Witness Name: Suzanne Rogers
Statement No: WITN2934001
Exhibits: WITN2934002 - WITN2934004
Dated: May 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF SUZANNE ROGERS

I, Suzanne Rogers will say as follows:-

Section 1. Introduction

1. My name is Suzanne Rogers. I was born on GRO-C 1956 and I live at GRO-C, Leeds, GRO-C I live with my husband and we have two children and a granddaughter.

2. My husband, David Rogers (born on GRO-C 1947) was infected with Hepatitis C (HCV) as a result of being given contaminated blood products. He has provided his own witness statement to the Inquiry (Witness Number WITN1496001)

3. This witness statement has been prepared without the benefit of access to my husband's full medical records. If and in so far as I have been provided with limited records the relevant entries are set out in the medical chronology at the end of this statement.

Section 2. How infected

4. David was first diagnosed with mild Haemophilia A (level 10 iu/dl) aged 16 in June 1964.

5. David received Cryoprecipitate and Factor FVIII concentrate (FVIII) to cover multiple teeth extractions, a hernia operation and a liver biopsy.

6. David attended St James's University Hospital, Leeds for his Haematology treatment. Originally David was under the care of Dr B A McVerry (who retired 10 years ago) and now he is under the care of Dr Lishel Horn. David also has to attend the Hepatology Centre at St James's Hospital for his liver where he has scans every 6 months.

7. David was given Cryoprecipitate (Cryo) in 1975 when he had several teeth removed at St James's Dental Hospital. He received 14 units of Cryo in January 1975 and another 14 units of Cryo in April and May 1975.

8. I believe that David has only been given FVIII on 5 occasions. He was given FVIII (BPL) on 4 January 1982 for dental work; Recombinate on 17 March 2004 for dental work; Advate on 25 June 2005 for his hernia operation; Advate on 9 January 2007 after his liver biopsy; and Advate around July 2011 for further dental work. I remember being told by Dr McVerry that all the FVIII became synthetic after 1995/96. I exhibit David's UKHCDO 04 Patient annual treatment record at WITN2934002.

9. David did not receive any advice regarding the FVIII. He was just informed that the FVIII would help him.

10. David was infected with HCV (genotype 1B) from contaminated blood products.

11. In around October 1995, David arranged an appointment at St James's Hospital after receiving a letter about being potentially infected with Hepatitis

C. At this appointment he had a blood test. When the results from the blood test came back David and I went to collect the results. He was told, without any compassion, by three people in a room that he had HCV. It was not mentioned at the time that he was infected with HCV by blood products. David was then told that he would need a further test for HIV and he had the blood test on that same day. However, when we received the results a few weeks later it was negative. When we left hospital we were both devastated. We both broke down and sobbed in the car.

12. David then had to attend a liver clinic on a regular basis for blood tests. The waiting room would be full of drug addicts and people from prison. It was a terrible experience. David's notes also had a yellow sticker on them which said '*Danger Infected*'. This was very upsetting.

13. Initially David was not given adequate information to mange the HCV. It was only in 2007 that information was provided. David was never advised on how to not infect others.

Section 3. Other Infections

14. David received a letter dated 8 July 2005 advising that he was 'at-risk' of vCJD because he received factor concentrate manufactured from UK-sourced plasma between 1980 to 2001. I believe that he has been tested for this and is clear.

Section 4. Consent

15. David was not given adequate information about the purpose for which blood tests were taken.

16. From his UKHCDO records his blood was tested for HIV in 1986 but we were not told about this or that he was clear. I attach the UKCDO 07 Patient HIV data record at WITN2934003.

17. As far as we are aware David's blood has not been used for research purposes without his consent. David was a participant in the experimental triple antiviral treatment for HCV with Pegasys Interferon, Ribavirin and Telaprevir in 2012.

Section 5. Impact of the Infection

18. David had a liver biopsy on 9 January 2007. The biopsy showed David has liver cirrhosis with chronic hepatitis consistent with HCV (fibrosis stage 5 – 6). The 2007 biopsy also diagnosed hereditary haemochromatosis which means that David has high ferratin (iron) levels. He had to have multiple weekly venesections (removal of blood) before he could start his treatment for HCV, as this would improve the chances of a good response to the HCV treatment

19. David has undergone two treatments for HCV. The first treatment in 2008 / 2009 cleared the virus but unfortunately the HCV then returned in 2010. The second treatment in 2012 / 2013 cleared the HCV again.

20. David suffered from strong flu symptoms during the first HCV treatment and lost a lot of body mass. The side effects were dreadful. After the treatment completed we were told the virus had cleared, and we believed it would never return. Therefore, a year later when we were told it had returned we were devastated.

21. On 6 November 2012 David started a new drug called Telaprevir. It was a 12 week course of taking medication every 4 hours, 24 hours a day, which then led on to Interferon and Ribavirin for the 11 months following this. I was given a one day tutorial showing me what I needed to do before giving David this treatment. I had to prepare food with 20 grams of fat for David to eat before every treatment as the Telaprevir burnt the oesophagus.

22. The hospital suggested that I feed him either 4 melted Mars Bars, porridge with Jersey cream or liquidise a frozen Morrison cheeseburger to line his stomach. It took about one hour for him to eat this before I could give him the

drugs. It was really hard to encourage him to eat as he felt permanently sick and had no appetite. It was exhausting for me as I had to prepare this every 4 hours for 11 weeks.

23. Within 24 hours of starting the second treatment David became bed bound, couldn't breathe and had no energy. He had horrendous side effects, including extreme full body skin rashes, skin scarring, headaches, sickness, extreme weight losses, deep depressions, and in some cases suicidal tendencies. It also caused severe white blood cell destruction, resulting in dangerous immune system levels. The side effects were very deliberating, and caused David to be so unwell. Within 3 weeks he looked like he had been burnt by a kettle and he was critically ill 3 times when he was on this treatment.

24. Of the complete group of 60 people selected for the Telaprevir trial, 35 people abandoned taking the drug after only 4 weeks. By week 10, only 12 people continued at St James's Hospital. David was only 1 of the 3 who made it to week 30 plus.

25. Telaprevir caused the death of some of the small group of people selected to be the guinea pigs to test the drug. I saw a newspaper article which read article '*three men die in St Thomas' Hospital due to new drug Telaprevir*'. I was so concerned for my husband's health. I found out that it had been banned in America but he was still getting it. Telaprevir has now been withdrawn due to the severe side effects and in America the people on the original testing are in a legal action due to deaths and side effects of being given this drug.

26. The treatment was so awful it resulted in David having to be nursed from home as his doctors felt he would be ill advised to be nursed in hospital due to the high level of infection risk. On 31 July 2013 it was recommended that David stopped both Interferon and Ribavirin as he was too ill to carry on. Fortunately the treatment cleared the HCV and David is still in remission.

27. Shortly after David's completion of the clearing treatment, my heath took a turn for the worse. I was ill for 4 months with pleurisy which developed into full pneumonia and shingles. The doctor explained that my poor health was due to my immune system being compromised due to being so tired and exhausted from nursing David throughout his 11 months of treatment. My body had shut down.

28. I had to be tested for HCV about 4 years after David was diagnosed. David received a call asking if he was coming into the clinic and if so whether they could also test me for HCV as he could have passed it on to me. I had to spend 6 weeks in a nightmare wondering whether I had been infected. This was awful for David as well because he did not know if he had infected his wife and children.

29. I was given the all clear in June 2000 and this was a huge relief and I exhibit a letter confirming this at WITN2934004. Dr McVerry said that I was lucky as I was the only spouse at St James's who had not been infected in one way or another. This was at the height of the stigma.

30. We did not tell many of our friends about David's infection because of the stigma.

31. Our children have been distressed by their father's health over the years. Due to the fact our daughter was getting married in GRO-C 2012 we did not tell her that the HCV had returned in 2010, as we wanted to wait until after the wedding so it did not overshadow her day. She was very hurt that we kept this information from her.

32. While David was on the first clearing treatment he had to work even when he should have been at home recovering because we needed to be paid a full salary. Our house was part of his contract of employment, so we anticipated we would have to leave when David retired. He had planned to work until 65 and then do consultancy work for a further 5 years. I had started my own

business, which was a memorial masonry company, which had a good reputation and was very successful.

33. David was so unwell during the second clearing treatment it resulted in him having to retire from work aged 65. I had to dissolve my business around this time, as I was David's primary carer. I had no choice but to concentrate solely on David's health. This meant that our financial plans were totally changed as I had planned to work until I was 65 years old to build up enough savings to purchase our own home. David's HCV and treatment brought forward our life plan by about 10 years.

34. We struggled to get a mortgage due to David's infected status and the fact I had also been tested for HCV. We would have bought a much larger house if we could get a mortgage and I could have carried on working.

Section 6. Treatment/care/support

35. There was a delay in David beginning the Telaprevir treatment as we had to wait for the government to clear funding for it, which was given in April 2012. I believe the trial for 60 patients cost about £200,000 each.

36. David suffered difficulties in receiving adequate dermatological care when he was on the Telaprevir trial in 2012.

37. Neither David nor I were offered any counselling or psychological support.

Section 7. Financial Assistance

38. David was not aware of the Skipton fund until Dr McVerry informed him. Dr McVerry then very helpfully filled out the forms for David and all he had to do was sign. David received £25,000 from the Skipton Fund.

39. David now receives about £1,500 per month from EIBSS as it has just gone up.

Section 8. Other Issues

40. We never thought we would get this far and consider that we are lucky to be all here.

Anonymity, disclosure and redaction

41. I confirm that I do not wish to apply for anonymity.

42. I do not wish to give oral evidence to the Infected Blood Inquiry.

Statement of Truth

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

Signed. GRO-C ....

Dated....22nd May 2019....