

Witness Name: JULIE LEAR

Statement No: WITN4703001

Exhibits: 0

Dated: November 2020

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF JULIE LEAR

I, JULIE LEAR, will say as follows:-

Section 1. Introduction

1. My name is Julie Lear. I was born on GRO-C 1964 and I live at GRO-C
GRO-C GRO-C.
2. My brother, Nicholas James Calder (born on GRO-C 1974), was co-infected with the Human Immunodeficiency Virus (HIV) and the Hepatitis C Virus (HCV) through contaminated Factor VIII (FVIII) concentrate. He died on 20th December 1999, aged 25.
3. This witness statement has been prepared without the benefit of access to my brother's full medical records.
4. My mother, GRO-B, has provided a Witness Statement to the Inquiry (Witness Number GRO-B). My sister-in-law, Lyndsey Calder, has also provided a Witness Statement to the Inquiry (WITN4450001).

Section 2. How Affected

5. I am oldest child of three. My youngest brother Nicholas (Nicky) had severe Haemophilia A. My other brother Darren does not have haemophilia.
6. Nicky was under the care of Dr Cecil Reid, Consultant Haematologist at Northwick Park Hospital. Our parents received a letter from Dr Reid in September 1985 informing them that Nicky was infected with HIV. Nicky was then just 11 years old. The letter stated that children infected with HIV were unlikely to go on to develop AIDS.
7. We moved to Milton Keynes in 1987 and the Royal Free Hospital then had responsibility for Nicky's haemophilia care. Our parents and Nicky received a letter in August 1990 from Christine Lee at the RFH stating that Nicky had been identified as being HCV positive from a blood test conducted in June 1990.
8. The information provided to our parents was far from adequate. They should have been informed of the diagnosis at a face to face meeting and given as much information as possible at that meeting and subsequent meetings to help them understand and manage the situation they found themselves in. All we knew was what was reported in the media and we clung to the hope that Nicky would remain well and that the HIV would not seroconvert into AIDS.
8. Our parents were not informed of any risk to Nicky of exposure to infection through FVIII concentrate before he was given the treatment. In 1983 when HIV hit the news, our mother (Mum) contacted Dr Reid and the Haemophilia Centre and she was assured that the risk of him contracting HIV was 'minimal' and to continue with his prophylactic home treatment. Mum decided nevertheless to only treat Nicky on demand to reduce the 'minimal' risk, a decision the doctors were unhappy about.

Section 3. Other Infections

14. I do not think that Nicky was infected with anything other than HIV and HCV.

Section 4. Consent

15. I refer to my mother's Statement in relation to the issue of consent. My parents were not informed that Nicky was being tested for HIV until at a routine check up in July 1985 when my mother was told that they would 'repeat the HIV test' because the test undertaken in May 1985 was lost. My mother had not been aware of and had not consented to such a test (in May). My parents then knew nothing about the subsequent HCV test carried out in 1990.

Section 5. Impact of the Infection

16. I was 20 years old when my parents were told of Nicky's HIV infection. As Nicky was just 11 years old, they decided not to tell him. They also chose not to tell Darren (then 13 years old) but they did confide in me. With all the hysteria surrounding HIV/AIDS in the media, they could not tell anyone outside of the family. Even within the family there were problems caused out of fear. It came to light that a cousin had informed his family not to see us or have anything to do with us "because Nicky had AIDs".

I left home at 19 however kept close contact with Nicky and as my little brother we were always very close. When Nicky built a relationship with Lyndsey, he turned to me to help explain to Lyndsey his condition. She was very young and whilst we explained in depth to her I don't think she understood the full implications of what we were telling her.

Nicky and Lyndsey spent a lot of time helping me babysit for my children when I was working and the relationship always remained close. Sometime into their marriage Nicky and Lyndsey had some marital problems and I believe that Nicky's condition had a bearing on these problems. It was a huge thing to deal with for two people so young. Nicky turned to me again for advice and I did the best way I could to help them through the difficult times they were experiencing, particularly the difficult situation they had to go through to be able to have Connor.

Nicky from the day he was born was a chubby cheeky character. I think for me the most difficult thing that I had to watch was the demise of this child I remember so fondly. Nicky became ever increasingly unwell and spent a lot of time in and out of hospital for a number of ailments linked to his condition.

Watching him lose weight and look so unwell was very daunting. Nicky had to take a cocktail of tablets and watching him try to swallow these when he had such severe thrush was heart breaking. I remember one significant time when he was taking his medicine his words to me were "They are using me as a bloody guinea pig!"

Whilst we all knew and "accepted" Nicky's condition I don't believe that any of us in the family really expected Nicky to die, certainly not at such a young age. I believe this is something that we did not want to think about. As the years went on however Nicky's health deteriorated rapidly. He became so weak and weighed very, very little for a man of his height.

When Nicky died, I can only describe it as the worst time of my life. Not only had I lost my little brother my children their uncle but also my best friend. When life for me wasn't going to well even with all that he was going through himself Nicky would be the first person to come to my aid with his support. It has taken me months to write this statement as I feel the only way I could get back on with life for my children's sake was to bury all my feelings. I feel losing Nicky so early has made me into an over protective mother of my own children, always fearing that I would lose them at a young age too. Before Nicky died I know I was not like this.

I will end this with, at no time has my family, or even Nicky when he was alive, been offered satisfactory support to deal with the whole situation. I think Nicky had some counselling but I can't swear to that. Certainly, my brother Darren and myself have never been offered counselling or support. Darren I know has been on a waiting list for 3 years to get some counselling, as he has suffered from survivor guilt that it wasn't him that was born with Haemophilia or got infected and died. To my knowledge Darren is still waiting for this.

Section 6. Treatment/care/support

None of us have been offered any counselling or psychological support.

Section 7. Financial Assistance

I refer to Statements of Lyndsey and my mother.

Section 8. Other Issues

Anonymity

I do not wish to remain anonymous and I do not want to give oral evidence to the Inquiry.

Statement of Truth

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

Signed.....**Julie Lear**.....

Dated13/12/2020.....

I have approved my Statement and I have printed my name in place of signing it.