

Witness Name: SUSAN ANNE COYLE

Statement No: WITN1171001

Exhibits: WITN1171002-4

Dated: DECEMBER 2018

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF SUSAN ANNE COYLE

I, Susan Anne Coyle will say as follows:-

Section 1. Introduction

1. My name is Susan Anne Coyle. My date of birth is the GRO-C 1951. I live at GRO-C I am by occupation a retired nurse. I have three daughters, Sarah, Rachel and Holly and four grandsons (two of which have haemophilia) and one granddaughter.
2. My husband, Brian Richard Coyle, was co-infected with the Hepatitis B Virus (HBV) and the Hepatitis C Virus (HCV) from contaminated blood. He died from renal cell carcinoma (kidney cancer) on 10th July 1996 at aged 49.
3. This witness statement has been prepared without the benefit of access to Brian's full medical records. If and in so far as I have been provided with limited records the relevant entries are set out in the medical chronology at the end of this statement.

Section 2. How Affected

4. Brian had severe Haemophilia A. He was diagnosed from birth, his older brother, Joe, had also been diagnosed by that time.
5. Brian was treated at the Oxford Haemophilia Centre, at the Churchill Hospital under the care of Dr Rizza, Dr Matthews and Dr Giangrande. He was initially treated with plasma and then cryoprecipitate.
6. He was treated with Factor VIII (FVIII) from 1973 or 1974. I remember Brian taking FVIII with him on our honeymoon in 1974, so he must have started treatment with FVIII before then.
7. I refer to **Exhibit WITNXXXX002** being Brian's Hospital and Home Treatment Record listing the product/material supplied and used. Sheet No 8 of the Home Treatment Record is missing, being the product/material supplied from end January to the beginning of September 1985.
8. I refer to **Exhibit WITNXXXX003** being Brian's National Haemophilia Database Record from the date of 4th January 1978. The record appears to be inconsistent with the data provided under **Exhibit WITNXXXX002**.
9. There were no warnings from the hospital of the risks associated with FVIII blood products and Brian and I were unaware of any danger until the mid-1980s. Through the media, we were made aware of HIV and AIDS and I recall Brian telling me that he was going to be tested for it by the hospital. I distinctly remember that he said "They are going to test me for it. If I am positive then you could be positive... and so could Holly." Sarah and Rachel were only 8 and 6 at the time, and Holly had only recently been born. Although we were concerned, we thought "We will be fine because Sarah and Rachel are fine". Because of the media we associated HIV/AIDS with the gay community and/or promiscuity. We were optimistic and did not worry too much. Thankfully, when Brian was tested the results came back negative.

10. I do not recall Brian telling me that he was going to be tested for any other infection, but at some stage quite, early on, I knew that he was HBV positive. I was not really surprised I was vaccinated against HBV, as I was working as a nurse. Eventually, Brian and I found that he had tested HCV positive as well.

11. Because of the passage of time, I cannot recall when it was that Brian was informed that he had been infected with HCV. I refer to **Exhibit WITNXXXX004** being a record of a hospital appointment Brian and I attended on 30th July 1993. It would appear that we were informed of Brian's HCV status by Dr Giangrande at that time and that the conversation was secondary to the issue of intended knee surgery. It would however appear from Brian's medical notes that he was first tested HCV positive in June 1990.

12. When Brian was informed that he had contracted HCV, no information was provided about how to manage or understand the infection. It was almost as if Brian was expected to just live with it. If there were any resulting problems they would apparently look at that issue then. Brian was not offered any treatment or medication for his HCV and we were not advised of any potential medical complications. We had three young girls and we were both working full-time. Brian seemed to be well, so we just got on with it and carried on as normal.

Section 3. Other Infections

13. I am not aware of any other infections that Brian contracted as a result of receiving contaminated blood products.

Section 4. Consent

14. I am not aware that Brian was treated or tested without his knowledge, consent or without being provided with adequate information. His medical notes and records appear to indicate that he was tested on quite a few occasions, more frequently than I was aware.

Section 5. Impact

15. Brian was often in pain with his joints but he did not complain much when he felt unwell. He began to complain of a pain in his back/side. He suffered with night sweats, high temperatures, coughing and breathlessness. We went back and forth to the Oxford Haemophilia Centre in the latter part of 1995. We were told several times that Brian had a bleed in his kidneys and then treated him with FVIII.

16. I remember Brian was exhausted by the time we got to Christmas 1995 and he slept for the best part of Boxing Day. Brian became very unwell in the New Year. He noticed blood in his urine. He had lost almost two-stone in a very short period of time. He had a horrible grey, yellow, white tinge about him and just looked ill. Brian rang me at work one day and told me just how much pain he was in. I insisted upon taking Brian to the GP and at that appointment, in February 1996, our GP listened to what we said, took us seriously and arranged tests.

17. On 8th March 1996, Brian had his first ultrasound and chest x-ray. A week later, on 15th March 1996 he was informed that something was showing up on the x-ray which could be either a blood clot or a carcinoma. After various other tests, we received a diagnosis on 15th April 1996 that they had found a large tumour in his kidney and lung secondaries. A few days later they conducted further tests and we were informed that it had spread to all of his glands and there was nothing more they could do.

18. I took unpaid compassionate leave from work for six months to care for Brian at home. However, just three months later on 10th July 1996. He died at home and I was at his bedside when he went.

19. I recall our daughter Sarah asking the nurse why her father would get this. The nurse said "anyone can get this... he has just been unlucky". It was only

much later that we have realised the correlation between Renal Cell Carcinoma and HCV. I believe Brian's symptoms should have been investigated properly sooner. I cannot help but wonder if the medical professionals caring for Brian knew about the connection at that time but did not say anything to us.

20. When we were informed of Brian's diagnosis, I felt incredibly sad for him because he was so accepting of everything that had been thrown at him. I knew as a nurse what Brian would be likely to go through: bony secondaries, ascites, pneumonia, pain or fear. As a wife, I was very, very frightened for him and felt sick with worry all the time.

21. During Brian's last few months, I had problems sleeping. I would have awful dreams, which caused me to cry and cry at night and thrash around. Brian was frightened. I would inadvertently knee him in the back, and it would sometimes take ages for me to calm down. The children and I found it very upsetting to see the weight coming off him so quickly and I always had to encourage him to eat anything. I also had to help Brian wash and to turn him over, sit him up and lay him down.

22. I met Brian when I was seventeen years old; he was my first and only boyfriend and I really did love him. We always stuck together and never considered leaving each other. I will never be able to put my arms around anybody and feel the same kind of love, tenderness and gratitude as I did with him.

23. In some ways, we miss Brian more now than we did at the time. Having had two grandchildren with Haemophilia, we wish that Brian was around to talk to them about their condition and offer them support. Knowing now that HCV significantly increases the risk of developing renal cell carcinoma resulting in Brian's death is even harder for us to bear. He was given contaminated blood through no fault of his own and paid the ultimate price with his life.

Section 6. Treatment/Care/Support

24. Following Brian's death, I told the staff at the Oxford Haemophilia Centre that I believed something should have been done sooner to investigate Brian's illness. Had someone acknowledged that he had attended the centre three times over a two-week period, they may have been able to pick up the tumour sooner and could have treated him. One particular nurse has told me that if someone now attends the centre complaining of the same issues, they will no longer assume it is 'just a bleed'.

25. Brian was not offered counselling or psychological support when he was diagnosed with HCV. When he passed away from Renal Cell Carcinoma our family were not offered any counselling or psychological support.

Section 7. Financial Assistance

26. Following Brian's death, I received £20,000/£25,000 from the Skipton Trust. I claimed this assistance myself and did not encounter any difficulty when doing so.

Section 8. Other Issues

27. There are no other issues.

Anonymity, disclosure and redaction

28. I confirm that I do not wish to apply for anonymity and that I understand this statement will be published and disclosed as part of the Inquiry.

Statement of Truth

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

Signed..... GRO-C

Dated 14th December 2018.

MEDICAL SUMMARY

(This summary is not intended to be exhaustive but sets out key points in the records relevant to the Statement)

27.08.1981	'Hepatitis B Antigen not detected'
08.10.1984	'Anti-HBs positive'
08.07.1987	'Mr Coyle has been tested 16 times in all, the last time being on 16.3.87. On all occasions he has been anti-HIV negative.'
20.02.1990	'Anti-HBs detected' 'Hep C Ab Not detected'
06.06.1990	'Anti-HCV detected'
25.08.1992	'Anti-HCV detected, HCV RNA detected'
30.07.1993	Patient informed of HCV status