

Witness Name: Carol Anne Valentine

Statement No: WITN2950001

Exhibits: WITN2950002-3

Dated: 29 April 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF CAROL ANNE VALENTINE

I, Carol Anne Valentine, will say as follows:-

Section 1. Introduction

1. My name is Carol Anne Valentine of GRO-C Connecticut, GRO-C USA. My date of birth is the GRO-C 1964. I work part-time in retail and I am married. We have three children.
2. I make this statement in relation to my late brother Malcolm Alexander Russell (Malcolm) who was born on the GRO-C 1956 and sadly passed away on the 12th March 1990 aged only 33 as a result of receiving contaminated blood products.
3. This statement has been prepared without the benefit of access to Malcolm's full medical records.

Section 2. How Affected

4. Malcolm suffered with severe Haemophilia A. He was diagnosed when he was 18 months old.
5. Malcolm used to live in the North of Scotland and he was treated at the Royal Infirmary in Edinburgh throughout his childhood. However, when Malcolm was 13 years old, our family moved closer to Oxford specifically so that he could be treated at the Haemophilia Centre at the Churchill Hospital which was regarded as the best Haemophilia centre in the country.
6. He was under the care of Dr Charles Rizza who was the chief consultant at the time. He was also under the care of Dr Matthews.
7. Malcolm received blood products from the time he was diagnosed until he died in 1990. When he was treated at the Haemophilia Centre in Oxford I recall being put in the back of the car numerous times late at night and driving there so as Malcolm could receive treatment. Once home treatment was made available he started receiving Factor VIII concentrate. The name I recall or have seen mentioned is Armour.
8. As far as I am aware, my parents and Malcolm were not given any information or advice at the time in relation to the risks of being exposed to infection from blood products,.
9. Malcolm contracted Human Immunodeficiency Virus (HIV) as a result of receiving contaminated blood products. He was told that he had tested positive in August 1985.
10. In July/October 1983, I believe he also contracted Hepatitis B as a result of receiving contaminated blood products.

11. Following the 1991 litigation we were advised that all Malcolm's medical records were to be returned to the relevant Health Authority and therefore I do not have all the records.
12. In August 1985, at the age of 29, Malcolm had a meeting with Dr Rizza at the Haemophilia Centre in which he was told that he had contracted HIV. Additionally, there is now produced and shown to me marked "WITN2950002" a copy of the letter Malcolm received from the Haemophilia Centre in about June/July 1985 advising him to take "simple precautions", to avoid contamination of work areas with patient's blood, not to leave blood stained needles unguarded, and adults to use a sheath during sexual intercourse. As far as I know, this was the only information which was provided to Malcolm at that time in relation to the risk of transmission of the infection to others.
13. I do not believe that adequate information was provided to Malcolm to enable him to understand or manage the infection. I do consider that information should have been provided at the time of diagnosis.
14. We looked after Malcolm for three weeks before he died and dealt with his bodily fluids; nobody provided our family with any information on what precautions should be taken apart from to wear gloves.
15. My sister in law, Elvira, kept Malcolm's diaries in a box for years. I did not know of their existence for a long time. From Malcolm's diary entries, his second home was the Haemophilia Centre. He had a close relationship with Dr Rizza and Dr Matthews whom he relied on and trusted. Prior to being told of his HIV diagnosis, he wrote in his diary that he began to be worried that there was a potential cover up, he felt there was something untoward going on, especially having regard to all the tests that had been conducted. He felt there was something untold going on that he had not been a party to. He recorded that something was missed and he was very angry about it.

Section 3. Other Infections.

16. I do not know whether Malcolm received any other infections as a result of being given infected blood products.

Section 4. Consent.

17. Malcolm was being tested but he did not know what he was being tested for. He made a note in his diary of the four occasions when tests were conducted. However, he was advised by Dr Rizza that in fact ten tests were conducted, but he was only aware of the four he had made a note of in his diary.

Section 5. Impact

18. Malcolm was married to Elvira, a Swiss German national, and they had a son who was aged 5 at the time Malcolm died. After Malcolm married, he and his family continued to live in the Oxford area. Elvira and their son continued to live there after Malcolm died but they have now moved to Switzerland. Elvira remarried and her married name is Kuhni.

19. Malcolm worked for the Oxfordshire County Council as an assistant accountant.

20. He was 29 years old when he was diagnosed with HIV, but I recall that he suspected something was going on before the diagnosis. Therefore, mentally he began to have a complete lack of trust in what he was being told. He began to suspect that there was something wrong with him. He was very aware of things going on. He became very angry due to his ill-health and wanted to know what was happening to him and wanted somebody to tell him the truth.

21. I was very close to Malcolm. He was strong-willed which he had to be as he suffered so much during his lifetime. In his diary he refers to him looking for jobs but he was regularly turned down for the positions he applied for and he

questioned whether this was in relation to the association of infections with Haemophilia. He considered this to be the reason why he could not progress his career. Eventually, he had to take a job which would accept him, it was lower paid which was devastating for him as a bread winner.

22. In a diary entry written by Malcolm, he noted that in March 1985 he suffered with thrush in his mouth which was before he was told he was HIV positive. In June and July 1988, he developed pneumonia. He wrote in his diary about becoming severely anaemic and contracting cryptosporidium. He suffered with terrible sickness and diarrhoea which was the start of his deterioration. He was not gaining any weight, instead, he suffered from weight loss due to his symptoms.
23. His liver was not functioning properly. He was admitted to the Churchill Hospital for a couple of months where he was placed on a drip and prescribed large doses of morphine. I visited him often and I recall that he just wanted to come home. We looked after him at home for approximately three weeks before he died. He had a strong heart, it was the body that had failed him completely. Mentally and physically he totally broke down. Towards the end of his life, he weighed about 5 stone and was 6 foot tall.
24. Between 1982 and 1984 Malcolm spent a lot of time in hospital. He had been involved in a motorbike accident and broke his leg. The long lasting effects of his injuries were bad joints and he walked with a limp. Therefore it was normal for Malcolm to attend the hospital so often, for either days or weeks on end.
25. Malcolm received AZT treatment when he contracted AIDS but he suffered with really bad side effects. In December 1988; he suffered with extreme anaemia. I do not recall the other side effects and prefer to block them from my memory.
26. I do not know whether Malcolm experienced obstacles in receiving treatment. Unfortunately, I cannot comment on whether Malcolm should have been offered other treatment or what treatment was available.

27. I am eight years younger than Malcolm. When he was diagnosed with HIV, I was aged 21. I do not think he shared the diagnosis with anybody at first. At one point I lived with him and Elvira for 6 to 8 months, and I recall a time when Malcolm cut his finger which resulted in severe bleeding, it really put Malcolm and Elvira on alert. I remember they were very dismissive of me and tried to get me away from the blood. At the time, I did not understand why but in retrospect, I now know that they wanted to protect me. I do not think that my mother knew about Malcolm's infection at first either. My father had passed away by this time.

28. I became aware that Malcolm was HIV positive when he contracted pneumonia in 1988. Malcolm told me because he thought this would be the end of his life. I was shocked and upset. I never grew up with a father as my father died when I was 7 years old. I was very close to Malcolm who was like a father figure to me. It was my desire that Malcolm would give me away at my wedding. Sadly, he did not live long enough to do so.

29. The AZT treatment gave some hope but after realising that it was failing, all hope was gone. He went from a very strong man to a shadow of himself. He was a tough cookie and growing up he was always a strong character. But at the end of his life he could not sit up on his own and he felt there was no point in him living anymore.

30. My mother never got over his death and I do not think she ever will. Her whole life revolved around Malcolm and she had moved her entire family down to Oxford and my father took a lower paid job so as Malcolm could get the best care possible from the Oxford Haemophilia Centre. I remember her telling me that she did not know whether they would have enough money to give him a proper burial. She just never knew when he might die. The ironic thing is that Haemophilia did not kill him; instead his death came as a result of treating it. A sad 29 years has passed and my mother is still heartbroken and told me recently that she would never get over it.

31. It was a strange thing, he was a big character in our family. He was the magnet that kept everything together. His loss changed the dynamics of our family completely and we all grew apart. It was tragic.

32. Malcolm struggled to get a job as I have mentioned above and according to Elvira, it was very difficult at the time. Malcolm felt he had no career prospects due to the relationship between Haemophilia and HIV. Also we were living in a small town and my nephew went to a small school where the Haemophilia Centre advised Elvira to tell people that Malcolm had died of cancer so as to avoid my nephew being bullied at school or losing friends. So this is what we have been telling people throughout our lives. We kept it a secret and it was only really in the last 10-15 years that I have started telling people that my brother died from AIDS. My nephew did not know that his father passed away of AIDS until Elvira submitted the paperwork for the Inquiry last year and decided to tell him.

33. Malcolm's life became more difficult for him after the media had published stories in relation to Haemophilia and HIV; as people were aware that he was a haemophiliac. This was unfair as it made people become prejudiced against him and others in a similar position.

34. The period leading up to Malcolm's death and afterwards was heart breaking. After he died we learned that a post mortem would have to take place which was very distressing. The conclusion of the post mortem was that his death was "as a result of an accident". There is now produced and shown to me marked "WITN2950003" a copy of Malcolm's death certificate. It was very upsetting.

Section 6. Treatment/Care/Support

35. Malcolm did not receive any psychological support or counselling. My mother and I were not offered any counselling; neither at the time when we were looking after him in the last weeks of his life or after he had passed away. We never received

guidance on how to look after him properly; we just used rubber gloves when we handled his bodily fluids on a daily basis when he was dying. We washed his sheets and clothes and dressed bed sores that he had over his body from lying in the same position.

Section 7. Financial Assistance

36. Malcolm received disability allowance when we were looking after him at home but Elvira would know more about the money he received.

37. I believe Elvira received compensation in the 1991 litigation but I am unaware of the details.

38. I have not received any financial assistance.

Section 8. Other Issues

39. I have no other issues to comment on.

Anonymity, disclosure and redaction

40. 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.

41. I do wish to be called to give oral evidence if I can assist the Inquiry.

Statement of Truth

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

Signed... GRO-C ...
Carol Anne Valentine

Dated: 29th April, 2019