

Witness Name: Neil Long

Statement No: WITN7506001

Exhibits: WITN7506002

Dated: November 2022

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF NEIL LONG

I, Neil Long, will say as follows:-

Section 1. Introduction

1. My name is Neil Long. I was born on GRO-C 1971, and I live at GRO-C
GRO-C, Worcestershire GRO-C.
2. I make this statement as the son of Keith Long (born on GRO-C 1949)
who was infected with HIV, Hepatitis B Virus (HBV) and Hepatitis C Virus
(HCV) as a result of receiving contaminated blood products. He died on
GRO-C 1998.
3. This witness statement has been written with the benefit of access to some
of my late father's medical records.
4. My brother and mother have also given statements. My brother's statement
is **WITN7441001**. My Mother's statement is NOT RELEVANT

Section 2. How Affected

5. My Dad had severe Haemophilia A. I understand from my mother that when my Dad was a child, there was no real treatment for bleeds but later he would receive transfusions with Fresh Frozen Plasma and from 1968 he was given Cryoprecipitate. In 1977 he was transferred to Factor VIII products. Please refer to paragraphs 9-15 of my Mum's statement.
6. My Mum would administer Factor VIII to my Dad. Watching Mum inject Dad so many times when I was young has given me a phobia of needles.
7. Dad was treated at the Queen Elizabeth Hospital in Birmingham. He was mainly treated by Dr Franklin, a Consultant Haematologist. My Mum also lists other Doctors who treated him in her statement at paragraph 9.
8. My Dad was given Factor VIII products from 1977 until he died. He protested the move from Cryoprecipitate to FVIII but he was told that this would be the only way to prevent a haemorrhage, I refer to my Mum's statement at paragraph 14.
9. I am unaware of the specific date that my Dad was infected but paragraph 19 of my Mum's statement suggests that he was infected with Hepatitis C following his first exposure to FVIII on 29th June 1977.
10. Dad was first tested for HIV in December 1984, the results were reported in early 1985 and I believe that he was informed in 1986. Please refer to my Mum's statement at paragraph 20 for further detail.

11. As I was a teenager at the time, my parents protected me as much as they could from what was going on. But as it turns out, they did not receive much information about Dad's infection either. My Dad was not informed of the risk of infection. He felt the doctors at the time did not even know about it themselves – see paragraph 17 of my Mum's statement.

12. I believe that my Dad found out about his Hepatitis C by accident in 1994. He had gone into hospital for a bleed in his ear and one of the junior doctors mentioned to him that he had Hepatitis C, as well as HIV. I refer to paragraphs 25 and 26 of my Mum's statement.

13. My parents were not given adequate information regarding my Dad's infections. My Mum was told to carry on administering Factor VIII but just to use gloves and to wear protection during sex. Similarly, they were given no guidance on how to manage his HCV diagnosis, see paragraphs 22-26 of my Mum's statement.

Section 3. Other Infections

14. I do not know whether my Dad received any other infections.

15. Paragraph 28 of my Mum's statement suggests that he was also found to have Hepatitis B surface antibodies and core antibodies.

Section 4. Consent

16. I assume that my Dad was tested for HCV and HIV without his consent or knowledge as he was surprised when he heard he was HCV and HIV positive. Although, my Mum's statement at paragraph 28 suggests that he knew he was being tested for HIV in 1984 .

17. I do not know whether Dad was tested for research purposes.

Section 5. Impact

18. My Dad suffered with a catalogue of physical and mental effects as a result of his infections. Dad used to enjoy every sport under the sun but after he became ill, he was jaundiced and lost weight was not physically active anymore. His inability to do things he once enjoyed was also due to the deterioration of his mental state. He became depressed and socially reclusive due to the stigma surrounding his illness.

19. I remember that Dad wanted to have AZT treatment but faced obstacles and was told he could not have it. He ended up writing to his MP requesting access to the treatment. However, once he began taking AZT, it turned out that it had harsher side effects than the illness itself so in the end he could no longer take it. I am not sure how long he took it for but for its duration he suffered with nausea and itchiness. He also became very bad-tempered and agitated. I am not aware of any further treatment which should have been made available to him.

20. Dad's illness has affected my whole life. I was there when my Dad died and the painful memory of that sticks with me to this day. I find it hard to talk about, even now. At the time it affected our relationship massively. I remember when I was younger that I was using a shaving razor and my Dad was unsure if I had used his instead and went ballistic out of concern. As Dad's illness progressed, he became mentally unwell and would fly off the handle at everything.

21. There was so much stigma at the time around HIV made worse by the mass negative publicity associating it with drug users and homosexuals, especially at the time of Freddie Mercury's death. At my first job I was asked about my Dad but felt I could not tell anyone what was happening.

22. I feel that my Dad's death has altered my outlook on life and has contributed to why I live like there is no tomorrow. For example, I am not risk averse at all and love dangerous sports such as scuba diving and sky diving.

23. My family also suffered greatly because of Dad's infections. My younger brother Ian never really knew the old version of my Dad before he became ill. I feel sad that he only saw him after his temper changed. I think that my Dad's personality rubbed off on Ian a bit as he was home a lot and he is now bad-tempered himself, like my Dad used to be. Both Ian and I lost a father figure in our life which was important for two boys to have growing up.

24. My Mum was never quite right after Dad died. She never re-married nor moved out of the home. GRO-C

and I look after her as much as we can.

25. I was never particularly academic when I was younger. In hindsight, everything that was going on at home affected my education. I was preoccupied with my family life and felt very stressed about someone finding out about what was going on. This meant that I could not focus on schoolwork as much as I should have. Also my attendance was not always good as I would leave school to come over to the hospital to help. Although I achieved an O Level in Art, I think the situation affected my education more than I had realised at the time.

26. My Dad and I used to run the family business, Horley's, together but as Dad became progressively more unwell his mental health declined and he became dependent on alcohol. He went to rehab and was unable to work for the business anymore. This caused a financial strain on the family as my Dad was a clever entrepreneur and we lost his expertise to run the business.

27. Similarly, my Dad's sharp mind for business would have been really useful when I started my own business. When I began my business venture, I was unsure as to how to plan long term so ended up cramming everything in at the beginning. If I had been able to receive my Dad's business advice, I feel that my business may have been more profitable.

Section 6. Treatment/Care/Support

28. No counselling was ever made available to me and I am unaware if it was offered to other members of my family. I refer to paragraph 26 of Mum's statement which states that they were not offered any counselling post diagnosis.

29. As mentioned previously, my father originally faced obstacles in obtaining AZT treatment.

Section 7. Financial Assistance

30. I believe that my Mum received some money from the MacFarlane Trust but I am unaware of any amounts or obstacles in obtaining this. I refer to paragraphs 64-72 of my Mum's statement for further details.

Section 8. Other Issues

31. I feel as though I have almost pressed a 'delete switch' to block out the traumatic memories of my Dad's infections. No family should have to go through what my family did and it makes me so angry to think that all of this pain could have been avoided.

32. I believe that politicians, especially those such as Kenneth Clarke, should be held fully accountable for the gross injustice which their negligence has caused. Compensation is not enough, they should see prison time.

Anonymity, disclosure and redaction

33. I do not wish to apply for anonymity, and I understand that this Statement will be published by the Inquiry.

Statement of Truth

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

Signed GRO-C

Dated 03 November 2002