. It was also very disruptive for the grandchildren themselves. They couldn't understand why they suddenly didn't see grandma at weekends because grandma was upstairs in the dark. I was very close to my grandchildren, especially the eldest – we were helping bring her up [REDACTED] GRO-C [REDACTED] She was the most affected by it. She would have been aged five when I started treatment and she really missed me. She would come and see me upstairs in bed, but she couldn't understand why I didn't want to play.
70. My children were devastated by my diagnosis. They started treating me like an old lady and as if I had a death sentence. They were especially affected when [REDACTED] GRO-C [REDACTED] it really brought home the severity of it.
71. Two of my children were around whenever they could be, but not long after my diagnosis my son with the three children moved away. It might have been coincidental, but I felt that maybe it was because of my inability to look after the grandkids, and that his wife might have felt I had let them down so they moved nearer to her family. We don't see them now as much as we used to.
72. I went from being the matriarch of the family, the go-to person, to suddenly being put upstairs in a bed and not being useful. I didn't have anything to offer. That probably contributed a lot to my depression.
73. Christmas 2009 was a sombre Christmas. I had told the kids about my diagnosis. I wanted to start my treatment, but I had been told to wait until after Christmas. It was an awful time. I remember thinking I was really looking forward to Christmas 2010, when I would be over all of this, but then by the time Christmas 2010 came round I was still feeling the effects of the treatment.
74. Even after being successfully treated, I still feel an impact from the hepatitis C upon my private and family life. Being extremely tired means

that I need early nights, so that affects our social life, as do my dietary restrictions. I also feel less sociable as a side effect of the illness and treatment.

75. It has affected my personal relationship with my husband. We have stood the test of time; when you are that ill it makes or breaks you. I had been at death's door before in 1980 – it has been hard. When I started Interferon and Ribavirin, my husband had to take on all the housework – all the cleaning, cooking and looking after the grandchildren. In 2012 he switched from full-time work to part-time work so that he could help look after the grandchildren and do everything else. He retired altogether in 2015.
76. The illness has changed me. I could be awkward and a perfectionist anyway, but the illness has made me worse; I have less tolerance and I get very anxious. My husband puts up with it. There are times where he feels he can't do anything right even when he's not doing anything wrong.
77. I am also much more sensitive when people make assumptions. Doctors have always asked me if I am a heavy drinker to see if the liver damage could be because of alcoholism. I don't drink. Even recently I was told "Oh, come off it, you must drink" by a nurse at the practice. I get very sensitive to these sorts of comments whereas before I got ill, I would have laughed it off.
78. Having this hanging over me has made me constantly think about what will happen if I am not here one day. For example, I am a bit of a hoarder, but I have started clearing things out because what if I got a positive result on my six-monthly blood tests. I think about what I want to leave behind. I want things to be nice and straightforward; I think about putting things in order, like our wills. I make sure this is done before we go away anywhere too, it's the anxiety. I know it annoys my husband sometimes; we didn't care too much about this before, but the illness changed us.
79. It affects my family life in other ways. In 2013 my cousin was ill with leukaemia. We went to the hospital and we were asked about being matches for stem cells. I told them that I had hepatitis C and they wouldn't even test me. My cousin passed away that year. I cannot give blood or organs, even if one of my children or grandchildren needed it.
80. Since being diagnosed, I have felt like a guinea pig. I was the only person my GPs ever met with hepatitis C; I think I was one of the first people a lot of the medical staff had come across and treated.
81. I didn't know that this had happened to so many people – I had never spoken to anyone else who had contracted hepatitis C through infected blood before attending one of the Inquiry's engagement meetings. Through that meeting I also realised that other people had found out

about their infection a lot earlier than me. I found attending the engagement meeting really affected me; I just wanted to go home afterwards.

82. The impact on my career has been significant. I used to work as an NHS clinical governance and audit manager. That included lecturing to doctors and nurses on clinical governance and audit and how to do audit. I was in charge of 20+ staff and responsible for three hospitals; I held a Grade 8 post and was very senior. I began doing clinical audit in 1989 when people realised that doctors weren't looking at deaths properly. I was one of only 23 people in the entire country doing this work. In the beginning, I was challenging consultants on their practices and how they recorded deaths. It was a very challenging role and I enjoyed it as I had a very inquiring, analytical and organised mind. But now I feel I have deteriorated mentally and cannot work.
83. I retired in December 2006 when I was 55. Although the NHS allows you to retire at 55, my decision was mainly because I was extremely tired and felt I couldn't give it my all anymore. I had also just got a new grandchild GRO-C so we needed to help them out. If only I had been well though, I would have taken a break to help my daughter and then gone back to work. I had planned to work to normal retirement age.
84. Unfortunately the extreme tiredness did not go away when I stopped working. After I completed the interferon treatment I was still too tired to work full-time. I wanted to do something to keep my brain going though, so I became a governor at the local NHS Trust, which challenged me to become mentally and physically active again. It is a voluntary position – I cannot take on a paid job because of the tiredness. With voluntary work I can walk away when I want to. I also believe very strongly in what I am doing as lead governor; I work a lot on patient care and initiatives such as encouraging patients to get up and dressed and out of bed. I understand how vulnerable patients are from my own experiences.
85. If I had not had to stop working I would probably be a Director by now. The Trust have even offered me part-time work for when I finish my term as a governor; they want to keep me on but I don't want paid work because of the tiredness, so I keep saying no.
86. If I had not retired I would have also taken part in educational courses through work; I used to go on a lot of courses as part of my job. In that sense, hepatitis C restricted my education.
87. Because I didn't know I had hepatitis C when I retired, I took normal retirement. If I had been in post when I found out that I had hepatitis C, I could have retired under ill health and that would have given me a very different pension.

88. I have incurred financial costs through hepatitis C. Initially I paid to see the consultant privately in order to speed things up, as the wait for an NHS consultant would have been 3-4 months. That appointment cost me £140. I have also had to spend money travelling to and from appointments and on car parking – particularly every time I have to go for a hospital appointment. I also had to pay for the interferon and ribavirin prescriptions as well as the various prescriptions for the side effects, as I was not entitled to free prescriptions being under 60 yrs. I also had to pay for copies of my medical records to prove that I'd had blood transfusions and to identify the batch numbers.
89. It has never occurred to me to declare my hepatitis C on travel insurance forms. I do not know what the impact of it would be upon insurance premiums.

Section 6. Treatment/Care/Support

90. I have not really had any difficulties with obtaining treatment, beyond that if the first round of interferon had failed, I was told that I would not be given another round.
91. I did have to ask for an HIV test on more than one occasion, as is shown by the lists of questions I made in preparation for my appointments with doctors.
92. When I was first diagnosed with hepatitis C by my GP, I requested that she refer me privately to the consultant. This was because the NHS waiting list to see him was 3-4 months, whereas I was able to see him privately within 2-3 weeks. Had I not been in a position to do so, it would have delayed my diagnosis and treatment.
93. As mentioned earlier, I did feel that I lacked support during my treatment with Interferon and Ribavirin. I did not feel confident with administering the injections myself and I would have liked more support. On several occasions I rang the specialist nurse with questions but was not given any answers or support.
94. I have never been offered counselling or psychological support in connection with hepatitis C.
95. However, even very recently (18th December 2018) when referred by my GP to a consultant for a fibroscan, I was dismayed and upset by the complete lack of empathy and support afforded me. The consultant was dismissive in his approach and whilst he reluctantly undertook the fibroscan he went on to tell me I didn't need to be seen again nor have further blood tests, as in his opinion I was 'cured' and such tests were wasteful of both time and money. He went on to suggest I put the matter to bed and forget about it. He even asked me whether I'd had got my pay out. Whilst taken aback by this question I did confirm I had received

a payment from the Skipton fund. I left this consultation feeling I had been treated as a neurotic, pessimistic nobody. I had become a vulnerable patient and allowed myself to be intimidated by someone who one would presume to be a professional.

Section 7. Financial Assistance

96. I found out about the Skipton fund myself on the internet when I was first diagnosed and was looking for information on hepatitis C. I took the forms with me when I saw the consultant in November 2009. The consultant didn't appear to know what to do with it. I believe he submitted the forms as I did not get to see what he had written, but I did receive payment from the fund.
97. As soon as I stated to the Skipton Fund that I had blood transfusions at Billinge, I submitted copies of my medical records with batch numbers to them, they never questioned it or asked for further details.
98. When I applied to the Skipton Fund, I received a lump sum payment of £20,000 in 2010. In December 2016 I started getting a monthly payment of £252.50, which equates to £3,000 per year. I also get £500 for my winter fuel allowance.
99. In January 2018 I applied for the Special Category Mechanism (SCM). Anyone who is classified as Stage 2 automatically gets the SCM payment, but because I am classified as Stage 1 I had to apply with a good case. My GP had to back me up. I was awarded SCM because of the mental implications of my illness, such as the anxiety I suffer. When I applied for SCM, I wrote that if I died as a result of infected blood there would be no provision to my children or grandchildren, who would be deprived of my existence because of medical negligence by the NHS administering contaminated blood. That is a statement of my feeling. Why should they suffer? A copy of my statement for my SCM application is exhibited as **WITN02230014**.
100. The SCM payment was backdated to 27 October 2017 and I received a one-off payment on 27 March 2018 of £4797.50, calculated as £1262.50 per month.
101. From 1 April 2018 I have received a monthly payment of approximately £1500, which consists of my SCM payment and my previous monthly payment of £252.50. I have been told I will also receive £519.00 for my winter fuel allowance during December 2018.
102. Originally I applied through the Skipton fund, but that merged with the Caxton fund. I applied to the Caxton fund for my SCM payment.
103. I did not have any difficulty in applying for the Skipton fund. I did have to pay my GP £50 to fill in the form, but I was able to claim that back.

They did not impose any conditions on the money, but I did have to sign something to say we would not take any further action legally.

104. I don't know what happened to the documents that I sent to the Skipton fund. If they have my documents still, then I want those documents to be passed on to the Inquiry.
105. There is one thing I would like to know about financial assistance: why does it vary so much? If you have been infected, you have been infected. I know the amount varies between Scotland and Wales, but why should some people get more money than others? Someone who is terminal gets a lot more than someone who isn't. It should be universal.

Section 8. Other Issues

106. Something I would like to emphasise is that at various points through my diagnosis and treatment for hepatitis C, I was told that I was **lucky**. I was told I was **lucky** that I only had hepatitis C and didn't also have HIV; **lucky** that my Liver damage was mild to moderate; **lucky** that I was getting treatment for hepatitis C on the NHS; and **lucky** that I had the blood transfusion(s) that infected me, as they saved my life.
107. Being told I am lucky makes me angry. Yes, the blood transfusion saved my life – but I still got hepatitis C. When the consultant told me that I was lucky, I could have killed him. You don't say that to someone when they have been given a life sentence. I was annoyed and upset. At one point I was told I was lucky not to have been infected with HIV; that I was one of the "lucky ones" to just get hepatitis C.
108. I have been fortunate that the blood transfusion meant that I could see my children grow up and see my grandchildren. You have to always think of something positive. I want people to learn something from this. It is so bad when people suffer and no one is even learning from it.
109. It is very important to me that other people who have had blood transfusions find out if they have hepatitis C. I want the message to go out to other people about getting tested. I have been able to identify the batch numbers of the blood taken out for my operation, some of which was returned unused. Blood bearing the batch numbers either side of these may well have infected others.
110. I also want to know why they were importing blood when we had blood available in this country.
111. Another issue is my medical records. I have had difficulty getting hold of them. After I had the hysterectomy in 1980 we enquired about getting

my records as someone said we had a case. We were told then that my records were missing. Later, when I worked in clinical audit in Wigan, I tracked down my records. They weren't lost. I shouldn't have looked them up – I would have been sacked if I had been found out – but I did.

112. When I found out I had hepatitis C I went back and asked for my records again. Again they said they couldn't find them. Then they did manage to find them, but they could only find partial documents. They had records of my transfusions, but things I had seen myself when I had looked at my records in Wigan were missing, such as comments from doctors etc. I paid the fee and photocopied the documents then and there. The staff wouldn't let me look at anything besides the transfusion documents; they stayed with me the whole time. The investigators have taken photographs of these documents and they are exhibited as **WITN0223002-7**.

Exhibits

WITN0223002	Record of my blood transfusion on 9 October 1975
WITN0223003	Record of my blood transfusion on 11 August 1980
WITN0223004	Record of my blood transfusion on 14 August 1980
WITN0223005	Record of my blood transfusion on 7 September 1980
WITN0223006	Record of my blood transfusion on 8 September 1980
WITN0223007	Letter from EAM Normington to Dr Burnett dated 15 October 1975 re: my blood transfusion on 9 October 1975
WITN0223008	Contemporaneous record I made of questions that I asked during my appointment on 24 August 2009 with notes of the answers given
WITN0223009	Contemporaneous record I made of questions that I asked during my appointment on 8 September 2009 with notes of the answers given
WITN0223010	Contemporaneous record I made of questions that I asked during my appointment on 5 October 2009
WITN0223011	Contemporaneous record I made of questions that I asked during my appointment on 3 November 2009 with notes of the answers given

WITN0223012	Contemporaneous record I made of questions that I asked during my appointment on 26 November 2009
WITN0223013	Contemporaneous record I made of questions that I asked during my appointment on 28 January 2010 with notes of the answers given
WITN0223014	Copy of the statement I submitted to the Caxton fund for SCM payment dated 13 December 2017

Statement of Truth

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

Signed

GRO-C

Dated 10th January 2019.

