

Witness Name: E A Burkert  
Statement No: WITN1125001  
Exhibits: WITN1125002-3  
Dated: February 2019

## INFECTED BLOOD INQUIRY

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### FIRST WRITTEN STATEMENT OF EILEEN ANNE BURKERT

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I, Eileen Anne Burkert will say as follows:-

#### Section 1. Introduction

1. My name is Eileen Anne Burkert. I live at GRO-C  
GRO-C West Yorkshire, GRO-C My date of birth is GRO-C 1968. I currently work as a support assistant in a special needs school.
2. I am preparing this statement in relation to my father Edward Burkert who was born on GRO-C 1937 and died on 15<sup>th</sup> April 1992. He was 54 years old and died as a result of receiving contaminated blood products.
3. **This witness statement has been prepared without the benefit of access to his full medical notes and records.**

#### Section 2. How Affected

4. My father had moderate Haemophilia A from birth with a clotting factor of 2%. He received all his treatment from the Haematology Department at the Bradford Royal Infirmary under Dr Parapia.

5. I attach as **Exhibit WITN1125002** the treatment schedule I have received from the haemophilia database which shows that he received Factor VIII BPL from 1977.
6. My father was a Landscape Gardener and the sole parent of 5 children. My four siblings are Stephen, Colin and Keith Burkert and Carol Prior; two sets of twins; one set older than me and one set younger. My mother left us in 1974 and GRO-D she did not help in our upbringing.
7. We lived in a Lodge in a park and Dad was the gardener responsible for the park. I remember when I was little that he had a permanent limp but when I was little I don't remember him going to hospital. He had bad legs and lots of pain in his hips which I now know was from the haemophilia.
8. When our mother left us we had to move into a council house as Dad had to give up his job to look after us all and the house that we were living in only came with the job. He did odd jobs gardening and decorating to earn enough money to get by and to look after all of us. He was well known in the neighbourhood.
9. When I was 12 I recall going to the hospital with my father and my sister to meet his haematologist and to be tested in order to see if any of us had haemophilia. My sister and I are both carriers. I remember that my father made it clear that it was important that we were aware of the risks of having children.
10. When I was about 13 or 14 I went with Dad to the hospital. They showed him how to inject Factor VIII when he had a bleed. I remember asking him why I was there as well and Dr Parapia said that if he had a fall then I would know what to do and how to inject him. He then started home treatment.
11. I think it was in about May 1984 when a nurse came to our house and removed all the Factor VIII which was stored in a small fridge in the dining room at home. They did not tell us why they were taking it all back. I remember that they appeared to be in a panic as they removed all the bottles.

12. After that, I cannot recall my father administering any treatment to himself at home; he always went to the hospital.

13. I know now that his first positive test for HIV was on 22<sup>nd</sup> August 1985 and I refer to **Exhibit WITN1125002** which shows this and also confirms that he died from AIDS. I have been unable to recover the majority of his medical notes and records. I believe they were destroyed. My father died on 15<sup>th</sup> April 1992 and I attach as **Exhibit WITN1125003** a copy of his death certificate. The cause of death by AIDS is not recorded on the death certificate.

### **Section 3. Other Infections**

14. I am not aware of any other infections but I believe that he was also infected with Hepatitis C (HCV) due to the way he looked when he died. He became very yellow.

### **Section 4. Consent**

15. It is my belief that my father underwent multiple tests but I cannot be sure that these were without his consent. I am unable to provide any information in this regard as I have been unable to recover the majority of his medical notes and records. He was a very private man and because we were so young he did not tell anything to do with his infection.

### **Section 5. Impact of the Infection**

16. My father was a relaxed and loving father before he was infected with HIV. Whilst he kept the knowledge of his infection to himself I now know why he began to distance himself from us. This was approximately in 1985 onwards.

17. His behaviour towards me and my brothers and sister changed. He started giving my sister and I colour coded towels for when we were having our periods and became very angry if any of us used his razors. If he had ever

cut himself in the past, he would allow me to help clean the wound and put a plaster on it, but suddenly he wouldn't let me even touch him if he was bleeding. He would not be close to us and cuddle us; he was less affectionate. I remember that once he had a skin tag which he had knocked and it was bleeding and I went to dab it but he didn't allow me to help him, he brushed me away.

18. He started spending a lot of time with his brothers. Two of his brothers were haemophiliacs and were also infected with HIV and HCV.

19. His first brother died in 1987/1988; he was about 36 years old when he died. Dad's other brother died in 1995 after my father. We also had a cousin who was a haemophiliac and was also infected with HIV and HCV who died in 1997/1998. We were told that the first brother had died from a stroke. My Aunt has told me that my Uncle would go for blood tests very regularly without being informed what the tests were for.

20. In January 1985 my father had started working as a bookbinder at Remploy in Halifax. This was a company which employed disabled people. He loved this job and the environment in which he worked but he had to let this job go. I do not know whether it was because of the stigma that had been attached to haemophiliacs and the link with HIV or whether he felt he was just too unwell to continue with it. He gave up his job in 1989.

21. My father seemed to age overnight and became a very old man. It breaks my heart that he carried the burden of his death sentence alone and did not tell us. He always wanted to protect us.

22. As I was not aware of my father having HIV and AIDs until two days prior to his death; I am not sure about the course of his illness. I feel that my father's death came very suddenly, and he was not in hospital often between 1985 and 1992.

23. I went straight to the hospital when I had been told that my father had been admitted in April 1992; he was in a coma. First of all I went to the

haematology unit as I thought that was where he would be but he was not there; he was in intensive care. My father's girlfriend had called an ambulance because he had collapsed at home. I noticed that he had a black eye. I was told by my father's girlfriend that a lamp had fallen on his head a couple of days previously. He was never a dramatic man and always tried to deal with things on his own.

24. Physically my father had become a shell of the man he once was; he looked as though he would fall apart at the touch of finger. He had suddenly become very frail and old; he had nothing to him, just skin and bones.

25. I remember certain things from when he was in hospital and just before he died. I find it strange that we were not asked to put on gloves or a mask when touching him; he was treated as if he wasn't infected. I do recall him having blood on his face and no precautions were taken.

26. We were called into a room by some of the nurses at the hospital and we were told that Dad had had a bleed to his brain and that he was infected with HIV and also had AIDS. We were told that he would not wake up. There was no compassion, no counselling. I know that my father had told his brothers about the HIV but they had not told us and it was a complete shock.

27. As our brother Colin was working in London and was not with us we did not feel it was fair to turn the life support machine off without Colin.

28. Colin came to the hospital and my father's life support machine was switched off the next day; 15<sup>th</sup> April 1992.

29. We were told to say our goodbyes then as we were told that we would not be able to see him again once he had left the hospital. Once the life support had been turned off it had to be the last time we see him.

30. We struggled to find a mortuary to take his body due to him dying from AIDS. A nurse had told me that he would have to have a closed casket and that he

would have to be cremated. I did not want him to be cremated as I wanted a burial. I wanted to be able to go to his grave and to talk to him.

31. I was only 23 when my father died. Before his death I was aware of AIDS having watched stories about it on EastEnders and the horrible adverts on the television with the gravestones; it was made out to be a disgusting illness.

32. When I was called to the hospital two days before my father's death, I was told my father had AIDS. I was in pure shock. At the time, it didn't really register, and I was more worried about the fact my father was dying.

33. However the stigma surrounding AIDS was huge, and it was something that hit my family hard. It was handled very badly. I was told in a matter of fact way, with no support or kind words from any members of his care team.

34. After my father died; it was not spoken about within my family and it became a taboo subject. None of his friends had any idea that he had AIDS and the stigma surrounding it caused us to tell everyone that he had died of a cerebral haemorrhage.

35. The funeral was packed with people. It just showed how well loved he was but I felt as though I was lying to everyone about what had happened to him. After his death I had no choice but to get on with my life but it was hard and there were repercussions. I have never married my long term partner as I do not want to lose my father's name; it is the last piece of him I hold on to. I also did not want anyone else to walk me down the aisle; there is no replacement for my father.

36. In 2000 my brother Keith took his own life. The death of my father had hit him harder than any of us; he was only 19 at the time. He still lived with our father, so not only did he lose his father but he lost his home too. When life became too much to handle in 1995, Keith started relying on alcohol and spent the next 5 years in and out of rehab, eventually losing his job. No matter how much help his family tried to give him, he pushed us all away. When he was no longer able to cope he hanged himself.

37. I was never allowed access to my brother's medical records, but I did speak to one of his caseworkers at the time who told me that he had severe mental problems stemming from my father's death and illness. Keith had become a very paranoid, scared man who was convinced that he had caught HIV and AIDS from my father.
38. It still feels like a bad dream and both the loss of Dad and Keith has left a massive hole in our lives.
39. In 2010 I started researching the Contaminated Blood Scandal. I could not quite come to terms with what they had put my father through. He has missed so many opportunities and life events; he was robbed of the chance of meeting his grandchildren.
40. Prior to this time, I had no idea that there was a campaign going on, or any form of litigation.
41. I received counselling myself in 2011 when things became too much to cope with. However, I felt that the therapist was unqualified to help with my issues, and I feel a specialised counsellor should have been made available to us after my father's death.
42. One day I stumbled across the Tainted Blood website, and I can honestly say that they have given me the only support through the whole of this traumatic experience. In 2017 I joined Facebook in order to join the Facebook groups and have had further support from this.
43. I have mentioned above that the death certificate does not mention AIDS from which he died. I feel as though there was some sort of cover up going on.
44. I became obsessed with finding more out about his death. I now know that a cerebral haemorrhage is one of the major causes of death in those haemophiliacs that are infected with HCV.

45. The obsession nearly caused the ruin of my long term relationship. We split up when Keith died but we have since got back together. We have two boys. Jake was born on [GRO-C] 1998 and [GRO-C] was born on [GRO-C] 2004. My eldest son is very supportive of the work I have been doing for the campaign.

46. I feel very strongly that the hospital killed my father and that the impact of losing our brother too as a result was a double blow. My father looked after all of us but they just didn't look after him.

#### **Section 6. Treatment/care/support**

47. I remember that my father had to have all his teeth taken out due to bleeding gums and I remember visiting him in hospital and he had clamps on his jaw; but he never told me why. After his teeth were removed, he was fitted with false teeth supplied by the hospital. I am not aware of any other medical or dental issues. However without access to his medical records I cannot be certain.

#### **Section 7. Financial Assistance**

48. I feel like there was a total lack of support in terms of financial assistance. My father was not a wealthy man and had five children to support. He was in receipt of benefits throughout my childhood.

49. My Aunt told me that my father had received an ex-gratia payment of £20,000 in 1989 and I think that he used that to buy our house from the council and renovate it. I believe this payment was from the MacFarlane Trust. However, when we left the hospital on the day of his death we have not been contacted by anyone with regard to his death.

50. As my father had no will, and died in testate I phoned the Macfarlane Trust in 2018 enquiring whether they had paid for my Father's funeral. I received a



letter in response, stating that they needed permission from the Executor of the Will to communicate with me, but there was no Will. As a result, the Trust has refused to give me any of my fathers records. We ended up having to pay for the funeral through social security, which was a loan secured against the family home. It was eventually paid off when my brother Stephen bought the house.

51. I found out about the Skipton Fund from the haemophilia website and I rang them to get an application for a Stage 1 payment which I then sent to the hospital. I waited months and months for Dr GRO-D to complete the relevant forms, eventually securing the payment.

52. In approximately 2013 I was reading through the HQ magazine which I received from the haemophilia society and there was a headline "Contaminated Blood Stage 2 payment made without medical records". We had no proof that Dad had died with HCV, although it was clear at the time of his death that he was infected. It was evidenced that my father had cirrhosis of the liver. I rang the magazine and they put me in touch with the guy who was the feature of the article. I researched coinfection of HIV and HCV and the effects it had. I made an application for Stage 2 payment but a letter came back declining this as they had said that I had not proved my father had had cirrhosis of the liver. I appealed the decision and worked hard on preparing a booklet all about my father's condition. The appeal date was in January 2014 and I was paid £50,000 on the balance of probability that he did have the infection, on 6<sup>th</sup> February 2014.

53. I believe my father also received a payment of £23,500 from the HIV litigation in 1991. This was the amount a single infected man received. I am appalled by this as he had been infected in 1985 and at that time he had five children to support. The reason he was only paid a single man's allowance was because by that time his children were all over the age of 18. My Aunt has told me that my father was pressured into signing a waiver for the payment. This has also destroyed me as I wondered why my father's life was worth less than someone else's.

54. My father had received the same amount as his nephew who was living with his mum and dad. For me, it is not about the money itself, it is about receiving answers and respect for my father.

### **Section 8. Other Issues**

55. There was absolutely no support offered to me; not after my father's death or my brothers. It is my belief that had Keith been given the support he needed he would still be alive today. I feel like the NHS completely failed my family. What happened to my father and brother caused me to have a breakdown and almost wrecked my relationship with my partner. The only support I have received I have found myself through Facebook groups and Tainted Blood.

### **Anonymity**

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

57. I do wish 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

EILEEN ANNE BURKERT

Dated... 27th FEBRUARY 2019 .