

Witness Name: Ian Long

Statement No: WITN7441001

Exhibits: Nil

Dated: November 2022

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF IAN LONG

I, Ian Long will say as follows:-

Section 1. Introduction

1. My name is Ian Long. I reside at GRO-C Birmingham,
GRO-C My date of birth is GRO-C 1975. I live with my 11 year old son.
2. This witness statement has been prepared without the benefit of access to my father Keith Long's full medical records. We have some of his records, but not all of them.

Section 2. How Affected

3. Growing up we had a normal loving family, as a family we enjoyed sport and would take part in football, cricket, fishing, all sorts really even including scuba diving. My father was very active with us. He had his own business, he worked in engineering first of all for 21 years then ran his own haulage company.

4. My father had Haemophilia A. He had it severely, my mum used to inject him with Factor 8 at home, he would have bad bleeds into his elbows and knees, they wouldn't straighten, they were very deformed. He had bleeds regularly.
5. My father attended the Haemophilia Centre at the Queen Elizabeth Hospital mainly.
6. My father was given infected blood product in the late 70s to early 80s.
7. I do not believe my father was given any advice or information about the risks of being exposed to infections as a result of being given the Factor 8 treatment. He was on cryoprecipitate, but because Factor 8 was cheaper his treatment was changed to that, he didn't have any choice in the matter they just changed it because of the cost, the doctors told him it was a better treatment. My father protested and didn't want to change but he was ignored. He was against switching to Factor 8 because he had seen an article in the newspaper in May 1983 which said about Factor 8 presenting an HIV risk but when he raised this with his doctors his concerns were dismissed.
8. My father was infected with HIV, Hepatitis C (HCV) and Hepatitis B (HBV), I am not aware of any other infections, but there may have been as me and my brother were quite young at the time, so we were protected from it. We started to realise ourselves watching the news, when our father would tell us to be quiet when anything linked with it came on the news, we were told to be quiet so he could hear what they said so, it sort of clicked, we clicked on a little bit then, but we were protected from it and the stigma before then.
9. My father was informed of the infections at the hospital. He was first tested for HTLV3 antibodies in December 1984, the results were not reported until April 1985 and he was informed of the diagnosis at some point before 21st February 1986. He did not wish to know the details of his infections and at first was told to behave as if he was HIV positive. He had previously told the doctors he didn't want to know any more about any infections, but one of the junior doctors informed him of that infection when my father didn't think he had it. This would have been in around 1994 or 1995.

10. Adequate information was absolutely not provided to my father to help him to understand and manage the infections. I know this from talking to my mum. Later they were then concerned about my mum potentially being infected with Hepatitis. Information should have been given to my father much earlier, as soon as they were aware of the infection at the very least.

11. I can remember my parents were not happy with the way the results and information about the infections were given to them, they criticised the doctors about the way they handled it, they were not happy at all about the way it was dealt with.

Section 3. Other Infections

12. Other than the infections previously mentioned I am not aware of any other infection my father contracted from infected blood products.

Section 4. Consent

13. My father was aware he was being tested for HIV but I don't think he was aware he was being tested for Hepatitis C.

Section 5. Impact of the Infection

14. My father suffered with both physical and mental effects from being infected with the viruses. He suffered with depression and with his nerves and he became an alcoholic as a result of being infected.

15. My father also suffered with insomnia and lost weight due to the infections. He also suffered with vasculitis and had a terrible rash on his feet.

16. My father was refused a mortgage as a result of being infected. He also wanted to have more children, he had always wanted a daughter but was unable to have more children because of the infections.
17. My father was treated with infected blood products from 1977 and died in 1998 so he lived for up to 21 years with the infections. I noticed a deterioration in him when I was around 15, so in about 1990. I really noticed a deterioration in his weight. I noticed a decline in his mental health a lot sooner, he was drinking a lot and his drinking had become quite an issue. I remember he had been to the hospital, that was the first time we found out his drinking was a problem, they turned around during the appointment and said in front of me that alcohol was a problem and mum and dad had to admit it in front of the doctors.
18. When I was a teenager, sometimes I would be up to no good and I would get in trouble when I came home, and even when I hadn't done anything wrong dad was always picking on me, mum would always rush me up to the bedroom out of the way. The infections affected him mentally massively, before he was a happy go lucky person who lived life to the full but when alcohol took hold it changed him.
19. He tried treatments for his infections, and they caused lots of side effects, he was being sick a lot, he was on AZT but I think he had really gone too far for the treatment to help.
20. My father struggled to get a dentist as no one wanted to touch him due to the stigma.
21. My father used to go to the British Legion a lot, everyone there was aware he was a haemophiliac, but when there was a lot in the paper about the infected blood scandal it stopped him going out and he started to drink more at home. My parents stopped mixing with people, they became isolated which had a massive effect mentally on them both. They stayed at home because people had started to ask questions and make jokes about HIV in the club where they used to drink, so they stopped going.

22. There was a stigma associated with the infections. It was all hushed up from me, they never told me until I was older. I remember one time I was playing up and my dad got upset and told me he was dying. They would see things about the infected blood scandal on the news and dad would have nightmares. Dad's infections were kept very secretive within the family, my dad's sister was nosey at times, it was even kept from her and from his mum, only my dad's father, my grandfather knew about it, I think his mum in the end knew as he had lost a lot of weight, so I think he confirmed it to her in the end as well as his sister.

23. Dad operated a light haulage business, but with his drinking he was not in a fit state to do the driving and eventually he had to give up work and lived on his pension. My brother worked for him at the time and in the end he had to do all the driving, my dad's nerves were shot and he couldn't drive on the motorway anymore.

Section 6. Treatment/care/support

24. A district nurse used to come to the house, mum got on quite well with her but that was it there was no other support that I am aware of, although I may not have been privy to it.

25. I can remember they asked my dad to take part in the Cook Report, they spoke to him while he was at the hospital about appearing on the show but dad declined as everyone would then know about it, it would get out in the community and we thought we might come under pressure from people in the local area, he really wanted to have his say though but didn't because he wanted to protect us.

26. People were painting red crosses on people's doors back then if they suspected someone who lived there had HIV, at the time it was associated with drug use, I think there is still a stigma now, so I do not tell many people what dad died of, I say he passed away from a brain hemorrhage if I am asked.

Section 7. Financial Assistance

27. I believe there was a one-off payment of either £80,000 or £85,000 from the McFarlane Trust, it has now changed to EIBSS and I know that has caused my mother some stress.

28. There were always difficulties in applying for financial assistance, it was always means tested and they kept trying to take it off my mum, she worked and she wanted to work, so as soon as she started to work they started to try and take it off of her.

Section 8. Other Issues

29. I really want justice for my mum and dad, this has really affected my mum's life massively as well as our own. My mother never had a relationship with anyone else after my father passed away, she never moved on and started to drink, mum just gave up at the end of her life. She was on anti-depressants when my dad was ill, and they brought on the change. We had to look after her and used to go around 2 or 3 times a day.

30. I think the people who hid this for so long should see jail time, I genuinely do. GRO-D for what he said on the news and TV, people like that should see jail time. It has been hushed up over the years and kept buried, the evidence is it is likely manslaughter what they have done.

Anonymity


31. I do not wish to remain anonymous.

32. I do 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 29th Nov 2022