

Witness Name: Averel Sutton

Statement No.: WITN4676001

Exhibits: Nil

Dated: *x 25 January 2022.*

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF AVEREL SUTTON

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 03 September 2020.

I, Averel Sutton, will say as follows: -

Section 1. Introduction

1. My name is Averel Valerie Sutton. I was born on GRO-C 1942 and I live in a small village near GRO-C. My full address is known to the Inquiry. I am retired and I currently care for my teenage grandson who lives with me.
2. I intend to discuss my daughter Caren Hague Nadeau's infection with Hepatitis C (HCV) which I firmly believe she contracted from blood plasma which she was treated with following an operation for an intussusception of her bowel when she was a baby.
3. Caren has already made a statement to the Inquiry and her witness statement number is WITN4216001. Caren was a very young baby when she was infected so does not have first-hand memories of the events which led to her being infected. I therefore make this statement in support of the account she has provided.

4. This witness statement has been provided without the benefit of access to my daughter's full medical records, the most relevant of which have either been lost or destroyed.
5. I can confirm that I have chosen not to have legal representation and the Inquiry Investigator has explained the anonymity process to me. I do not intend to seek anonymity.
6. I can also confirm that the Inquiry Investigator has explained the 'Right to Reply' procedure, and that if I am critical of a medical professional or organisation, they will have the right to reply to that criticism.
7. I wish to acknowledge that naturally as time passes, memories can fade. My daughter was a young baby when she was infected. I have been able to provide approximate timeframes for matters based on life events. However I can only recall to the best of my ability, and these timeframes should be accepted as 'near to' rather than precise dates.

Section 2. How Affected

8. My daughter Caren was born in Liverpool on GRO-C 1965.
9. In early 1966, when Caren was 5 months old, she became ill and started vomiting a lot. When it first started, we assumed it was normal reflux or a stomach bug she had picked up, however it seemed to be going on and on and we became increasingly concerned.
10. We sought advice from our GP Dr Michael Altman, who made several home visits to see Caren. Dr Altman thought it was an infection and my husband was convinced she had swallowed a button or another object which was causing her to vomit. However, as the situation continued, we started to consider that her bowel might be blocked as she was not passing any stools.

11. On the fourth day of Caren vomiting, we contacted a paediatrician at Alder Hey Children's Hospital. We were living in Southport so this was the closest specialist children's hospital to us at the time.
12. By this point, Caren had started to go in and out of consciousness. We were told to bring her in immediately. They said to not even wait for the ambulance as it may take too long; we had to just get her in the car and drive to Alder Hey right away. My husband Brian always drove quite fast but that day he flew in order to get her there as quickly as he could.
13. We arrived at the hospital at around 9pm. Initially the doctors thought Caren had meningitis, and they started carrying out tests on her straight away.
14. They soon realised it was not meningitis, and Caren was in fact diagnosed with an intussusception of the bowel. This meant the upper part of the bowel had dropped into the lower part, in a telescopic action. This caused a blockage and is very dangerous.
15. The medical registrar spoke to Brian and said intussusception was quite common in babies but it could be very tricky. They said they would have to operate immediately.
16. After we had spoken to the medical registrar, the surgical registrar came up to speak to us. The head paediatrician, who I believe was called Dr MacKenzie, was contacted. He came in performed the operation which took place in the early hours of the morning.
17. Caren came out of theatre around 3am. I remember clearly seeing two intravenous drips either side of her forehead and questioned what they were for. It was Dr MacKenzie or another member of medical staff in the hospital who confirmed to me what was in the drips, and that one of the them was blood plasma.

18. Caren did not have much hair at that age, but her temples had been shaved, and she had one drip going into each side of her head. Her arms were tied down to prevent her pulling them out. It was very distressing to see.
19. Caren's Alder Hey records have apparently been destroyed so we have, to date, not been able to prove she had the blood plasma transfusion. However, I have a very vivid recollection of what I saw that day and also of what I was told by hospital staff about her being given blood plasma. It was a week I'll never forget. A mother doesn't forget when she almost loses her child.
20. I stayed at the hospital with her for a couple of days following the operation, and then we were able to bring her home.
21. The operation had been successful, and she had no lasting internal damage. She had had her appendix removed at the same time as her bowel operation. It was just a case of dressing the wound every day, so it was felt she should go home as soon as possible.
22. Dr MacKenzie said if someone less experienced had operated, they would have cut her bowel open, taken out the excess and sewn her back up, but he had put a tuck in it to prevent seepage, which meant she was able to heal a lot quicker.
23. She did not have any other operations as a child or young adult which gave rise to blood transfusions.
24. Once we were able to go home, we went about our lives. There were no obvious signs of her HCV infection while she was a baby. My husband and I focused on work, family and bringing up Caren.

25. As a teenager, it was suspected that she may have glandular fever for which she was tested but found to be negative, as she was always lacking energy.

26. It was only much later, in 2017, that she was finally tested for HCV. After her result came back positive, she was very distressed. She found it very difficult to cope with the unwelcome news and with life in general, and she became suicidal.

Section 3. Other Infections

27. I do not believe Caren was exposed to any other infections. In her statement, I believe Caren mentions that she tested negative for HBV and HIV.

Section 4. Consent

28. I did not sign any consent forms, but it is possible my husband would have provided consent. He spoke more to the doctors than I did at the time.

29. I do not recall any information being provided to us regarding the risk of infection from blood plasma. If my husband had been given that sort of information, he would have mentioned it to me before making any decision.

30. In those days things were different. Patients and parents of patients were not provided with information and asked for consent in the same way they are now. We simply were not given that level of information nor would we have expected it back then.

Section 5. Impact

31. When Caren became ill as a baby and subsequently needed the operation which gave rise to the treatment with the blood plasma, it was an incredibly stressful and emotional time.

32. The whole time was very challenging. During Caren's stay in the hospital I was sleep deprived and emotional. It was awful to see your baby in the state she was in, and it was a very scary time for us all.
33. It was a great relief when she was brought up from surgery and we were told the operation had gone well. However, it was incredibly distressing to see her with two cannulas in her head, with her arms tied down to prevent her from pulling them out when she woke up. She remained in this state for a day or so.
34. It was only my husband and I who were there, we didn't have any other visitors. My mother and father in law were actually staying with us at the time as they were moving house, but we didn't want lots of visitors around. It was too stressful.
35. Once Caren was discharged from hospital, we came home and got on with life.
36. She used to get worked up about everything, she was highly strung and always very anxious, and still is. The knowledge of her having been incubating an HCV infection for all those years has made this a lot worse.
37. I was absolutely horrified at the news, and it was difficult to deal with the fact that my daughter had been infected with HCV at such a young age when she was totally helpless, and during a life-saving operation. It was heart-breaking to think that she even contemplated taking her own life because of that infection.
38. When she was told it would be a 6-9 month wait before she could have treatment, she couldn't take it. She was crying a lot, all the time in fact. She was very depressed.

39. It was a very emotional thing for us all realising why she had been so fatigued and lethargic for most of her life. Then when she was not able to have treatment straight away, it compounded her distress at her situation.
40. She decided to go private for treatment in the end. She was desperate to the point of being suicidal and she couldn't cope knowing she was infected with HCV and not doing anything about it. I will discuss her treatment further in Section 6.
41. She worries a lot about things and even now has been extremely anxious about the current Covid risk.
42. She saw a lady psychologist called Marie who helped her a lot. She didn't have medication but had a lot of one-to-one therapy which helped her a great deal.
43. We were all tested for HCV. Myself, Caren's husband Pierre and the girls. Fortunately, we were all clear.
44. I've only seen her twice in person in 18 months due to the coronavirus pandemic. She is very worried and apprehensive, and any worry she would have has naturally has been exacerbated by her experience with HCV.
45. The whole experience has had an impact on my confidence in the NHS. Following what happened with Caren as a baby, if we could go privately we did so. We felt that someone should have picked up on her bowel intussusception earlier than they did. Obviously now knowing she was also infected with HCV during this episode makes it far worse.
46. Once she reached adulthood, Caren had many blood tests over the years but her HCV wasn't picked up. I really don't understand how it went undetected for such a long time.

Section 6. Treatment/Care/Support

47. Caren was devastated about the diagnosis and felt she needed treatment sooner than the National Health could offer as she could not cope with knowing she had HCV and nothing was being done.
48. She explored options with Pierre and decided to pay privately for treatment. Her medication was called Maviret. This was taken in tablet form.
49. Her medication cost around £26,000. I am aware that the NHS also charged a ten per cent handling fee on top but I am unsure if it was included in the total or was an extra expense.
50. As far as I am aware she did not experience any noticeable side effects from the treatment.
51. As soon as she started the treatment, she started feeling happier. She said it was like a black cloud had been lifted. She had been in a dark, dark place before starting treatment. Once she was able to access the medication and embarked on the treatment course, it gave her hope.
52. Caren started the treatment course in around September 2017 and had finished by Christmas time. Fortunately, by this point she had already cleared the virus, and thankfully, things have been okay since.

Section 7. Financial Assistance

53. I am aware Caren made a claim to Skipton Fund, and that it was turned down. I can't remember exactly how Caren felt when her application was refused, but I don't think she would have been very happy.

54. As far as I am concerned I would like to know the actual reason why she was turned down. It was a struggle for them to raise the funds but something they felt was a necessity for the sake of Caren's sanity.
55. I am aware that she has been placed in a difficult position in respect of being able to prove the fact of her transfusion with the blood plasma. It is extremely unfortunate that her medical records from Alder Hay have been destroyed, but when she was asked to source them in 2017 for the Skipton Fund it was 40 years after the event. Did they really expect her to find them?
56. As I said earlier in my statement, I remember clearly and unquestionably that she was given a blood plasma transfusion following her operation on her bowel. It is not Caren's fault that those records are no longer in existence but it has left her unable to obtain the financial support she should be entitled to.

Section 8. Other Issues

57. I feel that Caren has been greatly let down by the NHS. They caused her to become infected with HCV in the first place when she was a helpless baby but they haven't done anything to help her to overcome it.
58. Many of the doctors who treated Caren are now dead, I am aware that the GP Dr Michael Altman has passed away. It therefore will not be possible to get any answers from most of them directly.
59. Caren was lucky in that she had the family support and financial capability to seek treatment privately but most people who have been infected aren't in that position.
60. If others who find themselves in a similar position to Caren are lacking in education or financial means, or their mental health isn't good, then who is

going to fight for them? I have seen the effects of this infection first hand and it is hard enough to cope with without having to fight the system at the same time.

Statement of Truth

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

Signed

GRO-C

Dated X

15th January 2022.