Witnesses Name: Alan Percy Fowle
Statement No: WITN 1805001
Exhibits: 0
Dated: April 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF ALAN PERCY FOWLE

I, Alan Percy Fowle, will says as follows:

Section 1: Introduction

1. My name is Alan Percy Fowle. My date of birth is GRO-C 1942. I am married and live with my wife Christine Fowle at GRO-C GRO-C We have one 45 year old daughter who is married and lives with her husband and 2 children at her own home.

2. This statement is prepared as the father of Christopher Fowle who was infected with HIV from contaminated blood. My wife's name is Christine Fowle and she has prepared her own statement under WITN1649001.

3. Christopher was born on GRO-C 1974 and died of AIDS on GRO-C 1996. He was aged 21 and single at the date of death. At the time, we lived as a family in Harrogate in Yorkshire.

4. I make this statement without the benefit of access to my son's medical records.

Section 2. How affected

5. Christopher was a 1 year old when he was diagnosed with severe Haemophilia A. Up to the age of 2, my wife and I took him to St. James's Hospital in Leeds for treatment and from the age of 2, we started to take him locally to Harrogate General Hospital. As a child, he had minimal bleeds. I do know that in his pre-school days he was treated intravenously with Cryoprecipitate. I remember Christopher being under the care of Dr McAvoy, the main consultant in the Haematology Department in Harrogate.

Factor VIII (FVIII)

6. When he started school, Christopher was getting bleeds more often because of knocks he was getting from running around on the concrete playground. My wife and I shared the responsibility of taking him to hospital on average 2 or 3 times a week which placed a huge strain on us. After 6 months, we withdrew Christopher from this state run school and moved him to a private school which was better supervised and had safer play areas.

7. Christopher was treated with FVIII products shortly after he started school. Before then, he treated with Cryoprecipitate which was painful due to the volume necessary. I was pleased when the doctors informed me that it was being replaced with a new product called Factor VIII. I was led to believe these products were less painful to administer and patients were able to treat themselves with it. Of course, Christopher was too young so my wife and I had to be trained to do so. I was happy with this arrangement because it meant we no longer had to wait at hospital for him to receive painful injections.

8. The doctors showed my wife and I how to mix the desiccated block of FVIII in high quality water in small bottles. We were told these bottles had to be kept below a certain temperature.

9. Unfortunately, my wife and I did not have the confidence to treat our son so we decided that it was in his best interest to be taught how to self-administer.

It was for this reason, we arranged for him to go to a residential (Welburn) school in North Yorkshire where treatment and training were available. Even though he hated the school due to the fact that the pupils were mostly physically disabled with him being the only hemophiliac, we promised to move him to the normal school when he was confident of being able to treat himself.

10. The doctors told us it was safe for us to take the FVIII products with us abroad on family holidays. Apart from holidays, the fact that Christopher was now able to treat himself at home was much welcome because the flexibility meant that we could focus on running our small family business of about 25 workers.

11. The doctors never said anything negative about the FVIII products and it did not cross my mind to question their professional judgment. I did not think that the doctors would ever treat anyone with products that were unsafe.

12. My wife and I had difficulty injecting Christopher with the products because we were afraid of making a mistake. On a couple of occasions when we were away from home we took him to the local hospital with the bottles containing the FVIII products that we had mixed but the local doctors refused to carry out the injections. From these experiences, we decided that we could not rely on other hospitals and that we had to become proficient in treating our son ourselves, hence the reason for sending him to a special school to learn to inject himself.

13. I still had to take Christopher to our local hospital when he had severe bleeds. After about 3 years of treatment, Dr. McAvoy called my wife and I to see him at the hospital. He informed us that Christopher was *HIV positive.* We were told Christopher could expect to live for another 12 years. Needless to say, we were devastated because our son was an innocent 9 year old. His life was going to be cut short because he had been treated with blood products that were not safe. We were told that the doctors were able to trace the contaminated blood to a NR donor who was HIV positive.

14. Having been told of this, I wanted to ensure Christopher enjoyed the remaining years of his life. It was a very painful time for the family. I wanted to ensure that I did all that I could to make him happy and to be strong for him. When he was 10 years old, my wife and I decided to buy him a remote control racing car and this gave him a passion. By the age of 12 he had become a young master at controlling it. We decided to put his name forward for competitions and in one year, my wife and I took Christopher abroad to compete with competitors from other countries. In this competition, he was the runner up for UK and that made me very proud. At the time, my wife and I had decided against telling Christopher about his diagnosis.

15. In the meantime, the doctors continued to provide us with FVIII products to enable us to treat his bleeds. By now, the hospital was heat-treating the products to eliminate any harmful bi-products and I was re-assured that these were now safe to use. If they had done so from the beginning, Christopher would not have been infected and he would still be with us today.

16. I believe the NHS did not heat treat the FVIII products because it was more expensive to do so. I also believe that the NHS failed to take reasonable steps to ensure that the blood being used to treat patients was safe.

17. After Christopher was infected with HIV we did not hear from the hospital again. The doctors never gave us any information or advice about how to manage his condition or about the risk of infecting others.

18. We broke the news of the infection to our son when he was 15 years old. Until then, only the immediate family knew. We knew Christopher was at age when he wanted to start relationships and we wanted to ensure he was fully aware. It was very painful for us to tell him that his life had been cut short and he could not have proper relationships.

19. When we told him, I do not know whether or not Christopher fully understood the implications. He had not even started to live his life and he was being told that he did not have long to live. I cannot begin to imagine what was going

through his mind when we built up enough courage to tell him. It was a very traumatic and very emotional time for all of us. No parent should have to witness their own child die. However, this is what we had to deal with through no fault of our own.

Section 3. Other infections

20. In addition to HIV, Christopher was also infected with Hepatitis C.

Section 4. Consent

21. I consented to Christopher being treated by the hospital. I placed utmost faith in the hospital to treat him using safe products. I would not have consented to him being treated by any product that would have put his life in danger.

22. Christopher was tested for HIV without consent. He was given tablets to treat him for the HIV infection with my consent.

23. I do not know whether Christopher was being tested for research purposes. If he was being tested for this, we would not have consented to it.

Section 5. Impact

Impact on my son

24. I did not see any physical change in Christopher in the initial stages. It was only after the effects of AIDS had taken hold that I noticed his body deteriorate. I do not know what was going through Christopher's mind when my wife and I sat down with him to break the news. I am not sure that he knew at that time what was going to happen. He was very young and I think he must have been confused and very angry.

25. After a couple of months, we noticed Christopher started to care less and less about what was happening around him. He only gradually began to understand he was not going to live a normal life and that it was going to end sometime soon. He was not mean to anyone, but we did notice his mood had

changed. He seemed to think that everything around him was short-term as he became more engulfed in his thoughts. I think he was struggling to come to terms with the fact that his life was being cut short.

26. Christopher once told me that he felt different when comparing himself with others. I know that he would have liked the possibility of going to university and one day get married and have children of his own but he realized that was never going to happen.

27. Instead of fulfilling his ambitions, Christopher left school at 15. Suddenly, an education meant little to him. His whole life plan was destroyed. It was heartbreaking for us to see him feeling lonely and sad. For this reason, we did our best to ensure that his remaining years were fulfilling. At the time we owned a small manufacturing company that made shower cubicles. He agreed to get involved in the business and did work for us on a part-time basis when he was well enough. We tried to keep him occupied and keep his thoughts away from HIV and AIDS.

28. Christopher's appetite diminished in the last couple of years of his life. As a result, he lost a considerable amount of weight and this is when he began showing signs of full blown AIDS. He started making frequent visits to hospital because of ulcers and, at one stage, district nurses started to visit him at home to treat him. I remember one district nurse said to me that Christopher had told her *"I have the most brilliant parents."* It was reassuring for me to know that my son accepted that we had done all that we could have done in a very difficult period in our lives.

29. My wife sometimes had heart to heart conversations with him. At first, he would be fine talking and then, all of a sudden, he would break down and cry uncontrollably. During the day, when he was around other people, he would be okay and managed to disguise his inner thoughts. As a family, we used to sit together and watch television and we would pretend everything was normal, but at times our son would suddenly get emotional and start crying.

Impact on me and my wife

30. As Christopher's health began to deteriorate in the last 2 years of his life, I gradually found it more and more difficult to cope. Towards, the final weeks when Christopher had lost much of his mobility, my wife and I had to deal with helping him up and down the stairs because we did not have a downstairs bathroom. For this reason, Christopher was moved into a hospice. After spending 2 weeks there, he passed away.

31. Christopher should never have lost his life. He was my only son. I have been denied the opportunity to see him get married, have children, travel and most of all sharing my life with him as I got older. I do not think time will heal my pain because I forever think about what might have been.

32. My wife worked part time for the NHS when Christopher was about 14 years old but then left to join the family business. As our son's health began to deteriorate in the last 2 years of his life, my wife had to give up my work and started to spend more time with him. It was painful for us to witness Christopher's health deteriorate and even though we knew what would happen, it was heartbreaking for us to finally let go.

Impact on friends and family

33. At 15, my wife and I decided to leave it to Christopher to choose the right time for him to tell others about his condition. I know he told a few female friends and they were incredibly supportive and were discreet. I do not know whether or not he told any other of his friends.

34. Christopher was very close to his sister. She has been left with no other sibling in her life and our family will never be the same.

Stigma of HIV

35. Not many other people knew about Christopher's condition. We kept it to ourselves mainly because of the way the media portrayed AIDS. We did not

want to try to explain to others how my son was infected with HIV at the time when we were trying to manage our own feelings.

Section 6. Treatment/care/support

36. So far as I am aware, he did not encounter any difficulties obtaining treatment for the HIV.

37. I do not know when Christopher was diagnosed with Hepatitis C. I do know that drugs were available to treat this virus but we were not told about it nor were we offered anything. The hospital should have advised me because of the risk of passing the infection to others.

38. My wife and I were offered counselling from the hospice but we never went.

Section 7. Financial assistance

39. At the age of 15 Christopher received a payment of £20,000 through the MacFarlane Trust. We were given information about this fund by the Haemophilia Society. Once the forms were completed, we received the payment without undue delay. We had to sign a waiver that stated that we could not make further claims and that if it was not signed, we would not receive payment.

40. At the age of 20 or 21 a further payment of £25,000 was awarded. This also came through the MacFarlane Trust.

41. In or about 2011, we received a letter from the Skipton Fund. It stated that any family member who was affected by Hepatitis C was entitled to a payment. We submitted the application form and we received £20,000.

Other Issues

42. When Christopher was 10 years old, my wife and I attended a seminar in Bradford ran by the Hemophilia Society. We spoke to a doctor who had found a way to separate white bloods from red blood cells by using a machine. These machines were under £100,000 and we consider the NHS via Government funding should have given financial support for this project. We feel that the Government's attitude to this project was generally negative.

43. Our feelings are that if this system had been adopted many deaths could have been avoided, including that of our son. More research could and should have been done.

Anonymity, disclosure and redaction

44. I confirm that I do not wish to have anonymity and I understand this statement will be published as part of the Inquiry.

45. I do wish to be called to give oral evidence.

Statement of Truth

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

Signed ...... GRO-C ....

Mr. Alan Percy Fowle

Dated this 26 ~~February~~ April 2019