

Witness Name: Maria Olivia Burke

Statement No: WITN1123001

Exhibits: 0

Dated: June 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF MARIA OLIVIA BURKE

I, Maria Olivia Burke will say as follows:-

Section 1. Introduction

1. My name is Maria Olivia Burke. I was born on GRO-C 1945 and I live at GRO-C
GRO-C Norfolk, GRO-C.
2. I make this statement on behalf of my late son, Francis John Burke Jr, (John).
He was born on GRO-C 1971 and died on GRO-C 1994 aged 23 as a result
of Hepatitis C (Hep C) and HIV.
3. My husband, also named Francis John Burke, has produced a witness
statement ('WITN1123001') for the Inquiry.
4. My husband and I are both retired and live together. We have an elder son
who is married and lives in New Zealand with his family.
5. This witness statement has been prepared without the benefit of access to my
late son'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

6. John was the youngest of the two brothers and was diagnosed with severe Haemophilia A when he was about a year old. We were in Spain on holiday when he suddenly had a bleed in the brain. The doctor in Spain told me to see a haematologist in England. My late brother also had Haemophilia and died as a result of it but I did not know what it was then. I believe Haemophilia runs in my family.
7. We saw a doctor in Kingston on Thames but that hospital was unable to assist John because they did not have the facilities or treatment. He was therefore transferred to Great Ormond Street Hospital (GOSH) and was treated at this hospital until the age of 13.
8. When he was 13, the professor said John had to leave GOSH and gave us a choice of 2 hospitals, either St Thomas' Hospital in London (STH) or St Peter's Hospital in Surrey (SPH). We chose STH.
9. At GOSH, John was treated with Factor VIII (FVIII) from the UK. However, at STH, he started receiving FVIII from American. Whilst John was at GOSH, I used to take FVIII home and administer it to John myself. At STH, I did not want to take home the American FVIII but a Dr Savage assured me that the American FVIII was heat treated and safer than the UK product. I was previously told by the doctors at GOSH that the American produced FVIII was contaminated. We used to receive regular updates about FVIII at the hospital. However, when John's care transferred to STH I trusted the doctors and agreed to use American FVIII. I was given this product to administer at home and that was the beginning of the end for John.
10. John was infected with HIV and Hepatitis C (Hep C) as a result of being given contaminated FVIII blood products.
11. Before John was transferred to STH he was tested at GOSH for HIV and he tested negative. Approximately a year later after being treated at STH, he was tested for HIV and tested positive.

12. I attended STH to collect some FVIII products and as I was walking down the corridor, Dr Savage said 'did you know, John has HIV' in the midst of other people. I was so shocked when Dr Savage told me and even more shocked when he told in the corridor of the hospital in front of other people.
13. John was only about 14 years old when I was told that he had HIV. I was too much of a coward and could not tell John about the infection myself. However, John found out that he was HIV positive when he was about 15 or 16 after a sister at the hospital told him whilst he was having his wisdom tooth extracted. I am unable to say how John reacted when he found out that he was HIV positive.
14. Dr Savage did not give us any information to help us understand and manage the infection and we did not have a follow-up appointment after being told about the HIV.
15. I believe that information should have been provided a lot earlier. The way I was told that my son had HIV was disgusting. It was done in the corridor in passing and it should have been done privately in a room with John.
16. We were not even told about the risks of others being infected as a result of the infection. I believe this information should have been given to us.
17. I do not know if John was ever told that he had Hep C. We only found out approximately 2 months after John died that he had it. We received a letter from the Haemophilia Society stating that he was also infected with Hep C.

Section 3. Other Infections

18. I do not know whether John had any other infections. I had a good relationship with him in the last few years of his life and he never told me about any other infections.

Section 4. Consent

19. I believe that John was treated with our knowledge as I used to take him to all his hospital appointments. However, this was only with assurance that the American FVIII products were safe to use.

20. However, I believe that John was tested without our consent. I believe this because we did not know or provide our consent for him to be tested for HIV at STH.

21. I do not know whether John was treated or tested without being given adequate or full information.

22. I do not know whether John was treated or tested for the purposes of research.

Section 5. Impact of the Infection

23. John suffered mental effects as a result of the HIV. He was too young to be told he had HIV and too young to be told that he would die at an early age as a result. Whenever we tried to talk to John about it, he would say there was nothing to talk about and avoid the conversation. He was trying to protect me by not looking upset and I was trying to protect him. It was a horrendous feeling for someone who was 15. I believe he suffered more mental effects than physical effects.

24. The nurses at STH were brilliant and told John to rest. He was told to have a good diet and watch what he ate. He had to change his way of living because of the infections.

25. John's health started to deteriorate in or about 1993. He was working at the time and I was in Spain visiting my family. He lost a lot of weight. I came back to the UK to care for John. The doctors sent him to a hospice to give me some time off. At the hospice, he did not want anyone there but us. He was not able to walk in his last 2 months and was bed bound. He started to deteriorate from the brain first.

26. John was given some treatment but I cannot remember what it was called. I believe he received some sort of treatment for his HIV, 2 years prior to his death. In the last couple of months, I know he was given morphine.
27. I do not know whether John had any difficulties or obstacles in obtaining treatment. I believe he might have as it was difficult back then whereas now it is more open.
28. I don't know what mental and physical effects John suffered as a result of the treatment.
29. John carried on having dental care at GOSH and then went to Guy's Hospital (GH) as he was requested to do so because of his age.
30. John's diagnosis had an impact on his private, family and social life. He got in with the wrong crowd and had some bad friends as a result of the HIV. He never admitted that they were bad people as he was a happy boy who got on with everyone and saw the good in people.
31. John's diagnosis had an impact on me physically, mentally and emotionally on my private, family and social life. It changed our life completely. At the time, we had lots of friends and we were a happy family but all of that just disintegrated within seconds. When I was told he had HIV, I just could not understand. The GP knew about this before I was told but he did not inform us. We suffered so much discrimination at the time. Thank God things have changed over the years and there is a better understanding of HIV now. I had a breakdown and I suffered the most as a result of what happened to John. I was in and out of hospital for more than a month after his death as I could not deal with it. I thought I had got over his death but I have not.
32. There was a stigma attached to the HIV at the time which made things a lot harder for us. My elder son told his friends who never let him down. However, I got nasty remarks from my friends and people around me. I never told anyone but John did as he wanted to know who his real friends were. The amount of discrimination we faced was horrendous. He was affected at school

as children were calling him names. We used to have a circle of good friends who distanced themselves after hearing of John's diagnosis.

33. John has suffered educational and work-related effects as a result of the infection. He had always wanted to be a doctor. He was very smart and he had really high hopes for his Maths exam. However, when he did his Maths exam he failed it and never went back to education after that. He was very upset with his results. He went to work instead and always made sure he had a job. He used to work night shifts as he did not like day shift jobs.

34. My husband and I had to give up work in the last year of John's life. I was an assistance nurse and my husband was a bus driver at that point. It was awful as we had a mortgage to pay.

Section 6. Treatment/care/support

35. I cannot recall if John or myself received any care and support as a result of what happened.

36. I was offered counselling after John died.

37. I do not believe that John was offered any counselling or psychological support. It would have definitely helped him if he was offered it.

Section 7. Financial Assistance

38. When John was 18, he was given a sum of £15,000 from the Macfarlane Trust and was asked to sign a waiver not to make any future claims. His friends borrowed this money from him and then disappeared.

39. We also received payments from the Skipton Fund to help with John's funeral costs.

40. In 2011, out of the blue, we received a letter stating that the Skipton Fund were giving £20,000 in payment to families where someone died of Hep C. We applied for this payment and received it. The process was straight forward.

Section 8. Other Issues

41. I want justice for what happened to John and want answers.

Anonymity, disclosure and redaction

42. I do not wish to remain anonymous.

43. I do not want to give oral evidence to the Inquiry.

Statement of Truth

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

Signed

GRO-C

Dated 12.6.2019