

Witness Name: Daniel John Smith

Statement No: WITN1526001

Exhibits:0

Dated: February 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF DANIEL JOHN SMITH

I, Daniel John Smith, will say as follows:-

Section 1. Introduction

1. My name is Daniel John Smith. My date of birth is GRO-C 1980. I married in September 2007 and I have 2 children. I work as a night manager in a garage.
2. I make this statement as the brother of the late Colin Smith who was born on GRO-C 1982 and died on 13 January 1989, aged 7, having been infected with HIV and Hepatitis C as a result of treatment with contaminated Factor VIII concentrate.
3. I am one of 4 siblings. My mother and father (Janet and Colin Smith) have also made witness statements to the Inquiry.

Section 2. How infected

4. **GRO-C** Colin was diagnosed with severe Haemophilia A as a baby. He was treated at the Heath Hospital in Cardiff (now the University of Wales Hospital).
5. Colin and I were very close. We were never apart so I saw him being treated with Factor VIII every day. We used to play together and whenever he had a fall, there was always Factor VIII at home.
6. My parents were informed of Colin's HIV status when he was 10 months old.
7. Initially Colin was given Factor VIII at the hospital. Later on he had home treatment.
8. I believe that Colin was infected at the hospital. He got infected with HIV, which developed to AIDS and he was also infected with Hepatitis C (Hep C). We did not learn about the Hep C infection until after he had passed away. The medical notes stated that the hospital staff were just going to keep an eye on him. I do not know when the virus developed into AIDS. The doctors were not very forthcoming when they were giving information to my parents. Many of the conditions that my brother had were not communicated to my parents and we did not find out about them until we got hold of his medical records.
9. My parents were told that Colin was treated with Factor VIII for his Haemophilia but they were never informed of the risks associated with Factor VIII or where it came from. When Colin was 5 years old my parents were told that he had full-blown AIDS and the next two years were going to be crucial in his life. We (his brothers) knew that we were not to touch Colin's blood. Our parents told us that he needed 'special blood'. I was sleeping in the same bed as Colin and he had regular nose bleeds, so at one stage I was particularly told to be cautious and not come into contact with his blood.
10. My parents were very honest with us. They told us before he passed away that he had been infected with AIDS but we did not fully understand what that meant, and my parents did not either at the time. I was not told what caused

the infection. No adequate information was given about how to manage the infection.

11. I believe it was incredibly insensitive the way in which my parents were informed about Colin's infections. They were informed in the corridor of the hospital. My parents were not told whether there were any treatments available at the time. My parents were not advised of the severity of the condition. I knew Colin knew he was going to die soon after my parents told him he had AIDS. They carried out various tests without informing my parents what the tests were for.

12. I received a letter when I was 13, which was addressed to my parents, to say that the whole family had to be tested because Colin had Hepatitis C. No further information was given to us from the hospital as to what caused Colin's Hep C. GRO-C

Section 3. Other Infections

13. I am unaware of any other infections, apart from HIV and Hep C, that my brother may have contracted as a result of being given contaminated blood.

Section 4. Consent

14. Colin was too young at the time to be told. All information had to be relayed to my parents because of his age. I believe that Colin was treated and tested without my parent's knowledge. My parents were completely unaware of what he was tested for.

15. My parents were not aware that Colin was tested for HIV. They could not therefore consent. My parents would have requested to be given full details about these treatments and tests before giving their consent.

16. I believe that Colin was tested and treated for the purposes of research. This is stated in the medical records. It states that the chimpanzees were too expensive to use because Colin was already infected with HIV. They wanted

to monitor Colin very closely to research his blood and see how the virus developed. I believe he was infected with a test batch of Factor VIII which was and which came from a prison in the USA.

Section 5. Impact

Impact on Colin

17. Colin knew he was dying. I slept in the Heath hospital with him during the last year of his life. He spent the whole time there and he had a room which was decorated with cards from his school friends and toys. I remember playing with Lego and we got into an argument, I said to him 'I will break your Lego', and he said 'do not do that, you will miss me when I'm gone'.
18. He lost a tremendous amount of weight and had to be wrapped up in sheep blankets. He spent his time from the age of 5 to 6, at home. If he was having a good day when he was 5 or 6, he would go to school in his wheelchair as he loved school. Other children loved him in Alway School, which I also attended. They knew he was very poorly but did not know about the AIDS.
19. He picked up infections very regularly and was admitted to hospital around the age of 6. My grandmother passed away 6 months before Colin. He mentioned that he was not scared of death. He said he knew he was going to see her and she passed away to be there for him and did not want to suffer any more pain. He was very weak and could not move. He had to be given a potty at the age of 7. He was permanently on the drip. He was in a lot of pain even when he was sitting down and at that time he was very frail.
20. As a child, I did not know what HIV was; I was too young. I thought it was a name for his 'special blood'. A week before the Christmas of 1988 my parents demanded that Colin come home because they knew that this would be his last Christmas. My parents bought him everything he wanted that Christmas.
21. I was confused. I did not know how he was going to die and did not understand it. I felt fear as Colin and I were always together and my older

brothers were close. I was scared and worried about who I was going to play with or sleep with. We had just lost our grandmother. I was fully aware what death meant. I knew I was never going to see him again. Many emotions were running through my mind but we had a truly fantastic Christmas together.

22. After his death, my world turned completely upside down. Right through my teenage years until I was 21, I was a complete mess. I struggled with school and every aspect of my life. It definitely affected my education. I never let anybody in my bedroom. I got rid of all of my things and kept Colin's. I protected all of Colin's belongings such as his clothes and toys and did not let my parents clean the room. I used to sleep with Colin's clothes so I could smell him.

23. My parents got me counselling privately and I improved emotionally. I did not want anyone around me and just wanted to know that Colin's things were safe. I would lock myself in my room and listen to music and my parents struggled to get me out of my room. I had counselling for 8 months and it really helped me at the time. I built a great relationship with my counsellor and for the first time since Colin's death my confidence grew.

24. My brother Patrick GRO-C to this day. Sometimes he would vanish and my parents would get a phone call informing them that he was at the graveyard. He would lie on Colin's grave sobbing. It took a lot of explaining from my parents for him to understand that Colin was not there, he was in heaven.

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25. Being that much older, my oldest brother married his high-school sweetheart at 18 years of age. He was older and able to process information differently. He got on with his life and moved out of the family home to begin his marital life.

26. Colin's diagnosis had a huge impact on my parents. When he was initially diagnosed with HIV, they were not told and did not to understand the severity of it and what it meant. They knew Colin was going to die in the last 18 months of his life when his health began to deteriorate. They felt a lot of fear and had many questions as to why and how he had been infected with the AIDS virus. They were absolutely petrified of the effect it was going to have on him and the effect on the whole family. They tried not to display many emotions in-front of us children but we would hear them sobbing at night and we would catch them having a break down in the kitchen. After Colin passed away, both of them had break downs and they struggled to maintain their marriage. They were blaming themselves and questioning themselves whether they could have done things differently.
27. We lost a lot of friends and family in the lead up to Colin's death because they thought they would catch AIDS. We fell out with a lot of neighbours because of the negative media coverage about AIDS. Colin was the youngest child in Wales to die of AIDS. Our house was photographed and was featured in a local newspaper. Our neighbours went ballistic because their houses were also visible in the photograph and they did not want to be associated with AIDS. Our neighbours vandalised our front door; the side of our house and 'AIDS' and 'dead' sprayed on the side of the house and carved into our wooden door. My father's dad had 'AIDS and 'dead' carved into his car. People knew I was sharing a bed with my brother and I was verbally abused by adults telling me I 'should be dead as well'.
28. My father is currently 66. At the time, he was in his 30s. He was in the army and used to drive mini-busses. He had always worked but eventually had to stop because Colin had to go to hospital very frequently for treatment. The nearest hospital was in Cardiff which was 20 mile away from our house. During Colin's life, my father had to live at the hospital and had to completely stop working. My parents bought used toys and put cling-film around them to make them look new.

29. My mother had 4 boys and if she was not at the hospital, she was getting us ready for school. My parents had to juggle many things at once and were struggled financially as we had no income coming in.

Section 6. Treatment/Care/Support

30. My parents arranged counselling for me through the Haemophilia society. I was not offered any counselling from the hospital.

Section 7. Financial Assistance

31. My parents received assistance with Colin's funeral costs but I am not sure where the assistance came from. My parents had their roof and gaffing replaced by the Skipton Fund. My parents did not receive any other funds or monthly payments.

32. I received some money because I was so badly affected. My other brothers did not receive any financial assistance. It was put in trust at the time for when I was 18. It was about £2,000 and I believe it was from the Haemophilia Society.

Section 8. Other Issues

33. My parents were not involved in any class action. They followed was the Penrose inquiry (Scottish one) which was 4 or 5 years ago. It did not end well. None of us got the outcome that we wanted. People referred to it as a 'whitewash'. There was a massive uproar when Lord Penrose announced his findings.

34. My parents have been into Parliament with billboards and have been heavily involved in the contaminated blood community. We trusted these people with our lives, and mistakes happen but not this many times and not to this extent.

35.They had their whole lives ahead of them and the stigma we all suffered was horrific.

Anonymity, disclosure and redaction

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

37.I wish to be called to give oral evidence.

Statement of Truth

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

Signed.....

Dated.....

Statement of Truth

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

Signed

GRO-C

Dated... 26.2.2019