Witness Name: David Rogers
Statement No:WITN1496001
Exhibits:WITN1496002 - 6
Dated: January 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF DAVID ROGERS

I, David Rogers will say as follows:-

Section 1. Introduction

1. My name is David Rogers, I was born on GRO-C 1947 and I live at GRO-C GRO-C Leeds, GRO-C I am retired and live with my wife of 44 years. We have two children and a granddaughter.

2. This witness statement has been prepared without the benefit of access to my 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

3. Prior to being diagnosed with Haemophilia I had bleeds. I was first diagnosed with mild Haemophilia A (level 10 iu/dl) aged 16 in June 1964.

4. I received Cryoprecipitate and Factor VIII to cover multiple teeth extractions, a hernia operation and a liver biopsy.

5. I attended St James's University Hospital, Leeds for my Haematology treatment. I was originally under Mr B A McVerry, Consultant Clinical Haematologist, who retired about 10 years ago. I am now with Dr Lishel Horn who is my Haematologist Consultant. I also attend the Hepatology Centre at St James's Hospital for my liver where I have scans every 6 months.

6. It is my understanding that I was given Factor VIII when I had several teeth removed at St James's Dental Hospital. My medical records show that I was given 14 units of Cryoprecipitate in January 1975 and another 14 units of Cryoprecipitate in April and May 1975, which was shortly after my wedding on GRO-C 1975 as seen in WITN1496002.

7. I was definitely given Factor VIII at St James's Hospital was on 4 January 1982 when I had 3 further teeth removed, as seen in my medical records at WITN1496003.

8. From my medical records, the other occasions when I was given Factor VIII were: - 17 March 2004 when I was given 2,000 iu Recombinate to cover dental work; 25 June 2005 when I was given a total of 4,000 iu Advate for my hernia operation; 9 January 2007 when I was given a total of 13,500 iu Advate after my liver biopsy; and around July 2011 when I was given 2,500 iu Advate for further dental work.

9. I did not receive any advice regarding Factor VIII. All I was told was that this would help me. Nobody ever explained what it was for.

10. I was infected with Hepatitis C (genotype 1B) from infected blood products.

11. The first information I received about Hepatitis C can be seen in a copy letter from my medical notes dated 10 October 1995 which asked me to ring the clinic to arrange a blood test as seen in WITN1496004. I called the hospital and they said they would send me an appointment but it may be a couple of months. Initially I was told not to worry. When I was arranging an appointment at St James's Hospital, they told me it was just to bring my Factor VIII records up to date. From memory, I think I had my first blood test Hepatitis C in 1996; however, there is no reference to this in my medical records.

12. When the results from the blood test came back I was invited in to the hospital and was told, without any compassion, by three people in a room that I had Hepatitis C. I was told that I might need treatment for Hepatitis C but I was sent away and told not to worry about it. It was not mentioned at the time that I had been infected by blood products. I was told that I would need a further test for HIV and I had the blood test on the same day. I left the hospital with my wife and we were both devastated. We sobbed in the car for what felt like forever. I rang my GP the next day and he was also appalled to hear about the way I was told. I found out that there was an inquiry at St James's Hospital into the way that individuals were told about their infections.

13. A few weeks later I was called back and told that I did not have HIV. This was a relief although I still had no idea about the implications of my Hepatitis C infection.

14. Later, when I began attending the liver clinic for regular blood tests with my wife, the waiting room was full of people from prison and drug addicts. It was an awful experience and in the beginning I felt that I was treated as if being infected with Hepatitis C was my own fault. Also my notes when I went for blood tests always had a yellow sticky note on it which said '*Danger Infected*'. This was awful to see.

15. Initially I was not given adequate information to manage the Hepatitis C infection. It was only by 2007 that more information provided to me.

16. At no point was I ever advised on how to not infect others. My wife was only tested 4 years after I was diagnosed. We had to spend 6 weeks in a nightmare not knowing whether I had given Hepatitis C to my wife or children. When my wife was given the all clear in June 2000 this was a huge relief. Mr McVerry told us that my wife and I were some of the lucky ones. He also commented that she was the only spouse who had not been contaminated in one way or another.

17. Mr McVerry told me that I was really unlucky to be infected with Hepatitis C and said I had a bigger chance of winning the lottery than getting infected, based on the limited number of times I was given Factor VIII.

18. Mr McVerry asked me to undergo a liver biopsy in 2000 but at the same time he warned me that it could be fatal due to my haemophilia. I did not want to have this biopsy due to the risk of bleeding to death and I was convinced that I would be the one where the biopsy would go wrong. At this time my children were around 17 or 18 years old and were still in education.

19. I found out that I could have a Fibro scan on my liver instead but unfortunately St James's did not have the facilities to provide this and they could not share the Fibro scan facilities at the nearby Newcastle Hospital. Instead, I had ultra sound scans from 2000 to 2001 onwards which showed there were no abnormalities highlighted on my liver, therefore I was made to believe everything was fine. I did not understand the importance of a liver biopsy.

20. I eventually had the liver biopsy on 9 January 2007. Mr McVerry said he would make sure that the top people would be looking after me. I was told that I had early liver Cirrhosis and I needed to undergo treatment for Hepatitis C. I was happy to start the treatment for the Hepatitis C but the biopsy also diagnosed hereditary haemochromatosis on 14 March 2007 which means that I have high ferratin (iron) levels. I had to have multiple weekly venesections (removal of blood) before I could start my treatment for Hepatitis C, as this would improve the chances of a good response to the Hepatitis C treatment.

Section 3. Other Infections

21. I received a letter dated 8 July 2005 advising that I am considered *'at-risk'* of vCJD for public health purposes because I received a factor concentrate manufactured from UK-sourced plasma between 1980 to 2001. However, it is my understanding that I have since been tested for vCJD and I am not infected with this.

Section 4. Consent

22. I was always told when Haematologists needed to take my blood but I was not given adequate information about the purposes for which it was taken. I was told when they were going to test me for Hepatitis C but it was in an uncompassionate roundabout way. The only blood test I know that they took was for my Ferritin levels.

23. As far as I am aware my blood has not been used for research purposes.

24. I was a participant in the experimental triple antiviral treatment for Hepatitis C (Pegasys Interferon, Ribavirin and Telaprevir). I was initially rejected for this treatment due to my age but Mr McVerry fought my corner and I began treatment in November 2012. This NHS trial was restricted to 60 patients due to its expense. This was made up of 30 patients at St Thomas' Hospital, which started the trial first and 30 patients at St James's Hospital.

Section 5. Impact of the Infection

25. Everyone I used to speak to believed I could infect them with Hepatitis C. I was treated like a leper.

26. The liver biopsy on 9 January 2007 showed that I have liver cirrhosis with chronic hepatitis consistent with Hepatitis C (fibrosis stage 5 – 6).

Treatment for Hepatitis C

27. I have undergone two treatments for Hepatitis C. The first treatment cleared the Hepatitis C and I remained for one year after I completed the course, however Hepatitis C then returned. The second treatment cleared the Hepatitis C and I am still clear.

28. I was not able to begin my first treatment for Hepatitis C until my ferratin levels had been reduced by bleeding so I began combined therapy of Interferon and Ribavirin around 30 July 2008. I completed the course around July 2009.

29. I worked all the way through the first treatment of Hepatitis C. The strong flu symptoms gave me headaches I was breathless on exertion. I lost a lot of body mass and strength and had to delegate heavy lifting work to staff. At one stage after my white blood cell count dropped and I had to take injections. The side effects of this were awful. I also felt very low in mood at times.

30. After the treatment I was told I had cleared Hepatitis C. I was never told that St James's Hospital did not have the technology to show if the Hepatitis C had cleared completely and therefore I believed the Hepatitis C was gone and would never return and that I would just need routine annual blood tests to monitor the situation.

31. However, on or around June 2010, about one year after my first treatment finished, I had a relapse. The news was given much more nicely and sympathetically this time. I had a consultation with Mr McVerry who said I would be wasting my time having the same injections of Interferon and Ribavirin as the chances of clearing the virus would only be 20%.

32. During 2011 I was advised that the new drug Telaprevir would boost my chances of clearing Hepatitis C to 70%. Teleprevir was a 12 week course which then led on to Interferon and Ribavirin for the 11 months following this. In late 2011 the hospital was waiting for the government to clear funding as it cost about £200,000 each. This funding was approved around April 2012. I was also told that it would take a year to clear the haemochromatosis which needed to be done before I could begin the treatment. My daughter had a wedding planned in GRO-C 2012 so I decided to wait until after her wedding before I began treatment.

33. I started on Teleprevir on 6 November 2012. It had to be taken every 4 hours, 24 hours a day, and if one treatment was missed then the whole treatment would fail. My wife was told to prepare food with 20 grams of fat for me to eat

to line my stomach before every dose of Teleprevir went inside me. I was often given four melted Mars Bars or a liquidised frozen Morrison's beef burger prior to the drugs. I felt permanently sick and had no appetite, so it used to take me an hour to eat the food before each dose.

34. Within 24 hours of starting the Teleprevir I became bed bound and I had no energy. Every part of my body was blistered and covered in a weeping rash. I looked like someone had "*stood on me and burnt me*". I exhibit a photograph showing the rash in WITN1496005. The rash eventually went into my ears and by December 2012 I was completely deaf. When I was injecting myself with the injections for the low white blood count, my body was covered in bruises and rashes. Trying to find a spot on my body where there was no rash was very difficult.

35. Around this time my wife read the headline of a newspaper article *'three men die in St Thomas' Hospital due to new drug Teleprevir'*. We were very concerned but the hospital decided to continue with Teleprevir. The steroid cream I was first given for the rash did not help and the only relief I could get was by using about a bottle of Aveeno cream every day. I was provided with Aveeno cream from the manufacturer direct as St James's had told them about my rash. Johnson & Johnson were brilliant and used to send me the cream direct in bulk packages for free and in return I gave them some information.

36. In December 2012 I was so ill we went to the hospital. We were told that it was too dangerous to admit me due to my low white blood count and the risk of infection. Eventually I was told that the safest place for me was at home. The hospital told me they would courier drugs to my home and that there was a 24 hour helpline my wife could ring. I was told that absolutely no one could come to the house, so over Christmas so we were unable to see our family or friends. My immune system was absolutely flat. I was told that if the rash went into my mouth or in my eyes then, and only then, I was to contact the hospital.

37. In Mid January 2013 I went into the Chapel Allerton Hospital where I received ten light treatments for the rash. I also had to get special drugs from Australia

which had been developed for people with bad psoriasis. In January 2013 (week 9 of Teleprevir) I was told that I was the only one still on Teleprevir out of the 60 patients who had started the trial. I was told that 75% of patients had stopped after week 4. I then found out that Teleprevir had been banned in America in late 2012 but I was still receiving it. This was an awful shock.

38. I had a meeting with a head nurse who actually asked me how I had got to this place. I was extremely depressed and the nurse stopped the Teleprevir immediately, which was only 11 days short of the complete course. Although I had finished the Teleprevir, it still took months for it to get out of my system. My skin was still awful it was very itchy. Every drug I took I ended up taking another drug to rectify the side effects of the first drug. I continued the Interferon and Ribavirin for the rest of the 11 months.

39. It was explained to me that there would be some side effects but no one knew what they were as this was a trial drug which had not been used before. The side effects of the Teleprevir include bone density problems, I became very breathless and had to attend breathing clinics and my skin took about one year to recover. My hearing was ruined and I now have to use a hearing aid.

40. I was very very depressed on Teleprevir, which had a known side effect of suicidal tendencies. The first treatment for Hepatitis C did not cause depression like the Teleprevir.

41. On the 31 July 2013 it was recommended that I stopped both Interferon and Ribavirin as my body could not physically take any more drugs. I could not even walk to our front gates. As a result I decided to stop the treatment at early as seen in WITN1496006. Even though the treatment was stopped early, I cleared the Hepatitis C and I am still in remission.

42. The combination of Hepatitis C and the Hemochromatosis has affected me badly. My physical wellbeing is still affected as a knock on effect from the Teleprevir. My joints hurt and I get breathless when I go out. My eyes have been affected and I have new glasses every year due to my eyesight deteriorating so quickly. I also now wear a hearing aid.

43. When I had to go to my dentist previously I had to fill in a lot of forms. Only last year or the year before a local dentist accepted me. It was the Dental Hospital who told me I had to sign up with a local dentist for check ups.

Impact on private, family and social life

44. Our children have been devastated. My daughter was beyond angry with us for not telling her that the Hepatitis C had returned in 2010. We waited to tell her after her wedding as we did not want this to overshadow her day. She was also angry that my work status had been taken away as I could not continue working.

45. My son knows that I was infected with Hep C but sadly we are estranged from him. We are still in close contact with my granddaughter though who is very upset at my infection and wants my name cleared as I did not do anything wrong.

46. We have always liked eating out in nice restaurants but this stopped when I began treatment for the Hepatitis C as I am unable to eat a lot now.

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47. We did not tell many friends about my infection because of the stigma.

Work related effects

48. I worked as General Manager of the Leeds Jewish Orthodox Cemeteries for 35 years. I used to work very long hours and was able to pick up heavy headstones with no problem before I began my Hepatitis C treatments.

49. I had to disclose the infection to my employers in 1995 as I was coming into contact with the general public. My employers wanted to know what risk I was to the community. I was not aware they had contacted my insurance and doctors. They did later apologise for not asking my permission before contacting my doctors.

50. At the start of my first treatment in 2008, my employers were initially quite sympathetic but then I began attending St James's Hospital once a week for a 4 hour period for the treatment. After having the treatment I was very sore. The first day after the treatment I suffered from flu like symptoms which would carry on into the second day and by the third day I felt like I was just getting over the flu. On the fourth day I felt back to normal. The treatment continued for 11 months.

51. St James's recommended I had the appointments on a Thursday afternoon so that I would have more time to recover and miss less time off from work. I worked a 5 and a half day week because it was for the Jewish community, and Sunday was a normal working day. After a couple of weeks it was agreed that I would have my treatment on a Friday morning instead, however this meant I would only have one day to recover as I had to be back at work on a Sunday. I only took 2 days off during the whole 11 month treatment. I worked at times that I wasn't well enough so I that could continue to be paid full salary.

52. Due to the horrendous side effects of my second treatment I had to stop work at around 65 years old. In late December 2012 I was given a sick note which I handed into work and once they received it they immediately stopped paying me. A couple of weeks later I handed in my notice as I was bed bound and I could no longer bear the thought of going back to work as I was in so much pain and had no strength or energy. I did not go back to work after this.

Financial effects

53. I had planned to retire from full time work at 65 but stay on as a consultant until 70, working shorter hours over 1 to 2 days to train up the next staff to Manager Level, to ensure that we still had money coming in. I was told by my employers that I could stay on as a consultant for as long as I wanted. I had not planned to stop work so early and lost 5 years income which has affected my financial position.

54. Under my contract I was given a house with my job which included all bills and maintenance in addition to a healthy salary. Working as a consultant to 70 years old would have also meant that I could have continued living in the house for another 5 years. After I handed in my notice I should have left our house 3 months later; however, the Trustees agreed that we could stay until after our daughters wedding.

55. When I left my job I had to purchase a home of my own but due to the infection I was unable to get a mortgage. My wife had also been tested for Hepatitis C and therefore she was unable to get a mortgage either. The house I bought in comparison to the house I believed I would have bought but for retiring early, was not in the same league. If I had the choice, I would have saved up more and purchased a larger house later on.

56. Also all my insurance went through the roof. I was quoted £2,500 for travel insurance just for a week's holiday. I am unable to obtain health insurance. I was unable to renew my life insurance when I was infected with Hepatitis C.

57. The financial effects are huge. I am fortunate that I am not on the breadline and that I was able to travel to hospital and was able to afford to pay for parking. There are people I know who missed hospital appointments due to not having enough money to get there.

Section 6. Treatment/care/support

58. I have not faced any difficulties obtaining treatment.

59. I have never been offered counselling or psychological support.

Section 7. Financial Assistance

60. I received £25,000 from the Skipton Fund. I did not know about it until Mr McVerry told us about this. He filled the forms out for me and all I had to do was sign.

Section 8. Other Issues

61. I would like the government to stand up and admit that they have been wrong. There has to be vilification and someone needs to say that what happened to everyone infected was through no fault of their own. I believe that the government needs to admit they were wrong.

62. By the late 1990s into 2000 there were more nurses who showed a lot more compassion, which compared to the care given by Macmillan nurses.

Anonymity, disclosure and redaction

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

64. 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....21ST JAN 2019....

Medical Summary

(This summary is not intended to be exhaustive but sets out key points in the records relevant to the Statement)

1950s	one unit of blood transfused (per patient in letter 05.04.2007)
16.06.1964	diagnosed with mild haemophilia
06.01.1975	Report found that after an injury and excessive bleeding for 3 weeks, patient was a Haemophilia sufferer. (27 years old).
January and April/May 1975	Patient had a tooth extraction and he was given first Factor VIII due to being a Haemophiliac.
04.01.1982	3 teeth removed St James's Dental. Given Factor VIII
26.03.1992	letter to patient inviting him for Hepatitis B Vaccination to those who are at risk of receiving blood products in the future
08.07.1995	Letter to Doctor from Haemophilia Unit at St James's University Hospital – informing doctor that Mr Rogers is part of the group being asked to take precautions to reduce the possible risk of further transmission of vCJD.
10.10.1995	Letter to patient re: the possibility of individuals being infected with Hep C following the infusion of blood products. Invited for blood test.
23.03.2000	Haematologist full blood test
07.04.2000	Letter Haematologist to GP – his viral studies show that he has not been exposed to Hepatitis A and B and should be vaccinated against both of these viruses now. It does show that he has been exposed to Hepatitis C and I will arrange to see him to take this matter further
10.04.2000	letter from Haematologist to patient 'Finally, your viral tests also show at some time in the past, that you have been exposed to Hepatitis C. Whilst this is certainly not a matter for alarm, I don't think we can ignore it, so I have asked my nurse to contact you with regard to a further appointment, so we can discuss this matter further.
27.04.2000	First dose of Hepatitis B vaccine and first Hepatitis A vaccine.
31.05.2000	Second dose of Hepatitis B vaccine and second Hepatitis A vaccine.
17.03.2004	given 2,000 iu Recombinate as prescribed then to St James's Dental for teeth extraction. No problems

25.06.2005	Having hernia repair at Leeds General Infirmary ... Treat with DDAVP. Post DDAVP level only 56% therefore given Advate 2,000 iu prior to surgery and 2,000 iu the following morning. (57 years old)
08.07.2005	letter from Haematologist advising exposure to vCJD between 1980 and 2001
Dec 2006	ultrasound of liver – showed what looked like normal appearances of liver (per letter 05.04.20007 from Dr Singh Liver Unit)
09.01.2007	Liver biopsy performed. Covered with 9 administrations of 1,500 iu Advate. Fibrosis 5/6
08.03.2007	Letter to Doctor from Haemophilia Clinic - patient has early cirrhosis
14.03.2007	DNA laboratory report. Diagnosed with hereditary haemochromatosis
25.04.2007	11 appointments for venesection (phlebotomy) until 11.10.2007. Aim to get his ferritin levels down to a satisfactory level before begin Hep C treatment so it will be more effective (per letter haematologist 19.04.2007)
11.07.2007	letter from Hepatologist to GP – I would estimate his chance of responding to anti-viral therapy in due course at around 30-40%. This is because of the co-existence of both genotype 1 and cirrhosis. Treatment, however, would definitely be worth doing. He is at increased risk of hepatocellular carcinoma with both of his liver co-morbidities.
07.02.2008	14 appointments for venesection (phlebotomy) until 15.05.2008
10.06.2008	Letter to patient from St James's University Hospital – advising patient they can now proceed with treatment for Hepatitis C.
30.06.2008	He commenced on Pegasys 180mcg and Copegus (tablets) 400mg am and 600mg pm. 11 month course with Pegylated Interferon and Ribavirin (per letter 05.11.2008)
17.07.2008	Letter from St James's University Hospital to Doctor – describing patients side effects from Hepatitis C treatment – flu like symptoms and tiredness
30.07.2008	Letter from St James's University Hospital to Doctor – details the discussion had with patient about his employers lack of knowledge regarding his illness. Patient is worried the side effects will impact his job and his employers will use this information to make him redundant.

	30.07.2008 commenced Pegylated Interferon and Ribavirin treatment (per letter 26.09.2008)
26.09.2008	Letter from St James's University Hospital to Doctor – HCV PCR RNA test, the test to detect the presence of the hepatitis C virus, came back as negative after 12 weeks of treatment. We will recommend that he receives a total of 48 weeks. The patient's wife is very worried as patient is unwell with headaches and flu like symptoms, was aching and very tired.
16.02.2009	currently well from a haemophilia point of view but has found Interferon and Ribavirin treatment difficult. Now coming towards the end of this treatment and being reviewed by liver team next week
27.07.2009	Letter from St James's University Hospital to Doctor – Hepatitis C treatment has now finished and patient remains in remission.
09.09.2009	letter from Haematologist to GP – Finally, the least of his worries his haemophilia, doesn't give rise to any problems outside trauma or surgery.
03.12.2009	Letter from St James's University Hospital to Doctor – patient has negative PCR 6 months after successfully completing antiviral therapy for Hepatitis C.
16.11.2010	Letter Haematologist to Hepatologist – unfortunately although he has been discharged by your unit a PCR done in June this year shows that he has relapsed after barely a year in remission
03.05.2011	began venesection as serum ferritin levels are still above 600 so he remains on a two weekly venesection regimen to try to reduce these to within the normal range before he starts further treatment for Hep C
15.07.2011	Due to dental extractions on 21.07.2011 will come to Day Unit for 2,500 iu Advate prior and collect tranexamic acid (63 years old)
22.02.2012	Letter from St James's University Hospital – Hepatitis C has come back. Advised to carry on taking monthly venesections for now.
06.12.2012	Letter from St James's University Hospital to Doctor – Hepatitis C treatment started on 06.12.2012 and patient self administers. Patient is taking Pegasys and Ribavirin. Telaprevir (capsules) … 750mg TDS to start 07.11.2012

01.08.2013	skin reaction to Telaprevir reviewed by dermatology team and has required oral Prednisolone and light therapy. Treatment discontinued through patient choice and intolerable side effects on 31.07.2013 (after 39 weeks of anti-viral therapy). David continues to suffer with facial skin problems
16.09.2013	has completed another course of Hep C Rx at end of July. Hep C pcr negative again. Had 10 weeks of Telaprevir – made him really unwell. Still bothered by photosensitive rash over face and torso. Seen in dermatology – new creams …. Has retired now. Slowly getting his energy back
20.10.2014	was apparently labelled as VWD in the past
27.10.2014	began venesection again
12.11.2014	David completed treatment for Hep C under the care of our liver team. He was managed with triple therapy with Telaprevir, Interferon and Ribavirin. He discontinued in July 2013, and his 6 months' post treatment PCR was negative.
14.01.2015	Letter from Haematologist to GP confirming patient will undergo genetic testing