

Witnesses Name: Christine Fowle

Statement No: WITN 1649001

Exhibits: 0

Dated: April 2019

## INFECTED BLOOD INQUIRY

---

### FIRST WRITTEN STATEMENT OF CHRISTINE FOWLE

---

I, Christine Fowle, will says as follows:

#### **Section 1: Introduction**

1. My name is Christine Fowle. My date of birth is GRO-C 1944. I am married and live with my husband 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 mother of Christopher Fowle who was infected with HIV from contaminated blood. My husband's name is Alan Fowle and he has prepared his own statement for our son under WITN 1805001.
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 our 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 husband 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.

6. When he started school, Christopher's bleeds became more often because of knocks he was getting from running around in the concrete playground. My husband 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 him from this state run school and moved him to a private school which was better supervised and had safer play areas.
7. Christopher was not comfortable being treated with Cryoprecipitate because this caused him pain. I was pleased when doctors informed me that Cryoprecipitate was being replaced with a new product called Factor VIII (FVIII). I was led to believe these products were less painful and that patients would be able to treat themselves with it. Of course, Christopher was too young at that time to treat himself and either my husband or I had to be trained how to treat him. I was happy with this arrangement because it meant that I no longer had to wait at hospital for Christopher to receive painful injections.
8. The doctors told us that it was safe for us to take the FVIII products on family holidays. Apart from holidays, being able to treat Christopher at home was very welcome because the flexibility meant that we could focus on running our small family business of about 25 workers.
9. The doctors never said anything negative about the FVIII products and it did not cross my mind to question the hospital's professional judgment as to whether or not the products were safe to use. I did not think doctors would use products on Christopher that were unsafe.

10. Christopher was treated with FVIII products shortly after he started school. The doctors showed my husband and I how to mix the powder in high quality water and put the mixture in small bottles. We were told these bottles had to be kept below a certain temperature before the treatment could be used.
11. Initially, my husband 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 a 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 we could not rely on other hospitals and that we had to become proficient in treating him ourselves.
12. Having learnt the process, I found that it saved me a lot of time but I still took Christopher to our local hospital when he had severe bleeds. After about 3 years of treatment, Dr. McAvoy called my husband and I to see him at the hospital. He informed us that Christopher was “*..infected with something..*” but was not able to tell us more. It was only sometime afterwards that the hospital confirmed that the infection was HIV and that Christopher could expect to live for another 12 years. Needless to say, my husband and I 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. The doctors were able to trace the contaminated blood to a NR donor who was HIV positive.
13. Having being told 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 do to make him happy and be strong for him. When he was 10 years old, my husband 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, we took him abroad to compete with children from other countries. In this competition, he was runner up for the UK and that

made me very proud. At the time, my husband and I had decided against telling Christopher about his diagnosis.

14. 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 blood to eliminate any harmful bi-products. I was told that it was safer to use. If they had done so from the beginning, Christopher would not have been infected and he would still be with us today.

15. 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 ensure that the blood being used to treat patients was safe to use.

16. From the age of about 10, Christopher was moved to Wellburn Hospital, in Newcastle. The Haematology Department at this hospital showed him how to treat himself with FVIII products. When he was comfortable with the process, we collected a supply of the products from Harrogate General Hospital and kept these at home.

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. When Christopher was 15 years old, we broke the news of the infection to him. Until then, only the immediate family knew. At this age we considered that he had to be told of the harsh facts because he was now going out with his girlfriends. It was very painful for us to tell him that his life had been cut short and he could not have normal relationships.

19. I do not know whether Christopher initially fully understood the implications when he was told. He had not even started to live his life and he was being told that he did not have long to live. 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 with safe products. I would not have consented to him being treated with any product that would have put his life in danger.

22. Christopher was tested for HIV without my 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 AIDS had taken hold that I noticed his body deteriorate. I do not know what was going through Christopher's mind when my husband 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 months after we had told Christopher of the sad news, he started to care less and less about what was happening around him. It was clear to me that 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 understandably changed. He

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

26. Christopher once told me that he felt different when comparing himself with others. I know that he wanted to university and one day get married and have children of his own but he realised this 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 them. 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. I 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 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 and then our son would suddenly get emotional and start crying.

#### Impact on me and my husband

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 husband 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 seeing him get married, have children, travelling and most of all sharing my life with him as I get older. I do not think time will heal my pain because I forever think about what might have been.

32. I 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, I had to give up my work and started to spend more time with him. It was painful for me 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 husband 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 of his other 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 our son'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. Christopher was given tablets to treat his HIV. So far as I am aware, he did not encounter any difficulties obtaining treatment.

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. The hospital should have advised me because of the risk of passing the infection to others.

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

### **Section 7. Financial assistance**

39. After 15 years or so, we received a payment of £20,000 from 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. After 20 years or so, we received another payment of £25,000 this also came from the MacFarlane Trust.

41. In and 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 husband and I attended a seminar in Bradford ran by the Haemophilia 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. At this seminar, I overheard someone say "*..they are not going to live long anyway..*" This is not what we wanted to hear bearing in mind that the NHS through their negligence caused the death of our son.

43. If the Government had researched more into the effect of heat treating FVIII before treating patients with it, many deaths could and should have been avoided.

**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 .....

**Mrs Christine Fowle**

Dated

Government funding, should have given financial support for this project. We feel that the Government's attitude to this project was generally negative. At this seminar, I overheard someone say "*..they are not going to live long anyway..*" This is not what we wanted to hear bearing in mind that the NHS through their negligence caused the death of our son.

43. If the Government had researched more into the effect of heat treating FVIII before treating patients with it, many deaths could and should have been avoided.

**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 |
|-------|

 .....

**Mrs Christine Fowle**

Dated this 26 <sup>April</sup> ~~February~~ 2019