

Witness Name: Cosima Dinkel

Statement No: WITN1191001

Exhibits: 0

Dated: January 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF COSIMA DINKEL

I, Cosima Dinkel will say as follows:-

Section 1. Introduction

1. My name is Cosima Dinkel. I was born on GRO-C 1971 and I live at GRO-C
GRO-C I am a freelance Graphic Designer.
2. I write this statement on behalf of my late father, John Michael Anthony Dinkel, born on GRO-C 1942. He died at the age of 48 years old on 15 August 1991, as a result of cerebral toxoplasmosis.
3. This witness statement has been prepared without the benefit of access to my late father's full medical records.

Section 2. How infected

4. My father had severe Haemophilia A. I am a Haemophilia carrier. I believe my father was given Factor VIII (FVIII) in or about the late 1970s.
5. I saw my father administer FVIII at home by himself as and when he had a bleed, but I am not sure if he received FVIII at hospital.

6. I believe that my father's main hospital was The Royal Free Hospital, London (TRFH). He was under the care of Dr Katharine Dormandy and Dr Peter Tuddenham. I believe he was also at some point under the care of Royal Sussex County Hospital.
7. I believe my father was infected with HIV and Hepatitis C (Hep C) as a result of being given contaminated FVIII, from which the HIV subsequently developed into AIDS.
8. I believe my father was told about his HIV infection after a knee operation in or about 1987 at TRFH. It was from this day onwards that he started to act very strangely and showed signs of depression. I am not sure when he found out about his Hep C.
9. When I was about 17 years old, my father was hospitalised after having a fit. It was at this point that my sister and I were told that my father was going to die of AIDS.
10. I am unable to confirm what information or advice was provided to my father about the risks involved in using FVIII, as I was very young and would not have been party to such information being given. I was not given any information, I did not do my own research and I did not speak to any doctors either. I only got information through my mother as my father never spoke to us about it.
11. I do not know how the information about the infection and the results of test were communicated to my father, but I know it was not done well and it was not easy for him.

Section 3. Other Infections

12. I am not aware if my father was infected with any other infections from the infected blood products. However, he did suffer from cerebral toxoplasmosis.

Section 4. Consent

13. I do not know if my father was tested or treated without his knowledge or consent. As previously stated, I was not party to any discussions he had regarding the infections. However, I do believe it is likely that he was tested and treated without his knowledge and without being given adequate or full information. I also believe it is likely that he was treated or tested for the purposes of research.

Section 5. Impact of the Infection

14. After his knee operation in or about 1987, my father became very depressed and withdrawn. He was not able to speak to us, his family, directly at all. He fell very ill and he just could not live his life anymore.

15. Prior to the knee operation, he was only confined to bed when he had bad bleeds but post operation, he was not well at all. He was sick all the time and bedridden. All through my teenage years he was very ill and we didn't have a proper relationship because he was not able to do the things a father would do for his children. I believe this made everything worse for him.

16. When we found out that my father had AIDS a few years prior to his death, it was like a bomb had hit our family. We tried to just get on with things and carry on the best we could because it was too awful to face what was happening. At that time I was studying and was trying to live a normal life, pretending like everything was alright. It worked to a point as I did well in school and got into college.

17. My father never had a conversation with me or my sister regarding his illness. I don't know what he told my mother at the time. I think it was very difficult for my father to acknowledge what was happening to him, let alone for him to talk to his family about it and this, coupled with the stigma attached to HIV/AIDS at the time, meant that it felt like a secret we all had to keep.

18. I believe my father received AZT as treatment for the HIV. I am unsure what treatment, if any, he received for the Hep C. At the time, I was not really aware of what was happening to him and what medicine or treatment he was having, as my mother was his main carer.
19. I do remember that my father hated taking the AZT treatment. I think this medicine made him feel very sick, depressed and really down. He also lost his appetite and lost weight as a result.
20. During this time, I was in a very strange situation as I could not speak about my father's illness with any of my family members or anyone. It was not something we could address.
21. Later, when my father passed away, I could not come to terms with it. The enormity of what had happened took a long time to sink in. As a family we did the only thing we could, which was to carry on as normal. At this time of my life I was desperate to be normal and do all the things I could. To a certain extent, I did try to live a normal life, but there was a black hole at the centre of it all, a looming shadow that hung over us.
22. To me it felt like a burden to tell another soul and so I did not. My father died in August 1991 and in September 1991, I went to Art college. I did not speak to anyone about the circumstances of my father's death. I pretended like everything was fine and never really dealt with my father's death until today.
23. Once I finished college and returned home after a few years, I felt all the grief and anger that I had bottled up over the years about the injustice of my father's death. I thought I was coping well by not speaking about my father, but this made it harder for me later in life, even now I feel like I never really dealt with it.
24. If my father died from an illness such as cancer, I would share my emotions with people but because there was a stigma attached to HIV, my family had to keep it a secret. The media portrayed it as a 'gay' disease, which I believe

was the reason why a stigma was attached to it. My father was kept in a ward where other gay men were dying from the disease. It was a very harrowing experience to go through.

25. After my father's death, when I was working, I was very depressed and had to see a counsellor and a psychiatrist who put me through a course of treatment. I had to take some time off work but it did not stop me from working. After 10 years, I felt the same depression again. The depression has been there on and off throughout my life.

26. Since my father's death, I have developed a way of behaving as if nothing happened and I have been behaving in such a way all my life. It is not the best way to deal with things and his death has impacted my life greatly.

27. I do not remember how hard it was for my father to get treatment, as I would not have been privy to such discussions in the family.

28. I do not know whether there were any treatments which ought to have been made available to my father. As previously stated I was not aware of what was happening to him or what medication he was taking until I was older, around 17/18 years old.

29. It is really only now that I feel able to face up to the truth and horror of the events that led to his death and the death of many others like him. I take no comfort from the fact that it happened to so many other people but this does strengthen my resolve that each and every individual, like my father, deserves an explanation and justice.

30. At the time of his diagnosis, my father was working as an art historian but he had to give up his job as he was too sick. I do not think he worked much in the last few years of his life as he was bedridden.

Section 6. Treatment/care/support

31. I do not know if my father was offered any counselling or support in relation to his infections.

32. I was only offered counselling and support because I went to my GP as I was suffering from depression. I believe that if we had been offered counselling together as a family, it would have helped us enormously. We were just left to deal with my father's death alone.

Section 7. Financial Assistance

33. I do not know if my father received any money from any of the Trusts or Funds that were set up. I believe my mother received a lump sum payment after my father's death but I am not sure how much.

Anonymity, disclosure and redaction

34. NOT RELEVANT

35. I do not want to give oral evidence at the Inquiry.

Statement of Truth

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

Signed... GRO-C

Dated... 26 January 2019