

Witness Name: Robert Steven
Statement No.: WITN5113001
Exhibits: Nil
Dated:



## **INFECTED BLOOD INQUIRY**

### **WRITTEN STATEMENT OF ROBERT JAMES STEVEN**

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 3 September 2021.

I, Robert Steven, will say as follows: -

#### **Section 1. Introduction**

1. My name is Robert Steven. My date of birth is **GRO-C** 1952 and my address is known to the Inquiry. My wife Barbara Steven had a blood transfusion and was infected with Hepatitis C. Barbara was born on **GRO-C** 1952 and died on 26 June 2020. My wife then infected me with Hepatitis C.
2. I intend to speak about my wife Barbara and myself. In particular, the nature of our illness, how the illness affected us, the treatment received and the impact it had on our lives together.

#### **Section 2. How affected**

3. Barbara was diagnosed with a rare kidney virus in 1989. We went to Derby City Hospital where the doctors informed us that the virus was not curable and that Barbara's kidneys would fail after time.
4. Once Barbara got the terminal diagnosis, she would have regular check-ups where she would normally see the doctor alone as I was either at work, asleep (as I worked shifts) or looking after our son Richard.
5. The regular check-ups were to check and get Barbara's medication right and to test her blood. I cannot remember the name of her medications. She was on many different drugs.

#### **Section 3. How infected**

6. In September 1992, Barbara was found to be anaemic. I cannot recall now if this was at the hospital or during a check-up at her GP. Her GP surgery was called the Mackworth Surgery (which later became the Charnwood Street Surgery and is now Horizon Health Care).
7. The Derby City hospital took her in to have a blood transfusion on 29 September 1992. It was a full blood transfusion, so she was in hospital for a couple of days to get all the units of blood inside her. The Derby City hospital had her under renal care doctors.

8. A few weeks later she had another blood test and it showed that she had Hepatitis C.

9. Barbara realised it was from the blood transfusion. The hospital denied it at first but shortly after agreed it is a possibility the blood transfusion caused it. She was then put under liver doctors, who sent her for a biopsy before they started the Interferon.

#### **Barbara's Treatment**

10. No information was given to us about the infection or treatments. Very little information was given by the hospital.

11. Very little advice was given to us, if any. We were 6 years into our marriage and quite active, but we didn't know much about it to know we should protect ourselves.

12. Barbara was given Interferon under liver specialist. She was one of the lucky ones and was cured.

13. Barbara was working in an office of the bus depot. She could have been promoted to office manager if she didn't get hepatitis C and the kidney virus.

14. We applied for state aid. The D.I.P. section allowed us to claim for a car, pension was half state aid and she would get sickness pay covered full time. This was her income.

15. The hepatitis C would create issues, the illness had gone away but she always had antibodies, so the hospital was wary whenever she was in. When she was getting treated for the kidney virus, she went on Haemodialysis known as E.M.O. dialysis and had a private room within the isolation unit (kidney unit).

16. The criteria for the isolation room was because she had hepatitis C.

17. Other patients were in a big room together during dialysis, but Barbara couldn't sit with anyone or chat with other patients. She was always stuck alone. Always in isolation treated differently because of hepatitis C.

18. Other than that she wasn't treated differently as far as she was aware. Barbara was very strong willed, she had run-ins with doctors now and again. She always wanted to know the truth but didn't always get it.

19. Barbara had treatment in 1993/1994. I can't remember the exact date or how long the treatment took, but it was prior to me finding out I had hepatitis C.

#### **My Treatment**

20. I was an electrician, fit and healthy and found out I had hepatitis C in about 2001. I started a new job at Rolls Royce where I had to undergo minor exercises when I joined their gym. My blood pressure was high so the gym staff/ trainers suggested I go and have my high blood pressure checked with my GP, as they did not want anything happening to me in the gym or at work.

21. I went to my GP surgery named Charnworth Street Surgery now Horizon and was put on blood pressure tablets. My GP suggested I go and get tested for Hepatitis C as Barbara had it.

22. I went back a few weeks/ a month after the test as I received no call or letter to

inform me about the results, and I was going in for regular blood pressure tests and tablets.

23. The doctor informed me that I have hepatitis C antibodies and I had another blood test. I went to Derby City Hospital, I can't remember the doctor's name, but in 2002 it was decided that I have a biopsy. I took a day off work for it.
24. The biopsy came back and showed the effects of cirrhosis of the liver, due to the Hepatitis C.
25. It was decided that I would go for treatment. I went on Interferon injections. This is when we met a nurse that went on to be a good friend. She showed me how to do the drug injections. She was the best thing that happened to us during this time.
26. The five weeks I was under the treatment knocked me sideways, I was off work and felt very rough. A few weeks into the Interferon injections I was meeting up with friends at the pub. I would go to the local pub my son was working at and I walked in and he told me I looked bloody terrible.
27. I would feel better a few days after the injections. I was injecting myself, it was difficult but I looked at the bigger picture to get cured.
28. I was on treatment for three months. On the 11th week, after seeing the nurse every week at Derby City Hospital, she told me the treatment had failed and wanted to try another one. The next treatment was based on my weight. The nurse got the all clear to trial it on me. It was the needles you injected directly not the plunge type. This treatment was better because it didn't knock me sideways. I was on it for 3 months, but this also failed.
29. I went to see my doctor and asked him what I needed to do at this stage. Doctor said nothing he has tried has worked, both treatments failed, and until they come out with another treatment there is nothing I can do.
30. I continued to go for regular exams and blood tests. It was still present inside me but it was manageable.  
  
The new treatment came out around 2015. I can't remember the name but it's the one that worked very well. I continued the treatment with the same nurse again.
31. She became even closer to us; she became a friend to me and Barbara.

#### Section 4. Consent

32. Barbara agreed and consented to the tests and treatments to treat hepatitis C.
33. At the time when I didn't know I had hepatitis C, I had a lot of bladder infections but not sure if that was a part of it or not - who knows.

#### Section 5. Impact

##### Barbara:

34. Like I said I cannot remember what treatment she was on, she would go to her

appointments alone. We would discuss her appointments when she was back home but we wouldn't go into detail.

35. Her side effects were rough at times. Barbara had general flu-like conditions, body aches and tired all the time. She never wanted to cook, she would generally struggle to get on with day to day things. She always had the underlying problems with her kidney. She was put on water retention tablets for her kidney virus, so her weight was going up, she put on a few stones and then they would change her tablets and she would lose weight again.
36. Luckily my mum would help out with my son and pick him up from school and help us a lot with Barbara being ill. I was working shifts; 4 on 4 off or 6am - 10pm sometimes, so different shifts. I would look after Richard (son) when I was off work.
37. Barbara's main illness (kidney virus) stopped her from working. I wouldn't say that having hepatitis C made life difficult for her.
38. When Barbara's kidney illness got bad, she was on dialysis. She had a big bag that would be attached to her during infusions. We found out we could go away with Continuous Ambulatory Peritoneal Dialysis (CAPD), you could tell the hospital and they would give you bags to take away or arrange it with the hotel we were staying at. Barbara would have 12 hour bags for longer flights.
39. We would pick up the bags at the hotel and carry on with the treatment abroad. We travelled all over the Caribbean. Everything was fine until we got to St Lucia.
40. Barbara was on an overnight treatment, the bag would work whilst she was asleep. We were given a machine that we took to St Lucia with us too. The bag was slightly different and a few days into the holiday she became ill.
41. She would remain in bed on the last days of holiday. We got a night flight back, Barbara had a 12 hour night bag on her. Once we got home we rang the hospital and went in, they said she had Peritonitis.
42. When Barbara first went on to Haemodialysis she had a ERM catheter which is a semi-permanent line attached to her chest so that renal dialysis could be done and later she had to go through 2 operations to have her Fistula fitted this because the first operation to fit a Fistula failed
43. Barbara went on dialysis 3 times a week for 4 hours and it was every Tuesday Thursday and Saturday evening 18.00 to 22.00.
44.  said she would donate a kidney to Barbara.   
 We went through a 6 month process with  
 she was the first choice for doctors.
45. Most of our friends around us and family were aware of what was going on.
46.  She went through the process until the final stage where the doctors said no to her kidney, as one of her kidneys was not working as well as the other.
47. It was then decided that  could donate. He was broadly compatible but he is blood type B- and Barbara was B+, so the kidney went through an anti-body wash before the transfusion.
48. Barbara was having blood washes right until the transplant and after. We stayed in Nottingham hospital then got transferred back to Derby City.



49. The first few years after the kidney transplant were fine. However, the kidney started deteriorating. The kidney virus had raised its ugly head again and Barbara had to go back on dialysis. She got steroid induced diabetes.
50. The hospital had to check the fistula was still working before she went back onto haemodialysis.
51. It was a great struggle. We went from one incident to the next. She had bad blood flow, and got her toes amputated. A year later she had a heart attack due to the bad blood flow. Then she had to get her left leg amputated.
52. She would have dialysis every few days. I was retired at this point so I went with her every time.
53. After they had removed her left leg she had a prosthetic leg fitted which she was just getting use too. When she had an abscess on her right heel the hospital tried to improve the blood flow but without any luck. The plan was to take the right leg off below the knee but because of Covid they had to delay the surgery and when she went in for the surgery they had to take the leg off above the knee.
54. Barbara then got sepsis. Which is when the doctors said you can either start treatment or go home and die with dignity.

#### Impact on my life

55. My side effects were also flu-like symptoms. My eyes would go blurry, I had blurred vision. For 5 weeks it was going into the hospital to take the tablets and injections.
56. Barbara was off work at this point, we would try and do things together after the appointments.
57. The first 5 weeks hit me badly, I told work and took time off work for 5 weeks.
58. I was a supervisor, and I wasn't on the shop floor I was supervising so doing more office work, it wasn't too bad.
59. When I was on the second treatment I carried on working as it didn't bother me at all. Similarly, the last treatment that worked very well in 2014, I carried on working.
60. My doctor told me my Cirrhosis was far gone, so that meant I could get the treatment. I had to be ill enough to get the treatment. The doctor told me it cost around £20,000 a shot. I don't recall the name.
61. I was told fairly quickly that the hepatitis C was treated and I was discharged.
62. I do not have long term damage from cirrhosis.

#### Stigma

63. No one treated us differently.
64. Education didn't come into it or stop anything due to age. It didn't make a difference.
65. Barbara stopped working when she became ill with the Kidney issues, and I took 5

weeks off for hepatitis C treatment and my workplace was ok with it. I was on sick leave and it didn't cost me anything financially.

66. In terms of the blood transfusion, I only know what she had told me as I wasn't there but she argued it at the beginning and told them that they gave it to her, as she would have regular blood tests and it was not showing until after the transfusion.
67. When we were going away on holiday she got a bladder infection and someone told us to get juice, but that made her potassium levels high so we couldn't go on holiday.
68. Barbara also had her thyroid removed.
69. Before Barbara found out about hepatitis C she did not experience any symptoms for us to think with hindsight and say that could have been because of it.

#### **Section 6. Treatment, Care and support**

70. When Barbara went in to Derby City Hospital with anaemia and had the transfusion where she contracted hepatitis C, the doctors did not inform us not to have sex, share tooth brushes etc. Otherwise we would have changed ways to accommodate that.
71. Facts were not given to her. Barbara was very clued on to what was going on, she would have said our lifestyle would need to change.
72. The only advice I was given when I was told I had hepatitis C was that if I cut myself I should go in to hospital to treat it. It was around the same time HIV came out so precautions were being taken.
73. When I went in for my biopsy they asked me the usual questions like how many units of alcohol do I drink a week, or if I take any drugs.
74. I was given advice on alcohol intake. We went out once a week, so I was only a social drinker when out with friends.
75. Barbara did not feel any guilt over me contracting hepatitis C from her, by that time, the kidney disease was taking over so we just said I would do the treatments and treat it. We were more concerned about Barbara's kidney failure. As long as the hepatitis C didn't affect me, we were not concerned. I went 10 years without knowing I had hepatitis C, we were always more worried about Barbara.
76. Barbara was very strong willed and minded, we just dealt with everything day by day.
77. My father died some time ago and I got depression and am suffering from depression now. I am getting treated for it, but I don't talk about it. Not sure if it is related to hepatitis C but it happened after my father passed away. In addition, I spent 5/6 years going through it constantly with Barbara.
78. There wasn't anything that both Barbara and I thought we should have received. Due to Barbara's kidney problem she was on the government allowance so we were living comfortably. I had a good job, we would use my income to pay for day to day bills and living expenses and we would save Barbara's money for holidays.

#### **Section 7. Financial Assistance**

79. We applied for Skipton at the end of 2015 and they came back to me in 2016. I have the letters.

80. Barbara and I sent our forms together. The nurse helped us fill it out and send it off. They came back and denied us as we did not fit the criteria, as they said Barbara's transfusion was in 1992, so was after their end date of 1991.

**Section 8. Other Issues**

80. Just like anything else we knew we got the hepatitis, we lived with it and got on with it.

81. The Skipton for being turned down was upsetting, we could have done with the money to make Barbara's life better near the end, but no other issues to mention.

82. Our generation got on with it and moved on.

83. The main overriding factor was the kidney problem hepatitis C was just another problem.

**Statement of Truth**

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

Signed

GRO-C

Dated

4/10/21

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