

Witness Name: B J Paintin
Statement No: WITN1454001
Exhibits: WITN1454002-4
Dated: February 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF BARBARA JEAN PAINTIN

I, Barbara Jean Paintin, will say as follows:-

Section 1. Introduction

1. My name is Barbara Jean Paintin and I live at [GRO-C]
[GRO-C] Warwickshire [GRO-C]. I was born on [GRO-C]
[GRO-C] 1948. I am a widow and I have never remarried since my husband died.
2. I make this statement as the widow of Frederick George Paintin (Fred) who was born on 10 December 1942 and died on 18 January 2000. His death certificate cites his causes of death as a) Hepatoma, b) Hepatitis C and c) Infected blood products. A copy of this is attached as **Exhibit WITN1454002**.
3. This statement has been prepared without the benefit of access to my husband's full medical records.

Section 2. How Affected

4. Fred suffered from severe Haemophilia A with a 0% clotting factor from birth.

5. When he was younger and had bleeds he took to his bed for a long time. His joints had been very affected by bleeds and he ended up with his legs in callipers. His older half brother died of haemophilia.
6. He received all his treatment from The Churchill Hospital and The John Radcliffe, Oxford. He was treated by Dr Rizza, Dr Mathers, Dr Trowell, Dr Giogrande and Dr Keeling.
7. Prior to 1985 he received blood transfusions and plasma but after 1985 he received Factor VIII for his bleeds. He was unable to administer it to himself as he had needle phobia. Our local doctors would come out to him and administer it. Our GP Dr Thorogood was so supportive; he was the doctor that insisted that infected blood products be put on his death certificate. I attach as **Exhibit WITN1454003** a copy of the list of Factor VIII treatments Fred received between 1985 and 2000.
8. Factor VIII was seen as a revolutionary treatment at the time. There was no indication or no information given to him in relation to a risk of infection as a result of receiving Factor VIII. He had been going to the Churchill Hospital for plasma prior to Factor VIII which was about 30 miles away from where we lived. From 1985 onwards the Factor VIII was kept in our fridge, it was wonderful. Throughout his life Fred had had weeks of bedrest and was in continuous pain. Suddenly he was able to have an injection and be able to walk properly, go on holiday, go to work.
9. In 1986 I think, Fred desperately needed to have his teeth out. He didn't want to because by then it was in the public domain that haemophiliacs were getting HIV from dental treatment.
10. In or about 1986 I remember ringing the company named on one of the bottles of Factor VIII in our friend and I asked them whether it was contaminated. The company were very non-committal and did not answer my question. However, they immediately rang my husband and he told me off for doing it.

11. On one of the days we went up to the Churchill Hospital Fred told me that I didn't need to come in with him and I waited in the car. On the way home he told me that the doctors had said he had Hepatitis C. He said to me "well I got over Hep B so I'll get over Hep C". We then went out for a meal. He always tried to protect me.

12. I think it was in the early 1970's when he contracted hepatitis B. I attach a document dated 8 February 1973 , **Exhibit WITN1454004**. This shows the diagnosis of Serum Hepatitis signed by Dr Loe from The Infectious Disease Department, The Slade Hospital, Oxford.

13. I do not know the exact date when he contracted Hepatitis C (HCV) and I do not know the specific date when Fred was told about it.

Section 3. Other Infections.

14. I know that he was notified by letter that he was exposed to the risk of vCJD. I know that he was HIV antibody negative.

Section 4. Consent.

15. Fred went regularly to the hospital for tests. I am not aware of what tests he was having and I am not sure whether he knew or not that his blood was being tested for infection. At one point, I do recall that he said these tests were pointless. He was trying to protect us all the time.

16. Fred had been used as a guinea pig in his life so it would not surprise me if his bloods were tested without his knowledge. When he was 9 years old he had to have his appendix removed. He required a blood transfusion during the operation. I understand that he was the first person to receive blood on the operating table from a live donor. This had never been done previously in the UK.

Section 5. Impact

17. Fred was a very private man and he was very protective of his family. He did not want to worry us all. He protected his parents as well who he was very close to. His death has impacted hugely on our daughter, Louisa who, as a consequence, suffered manic depression.
18. Mentally he was an extremely strong character but not in a macho-way. He never complained at all. He was a wonderful, smart and determined man. He always said that "*life was for living*".
19. He hated fuss and emotion. He used to worry about his family and not about himself.
20. Fred was asymptomatic with Hepatitis C until the late 1990s when he had long periods of jaundice. I said to him on more than one occasion that he looked yellow but he would answer saying "I'm alright, I'm alright. He just got on with life and had such a great attitude to life.
21. In 1998 Fred went on the liver transplant list. As there was a significant risk of infection from his teeth, he had to have all these removed. This operation took place in 1998. Fred was terrified of being on the transplant list but accepted it and carried a bleeper so that he was contactable at all times.
22. At the same time he started on a low sodium diet and whilst he lost a lot of weight; his liver function improved. Physically he improved and in November 1999 he was taken off the transplant list. On 9th November 1999 a CT scan showed no evidence of tumour. However, on 21st December 1999 an ultrasound showed a tumour present. He was told at that stage that he was too poorly for a transplant. I was very sceptical about this.
23. He appeared to deteriorate from that moment on. Physically I saw a difference in him when he was told he was no longer eligible for a transplant.

24. Just before Christmas 1999 we went to see Dr Trowell. She said in a very matter of fact manner that there was nothing they could do for him. He crumpled in the chair. At this stage I was unable to cope and had to walk out of the room as I was too emotional. My sister in law who was also there has since told me that during that meeting they said they would like him to go to a hospice. Dr Trowell said that they would try to facilitate wherever he wished to go. He said he would like to go to Ellen Badger Hospital and Dr Thorogood arranged for this to happen. This was where he had been born and this is where he died. This was the first moment that I had ever smelt death.
25. He was desperate to see the Millenium in at home which we managed to do. He knew he was going to die. He was so poorly at Christmas that Dr Thorogood had to come to our house. It was then that he said "you're not going to make it now lad".
26. I remember one night I was lying on the sofa crying; I thought Fred was asleep. He said "you can just stop that". He was always trying to protect me; to the very end of his life.
27. In the last two weeks of his life he had asked his sister who lived next door what she was doing. He was such a proud and strong man that he didn't tell her why but that was when she moved in and never left until he died.
28. We went on a cruise in August 1999; he wasn't really fit but I feel so guilty now that we went away and that he may have missed a transplant opportunity. Dr Thorogood has told me that he was too poorly at this stage but I still wonder whether the outcome would have been different if we had not gone.
29. Fred deteriorated very quickly towards the end of his life. He became very jaundiced and he lost a lot of weight.
30. He died on the 18th January 2000. Towards the end of his life I begged them to do something to ease his pain and Dr Thorogood told me at the same time that I was not the only one that loved him; he had become close to Fred.

31. Fred wanted me to continue to go on holiday after his death but I won't go with anyone else. I have not had any other relationship. Fred spoilt me to bits and he was the love of my life. Someone at the funeral came to me and said that I had looked after him so well and I remember saying "no, he looked after me".
32. His family were his world. My father originally was against us getting together because of his haemophilia. Fred would say that it was only because my dad worried about me but they later formed a great relationship.
33. In 1985/1986 I was working as an assistant teacher at Ilmington Primary School. At the time there were a lot of adverts on the television about AIDS and the implication was that you would get it if you were gay or a drug user. There was also, at the time, a connection between haemophiliacs and AIDS. I did not know whether anybody would say anything such as "I do not want her with my children". Whilst no one had said anything to me I decided to leave my position because of the stigma attached.
34. I desperately miss Fred. I used to sleep with his jumper for a long time after he died to keep me close to him. I have not thrown anything away and have kept his clothes. I remember that I had to have my engagement ring altered because I had lost some weight and when I was looking through his suits I found the exact amount of money in his suit pocket that it cost for me to have my ring altered. I find that very strange.
35. Mentally I could not lock the door to our house for a long time after he died because I felt that if he was not in the house, I did not want to lock him out.
36. I have been very upset since he died to learn that in some of his medical notes and records there is reference to alcohol and him drinking. When he went into hospital for the last time he was put on the liver ward and the nurses believed that it was to do with him drinking. This has upset me too.

37. I was also very upset with Dr. GRO-D as she wrote me a letter a week after he had passed away which said "so sorry to hear about Frank"; she couldn't even get his name correct

Section 6. Treatment/Care/Support

38. I do not know whether any treatment was offered to Fred in terms of counselling. I do know that he would not have gone to it even if they had as he was such a strong, proud man. No psychological support was ever offered to me.

39. His dental treatment was carried out at the Churchill Hospital and I do not recall that he was treated in any other way to patients who were not infected.

40. I believe his medical records are inaccurate; they also have information relating to other patients. They show that my husband received FVIII on 6 March 2000 but this was two months after his death so this is clearly wrong.

Section 7. Financial Assistance

41. Fred was Company Secretary of Hood Norton Brewery and he worked up until three months of his death. His company had been very good to him in the past. He never let his haemophilia and his treatment affect his work. The company paid for his funeral.

42. I have received both Stage 1 and Stage 2 payments from the Skipton Fund. I received separate payments of £20,000 and £50,000 in 2011.

43. On 24th February 2017 I received £10,000 from the Caxton foundation and also received winter fuel payments of £500 on 28th November 2013, £350 on

9th December 2014, £500 on 15th December 2016 and £519 on 30th November 2018 from the Caxton Foundation.

44. Ten years after my husband had died the Department of Works and Pensions wrote to me offering financial support specifically for his funeral. I find this disgusting behaviour.

45. I would not have known about any of the financial assistance available if it had not been for my daughter Louisa who joined the Tainted Blood group and saw online that these payments were available.

Section 8. Other Issues

46. Approximately three years ago in 2016 we were campaigning outside the Houses of Parliament. I remember a woman walked past and commented "*You should be ashamed of yourself*". I feel the stigma remains to the present day.

Anonymity, disclosure and redaction

47. I do not wish to have anonymity and understand that this statement will be published and disclosed as part of the Inquiry. I do not wish to give oral evidence.

Statement of Truth

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

Signed.....

GRO-C

Barbara Paintin

Dated..... *15th* *MARCH* *2019*.....