

Witness Name: S J Burkert
Statement No: WITN2884001
Exhibits: 0
Dated: February 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF STEPHEN JOHN BURKERT

I, Stephen John Burkert will say as follows:-

Section 1. Introduction

1. My name is Stephen Burkert. I give my sister's address for the purpose of this statement as [GRO-C] I was born on [GRO-C] 1965. I have been married to my wife Alison for 30 years and we have two children.
2. I make this statement in relation to my father Edward Burkert who was born on [GRO-C] 1937 and died on 15th April 1992. He was a haemophiliac and died from AIDS.
3. This witness statement has been prepared without the benefit of access to my father's full medical records.

Section 2. How Affected

4. My Dad was a moderate haemophiliac with a clotting factor of 2%. He had three brothers two of whom were also haemophiliacs. His parents had been divorced and they were unable to look after him. He had therefore been

raised and cared for by Dr Barnado's Children Home until he was 18 years old.

5. Dad married our mother in 1964 and they had 5 children together. Dad was a landscape gardener for the council parks; his haemophilia rarely kept him from working. Mum and Dad divorced in 1974 and Dad became the sole parent to all of us.
6. He received Factor VIII and prior to this Cryoprecipitate to treat his bleeds. He received all his treatment at Bradford Royal Infirmary. His haematologist at the time was Dr Parapiya and his nurse was Pauline Sharpe.
7. I feel that Dad was told that he was HIV positive in or around 1985. It was then that Dad's behaviour changed towards us. I believe that my Dad was infected through blood products received to treat his haemophilia. My sister is Eileen Anne Burkert and I have read the statement that she has given to the Inquiry. She has attached to her statement as Exhibits the treatment that my father received together with information from the Haemophilia database relating to the HIV infection and the confirmation that he died from AIDS.
8. I do not know whether my father had been told of any risk of the blood product he was receiving to treat his haemophilia.
9. My father was infected with HIV and Hepatitis C (HCV) but I do not know whether he was aware of the HCV as I understand that tests were not available for this until the end of 1991. I understand that most of his medical records have been destroyed as my sister has told me that she has been unable to locate them.

Section 3. Other Infections

10. I am not aware of other infections other than HIV and HCV. I think he would have been at risk of vCJD but I have no confirmation of this.

Section 4. Consent

11. My father did not discuss this with us and I am unable to say whether or not my father was tested and treated without his knowledge and without adequate or full information being given.

Section 5. Impact of the Infection

12. I feel that once Dad knew about his infection and looking back on his behaviour; he was angry and scared.

13. He suffered from severe weight loss and mood swings.

14. He became really thin and his skin had a tinge of yellow and I will say looking back that his HIV diagnosis sent him nuts on occasion.

15. When we were told about his infection at the time of his death it explained a lot of things to me. I finally understood his behaviour and it put things into perspective. I feel that Dad was tormented by the thought that he was going to die and leave his 5 children and grandchild behind.

16. He lacked physical energy as the infection progressed; he had been such an active man.

17. Dad carried on the best he could; he never told us about his illness or complained about himself. In fact he would play his haemophilia down and would always say there was nothing wrong with him and that he was fine.

18. Sometimes he would get angry and tearful when we were all together. I sensed there was something wrong but I had no idea of the enormity of it.

19. Looking back Dad seemed to deal with his infections by socialising more; he was on darts, dominoes and pool teams.

20. When Dad died it was a huge shock. Dad was a very fit man considering that he was a haemophiliac. He worked outside most of his life and was an avid cyclist in his younger days.
21. I was very angry when he died and I was completely floored when we were told of his infection with HIV and that he had died from AIDS. It was very hard to try and understand and even harder to talk about it. I did not want people to find out.
22. Having AIDS then was a big deal. I could only talk to my wife and close friends who knew and respected him. I was and I still am very angry that Dad only got to see my daughter for the first 18 months of her life and he has never been able to meet my son. My Dad died in April 1992 and my son was born in November 1992 which put a huge stress on my wife's pregnancy.
23. The stigma associated with HIV/AIDS in the 1980's and 1990's was horrendous. The very words were scary and not ones you shouted about. When Dad died I started to see my Uncle a bit more as he was infected with HIV too. I would ask him things but found it difficult as he knew he was going to die of AIDS too.
24. When my Dad died my Uncle just "zoned out" too and for weeks he would just go out into the garden and wouldn't talk to anyone. This was the second brother that he had lost to the disease.
25. This has completely destroyed our family. My siblings and I didn't really talk to each other and I felt that I had to be strong and take the roll as head of the family and that I should not show my emotions.
26. To make this more devastating my younger brother who was a twin took his own life 8 years after Dad's death. This, I understand from my sister, was due to the mental effect of having no one to talk to and no support network.
27. I have in total lost two Uncles, one Cousin, my Dad and my Brother. I am so angry; my life has never been the same. I am completely devastated; words are hard to find.

Section 6. Treatment/care/support

28. I do not know if Dad was ever offered any counselling or psychological support. I would hope so considering what he had to face. We were not offered anything as a family after his death; there was no support network.

29. We were told about his HIV when the nurses told us that he would never wake up and when we had to decide to turn the life support machine off. When he died we were given a bag with his belongings in and we were sent on our way and have not had one single word from anyone about his death which was on 15th April 1992.

30. I was 54 years old on GRO-C 2019 which is the same age as my Dad when he died. I have a heavy heart and I am finding it extremely difficult starting my days. This has got worse over the last 5 years.

31. I bought my Dad's house from the family when he died and the family then were able to pay back the DHSS the funeral costs. My family and I still live there.

32. I feel like I am living in limbo and feel there is nothing that I can do to stop how I feel. My wife has been my coping mechanism but that has taken its toll on family life over the past few years. It seems like she has only ever had to deal with death in my family and that has always been in tragic circumstances. I only seem to be able to open up when I have had a drink but on a daily basis I feel that I could explode.

33. Dad did not tell us about his infection so that he could protect us from the stigma. I feel that we were given his belongings when he died and were then left to our own devices and were completely forgotten. Dad was a single parent and should not have had to suffer this way through no fault of his own.

34. Dad was a fit and healthy man and I feel bitter that he was taken away from us so soon in such awful circumstances. We keep his memory alive through our children and although our son did not meet him we make sure that he is part of our conversations.

35. I am grateful to be able to give this statement and I feel that questions now need to be answered.

Section 7. Financial Assistance

36. I am unable to answer questions about what financial assistance if any Dad received after he was told he was HIV positive. Dad was a very private man and didn't talk about the situation.

37. When we did find out about the McFarlane Trust it was quite a shock as they did not offer us any money for the funeral. We had to go to the Social Security to ask for a loan in order that we could pay for the funeral.

38. In 2011 my younger sister started looking into what happened with the contaminated blood scandal through the internet. She discovered that Dad may also have been infected with Hepatitis C which was another blow to us all as none of us had ever heard of this. She discovered information about financial assistance from the Skipton Fund and applied. We got a payment of £20,000 and then a couple of years later she applied for the second stage payment. This was refused but she appealed and we were awarded a further payment of £50,000. These payments were not in the wider public domain and without my sister searching we would not have been aware of any such scheme.

Anonymity

39. I do not wish to remain anonymous. I understand that my statement will be published and disclosed as part of the Inquiry.

40. 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

~~STEPHEN BURKERT~~

Dated 29/4/19