

Witness Name: ROBERT WEHRLI
Statement No: WITN3895001
Exhibits: 0
Dated: NOVEMBER 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF ROBERT WEHRLI

I, Robert Wehrli, will say as follows:-

Section 1. Introduction

1. My name is Robert Wehrli. I was born on GRO-C 1975 and I live at GRO-C GRO-C Surrey GRO-C
2. My brother James Wehrli (born on GRO-C 1977) was co-infected with the Human Immunodeficiency Virus (HIV) and the Hepatitis C Virus (HCV) from contaminated Factor VIII (FVIII) concentrate. He died on GRO-C 1994, aged 17, having developed AIDS Related Complex (ARC).
3. This witness statement has been prepared without the benefit of access to my brother's full medical records.

Section 2. How Affected

4. James had severe Haemophilia A. He was prone to spontaneous, unpredictable bleeds and, because of the likelihood of sustaining injuries through being banged and bumped, never attended a mainstream school. He attended the Lord Mayor Treloar College, Holybourne, Alton, Hampshire as a day

pupil. Whilst at Treloar College, James was given FVIII. He was treated by Dr Wassef and then Dr Aronstam.

5. James was infected with HIV and HCV when he was 7 years old. I do not remember the specifics but I think my parents were told first. I remember speaking to James about being infected but, being so young, neither James nor I really understood what was going on. I then remember the jokes going around about HIV/AIDS and homosexuals. HIV/AIDS was all over the news. HCV wasn't a concern and it was played down. AIDS was the known killer of the time. HCV was not thought of as a death sentence like HIV.
6. James was identified as being infected from a blood test. We were told that the contaminated FVIII was made by the Armour Pharmaceutical Company in America.
7. My parents were never warned about the risk of infection from FVIII concentrate. From my family's point of view, FVIII was a godsend for James.
8. I do not know what specific advice was given to my parents and James about managing the infection. My parents had separated. We (my older sister, James and I) lived with our father and most of the responsibility in relation to James fell to him. My father was mindful of how James felt and wanted to shield his child as much as he could from being made to feel uncomfortable. My father would often administer the FVIII to James at home. He disregarded his own safety and refused to wear gloves whilst doing so. In stark contrast, the medical staff at Treloars College wore gloves and protective clothing. I remember watching with my father as a doctor treated James with FVIII at the end of a school day when we went to collect him. The doctor wore gloves and a plastic bib like James was a safety hazard. It was only when we were older that my sister and I understood the risk.

I then went on to develop OCD cleanliness disorder that has stayed with me throughout my life.

Section 3. Other Infections

9. I do not believe James was infected with anything other than HIV and HCV.

Section 4. Consent

10. I have no knowledge of James being treated or tested without the knowledge and consent of our parents and/or for the purposes of research. We have always assumed everything was done for James openly and transparently.

Section 5. Impact of the Infection

11. The gravity of James having HIV only really started to sink in when all the adverts surrounding HIV/AIDS cropped up on the television. No-one knew that James had HIV outside the family. Because of the panic and fear in others and the associated stigma we kept it to ourselves. James was embarrassed. I was embarrassed and I did not want other people at that time to think about James in a certain way. AIDS was associated with homosexuals and heroin addicts. An older neighbour once confronted me and said "I hear your brother has AIDS". He didn't actually know anything except that James had haemophilia. After James died, I told people that he had had a heart condition. I did not think they would believe he had contracted HIV from contaminated blood products and would make assumptions. I have no shame or embarrassment about it now. I am angry.
12. James was very caring and worried about infecting me and his friends with HIV. Without telling them why, he would never share a can of coke with them. He and I were very close. He worried about infecting me. As we were coming into our teens we each had an ear pierced (James at home with a needle, as my father would never have allowed it to

be done outside the home eg at a tattoo studio). I remember wanting to use his earring and James saying "Don't use it. It has been in my ear. It may have (traces of) blood on it". I put the earring in a jar of disinfectant and left it for a few days. Even though I had disinfected it, James still said "No. Don't take the chance. It's not worth the risk".

13. HCV was of no concern. I remember reading something about Pamela Anderson having hepatitis and there wasn't any kind of imminent fear surrounding it.
14. We had many sleepless nights. We all knew that HIV led to AIDS and AIDS killed you. My father always hoped there would be a cure for HIV/AIDS. "Hopefully they will come up with something" he would say. I remember my father being in contact with someone from abroad claiming to have a cure (a herbal remedy). He kept it in the box in the cupboard (for emergency use) but never gave it to James.
15. I began to develop a complex about cleanliness and germs. James and I were very close and I worried about being in physical contact with James. It started to become an issue between the two of us. My father realised it was becoming an issue and took me to a meeting with Dr Aronstam at Treloars College. There, Dr Aronstam explained to me that James had contracted HIV in a way (unique to him) and tried to assure me that I couldn't catch it from simply touching my brother. I remember him explaining to me that the blood from one person's body doesn't just fall out and into another's body. The meeting made no difference to me. I remember being belligerent and saying "I've heard that LSD *absorbs* into the blood through the skin" as an example. I was paranoid right up until James' death and beyond. My paranoia snowballed to the extent that I believed that strangers had HIV and I didn't want to touch them. I have been diagnosed with OCD cleanliness disorder, living with the condition since my teens and I am now 44 years old.

16. James' health deteriorated after his count started to drop. I recall him having a procedure in hospital wherein his blood would be taken from his body and run through a machine, then pumped back into him. I remember visiting him in hospital and, also, him having regular tests to check his count. He still looked relatively well until near the end and even went out with his friends. He said "my count is going down. I will do everything I can to fight this." He spoke like an adult, not the teenager he was.

17. James started to spend more time at home and it was not a drawn out period of time between becoming ill and the end. He went downhill quickly. James had bad night sweats (his T shirt would be wringing wet each morning). I have never known someone to sweat so much. He had a lack of energy and appetite culminating in him losing weight and he looked jaundiced in colour. It was like he had a flu that he couldn't shake. As his health deteriorated, he shuffled around the house like a little old man in a young man's body. It was terrible to watch.

18. I remember the day James died so clearly. He woke up that morning not feeling well. We called an ambulance but it didn't arrive until he was already gone. James' death came as a shock to my father. I was more realistic and I knew it was coming. I was drinking heavily at that point in order to cope. It was hard on all of us but particularly hard on my father and me. My mother lived in Basingstoke and my sister had her own place. My father and I effectively nursed James and saw things the other two did not. I still have visions of it all in my mind. My father is still heartbroken. He cannot speak about the loss of my brother to this day without breaking down.

19. At 44 years of age, I still have issues that stem from what happened to my brother. What happened to James has affected me in ways that I

could never have imagined. It has affected my family, how I raise my children and how I am with my wife. I have paranoid thoughts and consider the worst case scenario about everything. How this has affected me is immeasurable but the psychological affects include OCD, anxiety, depression and, at one time, alcohol issues.

Section 6. Treatment/care/support

20. We were never offered any form of counselling or psychological support before or after James' death. I had all the counselling under the sun when the full extent of how I had been affected eventually became apparent but I sought it out myself.

Section 7. Financial Assistance

21. My father signed the waiver and accepted £35,000 from the HIV litigation on my brother's behalf. My father used it as a deposit for a house so that James would have somewhere to live.
22. I wanted my father to just give James the money so he could buy anything he wanted to make him happy in his short life. My father, however, was always hopeful that James would survive and that he would need the money for a home as he would never be able to obtain a mortgage with his condition.
23. In relation to HCV, I am uncertain but I believe James might have self cleared it. The only money my father received was the money from the HIV litigation. He had no choice but to sign the waiver. He thought he would not have received any money for James had he not.

Section 8. Other Issues

24. I am looking for accountability in relation to what was done to James. The very thought that people

(Doctors and representatives of Trusts) sat in a room and collectively decided to keep the contaminated FVIII treatment in circulation knowing that people were dying turns my stomach. They *knew* something was wrong with it. They could have prevented this from happening to my brother but left unheated product in circulation.

25. People were being infected with viruses before my brother was even born. I want to know whether those responsible had knowledge of the risk of infection before my brother was even born.

26. This could have been prevented. My brother would have lived with having haemophilia but would not been infected. He would still be alive. It is appalling and still gets to my very core now.

Anonymity

27. I do not wish to remain anonymous but 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.

GRO-C

Signed.....

Dated 5.12.19