Witness Name: Lisa Rushton
Statement No: WITN1966001
Exhibits: WITN1966002-
WITN1966009
Dated: 1 May 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF LISA RUSHTON

Section 1. Introduction

1. I, Lisa Rushton, will say as follows.

2. My date of birth is GRO-C 1979. My address is known to the Inquiry. I live in GRO-C with my 22 year old daughter. I am unable to work due to chronic illness.

3. I make this statement on behalf of my mother, Jean Anne Farrugia, who was born on GRO-C 1949 and died on 13 June 2015.

Section 2. How Affected

4. I am one of three children. When my mother was pregnant with her fourth child she started to miscarry and needed hospital treatment. She was admitted to Birch Hill Hospital, Rochdale. She haemorrhaged and needed a blood transfusion. She received two units of blood on 17 June 1991 (WITN1966002). The batch numbers were 457231 and 457276.

5. I do not know whether my mother suffered any symptoms of the virus before she was diagnosed, however a request in her GP records for a full blood count dated 6 September 1993 records her complaining of 'dizzyness' (record available on request).

6. In 1995, four years after the transfusion, we returned from a family holiday to find a letter waiting on the door mat. The letter was from the Look Back Programme and informed mum she 'may be' infected with Hepatitis C ('HCV') and that she needed to make an appointment to get checked. All nine pages of the correspondence with the National Blood Transfusion Service is exhibited at WITN1966003. I feel that informing her by letter like this was an atrocious way to tell someone about an infection like HCV. I know that my mother found the way in which she was informed of the virus very upsetting, and this had an ongoing impact on her mental health. In correspondence between her psychiatrist and GP, dated 9 February 1999, several years after being diagnosed, her psychiatrist notes as follows:

'History of Presenting Complaint:

She had contracted Hepatitis C in 1991 following a blood transfusion and after that she had felt very low. She felt the manner in which she was contacted was unsatisfactory in that she had a letter in the post. She has been low ever since.'

(Correspondence available on request).

If the blood service knew the blood was infected then mum should have been informed immediately, before 1995, and in person rather than by post.

7. My dad remembers going to an appointment with mum at the blood service centre to see someone called Dr Love. Mum was given 20 years to live. GRO-C

8. As far as I can recall, in terms of the information and advice given, mum was just referred to a liver specialist and told not to drink any alcohol. Her GPs were very good and offered mum a lot of support over the years.

9. After testing, mum was told she had chronic liver disease. A liver biopsy in 1995 showed an inflammation score of 6 and a fibrosis score of 3-4.

Section 3. Other Infections

10. I do not believe mum received any infection other than HCV as a result of being given infected blood.

Section 4. Consent

11. I did not think mum was ever treated or tested without her knowledge or consent, or for the purposes of research, however, her GP records contain correspondence from the National HCV Register from 2001 which asks to review the histopathology of her liver biopsy. The stated purpose was for all patients enrolled in the register to have their biopsies scored consistently which would enable the register to evaluate each patient's disease and to relate the stage of liver disease to the interval since infection. The letter went on to explain that 'ethical approval for the collation of these biopsies has been obtained from both the Public Health Laboratory Service and the Multi-Research Ethics committees, and there is no formal requirement to gain patient consent'. This correspondence is exhibited at WITN1966004. She was quite open with us about things and never mentioned this to me which makes me suspect that she was not informed of this research.

Section 5. Impact

12. The physical and mental effects of being infected with HVC were horrendous for my mum. The physical effects were a steady but painful decline over the years but the mental impact seemed to happen almost overnight.

13. From the outside everything looked "normal" for a time. Mum still went to work in the first few years after diagnosis, but at home things were very different. Mum just seemed to give up on everything. Dad worked 12 hour night shifts seven days a week so missed a lot of what was going on at home. My sisters and I had to take up the running of the house; this in turn had a knock on effect on our schoolwork, especially our homework. I was 16 at the time mum was diagnosed, and both my sisters were younger than me.

14. Soon after being diagnosed mum went into a downward spiral. Her personality changed and she became very blunt. This was mostly felt by us three children. She was particularly harsh with me. Her relationship with dad suffered and they were not getting along. Mum received counselling at the time and was asked if she would consider becoming an inpatient on a psychiatric ward but she refused.

15. Mum's consultant was willing to treat her HCV but said that there was no funding available for treatment. Mum had to fight to secure funding for treatment with Interferon and her GP records contain a copy of a letter she wrote in 1996 asking why her treatment would not be funded (correspondence available on request). Treatment only started when the hospital trust agreed to fund her until the issue was sorted out with the appropriate purchasing authority (WITN1966005). I am shocked that she had to fight for funding when she had been infected through contaminated blood.

16. Mum started treatment with Interferon in March 1996 but the side effects were horrific. The blood results showed the treatment was working, but the Interferon was making mum suicidal. There were several occasions when she slashed her arms open with whatever she could find to cut them. Her GP records from this time record her experiencing very low mood and suicidal thoughts. The notes also record that she was self-harming and overdosing. An entry in 1996 notes, '*should she stop the Interferon? (Doesn't want to)*' (WITN1966006). She often said to me that she just wanted to see her blood to see if she could see anything in it. She reached some very dark places where she no longer wanted to live anymore. As young teenagers this was very hard to witness. She used us as her emotional outlet and this was hard on her and on us.

17. After she became suicidal the drug was quickly withdrawn for her own safety. She had only been on treatment for six weeks. A letter from her consultant gastroenterologist to her GP dated 2 July 1996 notes, 'serious depression like this does seem to be a significant problem in a few patients with Interferon treatment and I think that it is going to turn out to be a contra-indication to further treatment, although I have said to her that it does not necessarily remove the possibility of re-treatment in the future' (letter available on request).

18. After treatment was withdrawn in 1996 she was told she had not cleared the infection and it remained active. A liver biopsy carried out in October 1997 showed some improvement with inflammation of between 1-2 (down from 6 in 1995) and a fibrosis score of 3 (down from 3-4 in 1995). Correspondence from the consultant gastroenterologist to her GP dated 21 October 1997 confirmed, 'the liver biopsy fortunately showed evidence of marked improvement of her hepatitis C which makes it likely that the Interferon has been effective. Her most recent LFTs have been quite normal' (correspondence available on request). Due to the encouraging liver biopsy results I feel that Interferon would have been very effective for her, if it had not been for the side effects. I do not think any further

treatment was ever offered to her. As the infection remained active I think this was a great shame and I think the question of whether Interferon could be restarted should have been kept under regular review. Also, I believe that new treatments, perhaps with lesser side effects, ought to have been offered to her as they became available.

19. Mum was in constant touch with her GP with whom she had a very good relationship but she seemed to lessen her contact with the consultants for her HCV and her liver over the years as she felt there was little they could do as they never offered her anything.

20. Over the years, the pain throughout her body worsened and she was in some form of pain constantly. The GP records document that she suffered with pain in her joints, right upper quadrant abdominal pain which could double her up at times and mood disturbance.

21. She had to have extended periods of time off work with abdominal pain and depression due to her diagnosis with HCV. Mum worked in the job centre and dealt with many different people on a daily basis. She could talk to anyone and would know their life story within ten minutes. There was a woman who my mum saw frequently who had quit her job as one of her colleagues had HCV and the bosses had refused to fire this colleague. The woman said to my mum that she didn't want to work there any longer in case she caught it. For mum this was the final straw. She could no longer stand trying to manage the daily pain, fatigue and mental anguish, with the stress of dealing with members of the public. It was the stigma demonstrated in that last remark which made up her mind and she applied for medical retirement, which thankfully she was granted.

22. Although it was a great relief to her to stop working, she suffered financially and had to claim benefits. She claimed Incapacity Benefit and Disability Living Allowance. This was a very difficult and stressful process involving a lot of form filling which also took its toll.

23. Two years after mum was diagnosed I turned 18 and she told me she had found me a house and I should leave. She was very blunt with me. I then had a baby and it was two years before mum even wanted to know my daughter. Gradually though, mum's behaviours became more controlled, but outbursts were still frequent. After a few years it was like someone had flicked the switch back on, but only half way. She was never her old self again. She and dad separated and she moved out of the family home. They remained close friends and would holiday together and spend Christmas together. Mum became a doting grandma and mother even though behind the mask she was struggling.

24. My mum never hid her HCV status or how she was infected. Extracts in the correspondence with the Blood Transfusion Service (WITN1966003) from the consultant haematologist demonstrate that mum may have been treated unfairly by her employer and suffered stigma as a result. The letter notes that, 'She works as a Civil Servant and explained to me that she was required to notify her condition to her employer as 'hepatitis' is a notifiable disease as far as the Civil Service is concerned. There is really no need for her employer to know of her condition as she is not a Health Care worker and she was prevented from working until she supplied a certificate indicating that she was not a danger to her colleagues. I understand that she is now taking sick leave in any case. It would appear that medical confidentiality may not have been observed at her place of work. However, she seems to be coping with this and will be returning to work as soon as she feels better.'

25. Mum's health continued to deteriorate slowly. She continued to suffer with HCV related pain, fatigue and fibromyalgia giving her extreme pain all over her body. She had many health complications related to HCV over the years, including gastrointestinal issues which led to significant

weight loss. She had several surgeries and biopsies and, in the final years, she was frequently in and out of hospital with infections.

26. Mum still had mental health problems and severe depression which came and went. She sometimes suffered with hallucinations, saying on one occasion she saw a girl in flowing white night robes glowing in the garden. She struggled to remember much in the years after the diagnosis, saying it was a huge blank to her. Her GP records demonstrate ongoing input from a clinical psychologist for several years after the initial diagnosis and symptoms including sadness, depression and self harm (cutting). Correspondence from her gastroenterologist also documented that she continued to think intermittently about committing suicide, though this was less severe than when she was taking Interferon (correspondence available on request).

27. By 2011, mum's diagnoses included severe COPD, respiratory failure, cor pulmonale, Hepatitis C, rheumatoid arthritis, peripheral vascular disease and hyponatraemia. She was not told to what extent any of these diagnoses were linked to HCV. She became housebound due to the pain, fatigue and severe COPD and was unable to walk as she could not breathe and had oxygen at home, as well as a portable oxygen tank so she could leave the house for hospital appointments. My dad, my sisters and I all took turns in caring for her. My youngest sister lived with mum and would help her get in and out of the bath and would wash her hair. Dad would do all her shopping as she could not leave the house.

28. In April 2015 mum had a fall at home and broke her hip. She spent several weeks in hospital. During her stay she had sepsis on three occasions, her kidneys shut down and she contracted pneumonia so she was admitted to the High Dependency Unit (HDU). Whilst she was on HDU we were told she had 24 hours to live, but mum, true to form, bounced back. Her lower legs also filled with fluid during this time. They

were very sore for her to move and she couldn't walk or stand up. Her legs were leaking fluid constantly but the doctors said they didn't really know why. Towards the end of her six or seven week stay she was sent to an old rehab ward where she contracted a pseudomonas infection. The infection, together with her severe COPD, caused her to become very unwell, however, once a suitable antibiotic was found, she started to come round. At the end of a week she was discharged but deteriorated over the weekend. She would not let us call anyone for help but fortunately her COPD nurse called in at home the following Tuesday. She saw mum wasn't well and took the decision away from her and called an ambulance, which we were very grateful for.

29. Mum was admitted to a different hospital and I told them everything that had happened over the preceding six or seven weeks and what specific antibiotic had been the only one to work. I was ignored and she was given a different antibiotic. I kept on asking for the right antibiotic but it wasn't until the Thursday before she died that she was given it. By then it was too late. The infection had done too much damage and she was slowly suffocating and drowning from the fluid on her chest. She became more and more breathless.

30. Mum was already on a Do Not Resuscitate Order so she was placed on a syringe driver with sedation and moved to a private room. She died the following Saturday around lunchtime.

31. Three or four weeks after her death I had to go and formally identify her body with a Coroner's Officer. The image and smell of my mum is one I will never forget. In July the Coroner released her body for burial. Ten months after her death, in April 2016, I had to prepare a life statement for the Inquest. The doctor's report to the Coroner dated 19 August 2016 is exhibited at WITN1966007.

32. The impact of HCV on my mum's life and all of our lives has been utterly heart breaking. Though mum was very stoical HCV changed all of our lives for the worse. She died aged only 65. The pain and suffering, both physical and mental, which she endured was immense and her immediate and extended family are left with the memories of that suffering. I wish she was still here today to give the Inquiry her story herself.

Section 6. Treatment/care/support

33. Whenever mum had surgery she was told she had to be last on the list due to her HCV status and all equipment had to be double bagged. Correspondence in her GP records regarding an operation describe how her name would be added to the waiting list as well as the urgent waiting list, noting however that 'she understands that because she is a high-risk patient because of her Hepatitis C that the urgent waiting list will be limited somewhat because of this problem' (correspondence available on request). Her infected status therefore impacted on other treatment.

34. Further correspondence in mum's GP records from her consultant obstetrician and gynaecologist describes an operation to perform a hysterectomy in 2003. The letter describes the operation, but then adds towards the end, 'It was during the reperitonisation of the vault, that I pricked my finger, right hand, middle finger, dorsal aspect'. I do not know why the consultant felt it was relevant to include this information in correspondence to my mother's GP, and there is no further mention of it anywhere else. I recall at the time that the surgeon told my mother about the finger prick and made her feel absolutely awful, as if it was her fault. This letter is exhibited at WITN1966008.

35. When she went to the dentist he told her she had to get permission from her doctor saying it would be safe for him to treat her. She felt so

humiliated that she never went back and she therefore had no further dental treatment.

36. Mum came up against judgmental behaviour in the healthcare profession where I think she suffered the most stigma. Many doctors, nurses and other healthcare professionals would just assume that she was an ex-drug user until she put them straight. She was taken ill in Australia and a doctor actually asked what drugs she used to inject. She responded by educating him on the infected blood scandal and what an appropriate bedside manner was.

37. As a result of being infected in the way she was mum developed severe mental health problems. Although she saw counsellors support was not readily available even though she had been infected with contaminated blood. Counselling was not offered until she actively sought it. I do not feel that any thought was given to how she would be affected mentally.

38. What happened to mum has also impacted on my sister's decisions in relation to her own health as she now refuses any blood or blood products during procedures and operations.

Section 7. Financial Assistance

39. I do not know how mum found out about financial assistance. I know that she filled in the Skipton Fund forms and asked her GP to fill in the appropriate section. It took around three months for her to receive the payment and she received a Stage 1 payment of £20,000 in 2004. I could never quite understand why those infected with HCV got less money than those infected with HIV.

40. I myself have also accessed financial assistance. I rang the Skipton Fund in 2016 to update them on my mum's death and to stop her correspondence. I was advised to get in touch with the Caxton Fund,

which I duly did. I sent back the form and a copy of my mum's funeral bill asking for a donation so we could do something with mum's ashes. To my surprise they refunded the whole funeral bill. We were able to bury mums ashes in the family grave and provide a headstone, something we wouldn't have been able to do without that refund.

41. Mum also took part in a compensation claim and her case went to court. I recall she had to go to London to see a doctor, perhaps a psychiatrist. She received some compensation as a result, but the money was soon used up.

Section 8. Other Issues

42. Mum's Inquest took place in April 2016. During the inquest there were a couple of issues I raised which bothered me at the time and still bother me today. As I have set out above, mum was infected in 1991 and diagnosed in 1995, when she was told she had chronic liver disease. In 1995 her liver biopsy showed an inflammation score of 6 and a fibrosis score of 3-4, which improved to 1-2 and 3 respectively in 1997 after some treatment. After treatment was withdrawn she was informed she had not cleared the infection and it was still active. No further liver biopsy was ever performed and she died in 2015, 24 years after being infected and 20 years after failed treatment. In March 2015, three months before her death, a letter from her cardiologist to her GP noted 'tender hepatic enlargement'. In May, less than a month before her death, an ultrasound of her abdomen noted, 'the liver appears normal in size and outline but the liver echo texture appears coarse. No obvious liver lesions noted' (correspondence available on request). Despite all this, the post mortem recorded the status of her liver as 'unremarkable'. I asked the pathologist at the Inquest why there were no signs of any liver issues. I would have thought that over 20 years of HCV and chronic liver disease with no further treatment would have resulted in a swollen liver or some evidence of fibrosis. The pathologist told the court that he had only made a surface

cut into the liver. I do not understand why he did not properly investigate the health of her liver during the post mortem. I am concerned that he may not even have been advised of her HCV status. How can an Inquest look into the cause of someone's death without this essential information?

43. Mum's death certificate recorded the causes of death as 'I(a) Bronchopneumonia, (b) Immobility, (c) Post Operative Fixation of Fractured Neck of Femur, (II) Chronic Obstructive Pulmonary Disease (WITN1966009). I asked the Coroner to add HCV to mum's death certificate but was told it wasn't relevant. I simply do not believe this. I believe that mum's HCV was responsible for her decline in health which turned her into a frail and fragile elderly woman at the age of 65.

Statement of Truth

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

Signed GRO-C ....

Dated 09/05/2019......