

Witness Name: Sharon Lowry

Statement No:WITN2655001

Dated: 20 February 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF MS SHARON LOWRY

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 12th December 2018. I adopt the paragraph numbering in the Rule 9 request for ease of reference.

I, Sharon Lowry, will say as follows:-

1. **Introduction**

1. My name is Sharon Lowry and I live at GRO-C
GRO-C. My date of birth is GRO-C 1957.
2. My husband Alan Richard Lowry, known as Richard, died on the 28th November 2011 of Chronic Renal Failure with Cirrhosis secondly to Hepatitis C (HCV) which he contracted through contaminated blood.

2. How infected

1. Richard was considered to have mild Haemophilia and was infected with Hepatitis C through blood transfusions. Richard was treated with a number of blood products over the years for his Haemophilia and it is therefore unclear exactly when the infected blood products were given. Richard was predominantly treated at the Haemophilia Clinic at the Royal Victoria Hospital at Belfast.
2. Richard was my loving husband and father to our two sons. He was my best friend and soul mate. Richard had a successful career as a much respected and loved teacher. He was initially a Senior Teacher and eventually became a Vice Principal in a grammar school. Throughout the last twenty years of his life he had an increasing battle to try and stay in reasonable health so he could keep working.
3. Our first knowledge that Richard that contracted Hepatitis C was shortly after our younger son was born. It is lodged in my memory that he was told in the first half of 1991, however, the earliest mention of Hepatitis C in his medical records is in 1990. He went for what was supposed to have been a routine appointment at the Haemophilia Clinic on his own and he arrived home to tell me that he had contracted the Hepatitis C virus. I believe that it was Doctor Elizabeth Mayne who broke this news to Richard. It was suggested that if he was lucky, he might live for ten maybe up to twenty years but no other information was given to him at that time.
4. This devastating news came at a time when we were a young married couple enjoying married life with two beautiful boys, a baby and a two year old. We had always wanted more children but when we received the news we were left not knowing what the future would bring or how long Richard had. Nobody seemed to be able to explain anything or appeared to know anything about the Hepatitis C virus. I felt we were in

limbo for a long time, unsure to how it should affect what decisions we should make, even if we should have more children. We really wanted at least one more child, maybe two. I did have another pregnancy but lost the baby at fourteen weeks. After that we couldn't take any more devastating news.

5. I can see from Richards's medical records that there were a number of occasions when Richard could have been infected with Hepatitis C. He was treated with Cryoprecipitate in 1969 and again in 1970. He had a double treatment of Cryoprecipitate in 1970 and 1972. He was given further treatment with Cryoprecipitate in June 1972 and in December 1972 he was given fifteen packs of Cryoprecipitate. In 1973 Richard was treated with Factor VII Blood Product. There is then a significant gap in Richards's medical records until 1990 when his diagnosis of Hepatitis C was confirmed.
6. The risk of infection from receiving any of these blood products was never explained to patients during the seventies and eighties.
7. In the 1990s when Richard was informed he had been infected we were not given any information or advice at all. At a later date when we both went to the hospital together I asked Dr Mayne about the possibility of me having been infected with Hepatitis C or either of our sons. The people we trusted the most through our lives had been the doctors and both Richard and I, maybe naively, trusted Doctor Mayne. I was extremely dismayed when having suggested that maybe I should be tested for Hepatitis C, she laughed and told me they had no knowledge of wives or children being infected.
8. I must have given Dr Mayne something to think about as she phoned me later that evening and asked me to give a blood sample the next day. She must have rushed it through for testing as she phoned me herself to say that I was not infected twenty four hours later. That has

always stuck in my mind, the ambivalent attitude regarding a person's health. I was made to feel like a silly child for suggesting I should be tested but the response was a case of, it hadn't happened, at least not in Northern Ireland, so nobody had considered the possibility.

9. Richard developed many health issues over the next twenty years because of the Hepatitis C. He was in and out of hospital for all sort of treatments until 2009 when he was put on the liver transplant list.

10. By this time, Richard had also developed a heart problem and Diabetes. We spent ten weeks in hospital in Belfast in 2009 waiting for a donor organ before we were eventually flown to Kings College Hospital in London.

11. Waiting for a donor organ was intolerable for both of us. Because of Richard's height and size it was difficult to find a match. I remember we both broke down one day in the hospital. I was finding it hard to keep being strong and positive for Richard, we were worried that he was being bypassed and that younger patients were being given priority. Frequently his door would be closed, this would mean that someone had died on the ward and they were being taken out. After 10 weeks in hospital waiting, knowing his health was rapidly going downhill he started to believe that he would end up going out in a coffin and would not make it. Other times you would hear the commotion of people arriving to collect a patient to fly them to London for their transplant.

12. I remember a news item at the time where a distressed father was pushing to have his 18 year old son, who suffered from alcoholism, moved to the top of the transplant list. He stated in radio and television interviews that his son should take priority over other people waiting for a donor organ who were middle aged or older. My younger son heard

one of these interviews and I heard another and it was very distressing for us.

13. In November 2009 Richard underwent an eleven hour operation for combined liver transplant and heart surgery.
14. Richard was in Kings College Hospital for almost four months. I stayed in a bedsit beside the hospital and was with him every day helping to nurse him. The Liver Intensive Care Unit was brilliant. There was one specialist Nurse to each patient on a twelve hour rota but unfortunately the wards were not well staffed. Every time Richard was returned to a ward there were setbacks to his health and wellbeing and I had to raise the alarm. This would result in intensive care yet again.
15. Without the agreement of the Liver Intensive Care Consultants, another Doctor on a different ward discharged us and decided we should return to a Belfast hospital. I think he was as much concerned about my mental state as he was about Richards at the time.
16. On our return Richard spent over five months in the Royal Victoria and City Hospitals in Belfast. When he was eventually sent home during the summer of 2010 it was a heart-breaking situation.
17. He could not manage to sit upright for any length of time in his wheelchair, he had terrible bed sores, had lost so much weight, he was skin and bone and there was no flesh left on him. He was so weak and scared he kept breaking down. Richard did not have the will to live at that point; he was a broken man, not my lovely, big, six foot seven, strong man.
18. A special hospital bed with an alternating pressure mattress and attached compressor had to be installed in our kitchen as we did not

have a spare room in the house. A care package was put in place for carers to come at various times of the day to help Richard wash, dress and eat. Richard also had to go to another hospital three times a week for dialysis and as he was not well enough to drive himself this took most of the day as the bus would take a circuitous route to collect lots of patients.

19. With continuing complications and another trip to Kings College Hospital in August 2011 regarding the possibility of a second transplant, Richard was then sent home from there with the decision having been made that he was too ill for another transplant. Richard was told nothing more could be done for him. This was the most devastating thing anyone could ever be told. I had no idea how I could possibly tell our sons that news.

20. After the liver transplant Richard developed a massive hernia which became so large it affected his ability to move around and he became very self conscience of people staring when we went out anywhere. His mobility decreased gradually and he felt isolated and cut off from everyone. Even simple things become difficult to do and he was completely dependent on me. This was not the outcome we had hoped for and when Richard went back into hospital in October 2011 for what we thought was a small, routine investigative procedure, things went horribly wrong.

21. Richard suddenly became jaundiced and from that point he became withdrawn and uncommunicative. He had lost the will to live and for six weeks I tried to encourage him, talk to him and just get him to want to live.

22. My younger son [GRO-C] was extremely upset when he saw his Dad in hospital and couldn't get him to respond either.

23. Eventually the Consultant Ward Sister and Senior consultant had to sit me down and explain that I had to accept, he was too ill and dialysis was being stopped as Richards's body was shutting down. This is the most devastating thing for anyone to hear. I had spent so much time and energy over the previous two to three years working with various Doctors, Nurses and Physiotherapists, helping to nurse Richard back to at least some form of health, at times fighting for him, if things were not happening in the hospitals when they should have. It is very hard to accept you have to stop fighting for someone you love when you have been doing it twenty four seven for so long.

24. The next thing was making phone calls to my sons to say that nothing more could be done for their Dad, that he was dying and they needed to get the first available flights home from Dundee and Liverpool before it was too late. They found it very hard to accept that nothing more could be done, they were almost angry with me as if I had given up on their Dad. I know they didn't mean it, they were just hurting.

25. Richard died on the 28th November 2011.

26. We were both always so trusting of hospital staff, we would let them do anything they wanted to if they told us it was for the best. Given the magnitude of the contaminated blood scandal, it is clear now that was a mistake.

3. Other Infections

1. Richard received a letter from our GP in 2004, Doctor Gordon Kennedy, saying that he thought that because Richard had received infected blood products between 1980 and 2001, this put him at a small risk of developing VCJD. I don't know if anyone ever followed this up and tested him for that condition.

2. I can see from Richard's medical records that he suffered an infection in 2005 called Neutropenia which was infected by Leg Cellulitis.

4. **Consent**

1. I cannot say whether or not Richard received any test or treatment without his consent or knowledge. What I can say is that he trusted Medical Professionals and Medical Staff to treat him in whatever way they saw fit. He would not question it.

5. **Impact**

1. Over the years since his infection with Hepatitis C, various health problems arose for Richard. He suffered memory lapse which resulted in his admission to the Ulster Hospital in Belfast. I am not sure if this was the result of the ongoing stress of living with what is basically a death sentence.

2. Once Richard was informed he was infected with the Hepatitis C virus it meant that all medical appointments were at the Royal Victoria Hospital in Belfast. He attended Dental, Haemophilia, Cardiac, Diabetic, Oesophageal and Liver Clinics. This encroached on his job as instead of being out of school for an hour or a couple of hours he would have to miss a full day every time he had an appointment.

3. Over time Richard had so many appointments that he had to carry a special diary just keep track. We kept as quiet as we could about his health problems with work. We both worked in the same grammar school but we had already encountered people's ignorance regarding Haemophilia over the years when we organised collection days for the Haemophilia Society. We would receive some unpleasant comments

from some individuals who obviously did not know the meaning of the word or the condition.

4. A simple dental appointment became a day long appointment for Richard. He would be called in the morning and then have to wait till all the other patients had been seen and then they would treat him last because he had Hepatitis C. The same thing happened when he went for an oesophageal appointment because he would have to starve all day before an examination or procedure since he was the last person to be seen, creating worry as he was a Diabetic.
5. Further health problems were caused by the combination treatments Richard was given for Hepatitis C. These treatments I now consider to have been possibly experimental but at the time we were told that they had proven successful so they really gave us hope. Unfortunately, the treatments made Richard really unwell. The first treatment with Alpha Interferon and Ribavirin was unsuccessful as Richard's body couldn't tolerate it.
6. In 2004 further treatment was tried with Pegylated Interferon and Ribavirin but this had to be stopped as Richard developed a neutropenia infection. The effects of the treatment were so bad that Richard's haemophilia went from mild to severe. Richard always understated how unwell he was feeling and put up with things but the treatment really took it out of him.
7. Other health problems suffered by Richard were oesophageal varices, splenic vein thrombosis, type 2 diabetes, at first non-insulin but over the years on insulin, neutropenia and thrombocytopenia.
8. Richard had a mild aortic stenosis that unknown to him, was getting progressively worse because he was going to the gym to keep his fitness levels up, incase he ever needed a liver transplant. It seemed so

ironic that the keeping fit was exacerbating the heart problem. Finally, Richard was diagnosed with Cirrhosis of the liver.

9. Over the years Richard became more prone to illnesses and infections. He always felt exhausted and he was so desperate to keep working, the only way he could manage it was to go to bed as soon as he came home every day. At the weekends he had no energy to do anything but sleep. This naturally impacted on family life. It became almost normal for us. I tried to keep our boys busy so they would not be quite as aware of how little their dad was actually able to do.

10. Our friends stopped inviting us round for any social evenings as we could not stay long. A combination of tiredness and discomfort from Richard meant we always had to leave early. Everything became an effort. Richard wanted me to go to things without him but I chose not to as I didn't want him to feel isolated and completely cut off. Also, if Richard was asleep or resting then I needed to be around to give lifts to our sons so that they could have some social life.

11. In hindsight I think that Richard should have stopped working sooner than he did. He was just so worried about providing for the family.

12. [GRO-C]
[GRO-C] Richard just could not cope [GRO-C]
[GRO-C] so I was always the one to deal with the situation. Stress seems to be one of the major triggers [GRO-C] so that was more worry for me, especially when I was away in London with Richard for his transplant assessment over Easter 2009.

13. [GRO-C]
[GRO-C]
[GRO-C] This recurred [GRO-C] during the following Christmas period. Both of our sons had to come home that

year from university in Liverpool and Dundee to a freezing empty house not knowing how long we would be away or if their Dad would even make it home due to all the complications. I had to phone family and a friend to ask them to try and help my sons have some sort of Christmas to take their minds off things.

14. The effect of everything has had on going consequences for all of us. Peter, our younger son had to fly over to Dundee to start university life with no parental support to help get him started. He was very aware of all the other parents being there helping their sons and daughters with kitting out accommodation. It is hard enough leaving home for the first time so I felt guilty that I couldn't help him. Richard was in hospital awaiting a donor organ and getting very low, wondering if it would ever happen.
15. The time spent in London with Richard was just so hard. He took several days to come around after the transplant operation. One of the staff in the Liver Intensive Care Unit asked me to remove Richards's wedding ring as he didn't think he would wake up. Richard had to be frequently readmitted to the Intensive Care Unit on a number of occasions at my request as I repeatedly found that he was being neglected on the ward and he was at risk of infection.
16. Numerous times Richard would start hallucinating. On one occasion during the night I was called in to try and calm him down. I arrived to find three male Nurses sitting in front of the door to his cubical in case he tried to get out of bed. I think in his hallucination Richard possibly hit out at a Nurse. He was seeing things that were not there and believed that someone was attacking him. What is so strange about this is that Richard had no strength to sit up, support himself, and he couldn't feed himself but when he started hallucinating it would get so bad that adrenalin would kick and suddenly he had the strength to take a swing at me, shout at me and say all sorts of dreadful things or try and get out

of bed. In these instances, on several occasions, the staff had no choice but to intubate him again as he was in danger of doing himself harm. This was incredibly difficult to deal with as my husband was known for being a true gentleman, the big man and a gentle giant.

17. I was warned by one of the doctor's that over time this would cause damage to a particular part of Richards's brain. I did not dwell on this at the time as there were no other options. A few months before Richard died, when we were at home together, I had a couple of very alarming episodes when Richard started talking in a completely nonsensical manner and was looking at me waiting for a reply. It was extremely frightening. Spending a year in various hospitals with my husband was an experience that I will never forget or get over.

18. It is now seven years on and I still have bad dreams about everything that I witnessed during that time in the various hospitals. In Kings College Hospital I spent an average of ten hours every day at Richard's bedside helping to look after him. When we came back to hospital in Belfast, I was with him again every day from lunchtime through to late evening, sometimes until 9 or 10pm. There is not a day that goes by that a memory from that time does not pop into my thoughts. I cannot share any of this with my sons as they have found things hard enough and have admitted they do not want to know, they cannot cope with anymore bad memories.

19. GRO-C
Sadly during 2011, within 10 months, Richard's father and brother died and then Richard.

20. The impact on my life of Richard's infection with Hepatitis C is immeasurable. Before Richard became ill I had a good job as a contract carpet designer with a well known carpet manufacturer and then when our children were born I started working as a freelance designer and

had a promising and enjoyable career. I had to give that up quite suddenly when Richard became ill and went into hospital. He became scared and possibly panicked at the thought of maybe not being able to keep working. Back then it had suddenly hit home as to what sort of future we had ahead of us and the financial pressures that came with it. He asked me to change my work and get a job that would have a fixed regular income. It is a fact that mortgage companies consider it a risk to have someone paying a mortgage if they work freelance, no matter how good their income is.

21. Since Richard died, I am not in the financial position to do some of the things I would like to do. If my husband was still alive we would have been able to help our sons financially with either getting on the housing ladder or helping to pay for weddings. We had looked forward to being able to take some short breaks away together, maybe a special big holiday trip somewhere, something that we were unable to afford when the children were small but had talked about doing later when the boys had left home. I now find my life to be very solitary, sometimes extremely lonely. The people who we considered our friends are still "couples" retired from work, enjoying their time together and going on special trips, moving on with their own lives. People say all the right things but eventually they all drift away. I miss the fact that Richard and I were never able to achieve any of those things we talked about doing in the future, a special part of my life has been taken away from me.

6. Treatment/Care/Support

1. As for counselling or physiological help, there was never anything offered to me and I was never approached regarding this. Unfortunately, probably for me, I thought I was dealing with things quite well since losing my lovely husband when actually I was just keeping busy to stop myself thinking about things. My doctor told me that

sometime ago, that I wasn't actually dealing with things, I was shutting down.

2. I still get upset as there are constant reminders of the life we thought we would have or planned for. Every time I see a family together or see a couple walking hand in hand, I suffer this loss all over again. I hate buying cards for anyone and the boys have also found this, as you see the cards for 'dad' or 'husband'. All the special occasions are now hard to deal with.
3. The fact that Richard and I worked in a grammar school together for years makes it very hard now. I still, even after all this time, get very emotional on the last day of every term. Everyone is excited with getting off on holiday, talking about what they are doing. We use to love those times as we were both off together and we would make plans. Now the loneliness is incredibly hard and I miss him so much. We had so many things we were looking forward to doing together when our sons had left home; apart from the obvious ones like seeing your children achieve goals in their lives and getting married and having grandchildren.

7. **Financial Assistance**

1. As to financial assistance, I have no idea the dates when Richard received any money. It was a very long time ago, many years ago. I think two amounts were paid but considering what is paid for some people for whiplash or tripping on pavements at the time it was not an amount that was going to ease what was ahead of us.
2. Richard felt that the value on human life was disappointing and insulting. Naturally when you are paying a mortgage, have kids to support and have no idea how long you can keep working for you will take anything offered. We couldn't afford to take legal action. I cannot

- be sure who the money came through, it may have been the Skipton Fund. It was such a long time ago and it was Richard that dealt with that through his account.
3. Over the years another obstacle that anyone with Hepatitis C discovered was the issue of trying to get Life Insurance to help love ones when they died. Insurance companies did not want to know or if they did, they asked for large payments per month for a small pay out at the end.
 4. I received £10,000 in March 2017 from the Skipton Fund. The letter that I received beforehand basically said I could claim this as a one off payment but the door was shut as far as widows were concerned and I would have no grounds for any other payment. Naturally I took what they offered, I was in debt with various things going wrong with the house, my car and trying to help my sons. I had no choice, I don't earn much and I am 61 years of age and I now need to keep working for many more years which was not what Richard and I had planned.

8. Other Issues

1. Richard's medical records have a huge gap where there are no records between 1977 and 1990 when his Hepatitis C was confirmed. I believe they have been removed intentionally to cover up what happened.

Statement of Truth

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

Signed..... **GRO-C**

Dated..... 20/2/19