

Witness Name: Susan Annette Hopson

Statement No: WITN5543001

Exhibits: Nil

Dated: 23 March 2022

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF SUSAN ANNETTE HOPSON

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 15 October 2021.

I, Susan Annette Hopson, will say as follows: -

Section 1. Introduction

1. My name is Susan Annette Hopson. My date of birth is GRO-C 1959. I reside at GRO-C. I married my husband, Royston Hopson, ("Royston") in 1979, and we have four sons, two grandsons and one granddaughter. I retired in or around 2017. Before this, I was a Sewing Machinist and latterly I worked in a bakery.
2. I intend to speak about my infection with Hepatitis C ("HCV") after receiving a blood transfusion following the birth of my first child. In particular, the nature of how I had learnt about my infection, how my illness had affected me and my family thereafter, and the financial assistance I have received.
3. I can confirm that I have chosen not to have legal representation and that the Inquiry Investigator has explained the anonymity process to me. I do not wish to be anonymous as I wish for my story to be known in full.

4. The Inquiry Investigator has explained to me the 'Right to Reply' procedure, and I understand that if I am critical of a medical professional or organisation, they will have the right to reply to that criticism.
5. I wish to acknowledge that naturally as time passes, memories can fade. I have been able to provide approximate timeframes for matters based on life events. However, these timeframes should be accepted as 'near to' rather than precise dates.
6. I have constructed this statement without access to my medical records.

Section 2. How Infected

7. I met my now husband, Royston, in Bristol and married in 1979. He was working as a machine labourer and I was working as a sewing machinist. Royston now works as a security guard and will be retiring in 5 year's time.
8. We had our first child, Wayne, on GRO-C 1981 at Southmead Hospital ("Southmead"), Southmead Road, Westbury-on-Trym, Bristol, BS10 5NB. It was a difficult birth because he was a big baby but it was a relatively normal forceps assisted delivery. Following the delivery, there were no issues with Wayne, he was a healthy baby.
9. As I said, Wayne was a big baby and I suffered a haemorrhage, had anaemia and needed a blood transfusion. I was given four pints of blood, in those days, you were not offered the choice of a blood transfusion, you were just told you were having one. I wasn't told about any risks associated with the blood transfusion.
10. I had no issues after the blood transfusion and went ahead to have three more children. My four sons are now 41, 37, 35 and 31 years of age. For my three other sons, all were normal births and I did not have any other transfusions.

11. It wasn't until 10-15 years later (1991-1996) that I started to have health issues. I started getting bad knees. I initially put this down to a motorbike accident I had had previously, but when both knees started hurting I decided to get them checked out.
12. I attended my surgery at Frome Valley Medical Centre, 2 Court Rd, Frampton Cotterell, Bristol BS36 2DE and had a blood test, this was in the early 2000's.
13. Shortly after, I received a telephone call from the practice. I recall being on a bus at the time of the phone call on my way home, alone. I cannot remember whether I spoke to my GP or a nurse. She asked me very personal questions, including whether I had ever done drugs, had piercings or tattoos. I said no to all of these, bar one piercing which had been done professionally. She then asked if I had ever had a blood transfusion. I said that I'd had one blood transfusion in 1981, following the birth of my first son. She then confirmed over the phone that I had been infected with HCV. (Genotype 1)
14. I panicked at the beginning but I didn't really understand it. Years beforehand, I remember seeing a placard on a bus that said *'have you ever had a blood transfusion? If so, you should get tested.'* I remember thinking that I wasn't ill, so I didn't need to get a test. This was the first thing I thought about after I received the phone call from the practice. I wasn't given any advice from the practice about infecting others or how to manage the infection. When I got home, I googled HCV and realised it was quite serious.
15. When I told my husband about my infection, he was in denial but I cannot recall what he said. For the first year or two, I don't think we took the infection very seriously. The rest of my family were also in denial, not realising how serious it was.
16. Royston is a diabetic. I always had a fear that my kids were going to get diabetes, so we'd test them. We'd often test them with the same needle. After my diagnosis with HCV

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Section 3. Other Infections.

17. To my knowledge, I was only infected with Hepatitis C. I do not recall being tested for HIV or being told I was being tested for HIV.

Section 4. Consent

18. There are no concerns as to consent.

19. I was told I would be having a blood transfusion, as opposed to giving express consent. But this is what it was like in those days, you were not given a choice.

20. I took part in a trial for treatment. I consented to being tested for the purposes of research.

Section 5. Impact.

Mental/Physical Impact

21. I can't say that having HCV has had a particular effect on my mental or physical health that I have noticed.

22. Before being diagnosed, I didn't feel unusually tired. My energy levels were quite normal.

23. Whenever I have had alcohol, which was quite rare, I always knew straight away that something was wrong. I needed to go to the toilet straight away. I think this was my body inadvertently telling me it was poison. I don't really like alcohol, so I don't drink it.

24. I now have osteoporosis, arthritis and an underactive thyroid. I believe that these may have been a result of living with undetected HCV for so many years.

25. I also underwent early menopause at the age of 41 unlike my mother who was in her 60's. I have had to have two knee replacements and am on medication for my thyroid.

26. I can no longer be a blood donor, but I did give blood in Frampton Cotterell in 1983. The blood transfusion service were made aware of my HCV diagnosis. I feel guilty because I have obviously given infected blood to others, but I didn't know at the time.

Treatment

27. I am HCV Genotype 1. I had four different treatments for HCV. I do not recall the exact years of the treatments.

28. I recall around 5 years after I was told of my infection that I tried my first treatment. It was a tablet but I cannot recall what it was called. The treatment lasted three months. Initially, my viral load went down but shortly after, they came back up again. I was told the treatment was unsuccessful.

29. I had my second treatment about 2 years later. This was Ribavirin and Interferon treatment. It was a mixture of tablets, which I took once a day, and an injection, which I had once a week. I recall having my injection every Sunday. There were no side effects to this at all. Similar to the first treatment, my viral load went down but then started to go back up again shortly after. This treatment also failed.

30. I waited a further 3-4 years before my third attempt at treatment. I was offered a placebo trial, run by Bristol Royal Infirmary, ("BRI") Upper Maudlin St, Bristol, BS2 8HW. This trial was a tablet treatment. I remember after my first dose that I was violently ill. I felt sick for a very long time, but my viral load came right down. This stayed down for about three months before going back up again. This treatment also failed. At this point I thought that I'd just have to live with HCV.

31. My final treatment was around 5-7 years ago. This treatment was from America and was very expensive. The treatment involved one tablet a day for over 12 weeks. I had no side effects. This treatment finally cured my HCV infection. I was informed in person that my viral loads had gone down and my HCV was now undetectable.
32. I still had to do blood tests after this. I think I had another test a couple of months after the treatment completed to ensure that my viral loads had not changed. My viral load was still down so I was given the all clear.
33. I have had fibroscans to check my liver. I have cirrhosis of the liver, but I am unsure which stage I have. I believe that my liver is coping with it and thankfully is not getting any worse. I recall having a biopsy also, but I cannot remember when this was. It was definitely right near the beginning of my diagnosis.
34. I am still being regularly monitored for my liver. I am no longer under the Hep C clinic, I am under the liver clinic at BRI instead. BRI have always been good. I often have liver scans every 6 months, but as a result of the recent COVID pandemic, this changed to phone call check instead. My last fibroscan was a couple of years ago, so I am due another one soon.

Impact

35. Royston has told me that I am not the woman I used to be. He says that I am tired a lot more. I've put weight on, but who doesn't. I don't think it's really had an effect on me, but Royston would say that I've been bad.
36. I am a woman who's glass is always half full. I would often say that I am lucky that I had HCV and not AIDS. I have seen all the stories online and they are heart breaking. I have managed to live to see my boys all grow up and have their own lives. I had lived with HCV from the age of 21 and didn't know any different.

37. I think I have Fibromyalgia. I am definitely not depressed, but I definitely feel quite fatigued.
38. I don't think my diagnosis has affected my marriage.
39. I know that my sons do worry about me, my youngest son especially. As of last year, we have moved in with him as he is a carer.
40. I retired from work around 2017 because I became too tired. At this point, I was only doing 12 hours a week but it was too much. Thankfully, the financial assistance I have received helped me to retire earlier.
41. In terms of stigma, I felt dirty. I felt like I had AIDS. I was working in a bakery when I was diagnosed. I was worried that they wouldn't let me continue making sandwiches. Thankfully, they were good about my infection and just told me to wear gloves.
42. I felt very self conscious being put in the same boat as drug addicts and sex workers. When I was at the hospital for the HCV treatment I was surrounded by druggies and often thought that people would think of me in that way.
43. I only told close friends and family about my infection with HCV. They couldn't believe it. A lot of my friends had had blood transfusions themselves, so they were terrified.
44. GRO-C had had a transfusion in 1989 and went to the doctors last year to get a test. Her doctor said that she didn't need one and refused to test her for HCV. She kicked up such a fuss that they did finally do it. It is worrying that doctors are still refusing to do tests. If that were me, I probably wouldn't have pushed for a test. Luckily, she was negative.

Section 6. Treatment/Care/Support

45. I haven't faced any difficulties in terms of treatment or care.

46. I have never been offered counselling or psychological support. If I had been, I probably wouldn't have taken it.

Section 7. Financial Assistance

47. I applied to the Skipton Fund ("Skipton") for financial support in 2006. I was not informed by any medical professionals about Skipton, I was told about it from my father in law. (Skipton number 6642 refs)

48. I submitted my application to Skipton on 14 May 2006. I was still infected at this point. It took a little while for Skipton to agree my Stage 1 claim as they needed the evidence of the blood transfusion and my HCV infection. Other than that, I had no issues with it at all.

49. At this point, I was under Frenchay Hospital, Bristol. A nurse at Southmead assisted me with the application and I received a £20,000 one off payment on 18 December 2006.

50. I have also applied for Stage 2 Skipton financial assistance, but this has been rejected twice, despite Dr Fiona Gordon assuring me that I'd definitely get the application accepted. The positive part of me thinks that getting rejected is a good thing, because I cannot be that ill if I keep getting refused.

51. I have applied for a third time. I applied on 1st December 2021, but I am still waiting for the hospital to return my form. I have chased this up on two occasions but I am still waiting. It's not in my nature to keep calling them but I will try once more.

52. I now receive monthly payments from EIBSS. These didn't start until about 6 years ago. I get £1,600 a month, which has definitely helped. I was able to retire from work earlier. These payments are due to increase shortly.

53. I have also received winter fuel allowances.

Section 8. Other Issues

54. I think of myself as one of the lucky ones who didn't get HIV. As you can tell I have taken a very pragmatic view of my HCV and the effects it has had on my health. Leaving that aside, it is clear that some health professionals still want to hide what has happened. It should never be forgotten and it is important that the truth is established. How could they give blood to people without testing it? It should have never happened.

55. The only other point I would like to mention is that my son Wayne feels very guilty about what happened to me and the fact that it was his birth that caused me to have the transfusion. I have done my best to reassure him that I don't blame him but he still feels terrible about the whole thing.

Statement of Truth

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

Signed

GRO-C

Dated 23-3-2022