Witness Name: John Rice
(Senior)
Statement No:WITN2249001
Exhibits: None
Dated: 26th April 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF JOHN RICE (SN)

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 7th November 2018.

I, John Rice, will say as follows: -

Section 1. Introduction

1. My name is John Rice. My date of birth and address are known to the Inquiry. I am Helen Rice's husband. I intend to speak about my wife's experience of being infected with hepatitis C. In particular, I will talk about the nature of her illness, how the illness affected her, the treatment received and the impact it had on me and our lives together.

2. I married Helen in 1974, we have now been married for 46 years.

Section 2. How Affected

3. Helen was infected with hepatitis C because she was given infected blood products following a gallbladder operation. She was given four units of blood on that occasion, and she has never had any other blood transfusions.

4. Her hepatitis C is severe. She now has cirrhosis of the liver.

5. Helen received four units of blood. She didn't receive any other blood products.

6. Helen had her gallbladder operation at Stobhill Hospital in Springburn, Glasgow. I cannot remember the names of any doctors. It was only twenty-two years after the operation that she became very ill and was in a lot of pain, and so she had to stop working. We attended hospital and her GP many times. My wife's own GP, Dr Kelly, investigated and managed to obtain from her medical records the information that she received four pints of infected blood after the gallbladder operation. At least one of those units of blood would have been infected.

7. She received the four units of blood in May 1977 at Stobhill Hospital, following her gallbladder operation.

8. We were not warned beforehand about the risk of being exposed to infection as a result of the blood transfusion and had never even heard of this before. It took us just over twenty-two years to find out about the infection. My wife did not drink, she did not take drugs and she did not have sex with lots of men, so it took a long time to find out what was wrong.

9. My wife was not infected with any viruses other than hepatitis C.

10. Dr Danish was the one who told us that Helen had hepatitis C. He was a male doctor.

11. Dr Danish told us that Helen now had both hepatitis C and cirrhosis of the liver. He was quite cold with how he conveyed this to us.

12. No information was provided to understand and manage the infection. Everybody was ignorant as to what hepatitis C was back then in around 1999. Helen's friend Margaret who is a nurse had to explain it to her. Margaret put some bits of information in writing for my wife to be able to read about hepatitis C.

13. I think that information could have been provided earlier because we were completely lost. We had nowhere to go for information and didn't know what to do. It was not a nice situation to be in.

14. I think it is awful, the lack of information about this and the delay in communicating to us. It just so happened around the time of when Helen was diagnosed, that we saw GRO-A on TV from the Scottish Infected Blood Forum (SIBF). We found out more information for ourselves through discussions with people at the SIBF meetings.

15. We were told absolutely nothing about the risks of others being infected as a result of Helen's hepatitis C. The whole family – myself and our two children – had to be tested after Helen's diagnosis. I am not entirely sure when we were tested, but the results for all of us came back as negative. I believe that this would have been very shortly after Helen being diagnosed.

Section 3. Other Infections

16. I do not know if Helen received any infection or infections other than hepatitis C as a result of being given infected blood products. We have not received any more information or letters and could not possibly know whether or not that is the case.

Section 4. Consent

17. I could not say whether or not Helen was treated or tested without her knowledge or without her consent or without being given adequate or full information. I don't know if

anyone knew whether or not the blood Helen received at the time could have been infected but I think that it is likely that certain politicians and government officials knew more generally of the risk of infection. They were certainly aware that the blood could have been infected and yet they kept importing it from America and not treating it to remove any virus or bacteria. A lot of lies were told. They were not only getting blood from America, but also from Russia.

18. I think it is quite possible that Helen could have been treated or tested for the purposes of research. However, we don't know because no one would willingly admit that this happened.

Section 5. Impact

19. Helen being infected with hepatitis C had a huge impact on us.

20. The mental and physical effects of being infected with hepatitis C were very, very bad. I had to give up work and so did Helen. It was a real struggle, we had no money and she was very ill.

21. Many medical complications or conditions resulted from the infection. Helen experienced pain, memory loss, she became forgetful, clumsy and experienced bladder, bowel and thyroid problems.

22. Helen started getting hepatitis C symptoms twenty-two years after receiving the infected blood, and she then became extremely ill.

23. Liver replacement was not offered because Helen had a virus. Her treatment for hepatitis C was Ribavirin and Interferon. Interferon was an injection and Ribavirin was pills. Treatments were successful in that they saved Helen's life, but they were not successful because of what has happened since. The treatment has cured the virus, but there is no 100% guarantee that the virus will not return.

24. Helen was offered the treatment and did not face any difficulties or obstacles in accessing the same. But then again, she was so ill at the time that she would have accepted any treatment.

25. I do not think that there were any other treatments available. Nobody knew how to treat hepatitis C. If there were any other treatments, I do not know.

26. The treatment was a horrendous experience and had awful mental and physical effects. Helen lost all her hair, she was in constant pain, she could not sleep, she kept itching all over and was feeling really down and depressed all the time. The treatment lasted a year and she went for review 6 months into the treatment. There had been a slight improvement and it was decided that Helen should continue the treatment. If she had not been able to continue the treatment, she would just have been told to go home and die. I am not entirely sure, but I believe that Helen had her treatment in 2005.

27. Being infected with hepatitis C meant that there was a stigma about going to the dentist. Helen had to go to three different dentist before anyone accepted her. One of the receptionists said in a very loud voice: "we don't take hep C's in here!" It was very embarrassing because everyone could hear and the dental clinic was located in an area where many drug users attended. The dentist that agreed to treat Helen, is very good and looked after her as best as he could at that time.

28. Our family life was affected due to Helen contracting hepatitis C because we couldn't attend many social functions, or we could not attend for the whole duration of the event. We always had to leave early because Helen felt so exhausted. This included christenings, birthdays, weddings and it is only in the last few years that we have managed to go on holidays. The sun is good for Helen's joints as they are sore almost all the time. Sometimes, she is too tired to carry bags and fly abroad. There have been times when we were about to cancel a holiday. Having hepatitis C also meant that she couldn't spend as much time with her children and grandchildren as she would have liked because she was always feeling really ill.

29. It was also very worrying that our daughter was born a year before Helen was diagnosed with hepatitis C, and there was a real fear that she had contracted it in the womb. We did not know at the time whether or not she had, because the virus can be dormant for a long time, even as long as 27 years, before it shows up. We all had to go and get checked and that is when we found out that our daughter did not have the virus.

30. The stigma associated with a diagnosis of hepatitis C is constant because of your own self and what you perceive. You have to keep it from friends and family until you find out that the infection is not easily transmitted.

31. Helen gave up her work before the diagnosis because she was feeling really ill. She never returned to work. I gave up my work as well in 2001 so that I could look after her. I could not go back to work because the illness was awful. Even if I had gone back to work, I would not have been able to concentrate or do anything. It was devastating. Before she became so ill, Helen had always worked and I was self-employed. Within a day, everything was turned upside down and it was horrible.

32. We had to borrow a lot of money. I was told that if I had any tools from work that I had to sell them for money. We were very worried about not being able to pay bills and it was worse than anything else apart from the illness.

Section 6. Treatment/Care/Support

33. No care and support in consequence of being infected with hepatitis C were ever offered.

34. No counselling was offered either. We just had to get on with it on our own. We were never offered anything such as counselling or support and have never received anything. Support was non-existant and we definitely would have benefitted from this if it had ever been made available. It is only recently through SIBF that support has been discussed. I feel that one of the causes of there being no support was because doctors at the time did not have the knowledge to deal with these conditions.

Section 7. Financial Assistance

35. For a long time, we only received unemployment benefits and we did not get any assistance from any Charities, Trusts or Funds. At that time, we were not members of any group for affected or infected people.

36. It was only later that we became involved with what is now called the SIBF. We got involved with them in 1981. Their acronym stands for Scottish Infected Blood Forum. They help with advice and information on how to apply for financial help. We also support one another. The SIBF are a charity organisation, but they do not offer financial assistance themselves. It is there if we need it. The Government funded a group called the SIBSS, which stands for Scottish Infected Blood Support Scheme. We got help from them. We found out about them from the Forum and through Thompsons. Haemophilia Scotland also help.

37. We are currently receiving an annual payment of £27,000 every year. Stage-two cirrhosis people receive this payment. We also received two lump sums of £20,000 and £25,000 from the Scottish Government in 2005. These payments came from the Skipton Fund, again due to the cirrhosis.

38. There was application process for us, we obtained all of these payments through Thompsons Solicitors. The Skipton Fund was later transferred to SIBSS and payments carried on as usual.

39. We faced no obstacles when applying for or receiving these payments ourselves, but there are people who have not been as lucky and have not received anything.

40. The preconditions imposed on the making of an application and the grant of financial assistance were that all medical records had to be provided. We obtained these from the doctors at hospital and then Thompsons Solicitors took matters from there.

41. I would have loved for a financial system or assistance to have been in place for infected people in the earlier days, as we were struggling so much due to the fact that both Helen and I had to stop working.

42. All payments are received by Helen. Affected family members are not entitled to anything as yet. We are waiting to hear this week whether affected family members will have any entitlement.

Section 8. Other Issues

43. We have had no involvement in court proceedings as a result of Helen being infected with hepatitis C. We have, however, been involved in the Penrose Inquiry and we have been involved in campaigning with SIBF and jointly with Haemophilia Scotland. Our involvement in campaigning has been constant. We campaign through the SIBF and everything is done through them. We have regular meetings and we know what they are looking for and what their expectations are.

Statement of Truth

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

Signed **GRO-C**

Dated 26th April. 2019