Witness Name: Carole Butt Statement No.: WITN2057001 Exhibits: 0 Dated: 19 September 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF CAROLE BUTT

Section 1. Introduction

- 1. I, Carole Butt, will say as follows.
- 2. My date of birth is **GRO-C** 1943. My address is known to the Inquiry.
- 3. I live with my husband in Northamptonshire. We have two grown up children. I work part-time in radiology.

Section 2. How Affected

4. My father, Arthur Kirton, was born on **GRO-C** 1913 and passed away on 8 March 1980, aged 67. I do not know for certain, but I believe my father was infected with HIV from contaminated blood and that this may have led to his death. I want to provide this witness statement to the Inquiry because I want to describe what happened to my father and set out my fears that his illness and death may have been caused by

contaminated blood. I believe there may be others who, like my father, were infected and who died without ever knowing why they were ill. I would like the Inquiry to bear these accounts in mind when considering the very great impact infected blood has had.

- 5. My father had mild angina which was well controlled with GTN (glyceryl trinitrate) spray. He had no other medication that I can recall.
- 6. My father had recently retired, having worked all his life as a motor mechanic. One day, in 1979, he was mowing the lawn and had quite a bad chest and abdominal pain. He saw his GP who referred him to the hospital. He saw the head of the Haematology Department, Dr Robin Sheppard, at Northampton General Hospital.
- 7. At that time I was working at the same hospital as a phlebotomist and Dr Sheppard was my senior manager. I was in direct contact with Dr Sheppard as part of my day to day work and I recall him saying to me that he had seen my father at the hospital and that he had borderline leukaemia. I remember being shocked by this news as my father had no symptoms that I knew about. Dr Sheppard said the hospital would be giving my father a blood transfusion and that he would be better than new.
- My father had the blood transfusion in late August or early September 1979. I remember going to see him shortly afterwards on the oncology ward, the Talbot Butler Ward, with my husband and two sons. My father was later discharged home.
- 9. After that, each time my father was unwell, I would ring Dr Sheppard and he would tell me to bring him in so he could see him. As a result, we never went through the GP. I recall there was a second blood transfusion in around December 1979.

- 10. My father had still not picked up after several months and was more unwell than when he had first been admitted. This would have been in around early 1980. I informed Dr Sheppard who suggested he would give my father some more blood. My father had a third blood transfusion.
- 11. My father was again discharged home. I visited him every day. Around February 1980, about a month before he died, I went to visit him after work. He was in bed at home and, as I was talking to him, he opened his mouth and I noticed his mouth was full of blue ulcers. I had never seen blue ulcers before and I did not know what they were. I now believe they may have been Kaposi's sarcoma, a virus mostly seen in people with advanced HIV.
- 12. He became so unwell after this point that he went back into hospital. He may have been discharged home once more but, if so, it was only for a few days before he was readmitted to hospital because he was so poorly. There was no explanation as to why he was deteriorating. I did not know what was happening and I didn't ask for more information. It was a time when you just accepted what you were told and didn't ask questions.
- 13. On the day my father died I was working at the hospital. Dr Sheppard said to me he was pretty bad and his kidneys were failing. He said the only thing they could do would be to put him on dialysis. We didn't want to put him through dialysis as we knew it would be painful for him. For that last week he had been getting progressively worse and was bedbound.
- 14. I went home at lunch time and came back to the hospital at tea time. The sister on the ward said to me that they had nearly thought to call me in at 6pm. I knew what this meant: my father was dying. I sat by his bedside with the rest of the family. They didn't know what I knew from the staff. I couldn't tell my family what the nurse had told me because I would not have been able to control the emotion and would have cried. I couldn't let my father see me like that. We all left after visiting time. When we got

home we had the call from the hospital to say he had passed away. I knew we should have stayed, but we didn't, because I simply couldn't speak.

- 15. Dr Sheppard asked me whether they could perform a post mortem. I said it was not my decision and asked my mother and my sister. My mother did not want a post mortem and I told Dr Sheppard. I do not know whether one was done anyway. The death certificate records septicaemia and leukaemia.
- 16. We had the funeral and I went back to work. Some time later, perhaps two or three weeks, Dr Sheppard said to me that he wanted me to have a blood test. He said it was, 'to rule out that you don't have what your father had'. I thought nothing of it and agreed to it because during each of my father's hospital admissions I had always been the one to take his blood. I thought perhaps Dr Sheppard wanted to test my blood for leukaemia to make sure I was ok. I had my bloods done and he said they were absolutely fine.
- 17. I never saw the results myself. The tests did not go through my GP practice but through occupational health at the hospital. I am now back working at the same hospital but they say they have no records of me working there in the 1970s and 1980s. When the bloods were sent for testing the hospital would have had to put on the request what to test for, otherwise the lab would not have known what they were testing for.
- 18. As far as I am aware no information or advice was given to my father beforehand about the risk of being exposed to infection through a blood transfusion. Nothing was said to me at the time.
- I do not believe my father died as a result of borderline leukaemia and blood transfusions. I believe he was infected with HIV as a result of receiving contaminated blood. I believe he may have died from AIDS. I

think the blue ulcers in his mouth were Karposi's sarcoma is a strong indicator of HIV.

- 20. As far as I am aware, my father was never told of any infection from contaminated blood, and neither was his family. I do not know whether the hospital knew of any infection. He was not barrier nursed (i.e. placed in a side room with all staff being asked to wear gloves, masks and aprons). I believe there is a possibility the hospital might have known something about his illness which they were not communicating to us and therefore there is a chance that information was withheld from my father. However, I do believe Dr Sheppard thought he was acting in my father's best interests.
- 21. Although I have tried to obtain copies of his medical records from Northampton General Hospital they have told me that they have no record of him and that their systems have been renewed since he attended there. Their policy is to destroy records eight years from the date of death of an adult patient.
- 22. I have also tried to obtain copies of my father's GP records but have been informed by NHS England that the original records were destroyed some time ago, in accordance with their document retention guidelines.

Section 3. Other Infections

23. I do not know whether my father was infected with anything other than suspected HIV.

Section 4. Consent

24. I do not know whether my father was treated or tested without his knowledge, consent or for the purposes of research.

Section 5. Impact

- 25. For the reasons I have set out above, so far as I am aware, my father would not have been aware he was infected with HIV, so I cannot comment on the mental and physical effects of such an infection on him, aside from his physical deterioration from the time of the first blood transfusion in August 1979 to March 1980 when he died. During the months that lead up to his death he became very poorly and couldn't do anything for himself. He became yellow. He deteriorated every single day.
- 26. Our family has been devastated by the loss of my father. I feel very sad for him: he worked hard all his life and looked after his family. During his illness we knew we were going to lose him and we knew we could do nothing to stop it. I don't think you can get over the loss of a close family member. I grieved for many years.
- 27. I heard about the contaminated blood campaign, but it was several years before I realised this is something that could have happened to my father.
 I didn't tell a soul for many years because of the stigma associated with AIDS. It didn't matter how my father might have acquired HIV and AIDS, the stigma was still there.
- 28. I didn't mention anything for many years. When my mother died in 1996 I eventually told my sister what I suspected. Once I had said it out loud to her I felt the weight of the stigma lift a little. More and more information about the disease became available and the more I thought about it the more I believe that that is what happened to my father. At the same time my father was unwell there was a lady in our village who was also diagnosed with leukaemia and had several blood transfusions. She died around the same time. People were routinely transfused at that time and I wonder how many people this must have happened to.

Section 6. Treatment/Care/Support

29. Neither my father nor any of our family was ever offered counselling or psychological support as a result of his death.

Section 7. Financial Assistance

30. This section is not relevant to my witness statement as neither my father nor any of our family were aware, at the time of his death or for quite some years afterwards, that he may have been a victim of contaminated blood.

Section 8. Other Issues

- 31. I hope the Inquiry addresses the attitude of subsequent governments to the crisis and their failure to recognise the devastating effect contaminated blood has had on the lives of everyone infected and affected.
- 32. I hope the Inquiry will ensure that the mistakes made are admitted, learnt from, and never happen again.

Statement of Truth

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

Signed	GRO-C	