

Witness Name: JOHN CASSAR Statement No.: WITN0431/001 Exhibits: WITN0431/002-004 Dated: 18 October 2018

#### **INFECTED BLOOD INQUIRY**

# FIRST WRITTEN STATEMENT OF JOHN CASSAR

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 11 October 2018. I adopt the paragraph numbering in the Rule 9 request for ease of reference.

I, JOHN CASSAR, will say as follows: -

#### Introduction

- My name is John Cassar, my date of birth and address are known to the Inquiry. I am a widower and now live alone in a flat that I own. I have previously worked as a bus driver and freelance programmer for companies such as TSB and Lloyds, but have been retired for the past 30 years.
- 1.1. I was born in Malta, but have lived in the United Kingdom since 1963. I first met my wife, Antonia (neé GRO-C) in Malta and was married within three months of meeting her. Everyone called her Nina, which is how I will refer to her in this statement.
- 1.2. Nina was born on GRO-c 1945. Together, we had four daughters, born in 1963, 1967, 1972 and 1976. The eldest was born in Malta and the other three were born in Glasgow Rottenrow, via caesarean section.
- 1.3. I intend to talk about Nina's infection with Hepatitis C, which I believe she contracted following the birth of our youngest daughter, after receiving a blood transfusion. In particular, I intend to talk about the impact it had on our lives and those of our daughters', and how it lead to her death on 23<sup>rd</sup> June 2012.

### **Infected Blood Inquiry**

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1.4. I have prepared typed and written notes, compiled with the assistance of my daughter, Sonia, in response to the Rule 9 sent to me and exhibit these as WITN0431/002 and WITN0431/003.

### How infected

2. Nina was admitted to Glasgow Rottenrow Maternity Hospital on GRO-C 1976 to deliver our fourth daughter, Alison. Like our previous two daughters, this was by caesarean section, and for reasons unknown to myself, she required a blood transfusion during the operation. Consequently, she contracted Hepatitis C, which led to liver cirrhosis, and her death in 2012.

## Background

- 2.1. I had very little family and had lived in a home as a child before joining the Merchant Navy and subsequently became a butler for an agency in London where I had the privilege of serving some of the Royal Family and members of the House of Commons. It was during my time in the Merchant Navy that I first met Nina at a funfair in Malta and then bumped into her on the street a week later. Following a whirlwind romance, we married after three months together, and remained together until Nina's death.
- 2.2. We initially lived in Gloucester, though this was only for a short period of time. We then moved to Cumbernauld for a couple of months, before moving to Glasgow. We initially rented a house, before buying a property in the late 1960s. Following the demolition of that property, we applied for, and were given the flat, which I currently live in and now own. As such, I have very few expenses.
- 2.3. I was forced to retire from driving buses after suffering from a heart attack when I was 43 years' old. I continued to do some programming from home, partly for income, and partly as a hobby.
- 2.4. We always felt very at home in Scotland and have always been accepted by Scottish people. Nina had hoped to one-day return to Malta, but this was not a dream I shared.
- 2.5. On the birth of our fourth child, it was determined that Nina required a caesarean section, as the baby was quite large and she was not in a position to birth her naturally. It had, however, been a normal pregnancy with no complications. Nina was then given the recommendation to be sterilised, and not to get pregnant again.
- 2.6. I do not recall seeing the transfusion occurring and definitely did not receive any warning of the potential risk for infection prior to it occurring. I do not even recall being told that Nina would be receiving blood and moreover, I think that she was not in a position to be informed when the

- decision to transfuse was made. I believe the mind-set of the doctors at the time was very much 'if you needed blood, blood would be given'.
- 2.7. I cannot even be sure that the previous two births were done without transfusions. I can only surmise that it was the last transfusion that caused the Hepatitis C, as the symptoms only began after then.
- 2.8. It was not until approximately 2001 that we learned of Nina's Hepatitis C infection.
- 2.9. Nina had been desperately trying to work out why she was feeling so unwell, depressed and tired and had been visiting her doctor regularly. She had been diagnosed in the late 1980s with Diabetes and it was hard for her to establish which of her symptoms could be attributed to her Diabetes, and which were unaccounted for.
- 2.10. She was referred to a psychiatrist because she felt so depressed and we felt as though the doctors were saying it was all in her head.
- 2.11. Her GP conducted a series of tests to check for various viruses. The test for Hepatitis C is not normally included in the first round of testing, but once the GP had read in her medical notes that she had had a transfusion, it was decided that Nina would be tested for this.
- 2.12. She was referred to Glasgow Royal Infirmary (GRI) for these tests to be done. I did not go with her, though I think Sonia went with her at this time, as well as when she was finally diagnosed.
- 2.13. At that time, we were given some information by the consultant. We were told that Hepatitis C would affect Nina's liver, but that there was no cure. Nina was told she would have to attend every six months for check ups and to check on the progression of the infection.
- 2.14. We were not told about the risk Nina's infection could pose to those around her and I consider myself lucky that I did not become infected prior to knowing of her illness. I did my own research online, and took extra care by using gloves whenever Nina had any cuts or injuries, to reduce the risk of spreading infection.
- 2.15. I do think that the medical profession may have known Nina had Hepatitis C prior to telling her, however I can't be certain. Once it was known, she was referred immediately to Glasgow Royal Infirmary.

#### Other Infections

We have never fully been given information about Nina's infection. All we know is that she had Hepatitis C, but cannot be 100% sure that she was never infected with an additional illness. However, no additional acquired illness was listed on her death certificate, which is referred to as exhibit WITN0431/004. This is dated 26<sup>th</sup> June 2012, and lists (I) Hepatorenal

Syndrome; Liver Cirrhosis; Hepatitis C Secondary to Blood Transfusion and (II) Diabetes as the causes of death.

#### Consent

4. I do not know if Nina was ever tested without her knowledge or consent. She would frequently attend hospital and undertake blood tests related to her diabetes but we were never told that these tests would include tests for Hepatitis C.

### <u>Impact</u>

- 5. Due to her infection and even prior to being diagnosed, Nina suffered with depression, tiredness and a weakened immune system. She would be frequently run down and at times appeared jaundiced. Nina was embarrassed by her illness, and restricted who knew about it to those within the family.
- 5.1. We were sick with worry watching Nina get worse and worse. I would think about her all the time and fear the next day would be worse than the one prior; my daily life changed around her. When she came out of hospital, she required constant care, which meant I did not have time for myself.
- 5.2. I would be wary if I saw blood, which took a great mental toll on me. I don't remember her cutting herself in the two weeks prior to her death, but I would ensure that any risk from this was kept as small as possible. I would also wash things more carefully, including her clothes and bedding at a higher temperature. Her infection changed our whole way of life, but we just took each day as it came.
- 5.3. She did not complain about being kept in hospital for extended periods of time. On one occasion Nina was shouted at by an Orderly, whom she had requested help cleaning herself from. I don't think this was associated with the Hepatitis C, but it did embarrass Nina greatly.
- 5.4. Nina's Hepatitis C eventually caused her to develop cirrhosis of the liver, which eventually lead to a growth on her liver. This was discovered in around October 2011, during one of her regular liver check ups. We were told to take no action, and to monitor any symptoms from home.
- 5.5. Later, we were called in to speak with a Consultant and we discussed a liver transplant. At this time we were told that it would be better for her to wait and monitor the lump in her liver before going for a transplant.
- 5.6. In November 2011, Nina was informed that she should have the tumour removed. We were told that she would only be an inpatient for a few days before being discharged. This was to take place on 9<sup>th</sup> February 2012.

- 5.7. Following the operation, on 10<sup>th</sup> February 2012, Nina required 54 stitches in her stomach, as the growth was located on the rear of her liver, and was thus more difficult to remove. These stitches were removed 11 days later however the wound reopened and she required further surgery to close it again.
- 5.8. With the wound open, Nina was prone to infection. She developed a virus, the name of which I am unable to recall, and instead remained in hospital until 29<sup>th</sup> April 2012.
- 5.9. During this time, Nina developed oesophageal varices, which are common in people with cirrhosis of the liver. She began to vomit blood and needed surgery to band the varices. Additionally, I noticed her lower legs were swelling rapidly, and appeared to be retaining excess fluid. I was told that her kidneys had begun to fail. She had never had trouble with them before, so this came as something of a surprise. She had a tube inserted into her side to help drain the fluid, though this seemed to have little effect.
- 5.10. I would drive from Glasgow to Edinburgh at least once a day, and the girls would also visit when they could. Occasionally, I would surprise her with an additional visit in the evening after visiting earlier in the day.

5.11	. On the da	ay Nina was	placed on	life suppo	rt, my (	daughter	was on	her way
	to the hos	spital when ເ	unfortunate	ly, the taxi	she w	as in ove	rturned	en route
	and GRO-C							
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- 5.12. Following her discharge from hospital in April and with the tube still in situ, Nina returned home but was only home for a couple of nights before being admitted to Glasgow Royal Infirmary again, as she had been passing blood. She remained as an inpatient for a few weeks and then returned home. However, she was once again only home for a couple of nights before being re-admitted.
- 5.13. She remained in GRI until her death on 23<sup>rd</sup> June 2012. Nina had been in the Intensive Care Unit, and had been placed in an induced coma just prior to her death; the infection that had caused the swelling had begun to move to her brain and this was deemed the best course of action to protect her. We were then told that she was going into mass organ failure, and had to make the difficult decision to turn off her life support machine.
- 5.14. My daughters and I were at her side as she stopped breathing after the life support equipment was removed. I then went in to see her alone, and told the children that they could go in and see her once more if they wished, but as she looked so awful, they may not want to. They decided against it, so they could remember their mum the way she had been.

- 5.15. Nina remained in the hospital mortuary for a week before moving to the funeral parlour. I asked them to keep the coffin closed if Nina still looked bad, but to keep it open so that the children and I could see her one last time if she did not. They told me that they could not leave the coffin open because of their procedures.
- 5.16. No one at the hospital said anything that indicated they were treating Nina's body differently because of her infection and there was nothing visible to suggest that this was the case.
- 5.17. Due to the nature of Nina's death, it took some time before her death certificate was issued, and it was sent to the courts, as the cause of death was not considered 'natural'.
- 5.18. We were told that there was no cure for Hepatitis, but that there was a treatment called Interferon, available from the United States. She received this for three months, but the side effects made her feel so unwell that she stopped taking it. She suffered with weakness, vomiting and diarrhoea and tiredness, coupled with trouble sleeping, for which she was offered sleeping tablets.
- 5.19. There were no other treatments of which we were made aware; we placed our trust in the doctors to treat her properly.
- 5.20. I was only tested for Hepatitis C last year, which thankfully came back negative, but the children have never been tested. This is particularly frightening, as our family is continuing to suffer as a result of contaminated blood.
- 5.21. Hepatitis C made Nina feel very ashamed, and was something that she did not share with people outside the family. This made both her and the rest of the family scared, sad and depressed. When she appeared outwardly unwell to the extent that people would ask what was wrong, we would simply say that she had problems with her liver. We would never say it was Hepatitis C, because of the stigma attached to the infection.
- 5.22. As Nina wasn't diagnosed until she was in her sixties and the children were all grown, Hepatitis did not have any impact on her own or the girls' education. However, she was relieved from her job as a housemaid at the Holiday Inn, prior to her diagnosis, in 1995/1996. Her attendance had been so bad because of her illness that they could no longer employ her.
- 5.23. Nina's forced early retirement from work did have a financial impact on our family. We had been reliant on two incomes and had to adjust accordingly.
- 5.24. Moreover, upon Nina's death, I had to cease running a successful website which raised awareness of Maltese culture. I had temporarily stopped updating it when Nina went into care, but felt I could not resume it after

her death. Though it was a hobby, I had also been earning some income from it.

# Treatment/Care/Support

- 6. Nina's infection with Hepatitis C caused her great difficulty in receiving dental care. Her regular dentist refused treatment upon learning of her infection, and a second also refused treatment. It was only when our daughter, Sonia, spoke to her dentist and explained what had happened, that Nina managed to receive some dental care.
- 6.1. Counselling or psychological support have never been offered to me, with regard to Nina's illness. Prior to her death, Nina did not receive any counselling or psychological support regarding her infection with Hepatitis C.
- 6.2. It had been recommended that she see a psychiatrist, as there was a real belief that the symptoms she was experiencing were all in her head.

### **Financial Assistance**

- 7. We were never made aware of the fact that financial assistance was available through Trusts and Schemes. It was only when my daughter, Sonia, did some research, that we discovered that we may be eligible. We initially went to see a solicitor, who helped us find the Skipton Fund. We received a Stage 1 payment of £20,000 (minus £400 solicitor's fees) from them on 18<sup>th</sup> October 2004. We then received the Stage 2 payment of £50,000 when Nina developed cirrhosis on 26<sup>th</sup> October 2011.
- 7.1. The Caxton Foundation gave Nina her minimum wage for a year after she was forced to retire from work. This was a means tested payment and I have been lead to believe that we would have been entitled to an additional £10,000 but for my salary. They also provided me with £750 to cover the money I spent on fuel travelling between Glasgow and Edinburgh every day for six months to visit Nina in hospital. I received this on 24<sup>th</sup> July 2012. Lastly they assisted with Nina's funeral costs, giving us £4,000, also paid in 2012.
- 7.2. I have been in receipt of the Payments for Widows, Widowers and Civil Partners of beneficiaries who have died, which is provided by the Scottish Infected Blood Support Scheme (SIBSS) since April 2017. I receive £1,687.50 every month through this, though I have never spent a penny of it. Instead, I have kept it a separate account to pass to my children upon my death.
- 7.3. No amount of money will ever replace the hole left in our family caused by Nina's death.

# Other Issues

- 8. I understand that mistakes were made, but I think that once they were discovered, we should have been informed immediately and had the family tested for Hepatitis C. I think it's wrong for them to hide from their mistakes once they discovered them, they should have tried to rectify the situation.
  - 8.1.I have found that when I have tried to speak to doctors about Nina, including when Nina was alive, as soon as we mentioned contaminated blood, doctors would close up and not be willing to engage in conversation.
  - 8.2. The NHS and the Government knew the blood they were giving was infected and yet continued to give it anyway. The Penrose Inquiry established that England continued to give infected blood two years after Scotland had established the issues with it and withdrawn it from use. Why was this allowed to occur? Additionally, why did Scotland, in particular, fail to screen all recipients of blood as soon as they knew of the problems with it?

#### Statement of Truth

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

The option to remain anonymous has been explained to me and I have taken the decision that this is not something I wish to seek.

