

Witness Name: Elizabeth Jane Bye

Statement No: WITN1131001

Exhibits: 0

Dated: January 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN WITNESS STATEMENT OF ELIZABETH JANE BYE

I, Elizabeth Jane Bye will say as follows:-

Section 1. Introduction

1. My name is Elizabeth Jane Bye. My date of birth is the [GRO-C] 1952 and I live at [GRO-C], [GRO-C], Hants [GRO-C], with my husband. I am currently enjoying my retirement after working as a dentist.
2. I make this statement on behalf of my late father, John Kenneth Keen, date of birth [GRO-C] 1919. My father died at the age of 77 on [GRO-C] 1997 from liver failure.
3. This witness statement has been prepared without the benefit of access to my late father's full medical records.

Section 2. How Affected

4. My father suffered with moderate Haemophilia A with a 3% of clotting factor. He was diagnosed in the early 1920s, at the age of 2½.

5. My father's Haemophilia did not cause spontaneous bleeds and he was very good at managing it. He only required to be treated at the hospital whenever he had a bleed as a result of a bump or accident.
6. I am not sure when my father started receiving Factor VIII (FVIII). However, I believe it was in the early 1970s.
7. My father was treated at the Churchill Hospital, Haemophilia Centre in Oxford and as previously stated he was always treated at the hospital and never required to be treated at home.
8. He always tried to live his life very sensibly, whilst still enjoying it.
9. My father was a dentist working for the NHS. He retired in 1980s and he was looking forward to a long and healthy retirement. However, he started getting very unwell in the mid 1980s.
10. I believe he contracted Hepatitis B (HBV) and Hepatitis C (HCV), as a result of being treated with infected blood products.
11. I am not sure as to when exactly my father was infected with HBV or HCV. However, my father believed it was when he had his hip replacement surgery, which was in or about 1985/6 that he contracted HCV. He had HBV before this from previous contaminated blood products.
12. Initially, my father received blood products originating from the UK and at some point he started receiving the American blood products as well as British blood products.
13. Once there was a general realisation and raised awareness about the blood products coming from America being contaminated, my father had blood tests every 3 months. I believe that the tests were done to check for Human Immunodeficiency Virus (HIV). I believe my father started having regular blood tests between the late 1980s and early 1990s.
14. My father found out that he was infected with HCV in or about the early 1990s when he was very poorly because of Esophageal Varices. This is a condition

whereby the veins in the lining of the lower esophagus swell up and burst, caused by a significant damage of the liver. I am not sure how, if any, information about the HCV was communicated to him. I believe that he was only told about HCV because he had Esophageal Varices. This is a very serious and life threatening condition especially for a haemophilic.

15. I am not sure if any practical information was given to my father regarding his condition. I am aware that the doctors spoke to my mother but I am not sure what information was given.

16. I believe that both of my parents were not provided with adequate information regarding the infection.

17. I believe that my father should have been informed about the risks of being exposed to infected blood products, prior to being treated with it. Instead, not only was he told nothing about the risks, he was wrongly advised that it was safe.

18. Since he had worked in the health service and he had many friends who were also working in the medical sector, he did become concerned about the safety of the treatment. I believe that there were some rumours in the medical circle that something was wrong with FVIII. This did raise suspicion for my father. He therefore questioned the doctors repeatedly, and he was always reassured that FVIII was a safe product to use.

19. I am certain that my father would not have agreed to the hip replacement surgery if he knew that there was a chance of being infected with HCV or HIV.

20. My father trusted the doctors, as he had no reason to disbelieve them.

Section 3. Other Infections

21. I believe that my father did not contract any other infections as a result of the contaminated blood products other than HBV and HCV.

Section 4. Consent

22. I am not sure if my father was informed about being tested for HCV.

23. I do not believe that my father was ever provided with adequate information about the infection.

24. I am not sure if he was ever tested for the purposes of research.

Section 5. Impact

25. My father's lifestyle started changing even prior to finding out about HCV. He was first regularly tested for HIV, which caused him a lot of distress and worry. He saw many other haemophiliacs being tested positive for HIV, so he was worried that he would be positive.

26. Being infected with HCV had a massive impact on my father's mental state. Prior to finding out about his illness he was very outgoing and sociable. After he found out about it he became very depressed, nervous and withdrawn; he never wanted to go out. He also lost confidence and he constantly needed reassurance from us as a family that we will get through it.

27. My father used to be very active prior to being infected, but when he was told that he had HCV he was not able to do anything because of a mental barrier, as well as a physical barrier, so he gave up the things he always enjoy doing. He also relied very heavily on us.

28. He was also worried about what other people would think about him, because of the stigma that was attached to it. He looked very ill and yellow because of the effects of HCV. He was very worried about what people would say and worried that they would start asking questions. The way the media portrayed HCV was wrong. It made people believe that it could only be contracted if you were an alcoholic or a drug user.

29. My father completely gave up alcohol. He used to enjoy having an occasional drink, but because he was so ill and had such bad liver damage from HCV and HBV that he gave it up altogether.
30. It was a massive shame because my father retired and had a lot of plans as to what he wanted to do for his retirement, but he was robbed of that opportunity by the infection. I recall that my father had planned to go sailing, but he was no longer able to because he was poorly.
31. He also felt very guilty when he attended the hospital. He saw a lot of young people dying because of the infections and he felt guilty because he was in his 60s and still alive.
32. My father gradually became worse. As HCV is an insidious illness as it causes damage slowly, you do not know you have it until you become very ill. This is what happened to my father.
33. I believe my father missed out on a lot of things which he should have been able to do at the time, such as playing with his grandchildren and taking them for walks. He became very paranoid that he would accidentally infect them.
34. I believe HCV caused my father further health complications such as significant liver damage, skin problems, loss of weight and Esophageal Varices. It caused him to have all the symptoms of severe liver failure.
35. I believe my father started to receive Albumin treatment in relation to HCV in or about 1994 and he continued with this treatment until the end of his life. He spent a lot of time at the hospital.
36. I am not aware of any obstacles that my father faced in accessing any treatment.
37. My father's infection also had an affect on me as his daughter, as well as the other family members. We were very worried as to what would happen to him

as a result of the HCV. When the telephone rang, I was terrified as I thought something bad had happened to my father.

38. I recall an instance when I had to return home early from a holiday, as my father was very poorly because of his HCV.

39. We all kept my father's infection very private. A lot of our friends were medical staff so we felt comfortable telling them about it. However, we needed to be very careful with those friends who were not in the medical field, as we were afraid that they would not understand it or they would start questioning us.

40. I recall that my brother and I were very aware of the stigma attached to the infection and we were very cautious at all times as to whom we would mention it too. This was particularly due to the media portraying the infection in shameful way.

41. My father's HCV also affected my mother tremendously. She lived with my father so she felt the affects of his illness and the worried the most. She became a 24 hour carer and had no social life of her own during this time.

Section 6. Treatment/Care/Support

42. I believe the only treatment he received was Albumin treatment in or about 1994.

43. I am not sure if there were any other treatments available for HCV. I think that at the time this was all they could do to prolong his life.

44. I do not believe that my father received counselling. I am not sure whether he was ever offered it, but I do not believe he was.

45. Our family was never offered any counselling or psychological support prior or after my father's death.

46. I believe that counselling would have been helpful, particularly for my parents. I believe that it could have helped them to deal with the mental affects of the infection and perhaps my father would not have to deal with so much pressure as he did after finding out about infection.

Section 7. Financial Assistance

47. My father had no financial assistance.

48. None of us were ever provided with any financial assistance prior to my father's death or after.

Section 8. Other Issues

49. I recall that our GP was very supportive after my father's death. He often visited my mother and offered support, as she suffered greatly as a result of my father's death.

Anonymity, disclosure and redaction

50. I confirm that I do not wish to apply for anonymity. I understand that 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.....

24.11.19