

Witness Name: Lorna Jane Rusling

Statement No.: WITN1500001

Exhibits: WITN1500002-04

Dated: 20th March 2018

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF LORNA JANE RUSLING

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 5th November 2018.

I, Lorna Jane Rusling, will say as follows: -

Section 1. Introduction

- 1. My name is Lorna Jane Rusling. My date of birth is the GRO-C
 1954. My address is known to the inquiry. I am a retired nurse. I intend to speak about my late husband David Allen Rusling, date of birth GRO-C
 GRO-C
 1957 and his contraction of hepatitis C. In particular, the nature of his illness, how the illness affected him, the treatment he received and the impact it had on him and our lives together.
- I can confirm that I have appointed Thompsons Solicitors to be my legal representatives. I can confirm that the inquiry should send all correspondence regarding me to Thompsons.

Infected Blood Inquiry

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3. My husband and I were married for 18 years. My husband was known as Dave. We had a very loving relationship; he often told me I was the love of his life. We have two children together, Steven and Charlotte.

Section 2. How Affected

- 4. Dave was a haemophiliac. He had haemophilia type A and it was mild.
 Unlike many others with a more severe form of haemophilia, Dave led a normal, healthy life and his haemophilia did not affect him.
- 5. On 25th May 1977, Dave had to have a tooth extracted. He went to the Royal Infirmary at Sheffield for this procedure. As a preventative measure, to avoid excessive bleeding, Dave was given factor VIII blood products. From correspondence in my possession, namely a letter dated 13th June, 2003, I can say Dave was given batch number HL1283, Lister factor VIII concentrate. I do not know the name of the dentist at the Royal Infirmary in Sheffield who treated Dave. I produce in evidence a copy of this correspondence and identify it as WITN1500002.
- 6. Dave began working in Aberdeen in 1977. He was working in the oil and gas industry. I do not know all the details, but I believe he suffered a trauma injury whilst at work. He was taken to Aberdeen Royal Infirmary and was seen by Dr Audrey Dawson. He was administered with cryoprecipitate to assist in the clotting process.
- 7. The two occasions in 1977, were the only times that Dave received blood products despite him being a haemophiliac. It was on one of these occasions that Dave was given contaminated blood products and as a result contracted hepatitis C.

- 8. Dave told me that at no time, during either of the procedures, was any information or advice given to him beforehand about the risk of being exposed to infection. Dave was not offered any other treatment. The factor VIII was given as a preventative measure.
- Dave was infected with hepatitis C.
- 10. In 1994, I was working at the Sick Children's Hospital in Aberdeen. I read an article at work regarding haemophiliacs who had contracted hepatitis and HIV through receiving contaminated blood products. When I got home, I mentioned the article to Dave. Dave and I had previously discussed the two occasions in 1977 when he had received blood products. We decided we should both go and get checked out. Clearly, it was important for Dave to do so but also for me as I was working with sick children in a hospital at that time.
- Infirmary and saw Dr Dawson who took both our bloods for testing. We were being tested for HCV and HIV. We made an appointment to return the following week for the results. Dave and I returned to the haematology department at Aberdeen Royal Infirmary and saw Dr Henry Watson. He told me that the test results revealed I was clear of any infection. He then told Dave that his results revealed that he had hepatitis C. We were both in shock. He did say that it was likely Dave contracted hepatitis C following receiving factor VIII blood products in May 1977.
- 12. I would describe Dr Watson as professionally friendly. Hepatitis C was not really known about at that time so Dave and I did not get much information about it. Dr Watson did say that the risks of passing it on to other people were low. I remember he said hepatitis C does affect your liver and he referred Dave to Dr Andy Fraser, the hepatologist (liver specialist) at Aberdeen Royal Infirmary.

- 13. Dave and I were not given much information to help us understand and manage the infection but I believe that was down to there not being much information about hepatitis C at that time. We were told that the existence of Hepatitis C was only very recently known.
- Dave was infected in 1977 with hepatitis C. It was only when I read the article about haemophiliacs being infected with HIV and hepatitis C that we decided that Dave and I should get checked. The NHS clearly knew that haemophiliacs were being given contaminated blood. I will never understand why it was that Dave had not been sent for to be checked. He was infected for so many years before we discovered the truth. The longer you have hepatitis C, the less chance you have of being cured. It was explained to us that Dave had the most resistant genotype and that the length of time since the initial infection would affect the eventual outcome. The only other treatment that may be available in the future would be a liver transplant and that would be very problematic because of the risks due to his haemophilia. Further, as Dave did not know he had the infection for many years, he ran the risk of passing it on to others.
- Dave and I were told by Dr Watson that hepatitis C could be passed to others by blood-to-blood contact. I do remember we were told that the chances of passing it on were, however, very small.

Section 3. Other Infections

16. Dave did not receive any other infection or infections other than hepatitis C as a result of being give infected blood products as far as we were aware. I have been told his notes have been destroyed.

Section 4. Consent

17. I do not know if Dave's blood was tested without his knowledge, consent or for the purpose of research. I remember he was told he had been tested for hepatitis G, we were told this was a new strain of Hepatitis.

Section 5. Impact

- Initially there had been no noticeable impact from Hepatitis C to Dave. 18. Dave was a fit man and enjoyed playing sports like cricket and volleyball. It was not until he started taking the treatment that he became very ill. Physically he became exhausted. He started having aching joints and cramps that made him jump out of bed at night. He also suffered with very painful spontaneous bleeds requiring hospitalisation. He had treatment with DDAVP and powerful painkillers. On one occasion requiring intravenous morphine for two days before being allowed home on strict bedrest. He always healed better at home. The exhaustion, lack of concentration and brain fog meant he could no longer continue his successful career in the oil industry. This in turn led to lack of self-esteem, anxiety and fear that he would be unable to take care of his family. Our children were only seven and five years of age at that time. He worried that he would die and leave them. He worried about me also if he died prematurely. The initial effects of the treatment with interferon were only made worse with the knowledge it was unsuccessful and discontinued.
- When Dave started his second attempt of treatment this time with the addition of Ribovarin to the Interferon his health had deteriorated much further, he had cirrhosis of the liver. His bleeds became more painful and more frequent due to his liver disease and lack of clotting factor it could produce. His general health also deteriorated with frequent chest infections. He also got severe pneumonia requiring a stay in hospital with IV antibiotics this all lead to him no longer being able to work. He also had seizures and suffered a heart attack. Ironically, this second round of treatment was beginning to show good results in his hepatitis serum levels, but this was to no avail as his body could no longer fight

back. Dave was admitted to Aberdeen Royal Infirmary with suspected heart failure, breathing had been increasingly difficult for him and he was transferred to the Intensive Care Unit. After many tests and trying all treatments he was diagnosed with Idiopathic Fibrosing Alviolitis. This is a rare condition which has been linked to both treatment with Interferon and the presence of HCV. The result of this disease is complete shutdown of the lungs with a rapid frightening progress to death. Dave died two weeks after being admitted to hospital in GRO-C 2005 aged 47. During that final admission to hospital around 3/4 days before he lost his fight he was transferred from ICU to an old respiratory ward with outdated equipment and mostly elderly patients with Chronic Lung Disease. As he was wheeled into the ward he looked around in fear and asked me if this is where they had sent him to die. This ward was an open ward and as such I was not allowed to stay so I went home when Dave fell asleep. In the middle of the night I received a phone call to say that Dave had woke up in a panic, unable to breath. Even with his CPAP mask on he was scared and asking for me. immediately returned and at my insistence he was returned to ICU where he felt more secure in the modern equipped unit.

- Dr Fraser told Dave that hepatitis C was a progressive illness, he said there was a small chance of a cure with a new treatment that had been developed. I do remember he said to us both that even with the treatment, there was only a 10% chance of a cure. Dave agreed to the treatment, deciding that a 10% chance was better than no chance. He did tell Dave that the side effects of the treatment could be severe and that some patients could not tolerate it.
- 21. Dave was put on a three month course of interferon that was administered by injection three times a week. I remember Dr Watson saying that after injecting, he should take a paracetamol and go to bed.
- 22. Dave did not face any difficulties or obstacle in accessing the treatment of interferon.

- Dave and I were led to believe that the interferon was the only treatment available for hepatitis C at that time.
- As soon as Dave began taking the interferon, he became unwell. Physically, he had the worst flulike symptoms. He had rigour fever, he would shake and sweat profusely. I remember I was always changing the sheets on the bed, as they were soaked with his sweat. Dave would have to change his pyjamas as they were also wet through with his sweat. Mentally, Dave became very anxious, irritable and depressed. It is hard to say whether it was the treatment that caused his depression, or the fact that he had been told he had a terminal illness. He was a proud man who found it difficult to accept that this disease caused not only physical illness but also affected his mental health.
- 25. Dave's infected status did not impact on his treatment or care for any other medical or dental conditions.
- The impact for Dave of being infected with hepatitis C was ultimately 26. that he lost his life at 47 years of age. He was robbed of seeing his children grow up and robbed of his dignity. I have spoken earlier about the physical impact upon Dave, but equally important are the mental and emotional affects. For the first time in his life, Dave was unable to work and was forced to rely on the benefit system, which in itself is a minefield if you do not know how the system works. This undoubtedly affected his mental and emotional wellbeing. Having to ask for financial help from, not only, the system, but family and friends to keep our home at a time when our debts were spiralling out of control. Dave felt a failure, his Yorkshire upbringing had taught him that his responsibility was to look after his family. The thing that mattered to him the most, he could no longer do. That broke Dave. Dave's illness and ultimate untimely death also impacted on our children. Steven, our son, feels the negative impact on his life is due to his dad's illness and passing. As a teenager, Steven often had to look after his father as I became

very depressed and at times was unable to do so. On one occasion Steven witnessed his father having a seizure at home. This was very shocking for Steven and I know that it made him much more aware of the severity of his dad's illness. Up until the final year before his dad died Steven was doing well at school and achieved good standard grade results. In the year leading up to Dave's death, Steven failed most of his exams. Steven was a very good athlete, between the ages of 11 and 17, he was competing at a high level consistently in the top 2 or 3 in Scotland at his events. Dave was very proud of his son's achievements and loved going to watch him compete. When Dave could no longer work, he could not afford to take Steven to athletic events anymore. We could no longer travel as a family to watch him. I know this was of great sadness for Dave. After Dave's passing, Steven could no longer emotionally continue with his sport. It brought too many sad memories of his dad. Steven began drinking alcohol excessively

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Could be attributed to and certainly was affected by the death of his father and directly cost him everything valuable in his life. He lost countless jobs, friends and his relationship with his sister and other family members. It was hard to watch my son destroy himself in this way.

Our daughter charlotte was also severely affected by the loss of her father. Charlotte was a daddy's little girl, who always had a special place in his heart as he had in hers. She had always been a very happy child who always had a smile for everyone and had, and still has, a very caring heart. When she was young, her friends would sleep over, staying for dinner or just hanging out to play or sample some home cooking. However, with her dad's progressive illness and my increasing inability to cope, she had a very difficult time. The life she had known disappeared with our combined ill health. Charlotte was a bright pupil at school and like Steven's, her education suffered, as did her life with

her friends, her social life too. Her friends came to our home less and less. She would see her dad's health deteriorate and at times, her mum finding life difficult to cope with. She did not have the same clothes, the family holidays and carefree existence as her peers. Charlotte would see her parent's change, her Dad more often requiring hospitalisation and living with pain at times. She must have also been aware of the changes in his personality too, but they remained as close as ever until his final illness took him from her. Those last few days must be imprinted on her memory although she never speaks of them, preferring to remember the happy times she had with her dad. Charlotte could wrap her father around her little finger, just as it should be between father and daughter. Despite the fact it was immensely painful for her, she too was at his bedside, often in with him giving him hugs and making him smile. She hated the CPAP mask he had to wear which made speaking for him difficult. When she grew older, she would miss all the other important things she should have shared with her dad. Her dad teaching her to drive, seeing her dress for her school prom but hardest of all that he could not be there to walk her down the aisle when she married. Charlotte's wedding was a poignant day, full of happiness, but there is huge regret that she could not share it with her dad.

28. The impact of Dave contracting hepatitis C and his ultimate death has been enormous for me. From the time Dave was diagnosed with hepatitis C, my life changed forever. The initial three months of treatment for Dave were horrendous for me. As a nurse, I was giving him his injections which brought on terrible side-effects. Some days I would blame myself, it was me who had alerted him to hepatitis C and me who supported his choice to be tested and treated. I knew in my head that it was not me to blame but when he was ill, shaking and sweating in bed, it was what I felt; I was wracked with guilt. I started to feel completely lost. I was diagnosed and treated for depression; I found working more and more difficult and was on sick leave for almost a year. I was devastated and felt our future together had been stolen. As Dave's health deteriorated so did mine, despite treatment for my

depression and anxiety, I could not cope. I eventually attempted suicide. The medication and counselling I received from my GP did not help and I was referred to a psychiatrist. The thing that brings me the most pain and shame was my inability to cope. It was not the medical side of things, my training ensured I could do that, but mentally and emotionally, I was a wreck. This failure on my part had terrible consequences for my children, not only was their dad very ill but some days they would come home from school to find me sitting in the same place on the sofa as they left me. I cannot explain the depths of regret and shame I feel for this period of my life, I just know it will be with me always. In comparison to others infected with HIV, hepatitis C did not carry the same stigma. However, it is known as a disease associated with intravenous drug users. No one in the public knew about contaminated blood or haemophilia and treatment with contaminated blood products. The cover-up had ensured there was no mention in public information or in my experience to NHS workers. If you tried to explain, you were met with disbelief and knowing looks. Even in my recent role at work where HCV positive parents are seen, the presumption is always that they are drug addicts. Both of my children were affected by taunts at school, something I only learned later.

- 29. Contracting hepatitis C and the treatment Dave received affected his work life. When he was first diagnosed with hepatitis C, he had a good well-paid job in the oil and gas industry in **GRO-C** Dave was determined to find a better life and in the late 70s when the mining industry collapsed in South Yorkshire, he hitch hiked up to **GRO-C** to seek employment. Such was Dave's work ethic.
- When his health deteriorated and he could no longer earn a good salary, he worked for minimum wage, anything to reduce his dependence on Social Security benefits, nevertheless we had huge debts. Dave ended up working on minimum wage on night shifts in Asda stacking shelves. Dave hated this job. Dave would 'rob Peter to pay Paul' but that cannot be sustained. We defaulted on our mortgage

and other essential payments. By then my income had also dwindled, we struggled to pay the basic bills with two growing children and the normal expenditure required, often unattainable. Dave found this situation humiliating, no longer able to be the breadwinner he had taken as a vital role in his life. For a short while we had been able to use the money I had saved for the children's further education to keep our heads only just above the water, but not far enough to stop the debt collectors at the door. The Sheriff officers were at our door more than once demanding money we did not have. They had a very intimidating manner I spent many days scared to answer the phone or the door. I lived these times in constant fear of losing our home and the knowledge that this would mean Steven and Charlotte would have to move school and lose their friends they had known since nursery, one of the few constants in their young lives. Dave had no real life insurance; he had a small private pension. He had presumed he would live a normal life, work and provide well for his family, this was not the case. In the year before he died he was too ill to work at all.

Section 6. Treatment/Care/Support

- 31. Dave was not offered any counselling or psychological support as a consequence of what happened to him, we as a family were never given or offered any counselling or psychological support. I do believe some psychological support as a family would have helped us. As it was, our whole family unit was destroyed.
- 32. A few months after Dave died, I found a counsellor and this helped me to put my life back together.

Section 7. Financial Assistance

- Dave and I found out that we could receive financial assistance from Dr Watson at Aberdeen Royal Infirmary.
- 34. In July 2003, we received £20,000 from the Skipton fund. I have also received a further lump sum of £30,000 from the Skipton Fund. I did used to get £500 a year from the Caxton Foundation,that was for a winter fuel allowance.
- 35. For over a year now, I have received £1600 per month from the Scottish support system. I get 75% of what my husband Dave would have got if he were still alive.
- 36. I found the process of applying for financial assistance fairly straightforward. Dave just filled in an application form and Dr Watson had to authorise that Dave had got advanced liver disease.
- I did not face any difficulties or obstacles in obtaining financial assistance.
- There is a precondition for widows in relation to financial assistance. That is, if I re-marry or enter a civil partnership I am no longer eligible for financial assistance. This assumes that were that the case it would be the role of that partner to be entirely responsible for my financial security. The amount of financial assistance received in no way compensates for the devastation caused to my family as a result of Dave getting hepatitis C and ultimately losing his life. The monthly payment, however, does enable me to fulfil Dave's and my dream to retire in Spain. I am in a way living what we always planned together, our retirement in Spain but sadly on my own.

Section 8. Other Issues

39. I do not wish to remain anonymous in this inquiry

- 40. I do have documentation in relation to the batch numbers of the blood products Dave received at Sheffield Hospital in 1977. I can produce these documents in evidence if required. I also have Dave's death certificate clearly stating that Hepatitis C and cirrhosis of the liver contributed to his death. I produce a copy of his death certificate in evidence and refer to it as WITN1500003.
- 41. I want the inquiry to note that the UKHCDO make no mention of Dave receiving factor VIII blood products. I have a copy of their print out and I produce this in evidence and refer to it as WITN1500004.
- 42. Finally my message for Sir Brian, as I know he reads all the statements personally. I would ask you Sir Brian to do whatever is in your power to ensure that all victims' families are given financial recompense for their loss, along with those infected, still alive and suffering every day. I have written this statement often in tears not only for myself and our children, but for Dave because he is no longer here to do so.
- 43. I use the word compensation deliberately, it is how we in our Society recognise and measure fault and responsibility to those that are harmed. It is awarded as a right to those who have suffered rather than the current system where many are made to feel that somehow our government is doing them a favour by offering assistance.
- 44. Above all we want the truth and for those responsible to be held accountable.

Statement of Truth

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