

Witness Name: Joanne Lynn Richardson

Statement No: WITN1700001

Exhibits: 0

Dated: April 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF JOANNE LYNN RICHARDSON

I, Joanne Lynn Richardson, will say as follows:-

Section 1. Introduction

1. My name is Joanne Lynn Richardson. I was born on GRO-C I live at GRO-C. I have been married for 11 years and have 2 children aged 7 and 9. I run my own business and have been a Company Director and business coach for the past 10 years.
2. I make this statement on behalf of my late brother, Christopher John Fowle who was born on GRO-C 1974 and died on 22 June 1996 at the age of 22, having received contaminated blood products with which he was infected with both HIV and Hepatitis C, consequently developing AIDs.
3. My father, Alan Percy Fowle, has made a statement as per reference 'WITN1805001.' My mother, Christine Fowle has also made a statement as per reference 'WITN1649001.'
4. This witness statement has been prepared without the benefit of access to my late brother's full medical records. If and in so far as I have been provided with

limited records the relevant entries are set out in the medical chronology at the end of this statement.

Section 2. How infected

5. Christopher was diagnosed with severe Haemophilia A at the age of 1. Despite this my parents worked hard to give him a normal life and never restricted him from doing anything. In fact, he was encouraged to ride a bike, play with other children, etc. We grew up in a nice street and always felt a part of the neighbourhood in this way.
6. However I was always aware of my brother's condition and knew what risks internal bleeding or a head injury could be. I realised how important it was to keep an eye on him and so his diagnosis became a significant part of my life, despite him being only 2 years younger than me.
7. In the early days he was given cryoprecipitate to treat his haemophilia but it was very painful to administer. When Factor VIII concentrate (FVIII) became available, it was advertised as a brilliant new treatment and a quick way of treating bleeds. It was sold to us on the premise that the treatment had no risk and so it seemed like good news for us.
8. Christopher was treated at St James' Hospital in Leeds for the first 2 years of his life. After that, he was mainly under the care of Dr McAvoy at Harrogate General Hospital.
9. In around 1983, when he was 9 years old, Christopher spent some time at Welburn Hall School, which was a boarding school owned by Newcastle Hospital. He attended specifically to learn how to self-administer FVIII. He moved onto secondary school, Harrogate Granby High School a year later.
10. It would've been around this time, when my parents were informed that Christopher was HIV positive. My parents took the decision not to inform Christopher or myself at this point, as they believed we were too young to be burdened with this information.

11. Just before Christopher turned 15 and I was 17, my parents sat us down individually and told us about Christopher's diagnosis. There was so little knowledge around HIV at the time so in addition to receiving the horrendous news, I remember being really confused. We were sworn to secrecy and great emphasis was put on how the stigma would affect Christopher. I think my parents were worried about the possible repercussions and frightened of people's reactions if they were to ever find out.
12. My parents were told the infection would quite likely shorten Christopher's lifespan and that he would probably only live for another 12 years. They allowed Christopher to leave school from that moment.
13. I feel my parents felt obliged to tell Christopher about the HIV because of the risk he posed to potential girlfriends as he moved into adolescence.
14. Our parents were not given any information or advice beforehand about the risk of being exposed to infections. Nor were they provided with adequate information to understand and manage the infection.
15. Christopher was also infected with Hepatitis C but we did not find out about this until many years later. He was so very ill with the HIV that Hepatitis C was not even on our radar.
16. I believe the way the information about Christopher being infected with HIV was communicated to us was horrendous. There was no emotional support provided to us. For someone to be told their son or brother was infected with HIV; I find it remarkable that no further support or advice were given.
17. I also believe we should have been told about Christopher's Hepatitis C infection much earlier.

Section 3. Other Infections

18. I am not aware that Christopher contracted any other infections other than HIV and Hepatitis C from the contaminated blood products.

Section 4. Consent

19. I do believe that Christopher was tested without our parents' knowledge and consent and without being provided adequate or full information.

20. I assume from the overwhelming evidence that has been unearthed as part of this investigation that he was tested for research purposes to see if the virus would impact the haemophiliac population.

Section 5. Impact of the Infection

21. Our entire family suffered mentally as a result of the diagnosis. We were constantly on high alert. Christopher was angry and grew more and more withdrawn as he neared his late teens.

22. My mother became GRO-C and as a family unit we struggled. We never really spoke about it with one another. I believe we each confided in one friend with whom we were able to discuss the matter with. Additionally, we didn't really have much in terms of a big extended family; my mother was an only child and my father had 2 half-brothers with whom he didn't really speak.

23. Christopher also suffered numerous medical complications as a result of the infections. He had a couple of bouts of pneumonia and a fungal infection in his mouth, which was horrible for him. He also lost his appetite and as a result lost a lot of weight and became almost skeleton-like.

24. Christopher started to experience a real decline in his health from when he was 18 years old and became bed bound in his last year. He had a

bump/abscess in his calf all the while suffering from ulcers; none of which would heal. He would frequently be in and out of the hospital and different nurses started to visit him at home as he was so poorly.

25. Following a particularly bad bout of ill health, he was forced to stay at home as his mobility was greatly affected. All of this correlated to the full blown AIDS that had now developed. His body showed no signs of healing.

26. Christopher was taking tablets to treat the HIV but I do not remember what they were called.

27. In 1996, the decision was taken to put Christopher into a hospice so my mother could get a break. Only 2 weeks later, he passed away on 22 June 1996. We were absolutely devastated.

28. The fact that Christopher was also infected with Hepatitis C only came to light again in 2011. My parents received a letter from the Skipton Fund stating anybody who had been diagnosed with Hepatitis C was now being awarded payments.

29. Christopher was not treated for his Hepatitis C as the doctors failed to diagnose him with it when he first got it.

30. Christopher's infections had a huge impact on his private, family and social life. Even though he suffered from haemophilia, my parents encouraged him to live a normal life and play with other children. However, after he was told about the HIV, his world collapsed. He was definitely socially affected and kept his circle small from then on. He was terrified about people finding out and judging him.

31. There was definitely a stigma attached to HIV at the time. Christopher was very fearful and frightened of people as a result. He said once that a boy told him that he knew what it was he had. This is exactly why he was so scared.

32. He did a great job by not telling anyone. My parents were worried about how people would treat Christopher and what they would say about him. After he died, we talked about it more openly as there was no longer any risk to him.
33. Christopher's infected status and subsequent death had a massive impact on my parents and I. I'm amazed my parent's marriage survived through it all. The fact that this was all avoidable just makes it harder for me. It is hard for me to accept what happened and the way in which it all happened.
34. It has been 23 years since Christopher died but time has not healed the pain. It does not make any difference to me how long it has been, because I remember everything as if it was yesterday.
35. Even now I cannot sit and have a conversation about this with my dad, he just falls to pieces.
36. I am burdened with the thoughts of what could have been. My children would have had an uncle and potentially cousins too. It would have been nice to have had a bigger family. The fact that Christopher's death was so premature is difficult to swallow.
37. I believe Christopher suffered immense educational effects as a result of the infections. He was a bright child and very interested in engineering and mathematics. However, after his diagnosis he didn't see the point of continuing with his education. At the time he was 15 years old and at a pivotal moment in his life in deciding what to do next, before being made to live with this horrible burden.
38. In his late teens he just worked part-time with my parents, within graphic design as my father was an engineer. Had it not have been for the infections, I strongly believe Christopher would have gone to university and pursued a successful career.

Section 6. Treatment/care/support

39. Christopher was not given any counselling and neither was I. It is remarkable looking back at it now, that we were told this devastating news and just left to deal with it ourselves.

Section 7. Financial Assistance

40. When Christopher was about 16 years old, the Haemophilia Society advised us to contact the Macfarlane Trust. My parents completed a number of forms and signed a waiver declaring they would not make any further claim and so received a payment of £20,000.

41. I believe we questioned why the amount was nominal, however Christopher bought a car with the payment and it provided a little financial boost for him as he wasn't able to really go out and earn money.

42. Christopher received a second payment of £25,000 from the Macfarlane Trust when he was about 20 years old.

43. As previously stated, the Skipton Fund wrote a letter to us in around 2011 to say we were eligible for payment as family members of someone who was infected with Hepatitis C. I am not sure how much my parents received.

Section 8. Other Issues

44. Over the last 2 years, I have been involved in campaigning for the Factor 8 Group and Tainted Blood Group. This has consisted of attending meetings, court hearings and raising awareness on the matter. I also maintain an interest via social media outlets.

45. I did not imagine that there would be such publicity for the cause or that this scandal would ever be brought into the public eye. However following the Panorama documentary I have noticed growing support for the matter.

46. I feel the Inquiry has highlighted the need for people to have a voice. There needs to be an admission of responsibility and that the matter was wrongly attributed to a lack of budget rather than a lack of knowledge on part of the medical professionals. I do not believe those who acted, did so in ignorance; there was a blatant disregard for their consequences as it was only shortly after when heat treatment really began.

47. People have made decisions that led to hundreds and thousands of people dying. There needs to be some declaration of wrong-doing.

Anonymity

48. I confirm that I do not wish to apply for anonymity and that I understand this statement will be published and disclosed as part of the Inquiry.

49. I am happy to give oral evidence to the Inquiry.

Statement of Truth

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

Signed.....

Dated

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GRO-C

Dated

27th June 2019.