

Witness Name: Claire Miah
Statement No.: WITN4814001
Exhibits: Nil
Dated: 06 September 2021

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF CLAIRE KIMBERLEY MIAH

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 17 February 2021.

I, Claire Kimberley Miah, will say as follows: -

Section 1. Introduction

1. My name is Claire Kimberley Miah. My date of birth is GRO-C 1965 and my address is known to the Inquiry.
2. I live with my partner Phil and I have 3 adult children. I am a qualified nurse but I am currently not working in the health sector.
3. I contracted Hepatitis C from a needle-stick injury I sustained from an infected patient whilst I was working as a healthcare assistant in 2006. The patient I was taking blood from had been infected with HIV, Hepatitis B and C through receiving contaminated blood.

4. I intend to speak about my infection with Hepatitis C. In particular, the nature of my illness, how the illness affected me, the treatment I received and the impact it had on my family and our lives together.
5. My partner Phil was present with me for a brief period at the beginning of my meeting with the Investigator to make this statement, and he made some comments to the Investigator about the impact that the Hepatitis C treatment had on me. These are detailed under section 5 of this statement. He has chosen not to provide his own statement to the Inquiry.
6. Giving this statement has brought back a lot of bad memories for me. It is very strange thinking back and seeing how far I have come. It seems like it was years ago in a lot of respects, but I recently had my COVID-19 vaccination and it took me back to some of the side-effects that I experienced with my Hepatitis C treatment.

Section 2. How Infected

7. I am a qualified nurse. I qualified in 1986 and took a break from nursing when I had my children. Due to this break, my nursing qualification lapsed and I have not worked as a qualified nurse since about 1995.
8. In around 2002, I returned to the workforce after having my children and started work as a healthcare assistant at the Department of Genito-Urinary Medicine, which is part of Coventry Sexual Health Services at the Coventry and Warwickshire Hospital site. This falls under the Coventry Teaching Primary Care Trust. I will refer to this department as the '**GU Clinic**' throughout the statement. The work we

did at the clinic was mainly to do with sexually transmitted diseases and sexual health.

9. One of the clinics GU ran was for HIV. On the day in question I was allocated to take blood from the patients attending, to be tested.
10. On 2 November 2006, I was working at the clinic. We were busy on that day and we were short staffed. After taking a patient's blood I was taking the needle out of their arm to put in the sharps bin and it struck my finger. It struck the index finger on my left hand. I squeezed my finger right away and washed it under some water in the sink, as we had been taught to do.
11. I reported the needle-stick injury to the Consultant in charge of the clinic, whose name is Doctor [GRO-D]. I was brought into a room and put on PEP, which is like a prophylaxis treatment that prevents you from getting HIV if you have been exposed to it. I was then required to take whatever HIV drugs the patient was taking for a month, and was also given a Hepatitis B booster vaccination. I had previously had 2 doses of the Hepatitis B vaccine to get my titre levels up. All of this happened within 20 minutes of me sustaining the injury.
12. I also had some baseline bloods done right away at the GU clinic, and I am aware that these included tests for Hepatitis B, C and HIV. I was told that I would be tested again at 4, 12 and then 24 weeks later.
13. I realised that the patient was infected with HIV and Hepatitis B but did not know that they also had Hepatitis C.
14. After the injury I felt contaminated for the next 6 months that is the only way to put it, bluntly. It was 6 months of great worry for me. I wouldn't even let Phil kiss me. It was ridiculous for the first few months. I knew

that he couldn't catch anything from me, but this didn't stop the way that I felt. I felt terrified, dirty and contaminated.

15. I was like a pressure cooker every time my blood tests were approaching. I feared the results, and every time they were over I was relieved. All of my blood tests and initial treatment was done within the GU clinic.

16. I had my bloods taken again 4 weeks after the injury. At the 4 week mark I was tested for HIV. I was then tested for HIV and Hepatitis B at 6 weeks and I was tested for HIV and Hepatitis B again at 12 weeks. It was only at the 24 week mark that I was also tested for Hepatitis C.

17. Doctor [GRO-D] oversaw all of my initial tests and care within the GU clinic. I eventually confronted him and he admitted to me in a private meeting between us that the necessary Hepatitis C tests had not been done when they were required to be done. I was very angry about this. I told him that if it was him who had sustained a needle-stick injury, we wouldn't be in this position as he would have had all the necessary tests. He couldn't disagree with me.

18. I wrote to the Coventry Teaching Primary Care Trust about Doctor [GRO-D]'s failure to conduct the required Hepatitis C tests. They told me that I should have made the appointments for the blood tests myself, and that if I had made appointments for the tests when I was meant to, I would have been on the GU clinic's system. But, because I was a member of staff, the Consultants were very informal and just handed the forms to me and I had one of my colleagues take my blood, so I wasn't on the appointment system.

19. The Trust insisted that I would have been told to book the blood test appointments, and that I had failed to book them. Believe me, anyone

who has sustained a needle-stick injury is counting down to their next blood test, as you want to know that you are clear. When the trust requested my medical records, part of them seemed to have disappeared. I am not sure if they are available or not.

20. There is a page of my notes that on the front side details my needle-stick injury and the PEP I was given after the event, and on the back has a timeline of the blood tests I received, which confirmed that I did not have the necessary Hepatitis C tests at the necessary intervals. I made a photocopy of this page, but the photocopier was playing up and it copied the front page on both sides, so I did not get a copy of the timeline of my blood tests.

21. The next time I accessed these notes they had been altered. Doctor GRO-D had added to my notes, without my knowledge saying that was to be tested for Hepatitis C at 6 and 12 weeks after the injury. I do not have a copy of this annotated note or the original with the blood test timeline because of the photocopier playing up. I was told this by his colleagues.

22. GRO-C
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23. Around 2 weeks after my 24 week blood test, I was working with Doctor GRO-D at the GU clinic doing some biopsies and he said that he needed to see me and my line manager that afternoon. I was thinking that I had done something wrong. We went to his office and he said to me words to the effect of 'you had your blood tests 2 weeks ago', and then went on to tell me 'you've got Hepatitis C'.

24. I was just so shocked as I didn't even know that the patient who infected me had Hepatitis C.

25. Hepatitis C wasn't something that we dealt with in the department as it wasn't something that was really thought of as a sexually transmitted disease, so we knew very little about it, we only really knew that it was a blood borne disease.

26. I learnt that before I was given my diagnosis, Doctor [GRO-D] had informed my line manager about the Hepatitis C infection. I was fuming about this as it breached patient confidentiality requirements.

27. After Doctor [GRO-D] told me that I had Hepatitis C I had thoughts like, 'oh my god, I have infected Phil', 'am I going to die from this?'. I thought of my children, who knew nothing about it at the time.

28. Doctor [GRO-D] referred me to another Consultant for treatment. His name was Doctor [GRO-D] and he was a Gastroenterologist. Doctor [GRO-D] said that he would be coming to talk to me in a couple of days. Doctor [GRO-D] came into the department and spoke with myself and Doctor [GRO-D]. I had some additional blood tests to determine what genotype of Hepatitis C I had. At the time I was so shocked that I wasn't really taking in what he was saying, it was like he was speaking another language.

29. The first person I called after my diagnosis was Phil. He exploded at the thought that he might have it. He said to me, 'you said that it would be alright'. He was firing questions at me that I had no answer to as I didn't know anything about Hepatitis C.

30. It was made worse by the fact that he couldn't come to see me as he was working 400 miles away in his lorry. [GRO-C]

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31. From then on, it was a case of me googling and reading as much information as I could so that when I saw the doctors again I could go with an armful of questions.
32. I do not believe that Doctor [GRO-D] gave me adequate information to help me understand and manage the infection. He hardly told me anything about the virus and it wasn't something that we dealt with at the clinic, so I knew nothing about it. I was, however, told not to share towels, tooth brushes or razors, and to make sure that my blood did not come into contact with anything. I also put caps on our toothbrushes.
33. I was due to go on a holiday with my children in the next couple of weeks. I received a call from Doctor [GRO-D] and he told me not to drink alcohol on the holiday. I was looking forward to my holiday all year and when we were there it was the last place that I wanted to be because of my diagnosis. The kids knew that something was wrong, but they didn't know what it was, and I didn't want to worry them so I didn't tell them at that point.
34. I eventually had to tell them. My oldest son was in the navy at the time, so he was away from home when I was diagnosed. I had to tell him when he came home on leave as my Interferon Injections were kept in the fridge, and I didn't want him to touch my towels, toothbrush and medication.
35. When I returned from holiday I learned that I had genotypes 4a, 4c, and 4d. I knew that genotype 4 was the hardest to treat and that genotypes 2 and 3 were the easiest to treat. With genotypes 2 and 3

you could get away with 23 weeks of treatment and with 1 and 4 you needed at least 48 weeks of treatment.

36. Doctor [GRO-D] started me on a monotherapy of just Interferon at first. His reason for putting me on the monotherapy was that my Hepatitis was borderline chronic. I was just under the threshold for being diagnosed with chronic Hepatitis.

37. I confronted him about this as from my reading I thought that I should have been put on the combination Interferon and Ribavirin treatment. When I told other consultants at the clinic that I had been put on the monotherapy their opinion was that this was incorrect, and that I should have been put on the combination treatment. I was assigned a Hepatitis C nurse and he also agreed that I should be on the combination therapy.

38. After I confronted him, Doctor [GRO-D] eventually agreed with this and 2 weeks after commencing the Interferon I was put onto the combination therapy, which consisted of Interferon injections and Ribavirin tablets.

39. This first course of combination treatment did not work and the virus levels in my body never got to a level which became undetectable.

40. I had PCR tests at 24 weeks into the treatment and these results were given to me at week 27 of my treatment, showing there was a rise in the viral load. So Doctor [GRO-D] decided to stop the treatment at that point.

41. At the time, I was in touch with a doctor on the Hep C 'Nomads' online forum who had also contracted Hepatitis C through a needle-stick injury. He put me in touch with someone else who in turn put me in touch with Professor Dusheiko at the Royal Free Hospital in London.

42. Professor Dusheiko phoned me and asked me to explain my situation. He told me that my treatment should not have been stopped after 27 weeks. He said that I should be re-treated and that he was happy to have me under his care.
43. Professor Dusheiko said that my treatment would be for 72 weeks, as there was some research that showed that treatment for this longer period of time was successful in some cases. The treatment would be the combination Interferon and Ribavirin treatment.
44. Doctor [GRO-D] would not re-treat me as he thought there was no chance of me clearing the infection, so I got a referral from the GU clinic to be treated by Professor Dusheiko, and Professor Dusheiko was able to arrange the re-funding of my treatment. Doctor [GRO-D] oversaw my treatment, but I was really under the care of Professor Dusheiko at the Royal Free.
45. I started the second round of combination therapy on 9 June 2008 and completed the full 72 weeks. I think that I took the last Ribavirin tablets on around the 19th of October that year. I knew what to expect with the treatment this time around and I was more determined to get through it.
46. I cleared the Hepatitis C infection after taking the full course of treatment. I was told that the virus was undetectable in my body. Once you have stopped the treatment it can take about 6 months to fully clear the virus and there is a chance that it could come back within the 6 months. But once you have cleared it after that period, you have cleared it for good. My infection was cleared for good after the treatment stopped.

47. I do not have any tattoos and the ear piercings that I do have were done by myself.

Section 3. Other Infections

48. As far as I am aware, I did not receive any other infections besides Hepatitis C. Although the patient was HIV and Hepatitis B positive, I did not contract either of these infections from the needle-stick injury.

Section 4. Consent

49. I do not believe that I was ever treated or tested without my consent, without being given adequate or full information or for the purposes of research.

Section 5. Impact

Physical and mental impact of Hepatitis C and the treatment

50. Before my diagnosis with Hepatitis C I was experiencing a bit of pain in my liver area, but I never thought anything of it. I was not jaundiced. The doctors could not believe that I wasn't yellow as my viral load was so high.

51. The first Interferon injection I had was administered to me at in the HCV clinic by my Hep C nurse. I came home and it was probably within 2 hours that I started shaking uncontrollably. My children brought me a drink and the shaking was so uncontrollable that I was spilling it all over me.

52. I also started to feel very cold. I felt so cold, it was icy cold. I went to bed with a hot water bottle, quilts and a dressing gown. I felt frozen to the core. I also had a very unpleasant migraine.

53. I only experienced the body shaking after I received the first Interferon injection. For all of the other injections after that I mainly had migraines and felt very cold. These side-effects would usually last around 5-7 days after receiving the injection, just until I had to take the next injection and do it all over again.

54. I also suffered side-effects with the combination Interferon and Ribavirin treatment. One of the medications kills off red blood cells and the other one white blood cells. My haemoglobin count dropped to just over 8. Because of this I was very tired and I had no energy, I just wanted to sleep all the time. Sometimes I felt breathless. Because my white blood cells were low, I was getting mouth ulcers all the time. Sometimes, I would have up to 20 mouth ulcers. I wasn't very hungry during that time anyway, but it was too painful to eat with the mouth ulcers.

55. My partner has detailed to the Investigator some of the side-effects that I experienced during my treatment. He has described how I experienced huge weight loss. I was so thin that he could lift me over his head.

56. He has also attested to how tired I was all the time. I had no energy, and my partner has detailed how whenever he would come home I would just be lying on the sofa all the time. Another side-effect he detailed was how I lacked any emotion during that time, unless it was anger. He commented at the time that I shouldn't be on the road because of my road rage.

57. After about 12 weeks on the combination treatment, my hair started to fall out. It was falling out in handfuls. I had long hair to start with and ended up losing so much that I needed a wig. My hairdressers were brilliant. They shaved off what hair I had left and styled the wig for me.
58. Wearing the wig was horrible though. I couldn't go out if it was raining or windy. I was so conscious of it and felt that everyone knew it was a wig and was looking at me. It was also very itchy. I experienced itchy skin as well. I tried lots of different creams to stop the itchiness, and a lot of bath products for my dry skin. I also tried every mouth ulcer treatment known, none of which worked. My bathroom cupboard looked like a Lloyds pharmacy.
59. I experienced bone pain both during and after the Interferon treatment. The pain is so hard to describe. My bones and my joints just felt really painful. It wasn't anything I had ever experienced until I had treatment for Hepatitis C. The pain has been sporadic since I stopped the treatment.
60. For around 3 years it just seemed that my joints were always hurting, but it comes and goes now. I came to associate the bone pain with Hepatitis C treatment. I recently received the COVID-19 vaccine, it was the Pfizer vaccine. After the vaccination, some of the side-effects I experienced were feeling very shivery and my bones and joints hurt. The bone and joint pain was reminiscent of the bone pain I experienced while having the Interferon injections.
61. I also lost a lot of weight while on the treatment. At one point, they wanted to reduce the dosage of the treatment because I looked like I had lost a lot of weight, but I didn't tell them about the weight loss so that I could stay on the higher dose of the treatment. They weighed me

a couple of times, but I put weights in my pockets so that I would be heavier.

62. I experienced severe mental side-effects from the treatment. One of the main side-effects was changes to my mood. I developed a very bad temper. I was like a woman possessed. At my best, I felt like I had the worst case of pmt. The sound of a phone ringing would instantly set me off. I would feel like ripping the phone out and throwing it.
63. The first rage that I had was over a trip to McDonald's with my children. My children wanted to go to McDonald's to get something to eat. We got to the restaurant and there was someone in front of me in the line. I flipped, dragged my children out of the restaurant and drove 90 miles to a burger king. I was adamant that the burger king would be open. It turned out that it was actually closed.
64. I was so angry that I screamed at the children and drove the 90 miles all the way back home. When we got home, I locked myself in the bedroom and didn't come out for 2 days. It dawned on me that I was so angry that day that I could have killed the kids.
65. When driving, I would chase cars across the city if I thought that they had done something wrong. A police officer on his pushbike once cut me off and he got a mouthful from me. Phil told me that I should not be allowed out of the house due to my road rage.
66. There was an incident in Tesco where I was waiting to get some cheese from the fridge. There was a woman waiting in front of me who was messing about, taking too much time to choose something. I got so angry that I emptied the whole shelf of cheese into her trolley.

67. I then had to leave the shop right away as I feared that I would have physically harmed the woman. I am surprised that I wasn't banned from Tesco.
68. I remember another occasion where my son wanted some bread rolls. I told him there were some in the freezer and I emptied the whole freezer out onto the floor in our conservatory, and then told him to put everything back into the freezer. I felt as though I could have killed him.
69. My personality had changed and I was not a nice person to live with. My next door neighbour would ask the kids whether it was safe to come over to our house, given my moods, or would sometimes even ask them to put a white flag in the window to indicate whether it was safe to go in. My family had never heard me swear, but during that period they learned that I could swear. They were terrified of me.
70. The only emotions I had left were rage and anger. I felt like my partner and children could have been shot in front of me and I wouldn't have felt a thing. I was eventually prescribed antidepressants which calmed the rage a bit.
71. I feel bad for my children as they were only kids at the time and we lost three years of their life that we can't get back. My family and I can laugh about my behaviour now, but at the time it had a big impact on us.
72. At the same time as my diagnosis, I found out that my father had oesophageal cancer. At the time that I was meant to be there for him, I didn't want to see him as I had no energy.
73. I wouldn't have got through it all without my children. They had to grow up very quickly. My partner was only at home 1 night a fortnight

because of his job as a lorry driver. There was no point in him driving 100 miles home for me to be asleep, or to not let him in the house, which is something that I did on occasion. I turned him away from the house about 3 times during my treatment. My partner did not know what it was like for me being on the treatment and what I was going through.

74. I found an online support forum called 'the Hep C Nomads', which I have also mentioned at paragraph 41 of this statement. They were my saving grace and I went to them for information and support. Everyone in the group understood each other as we were all going through the same thing. There were all sorts of people in the group.

75. There were some drug users and also a couple of others who had contracted Hepatitis through needle-stick injuries. I became friends with people that I would have never had anything to do with because we were all going through the same thing. I still keep in touch with a couple of people from the group.

Stigma

76. Initially, I didn't tell anyone about my infection. I only told my immediate family. But, the more I learned, the more I wanted to be an advocate for Hepatitis C.

77. With a couple of people, I always felt the need to say that I contracted the virus through a needle-stick injury, because there was always an assumption that you got it through drug use.

78. On occasions where people knew that I was infected, they would take a step back. I thought, you're not going to get it from touching me. As I have already mentioned, when I was diagnosed, I didn't even want to

kiss Phil . I wanted to keep him away from me, even though I had worked with HIV patients and I knew about how diseases like this were transmitted.

79. Even now that I have cleared the infection, I don't like the fact that I will be treated as hazardous waste when I die. I know that I will be buried in a plastic bag because I have had Hepatitis C. I went through hell to clear the virus and it saddens me that I will still be treated badly because of it.

Financial Impact

80. I had only been on the Hepatitis C treatment for around 5 or 6 weeks when I had to take sick leave from my job in the HIV clinic at the GU clinic. I never went back to work at the HIV clinic.

81. After the needle-stick injury I was moved into an office job at the GU clinic. It was in a baby clinic working with health advisors. I only lasted for a month as I absolutely hated it, so I went and worked in community care for a few years and then in a Greggs for another few years. I never went back to work at the GU clinic or to work as a nurse. I stopped working altogether 3 years ago.

82. Because of the needle-stick injury, going back to nursing was a no go for me. There was no way I would ever handle a needle again. It was another reason behind why I could not go back to my work at the HIV department in the GU clinic; I couldn't handle needles anymore.

83. I thought about furthering my nursing studies and completing another course. However, the needle-stick injury put a stop to that as I won't touch needles anymore, and to complete the course I would have to use needles.

84. When I was working in the GU clinic I was working 3 days a week, but when I left the NHS to go and work in private community care I took a huge pay cut. The pay cut was not just in relation to my hourly rate, but also all of the holidays and other benefits that I received working for the NHS. I loved my job in the GU clinic and I would have been there until I retired if I did not contract Hepatitis C.

Section 6. Treatment/Care/Support

85. As I have already mentioned, initially Doctor [GRO-D] refused to give me the combination Interferon and Ribavirin treatment. He put me on the Interferon monotherapy. It was 2 weeks into the treatment that he agreed to give me the combination treatment, only after I had sought advice from other consultants and the Hepatitis C nurse that was assigned to me.

86. I did not have a good relationship with Doctor [GRO-D] as I would do my own research and reading about the disease and he didn't like the way that I questioned him about some of his decisions, such as the decision to initially put me on the monotherapy.

87. In addition to this, as I have also previously mentioned, Doctor [GRO-D] stopped my combination Interferon and Ribavirin treatment at 27 weeks as there was a rise in the viral load. This meant that I did not clear the infection. I had to approach Professor Dusheiko at the Royal Free to have my treatment extended to 72 weeks, which eventually cleared the infection. If it wasn't for my treatment being extended the infection would not have cleared.

88. During my first round of treatment my hemoglobin levels got so low that they had to reduce the dosage of the treatment. There were rescue drugs for this but Doctor GRO-D wouldn't give them to me. The Royal Free said that they would provide me with these drugs if I needed them.

89. The treatment I received for Hepatitis C caused lots of dental issues and caused some of my teeth to break off. My dentist was reluctant to give me any treatment as my blood count was always so low. I would have to bring a blood test with me to prove that I wouldn't die on the table. I was always the last patient of the day that they would see.

90. Coventry and Warwickshire Hospital occupational health arranged psychological support for me. It wasn't difficult to access. They sent me to see a psychotherapist. I had quite a few sessions, maybe around 8 to 12 sessions.

91. At the first couple of sessions I didn't say a lot and I thought it was a total waste of time, but by the end we were talking about anything and everything. I felt very angry about the fact that some blood tests for Hepatitis C were missed by Dr. GRO-D, as this could have put my family at risk. I felt guilty because of what my children had to endure when I was on the treatment, and I felt contaminated having the virus.

92. The psychologist helped me to see things in a different way, especially with the way I felt about the death of my father. I felt very guilty about his death as at the time that he needed me most I didn't have the energy to be with him because of the treatment. The psychologist made me realise that even if I didn't have the needle-stick injury I would have been at work all day anyway, and would still have had limited opportunities to see my dad.

93. She made me see that my kids were obviously really good kids before all of this happened, as if they were going to go off the rails they would have done so during those 3 years of my illness. During those years they raised themselves, they did the ironing, cooking and cleaning and their father was away at work 95% of the time. My partner being away so much at the time suited us both fine as he couldn't understand what I was going through, he wasn't seeing me day in day out, but the kids were. They saw me asleep on the settee all the time and they saw my moods. They would say 'mum's on one again' and clear out to go into their rooms.

Section 7. Financial Assistance

94. Doctor [GRO-D] suggested that I make an application to the Skipton Fund. He told me that I would get some compensation from them and he filled out the application forms for me.

95. Skipton declined my application on the basis that it was ineligible under the terms of the scheme. I was ineligible as I was not; a) a spouse or civil partner of the infected patient I received the needle-stick injury from; b) in a similar relationship with the infected patient; c) an other cohabitant; d) a mother or daughter of the infected patient.

96. I feel very annoyed about this. I feel that whether or not I was a family member should be irrelevant.

97. I don't know whether I would have felt differently about the whole situation if the patient had been a drug user. What happened has happened. The patient got it through no fault of their own and so did I. I was just doing my job.

Section 8. Other Issues

98. One question I had for the Investigator is; what does my Hepatitis C infection by needle-stick injury have to do with the Infected Blood Inquiry? The Investigator explained to me that the Inquiry is interested in my case initially as my Skipton application was refused but also my whole story.

99. From a healthcare point of view, I would like to see the introduction of legislation requiring the use of safety needles in the NHS. Safety needles are a kind of syringe that automatically re-sheaths the needle as you are withdrawing it, so that there is no chance of the healthcare worker sustaining a needle-stick injury.

100. I understand that the Inquiry is aware of the name of ~~person~~ the infected with HIV, Hep B and Hep C ~~person~~, who I was taking blood from when I got the needle-stick injury. It is among the Skipton application that I made. I don't now have those details

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Statement of Truth

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

Signed GRO-C

Dated 6/9/21