

Witness Name: Carol Lesley Prior

Statement No: WITN2932001

Dated: April 2019

## INFECTED BLOOD INQUIRY

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### FIRST WRITTEN STATEMENT OF CAROL LESLEY PRIOR

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I, Carol Lesley Prior will say as follows:-

#### Section 1. Introduction

1. My name is Carol Lesley Prior. I live at 30 GRO-C  
GRO-C My date of birth is GRO-C 1965. I currently work as a catering manager at Cross Lane Primary School. I live with my partner and my daughter.
2. I am writing this statement with regard 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

1. 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.

2. I refer to the statement of my sister, Eileen Anne Burkert, who has exhibited to that the treatment schedule of Factor VIII that Dad received during his life. He received Factor VIII BPL from 1977.
3. My father was a Landscape Gardener and the sole parent of 5 children. My four siblings are Stephen, Eileen, Colin and Keith Burkert. My mother left us in 1974 and GRO-D she did not help in our upbringing.
4. We lived in a Lodge in a park and Dad was the gardener responsible for the park. He had bad legs and lots of pain in his hips which I now know was from the haemophilia.
5. 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.
6. When I was about 15 I recall going to the hospital with my father and my siblings 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; my brothers were not haemophiliacs. I remember that my father made it clear that it was important that we were aware of the risks of having children.
7. My Dad was able to administer his own Factor VIII and kept his medication at home. 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.
8. After that Dad didn't administer any treatment to himself at home; he always went to the hospital.
9. My sister Eileen applied for his medical notes and records after his death and we now know that his first positive test for HIV was on 22<sup>nd</sup> August 1985. She was unable to obtain his full notes and records but received some sheets of

medical records from the Haemophilia Society which gave us this date and confirmed that Dad died from AIDS. My father died on 15<sup>th</sup> April 1992. However, the cause of death on his death certificate is not recorded as being from AIDS but that he died from a cerebral haemorrhage and haemophilia.

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

10. 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 so yellow.

### **Section 4. Consent**

11. 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 we 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 us much about his condition. I was the eldest sister but he did not confide in me; he wanted to protect us.

12. I feel very strongly that knowing what I know now I feel that my father may have been tested on without his informed consent and that he was simply viewed as some sort of guinea pig to the NHS. Of course I cannot be sure of this but this is my view; I have no medical evidence to support this.

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

13. I was 27 when my father died. I had watched his health deteriorate over the years. His personality seemed to change and he became an angry man. He became gaunt and frail. He had a yellowish tinge to his skin and eyes.

14. It was just before he died that I found out he had AIDS. We had been called to the hospital as Dad had collapsed at home and had been taken by

ambulance to Bradford Royal Infirmary. We thought he was in the Haematology Unit but he wasn't, he had been taken in to the Intensive Care Unit.

15. We were told that Dad had had a bleed to the brain and that he was also infected with HIV and had AIDS. We were told that he would never wake up; there was no compassion, no counselling. This was such a shock to all of us.

16. My sister Eileen, who was the closest to Dad, wanted to have him buried so we could all have a place to visit and celebrate his life. We were told in a very matter of fact manner that he had to be cremated because of his infection.

17. I feel now as if they were trying to hide the evidence; they were so very adamant that he must be cremated. We were not allowed to see my father's body again after the life support was turned off. I recall distinctly being told at the hospital to say my goodbyes now to Dad because he would have to be placed in a sealed coffin.

18. After the life support was turned off and our goodbyes had been said, my siblings and I were handed a bag of my father's belongings with his watch, glasses and walking stick and sent on our way. It was handled in a very cold manner. We had no support considering we had been told such a devastating thing that our father had died from AIDS.

19. We had to wait two weeks for the funeral. We had to fight to get a burial; I remember it being quite a hard but we managed to do this.

20. I remember at the funeral no one was allowed to touch the sealed coffin. It was wheeled in. My brothers and family were not allowed to carry him in. It showed no respect for my father. We had not even been given the chance to dress our father; the funeral home did not even ask us for clothes.

21. We were told that there would be no post mortem although for all we know there could have been but one that we did not consent to. I feel strongly that we had not been told things that were happening that possibly were.
22. I cannot describe my feelings but I know in my heart that my father was never laid to rest in his coffin; I do not believe he was in there and that is the reason my family were unable to carry him in to the church. It is for that reason I cannot visit his grave. I also think about how it must have looked to everyone in the church that my brothers were unable to carry their father in.
23. After my fathers passing we all seemed to close ranks. We did not talk about how he died; we could not understand.
24. Since my father's death I have suffered from depression. My younger brother Keith who was twin to Colin did not seem to cope with Dad's death and struggled over the next few years. He committed suicide in the year 2000.
25. After this I found it very difficult to go on, I am an emotional person and Keith's death completely floored me.
26. I was prescribed antidepressants and to this day I am still on medication. I feel they are something that I will not be able to withdraw from. I struggle everyday with my loss.
27. After Dad died I got married. However, because of the emotional issues I was carrying my marriage only lasted 18 months and I know that it ended because of how I had changed as a person.
28. I started a new relationship in 1995 with my daughter's father, Graham Root. My lovely daughter, Ellie was born in GRO-C 1998. When my brother took his own life in 2000 I broke down causing this relationship to break down and Graham and I split up.

29. I pushed everyone away; the only thing that kept me going was my baby daughter. I simply didn't want anyone else and became extremely overprotective of Ellie. I think that I felt that Ellie was all I had left and I could not bear to lose one more person. I wrapped her in cotton wool, trying to protect her from the harsh realities of the world.
30. It is only recently that I have made any sort of commitment to anyone other than my daughter. I have been in my current relationship for 5 years and have only just allowed him to move in. I have really opened up to him and he has become my rock.
31. After my father had died I was terrified at the possibility of having children. I think it had a big impact on why my marriage ended; not wanting to pass on the haemophilic gene. My father felt he was to blame and carried this burden.
32. I have had counselling and I have seen psychologists. They believe I am still suffering from PTSD from the trauma of losing both my father and my brother. My partner is a very positive influence on my life and often helps bring me out of my depression. More recently I have also been struggling with anxiety and everyday feels like an uphill battle. I am just grateful that my employers are so supportive during this emotional time.
33. To this day it still upsets me to know that my father never wanted to tell us about his illness and I often wonder whether it was through the fear of us potentially rejecting or blaming him. The stigma surrounding HIV and AIDs meant my father went through his illness all alone. I honestly believe if I was in that position I would have ended my own life. Right until the very end my father was still trying to protect his children and it breaks my heart that he carried such a burden for so long.

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

34. I am not aware of the treatment or support, if any, that Dad received.

35. There was no counselling or psychological support made available to us after his death. We were not contacted by anyone. I had to seek help myself. To this day I still struggle. I feel my family would not be so broken if there had been some form of specialist grief counselling available to us at the time of my father's death.

36. I had blood tests whilst I was pregnant with Ellie but I was not told why. I have assumed that this was routine. Some of my medical notes were found in Eileens' records which I find odd.

## **Section 7. Financial Assistance**

37. My sister Eileen has covered this in her statement. Application for finance was not easy and it took a great deal of work and effort by my sister to secure the Stage 1 and Stage 2 payments from the Skipton Fund. For me it is not about the money but about how Dad was treated.

## **Section 8. Other Issues**

38. It haunts me to this day that Dad carried such a burden in our home all alone. It truly breaks my heart that my poor father was given a death sentence after he had dealt with so much already in his life. He put his trust in the government to help treat his illness and prolong his life and to me they did the complete opposite.

39. In my eyes it was quite simply premeditated murder.

## **Anonymity**

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

41. I do want to give oral evidence to the Inquiry.

**Statement of Truth**

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

Signed.....  
CAROL LESLEY PRIOR

Dated.....2/4/19.....