

Witness Name: Theresa Smith

Statement No.: WITN0946001

Exhibits: None

Dated: 5/8/2019.

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF THERESA ANN SMITH

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 01 May 2019.

I, Theresa Ann Smith, will say as follows: -

Section 1. Introduction

1. My name is Theresa Ann Smith. My date of birth is GRO-C 1963 and my address is known to the Inquiry. I am a recently qualified nurse. I intend to speak about my infection with Hepatitis C and the infection of my son with Hepatitis C. In particular, the nature of our illness, how the illness affected us, the treatment received and the impact it had on us and our lives together and the dire consequences I suspect my son's infection has had and will have on him in the future.
2. I confirm I am not legally represented and that I am not seeking anonymity.

3. I have signed a consent form dated 04 July 2019 for the use of my statement and I am happy for this to be used in conjunction with my statement once my statement is signed.

Section 2. How Infected

4. I was infected with Hepatitis C by a plasma transfusion I received in Leicester Royal Infirmary in December 1983. I required an emergency appendectomy. I do recall having to sign a consent form and I did sign it, but I doubt I was in a fit state to give informed consent because I was in agony. Thinking back, I am not even sure if I knew that I was consenting to receive blood or, if indeed this was routine for an appendectomy.
5. The following year I noticed that whenever I got a cold or became otherwise poorly I would become jaundiced. Looking back, I now wonder if I was becoming poorly because the infection was weakening my immune system. The jaundice became quite severe at one point and I was sent to the Leicester Royal Infirmary for a biopsy.
6. The procedure was done on a busy ward, just with the curtains drawn around me. I was very ill after the biopsy, in fact I nearly died, as during the procedure the doctors nicked a blood vessel, but did not notice. I gradually became unable to breathe as I was bleeding internally and this was putting pressure on my lungs, but the nurse was not listening to me and just thought I was making a fuss. Eventually a nurse did come over, took one look at me and called a crash team. I received further units of blood to replace that lost internally.
7. Fortunately, I survived the biopsy, but this ordeal makes the series of events around it quite fuzzy. Around this time, as a result of the biopsy, I was advised that I had Non-A, Non-B Hepatitis, but I do not recall if I was told in the hospital or shortly afterwards by my GP. I did

not understand what Non-A - Non-B Hepatitis was and I definitely did not realise the serious consequences and complications of the infection. Nothing was explained to me about management of the condition or precautions to take. I did not fully comprehend that this was something that I had been infected with through the blood I had received.

8. In 1989, my son was born at Leicester General Hospital. It was a traumatic birth for both my son and myself as my son and I had to have an emergency c-section after 36 hours of labour. My son was born with his legs over his chest. When my son was delivered he immediately urinated, which is a sign of severe distress in babies. I required another transfusion at this time of 2 units of whole blood. I assume this blood was safe as it was after the introduction of heat treatment, but I do not know for sure.
9. The Hepatology consultant in charge of my treatment (Dr Cramp) informed me that there was only a low risk of transmitting Non-A, Non-B Hepatitis to my baby, around 5% during pregnancy, when I enquired about the chances of my son having been infected. Unfortunately, my son was infected with Hepatitis C in utero (though he was not tested at birth and we did not become aware of his infection until 2002).
10. I believe the Hepatitis C to have been the cause of the rare illness he was born with (Sacralagenesis) which means the sacral bones in his body never formed. This illness is a very rare complication normally confined to the children of women with diabetes; even then it is rare as only 1 in 20,000 babies of diabetic women are born with Sacralagenesis. However, I am not diabetic and I strongly believe Hepatitis C caused this illness, which has left my son severely disabled and will likely cause him to have bilateral amputations later in life due to increasing pain and complications as a result of both the illness, and also the surgeries necessary to alleviate the effects.

11. The doctors approached me just two days after the birth of my son to explain his illness to me once they had been able to determine the nature of his illness (due to not having encountered it in practice due to the rarity of the illness). This was a bad time as I was on my own on the ward and was suffering from the baby blues.
12. The doctor explained that my son had this rare illness and that he would never walk, that he also had Talipes Equinus as a consequence (an inward turning of both feet) and that he would only be able to crawl his whole life. - The same doctor also explained my son was at risk for Hydrocephalus (fluid on the brain) and Renal Failure. This news was devastating. Prior to his birth we had no idea that there were any problems and I am grateful that I did not smoke or drink as I would have blamed myself even more.
13. As my son being affected by a congenital illness could not be explained, the doctor informed me that they wanted to do some tests, as they knew I had received blood transfusions previously, so they wanted to test for HIV in case this was the cause of my son's disability. The results took six weeks to come back and the wait was agony as I feared I had given my son HIV and that he was going to die and it would be all my fault. I had seen on the TV that babies born with HIV were dying and the news around the illness at this time was very bleak and this frightened me. Fortunately, the test for HIV came back negative.
14. Despite these events, I was not officially told I had Hepatitis C until 20 years later, in 2002, when Dr Cramp at Derriford Hospital began treating my son and myself for the Hepatitis C infection. Dr Cramp was a world leader for Hepatitis C infection. I was only referred to him when I sought out treatment myself. It was only through a charity called The Lighthouse Trust, I believe it was called, in the 1990s, that I became aware that Non-A, Non-B Hepatitis was in fact Hepatitis C. I

cannot remember how I became aware that there were possible treatments for the illness. I asked my GP and was referred to Derriford hospital by him for assessment and I was subsequently enrolled on the trial.

15. It was only in 2002 after I approached Dr Cramp that my son was tested and found to be positive for Hepatitis C. He was only fourteen years old but was unable to receive treatment as a minor, so he had to wait until he was eighteen before treatment could begin.
16. I remember Dr Cramp had taken my bloods and he called me in for a chat. He explained my diagnosis and the implications, precautions to take and how to manage it in a calm manner. He also gave me my treatment options, including the chance to be one of the first groups included in the trials of Ribavirin and Beta Interferon. He was wonderful and really good at explaining everything. It is just a shame this information came over 20 years after my infection and I was only seeing Dr Cramp because of my own insistence.

Section 3. Other Infections

17. As far as I am aware, I was only infected with Hepatitis C, as was my son.

Section 4. Consent

18. I cannot honestly know for sure if I was aware or consented to all of my testing, but I do think, to the best of my recollection, that I did consent. A large amount of blood was taken during my pregnancy, but you never know at the time what they are taking it for and as far as I am concerned, I still don't know the reason.

19. I was part of a treatment trial, but this was with my full knowledge and consent.

Section 5. Impact

20. Honestly, I would say that I have been lucky, especially in comparison to some of the people infected or affected who died, or who lost loved ones or who had it so much worse than I did.
21. Physically, I did have periods of colds or flu-like symptoms and some jaundice, but this stopped after the initial twelve months after my infection as far as I recall. I did get liver spots, these red freckles on my arms, and Dr Cramp told me that liver issues or disease caused these.
22. Mentally, I believe the impact was greater. I did have a bout of depression that coincided with and was likely to have been caused by my treatment. Often, I have felt like there could be a ticking time bomb somewhere inside me caused by the Hepatitis C, particularly as the knowledge around the effects of the retroviruses grows, such as how chronic HCV infection leads to a number of serious autoimmune conditions.
23. It has also been difficult coming to terms with the knowledge that I was infected for so long without truly understanding the potential serious effects of the illness. I feel that I was given a misunderstanding of Non-A, Non-B Hepatitis, as another name for Hepatitis C, as for some time I thought I must've caught that somehow rather than been infected by medical treatment.
24. I did become very cautious once I understood my infection and would be a little over the top about cleaning up after myself. I had read that Hepatitis C could survive outside the body and so I would bleach everything because even if you cannot see bodily fluids, there may

still be traces. I know the guidance has since been revised and I am less over the top now that I have cleared the virus.

25. Now, I continue to live knowing that I am a living experiment in this illness and its long-term effects on our health as we do not yet know or fully understand the long-term implications for those of us who have survived.
26. I have experienced tremendous guilt over my son's illness following his birth as I thought I must somehow be to blame. I feared he would die as a baby. I also worry who will care for him when I am gone, especially if I do die young, as we still don't really know what will happen in the long term to those of us who are infected and the long-term outlook for my son in terms of his mobility etc are an unknown; firstly, as the prognosis for sacralogenesis sufferers is not clear cut due to its rarity, and also, as I fully believe that his illness has been determined by a different mechanism (i.e. HCV rather than diabetes), any prognosis would potentially be incorrect as it might therefore have a completely different progression from that which results from diabetic mothers.
27. I have on-going concerns that knowledge around the effects of contaminated blood is being kept hidden and not trickling down to GP level where it could be useful for patients for diagnosis and treatment. I am afraid that this is the case because I fully believe that the government do not want us to know as they do not want to admit liability nor do they want to be forced to pay out for the damage they have caused.
28. As a further medical complication of the Hepatitis C, I believe I have an issue with my circulation. I am currently under medical investigation for this issue. For the last twenty years or more I have suffered with excessively cold hands, even in warm weather though I do believe this got better for a while during my Hepatitis C treatment.

My hands become very cold and very painful and pale, almost bloodless in appearance. They look dead when this happens.

29. I can sometimes see the blood drain from my hands. When this happens normal tasks such as driving are painful and can be impossible to do. Fortunately, this has not impacted my work as of yet. I do worry that it could be an indication of something more sinister within my circulatory system as this same restriction of blood flow could be happening elsewhere in my body and I am unaware of it as there are no current symptoms.
30. In terms of my other treatment, I found I did not respond to anaesthesia while on Interferon, so I actually avoided treatment such as dentistry as much as possible as I still felt pain. Several years ago, when I did go to the dentist they were geared up as if I were radioactive or massively infectious; it was unbelievable. I do understand that they do not want to get infected, but I do think it was over the top and insensitive. Of course, I was treated last to avoid infecting others, but I was also informed that the instruments they used could not be used again and had to be sent to the hospital to be autoclaved.
31. Socially, I have fortunately never been a big drinker and therefore did not experience the cirrhosis which would have been expected from someone with a 20 plus years chronic HCV infection, which could possibly have led to my early death without my even realising that the HCV was the cause.
32. I have fortunately, never experienced shunning by friends when I have told them about the infection. I have always been open and honest with others about my infection and I do take precautions to avoid spilling blood and definitely to sterilise everything. However, it can be a difficult and embarrassing subject to bring up in conversation.

33. In terms of stigma, I have occasionally felt stigmatised when I explained I had Hepatitis C because it was associated with drugs and promiscuity by some and I know my son experienced a similar reaction once at Derriford Hospital! He had gone in for his treatment but had been bitten by a spider and was on anti-biotics as there were some tracking lines of infection from the bite. In the waiting room for treatment with Interferon a nurse saw it and asked "you've not been using IV drugs today have you?" My son was not and never has been, an intravenous drug user. This was simply stigma from stereotyping and my son didn't like it.
34. I do not feel it is correct to make judgements on other people's life choices (for example substance misuse), however, I experienced similar stigmatisation to my son from a local solicitor when I sought advice on suing for the infection because my solicitor assumed the infection was caused by drug use. I was outraged at this behaviour from someone in her position; I did not want people to make assumptions about me. I always felt compelled to qualify my infection by saying "I was given HCV by contaminated blood products". I feel the stigma has lessened quite a bit now, especially in the last year since the Inquiry began.
35. I do not feel my education has been overly affected, even my recent training.
36. My infection has affected my work to some extent. As a healthcare professional, I have to declare my Hepatitis C status and have regular health checks and screening, which does show the antibodies from the previous Hepatitis C infection but also shows that I am negative for the virus due to an undetectable viral load. I cannot say if my career has been inhibited by my infection or by caring for my son because I know no different and you have to deal with what life has given you. However, the issue with my cold hands could affect my

career, or possibly the course of my future health if it progresses and so I must get to the bottom of that.

37. Financially, I do not know the extent of the impact of the Hepatitis C infection upon me. I was lucky that I was a student during my treatment as I managed to avoid time off work. My son's illness has had significant impacts upon both the quality of his life and his ability to work.
38. Otherwise, I have been impacted as I would dearly love to be a blood and organ donor, but I have been refused and this makes me incredibly sad.
39. The impact for my son has been tremendous. As I explained above, I do believe my son's Sacralagensis and Talipes Equinus is caused by the Hepatitis C infection. It is only recently, possibly because of my studies to become a nurse and my own extensive research, that I have suspected this correlation. I believe that as Hepatitis C is a flavivirus, a particular type of retrovirus and that it could affect the development of the unborn foetus as has been shown in research into other flaviviruses, like Zika.
40. One of the effects of the Zika virus on an unborn baby is that it inhibits the growth of the bones surrounding the brain and so the brain becomes compressed, causing the Zika symptoms. I can see a similarity between the effect on the bones around the brain and my son's illness where a section of spinal bones did not form at all.
41. Furthermore, results from a study with cats (I know it is not a human study, but it is a study with another mammal), where pregnant cats were given Hepatitis C resulted in kittens being born with Agenesis, that is without some of their (spinal) bones, similar to my son's illness, where the sacral bones have not formed.

42. This illness has had a significant impact on my son. I was told he would never walk, but babies find a way and at two years old he picked himself up and walked across my kitchen floor. However, due to the illness he cannot walk without the aid of callipers (AFOs). It causes him constant pain and has ongoing complications.
43. He had his first operation, at only nine months old, to release the tendons in his legs so that they could release his foot and form a heel. He had 2 further operation at seven years old at Bristol where they had to break all the bones in his feet to build him new feet. However, a large number of operations that he was supposed to undergo have not taken place, presumably due to budget cuts.
44. He has to use callipers on his feet to walk and the increase in prosthetics due to returning veterans has reduced the potential for stigma. He rarely complains. He gets a lot of callouses as the illness and operations have left him with no fat on his feet, which also prevents further operations now as the risk of infection is too great. Whilst he can currently walk with the aid of medical AFOs, it is very likely that he will have to have both legs amputated eventually. He always describes walking on a day to day basis as like walking on broken glass so I am at a loss as to how he manages to do it.
45. Mentally, my son has a more positive outlook than me and that reminds me how lucky we are because we are okay. I know when he was first diagnosed he was a young teenager and so he worried about telling girls and his friends, especially as he could not receive treatment until he was eighteen as it was a trial.
46. He does put the illness to one side and he never goes for further check ups in relation to his Hepatitis C because he says that if something is going to kill him, then he doesn't want to know. I think he has enough on with managing his other illnesses. I believe part of the reason he does not acknowledge how badly this has affected his is because he has never known any different.

47. My son did have to go to a special school because the risk of him being knocked over in the playground was too much. He is an exceptionally clever lad and went on to study law at Plymouth. I do wonder how different his life would be had this never happened to him.
48. In terms of his work, my son did get a job in retail sales, as he is a very good salesman. He got a job at a furniture shop in Exeter and so he had to get the train and walk from the station. It was not far, but it was more than he could manage. On his first day he called me from work, having been on his feet for eight hours, and told me he was in so much pain he could not even get home. As he never complains and has reduced sensation in his feet, I knew it must have been really bad for him to say this to me. He had to give up the position and has not tried for another job since as I think he was crushed by that experience.
49. If someone somewhere made the decision to save a few quid by buying in infected blood from the USA and this has been the impact for my son then it is unacceptable and they should definitely pay for it.

Section 6. Treatment/Care/Support

50. As I explained, I sought treatment myself in 2002 and was referred to Dr Cramp who was excellent. He explained there was a trial and there were side effects, but if I wanted to I could be put on the trial and my son could participate once he was eighteen.
51. I went ahead with the trial, which consisted of Beta Interferon and Ribavirin. I had to inject myself in the stomach each week after mixing the medication and I also took a tablet every day. The treatment lasted six months. I responded positively to the treatment quite quickly, but was kept on the treatment for the full six months.

Fortunately, I cleared the virus to undetectable levels so I am now HCV negative.

52. The side effects of treatment were absolutely vile. I had previously gone to the gym regularly, but I could not go anymore as I felt I could not breathe. The side effects in general were quite nasty, but I feel I was lucky in comparison to most.
53. The treatment also affected me mentally as I experienced crushing depression. I recall being at a friend's house and feeling like everyone I knew had died and I just cried and cried with my head pushed down onto the work surface in her kitchen. It was a crushing feeling.
54. I saw a GP who insisted I had to wait two weeks before they could treat it as depression, but I knew this was a chemical response to treatment of the Hepatitis C as I was not a depressed person usually and I had been made aware that depression was one of the possible side effects. I insisted I would just see another doctor. I was put on antidepressants, again at my insistence and I was on them for quite a while. I also had to take daily anti-emetics as I was permanently nauseous from the treatment.
55. I was never offered any counselling or psychological support in relation to either my infection or my son's. I am unsure if there were other treatments available that I should have had, but I do feel I would not have been treated at that time had I not sought it out myself.
56. My son began treatment once he turned 18 and had the same treatment as I did with similar side effects. He was also clear of the virus after six months. As far as I am aware, he has never been offered counselling or psychological support, either.

Section 7. Financial Assistance

57. My son and I both registered with, and received the stage 1 ex gratia payment from the Skipton Fund. I cannot recall if I found out about the fund myself or if Dr Cramp mentioned it. I do recall that we were forced to sign a non-disclosure agreement and that the paperwork made it very clear that this payment did not represent any admission of liability on the part of the NHS /Government. That did annoy and frustrate me, but we both had to sign. We both received £20,000.
58. We now both receive regular payments from EIBSS. I only found out about EIBSS by accident, though to be fair I had moved house and so I am unsure if they tried to contact me about regular payments. I saw mention of regular payments in relation to a documentary I watched about Treloars and so I researched it and applied. To be fair to them, they did backdate the regular payments and were very helpful once I got in contact. I received £333 a month and my son got the same. This has recently increased and I do feel that is because the government are trying to mitigate the damage before the Inquiry finishes.

Section 8. Other Issues

59. I do wonder how many people died, not knowing they were infected or not knowing why or how they came to be infected. What happened was deliberate and so wrong. I feel the government wanted the cheap blood from America, the easier option and that they got complacent about our supply and the effects on our health I think it is a shame they focused on treating the problem with heat treatment as a response to the outcry around HIV about this time whilst neglecting the screening process for HCV.
60. In other countries, people have gone to prison and in my view, what happened was criminally negligent. This contributed to so many

deaths and the government were culpable as they knew about it, they were warned and they did not stop. If I had done what they have done, I would surely go to prison. I want an admission of liability.

61. I do feel the other inquiries have not fared well. For me, the results probably won't make much of a difference now, but I am hopeful they will make a difference for my son who will have to continue to survive after I am gone, whatever the future effects on his own health.
62. I am still very much concerned for the current health system as it is shockingly bad. I feel hospitals are failing due to a lack of care and resources. These are accidents waiting to happen and the government treat the health of the population with casual disregard.

Statement of Truth

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

Signed

GRO-C

Dated 05.08.2019