

Witness Name: Cheryl Ann Farrugia
Statement No: WITN3233002
Exhibits: WITN3233003- WITN3233005
Dated: 20th November 2019

INFECTED BLOOD INQUIRY

SECOND WRITTEN STATEMENT OF CHERYL ANN FARRUGIA

I provide this statement in response to a request under Rule 9 of the Inquiry rules 2006 dated 26th June 2019. I adopt the paragraph numbering in the Rule 9 request for ease of reference.

I, Cheryl Ann Farrugia, will say as follows:-

1. Introduction

1. My name is Cheryl Ann Farrugia. My date of birth is GRO-C 1954 and my address is known to the Inquiry.

2. How Affected

1. I write this statement in regards to my late husband Barry Daniel Farrugia.
2. My husband and I met in 1973 and married in February 1976. At the time I was 21 and Barry was 26 years old.
3. Barry already had three young sons from his previous marriage, Vince aged 7 and twins Tony and David aged 4. We lived together in GRO-C Essex, where Barry worked for British Gas as a gas technician and I was a nurse.

4. Myself and Barry share a son, Paul born in 1983. Barry suffered with mild haemophilia A, however he continued to live life to the full. As he wasn't afraid to have fun with the boys, he would often need treatment for internal bleeding that was caused by him boisterously playing with the boys, fixing his car or just enjoying himself.
5. I recall fond memories of Barry rowing the inflatable dingy we had for the boys. His arms would hurt the next day but he was so adamant he didn't want to miss out on activities with the boys. He was the life and soul of the party.
6. When I met Barry he started on Cryoprecipitate although over the years his treatment change to Factor VIII, Haemophil, Armour Factor VIII, NHS Lister and Porcine Factor. All the treatments listed above are mentioned in his medical notes. I refer to Exhibit WITN3233003, this is a copy of a note found in Barry's medical records, the note summarises Barry's haemophilia.
7. My husband received treatment at the University Hospital Wales under the care of Professor Bloom and Royal London Hospital Whitechapel under the care of Dr Brian Colvin. We frequently visited my family in Wales so there were occasions when he was treated at the University Hospital Wales.
8. I do not believe Barry had any blood transfusions so therefore conclude the infections he contracted were as a result of the various blood products that were administered to him for his haemophilia.
9. I recall on one occasion at Barry's niece's second birthday in 1981 he injured his ankle. He did this by standing awkwardly on a drain. Barry had to attend University Hospital Wales on that occasion where he was seen by Professor Bloom who gave him Factor VIII and cyclophosphomide as they had run out of porcine factor.
10. I have stated earlier in my statement that Barry was a mild haemophiliac; I would like to add that as time went on and as Barry got older his haemophilia became worse and he developed an inhibitor.

11.I believe Barry was not provided with sufficient information or advice beforehand or of the risks of being exposed to infection.

12.As a result of the various blood products Barry received for his haemophilia he contracted hepatitis B. He first tested positive in September 1977. He also contracted hepatitis C (which was referred to as Non A, Non B during that time) and first tested positive in July 1984.

13.Additionally we were informed that Barry had tested positive for the HIV virus in February 1985.

14.From the late 1970s to the early 1980s Barry's health was in decline. Bleeds seemed to be more frequent, even though his lifestyle hadn't changed, the bleeds were taking longer to control. This was all due to Barry's inhibitor.

15.Dr Brian Colvin told Barry of the various viruses he had contracted from the contaminated blood at the Royal London Hospital, Whitechapel.

16.I do not believe adequate information was given to Barry on how to manage the infections. Quite often it was requested I attended hospital appointments with Barry and I was often asked questions about my general health.

17.I believe we should have been provided with more information earlier on in order to help us understand the severity of the infections.

18.We were kept in the dark about how rapidly Barry's health was deteriorating, especially the HIV infection. We had no answers, or vague answers to the various questions we asked.

19.As well as Barry being infected with contaminated blood,

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3. **Other infections**

1. Barry suffered from other conditions associated with HIV and hepatitis such as Organic Brain Syndrome, CMV and EBV infection.
2. Barry also suffered from Chronic Hepatitis Australian Antigen, Ischiorectal Fossal Abscesses, warts, nose bleeds and oral fungal infections.
3. As his health deteriorated Barry's immune system weakened and he became more susceptible to infections.
4. In terms of his mental health Barry began to experience the effects of psychosis. This was absolutely terrible to witness.

4. **Consent**

1. I have no way of knowing for sure whether or not Barry was tested without his knowledge and consent.
2. I was never pulled to one side and told Barry was being tested for anything specific. We were simply told the results of blood tests and this is how we were told he had contracted HIV and hepatitis C.
3. I am also unsure if Barry was provided with adequate or full information but I strongly believe this to be true.

5. **Impact**

1. As mentioned earlier in my statement Barry and I welcomed our son Paul in 1983. We had longed for a child together for many years.
2. It really hurts looking back and thinking that we didn't know how little time Barry and Paul would have together as father and son.

3. As a family we enjoyed going on outings at the weekend when Barry's health allowed for this, but as time went on Barry found it increasingly difficult to even go for a short walk.
4. Barry began attending local university in the early 80s and gained a Higher National Certificate and Higher National Diploma in Business Management. He was so determined he even came out of hospital to sit his final exams.
5. The exams he sat and qualifications he earned meant that he was better placed to obtain an office based position within the gas board even though his health was ailing. It also meant that even if he was suffering from a bleed he could do his work whilst seated.
6. As his condition worsened he was often cold and had to wear several layers of clothing. Barry went from being a confident, witty and intelligent man to a man that had no energy to even carry out the smallest of tasks.
7. I would say Barry's infections had an enormous impact on his mental health. The walls of our home would be covered in post-it notes, each containing words and code, he started to communicate with us using these "codes". Barry developed a condition called Red Button Syndrome, this is mentioned in his medical notes. An example of the syndrome is when there is a sign which states "do not touch" the person would have the urge to touch it.
8. Day to day life was a struggle for Barry and bad behaviour from the children did not help matters. Tony and David were teenagers at the height of Barry's ill health and they showed a total disregard to family rules at this time. For example they would stay out later than they were supposed to, smoking and sniffing glue. Myself and Barry would often find ourselves out late at night looking for them.
9. On one occasion, we couldn't find Tony until after midnight, we had to call the police and report him missing. This resulted in Barry contacting his ex-wife

and Tony went to live with her in Luton. Within weeks Tony was placed into a local council care home in Luton.

10. Tony moving home to his mother broke Barry's heart, but he was more afraid that he would lose control and physically harm Tony if he continued to live with us.
11. Barry's health worsened and he could no longer play his guitar. This was heart breaking as his guitar had brought him comfort during times when he was at home and resting. He also couldn't remember how to turn on his Sony Walkman to listen to his favourite music.
12. Sometime after Barry was told he had been infected with HIV, he received some counselling. Also a medical social worker GRO-D would visit Barry at home. During one of the counselling sessions, Barry was told to draw what he thought was the image of the AIDS virus onto a notepad. He was then told to shout at the image to release some of his anxiety.
13. I don't think some of the advice the counsellor gave was beneficial as one night I was woken up by Barry shouting and screaming at the image. It was as if the advice had unsettled him. I recall Barry holding a large butchers knife and stabbing the image, he was stabbing it with such force that the tip of the knife went through the pad and embedded the table below. I refer to Exhibit WITN3233004, this is a note from Barry's medical records dated 26th April 1986. The note is of a meeting between Barry and a psychiatrist it demonstrates how rapidly Barry's mental health had deteriorated at the time.
14. This was all very frightening for the family, especially for Paul as Barry then insisted on sitting at the bottom of Paul's bed clutching the knife to defend Paul from attack. Following this incident I contacted Whitechapel Hospital to see if they could provide any assistance. The advice provided by Whitechapel Hospital was to get Barry to hospital where he could be monitored. Barry was subsequently admitted to a psychiatric ward. He was very upset by this and began crying and hanging onto us when it was time for us to leave.

15. When all of this was going on, Paul was only 3 years old. Paul didn't understand that his father was now locked on a ward with other frightening patients who were often screaming and shouting.
16. It became almost impossible to coax Paul onto the ward to visit his father, he became distressed on a daily basis. I took the decision that Paul should live with my parents in Wales.
17. I would visit the psychiatric ward everyday and try to act as though everything was normal. I relied more and more on our eldest son Vince, he would be there for me when I returned from the hospital, often listening to me discussing his father's condition through tears and sobs. I could not have gotten through that period without Vince's support even though he was only 17 years old at the time.
18. I remember my parents visiting when Barry was at the hospital on one occasion and my mother collapsed as she couldn't believe how bad his condition had become.
19. When we were told Barry was infected with HIV it felt as if our world was crashing down around us. Our first reaction was, how long did we have left together? Medical professionals could never provide an answer to this question. Our second thoughts were, how do we tell the boys their father had been handed a death sentence?
20. Our family as we knew it seemed to fall apart when Barry was diagnosed with HIV. Our older boys, Vince, Tony and David were even told not to publicise this fact.
21. There was a huge stigma attached to those who had HIV. The press at the time were publishing sensationalised articles on what they termed the "GAY PLAGUE". This had huge effects on the boys, especially the twins whose

behaviour became more and more unacceptable, staying out late, smoking, drinking, solvent abuse was I believe their way of escaping reality.

22. Many nights we lay in bed and cried together. Our situation felt impossible. I had to be tested for HIV and the wait for the test result became unbearable. The results eventually came back negative. Barry was so relieved that he broke down crying. I refer to Exhibit WITN3233005. This is a note from Barry's medical records which shows my HIV negative blood result.
23. Barry spent most of the last 6 months of his life in hospital, mostly on a psychiatric ward. His health seemed to improve during the August and he came out of hospital for a few weeks. We went to stay with friends in Wales. These friends were fully aware of Barry's condition. It was a lovely couple of weeks spent with friends and loved ones that were ready to talk about anything and everything, including HIV. Barry took this opportunity to say goodbye to those friends as I believe he knew his body would not be able to cope for much longer.
24. We returned to Essex and I had to return to work. Money was tight and we were struggling financially. The first morning I was back in work, my neighbour rang to say that Barry was walking up and down the street outside our house, with blood pouring from his nose. He had tried to stem the flow of blood by stuffing sheets of toilet tissue up each nostril resulting in blood soaked tissue trailing and dripping all over him.
25. Barry wanted desperately to return to hospital as he was so afraid that he would infect others. He was afraid to be on his own, he wanted someone with him all of the time. He felt vulnerable and became very childlike.
26. I recall going to the hospital with Barry and the nurses would frequently ask very personal questions about mine and Barry's sex life. They would also remark on whether or not we had separate cups and saucers.

27. We were told only to kiss each other on the cheek. I was warned not to passionately kiss my husband as there was a risk I could catch a fungal infection.
28. At the hospital I was often pulled to one side and asked if I had symptoms of a cold or a fever.
29. The day Paul was born GRO-C a blood sample was taken from him by Dr Colvin. This has always puzzled me as we never found out what this was for.
30. We lost many friends as being so secretive was hard. We would often turn down invitations to go places. We were advised by the hospital not to publicise the truth. We became good liars and well versed in putting on a front.
31. We also found ourselves having to make excuses to our employer on why we had to keep attending the hospital. Secrecy became the driving force in our lives.
32. The day Barry died started off as a typical day for me. I was at work, it was a sunny Monday morning, when the hospital contacted me to say that Barry was experiencing breathing difficulties and they asked if I could come in and see him as soon as possible.
33. I drove to the hospital on autopilot, parked the car and even listened to a song on the radio, which still to this day if I hear that song still brings a tear to my eye. The song playing was Wonderful Life by Black.
34. I walked into the hospital and started scrubbing up ready to go and see Barry when one of the nursing staff told me not to bother doing this as Barry had died a few minutes earlier.

35. I entered Barry's room in the hospital and he was lying in what looked like a large black bag with only his face uncovered. At this time I was told Barry was allowed to remain on the ward for a short time and that I was to contact our family to let them know.
36. I was in a state of complete shock, there are no words to describe how I felt at that time. Barry had been ill on many previous occasions. I was not prepared for his death. Our children and Barry's family were unable to say their goodbyes to him as after only a few minutes of him passing away Barry's body was taken off the ward. I was told at the time that this was for the safety of everyone, due to the body fluids and risk of passing on the infection.
37. The week running up to Barry's funeral was a complete blur, family came and family left. Tony was still in care at this point and David had gone to stay with his aunt.
38. Vince, Paul and myself still lived in Essex, I returned to work but with little or no family support nearby. As time went on I realised it was necessary for me to sell our family home in Essex and move back to Wales where I had plenty of family support.
39. Not long after me and Paul moved back Wales, Vince also joined us. He had been overseeing the sale of the house in Essex.

6. Treatment/Care Support

1. When Barry was admitted to Hospital in September 1986 for what would be the last time, he became ill very quickly. We asked if Barry could be moved to a Hospice. This was not possible at the time as they did not have the facilities to treat patients with HIV.
2. As previously discussed in my statement, Barry was assigned a Medical Social Worker, Mr [GRO-D]. Mr [GRO-D] was young and enthusiastic but unfortunately I believe he was met with a brick wall when trying to help Barry.

7. Financial Assistance

1. During Barry's lifetime he did not receive any financial support from any of the trusts or funds. I don't believe we knew of their existence.
2. In the early 1990s following Barry's death, I received a lump sum payment from the Macfarlane Trust. Prior to receiving the payment I had to sign a waiver which stated I would not make any further claims for compensation or take part in any action against the Government.
3. I also received a stage 1 payment from the Skipton Fund, the amount was for £20,000 in 2010/2011. I received £70,000 from the Skipton fund a few years later which was a stage 2 payment. These amounts have been shared equally between myself and Barry's sons.

8. Other Issues

1. I was 31 years old when Barry died. Shortly after his death it became necessary to sell our family home and move to South Wales to be close to my family, where I would have support.
2. I never received or was offered any counselling, I had a wonderful GP when I returned to Wales, Dr Kevin Hunt who would book my appointments near to his lunchtime so we could chat about my thoughts and fears whilst he ate lunch. I found him to be invaluable.
3. Over the year I had periods when I need medication to help get me through bouts of depression and periods when I have been unable to sleep.
4. My GP some years later remarked these bouts followed a pattern occurring around February and September each year, our wedding anniversary and the anniversary of Barry's death.

5. At times when I was not taking medication I relied on a few drinks each evening to help me sleep. I now have problems with my liver caused in part by alcohol abuse.

Statement of Truth

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

Signed.

GRO-C

Dated...20-11-2019.....