

Witness Name: Emma Louise Frame

Statement No: WITN1594001

Exhibits: 0

Dated: October 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF EMMA LOUISE FRAME

I, Emma Louise Frame will say as follows:-

Section 1. Introduction

1. My name is Emma Louise Frame (although my married name is Weatheritt) and I live at GRO-C Sunderland GRO-C I was born on GRO-C 1973 and I am a single parent with an 18 year old son, Charlie. I work full time as a medical receptionist.
2. I make this statement in relation to my late father, Jeffrey George Frame. He was born on GRO-C 1951 and died on GRO-C August 1991 at the age of 39 when I was 18 years old. My mother is Denise Susan Elliott (she has since remarried). My parents married on 24 July 1971 and I am their only child.
3. This witness statement has been prepared without the benefit of access to my late father's full medical records.

Section 2. How Affected

4. My father had severe Haemophilia A. He used different blood treatments such as cryoprecipitate, human, bovine and porcine blood and Factor VIII.
5. He received treatment from the Northern Haemophilia Centre in Royal Victoria Infirmary in Newcastle, under the care of Dr Peter Jones, who was the director of the Haemophilia Centre, and Dr Hamilton who was the Head of Haematology.
6. My father was diagnosed with Haemophilia when he was only a few months' old and received blood products from the time of his diagnosis until he died. He also received prophylaxis treatment.
7. After speaking to my mother I believe that no information or advice was given to my father in relation to any risks in using the blood products. Apparently he was informed of the benefits of the blood products but never any risks.
8. My parents had heard about people being infected through contaminated blood products in the news and so they asked questions about it but were told there was nothing to worry about and that the blood products were all safe.
9. As a result of receiving contaminated blood my father was infected with Human Immunodeficiency Virus (HIV), Hepatitis C (HCV) and Hepatitis B (HBV).
10. Whilst my father was alive we only knew that he had been infected with HIV. 12 years after he died my mother received a letter from the hospital stating that he had also been infected with HBV and HCV. They said that they kept samples of my father's blood and had tested it after he died.
11. In about 1984 a while after being told that the blood products were safe, my mother and father went to a meeting with Dr Peter Jones at the Centre and they

were told that my father had HIV. At the meeting my father was told how to prevent infecting other people, namely my mother. My mother said the news was given with regret. My parents were shocked and stunned, and found the news impossible to absorb. They were told not to worry.

12. Dr Jones also spoke about the virus being transmitted through sex, saliva and needles. I am told that nothing else was really mentioned in the meeting. My father's diagnosis was very early for HIV so there was not much information about it around.

Section 3. Other Infections

13. There is a strong possibility that my father was exposed to vCJD but it was never thought about until after he died. In reality, he would probably have had that too.

Section 4. Consent

14. My father was definitely tested and treated without his knowledge or consent.

15. He was tested for HIV without his knowledge as the Centre suddenly told him he had been infected. He was never told that he had HCV but 12 years after he died my mother was told so clearly his blood was tested without his knowledge and therefore without his consent.

Section 5. Impact of the Infection

16. I was only 11 years old at the time my parents were told of my father's diagnosis and initially they did not want to burden me with it. However, I found out about it inadvertently from a children's television news programme. As I was aware of my father's Haemophilia, I put the two together.

17. When my parents came in, I asked them if my father had AIDS. They sat me down and explained the situation to me.
18. My father was in denial of his condition right until the end. He just lived in excess as if there was no tomorrow. In a way, we all did, but it was a terrible strain on my parents. He did not talk to my mam about it but he let his frustrations out on her.
19. The situation ruined my childhood. I lost all interest in school and at about 14 years old I started suffering from panic attacks and so I saw a psychologist as I was worried that my father was going to die soon. I did not get any GCSEs. Though afterwards I had a successful career in painting and decorating.
20. I have suffered from mental health issues on and off since I discovered my father had HIV. At one stage I became very withdrawn and I only ever wanted to be with my parents; mainly my father as I did not know if he was going to live or die. I had three close friends who I confided in but I only spoke to them a few times about the situation; no one else understood. This was in the early 1980s when AIDS was all over the news and press being described as a disease only gays and drug addicts had. In total only these three friends, my close family and two of my parents' friends knew about my dad's illness. It is only since the contaminated blood scandal hit the press in the last few years that we have felt able to tell anyone else what happened to my dad.
21. In the four years before my dad died, I saw two psychologists, and then a bereavement psychologist after he died. I have suffered with and been treated for depression and mental health problems on several occasions since his death.
22. After my father died I became extremely angry with my aunts, uncles and grandparents as they never talked about my father. It was like he had never existed.

23. In 1984, when my father was diagnosed he was still working for the Port of Tyne Authority. He attended hospital with a lot of bleeds but he had a very understanding employer who knew about his Haemophilia (but not his HIV), and just assumed the hospital appointments were due to his Haemophilia, so my father was given time off and so he managed to hold down this job.
24. My father's HIV developed into AIDS before he died in August 1991. At the start of 1991 it became evident that my father's illness was progressing very rapidly. His personality and cognitive behaviour changed dramatically.
25. My father was poorly and took part in a couple of trials for treatment; mainly AZT. He became really ill with it and suffered with a lot of urinary tract infections. I believe it was the only treatment available at the time. He decided to stop taking the AZT medication as it was making him feel very poorly. He received treatment several times a day.
26. My dad changed as a person, it was this that changed about him the most. The physical changes came mostly at the end of his life.
27. As far as I am aware, his HIV infection never impacted his dental treatment.
28. My mother has said in her own words which I will repeat, "Having married against my family's wishes, we lived together for 20 years. Having our beautiful daughter and seeing her life destroyed was devastating. Prophylactic treatment opened up a new life for us and planning a long term future seemed possible for a time until that dream was brought to an abrupt end with Jeffrey's diagnosis of HIV. I was angry at him and the NHS for a long time and probably still am. To love and care for that special person and see their life trickle away was horrendous. His inability to be rational and control his actions was an almost daily struggle. I feel that I was the only one he could be angry with. When the time came to stop his treatment, I sadly agreed as he was no longer the man I loved and knew and I

wanted his suffering to end. He was only 39 years old and I felt he had been stolen from me".

29. As the disease progressed, my father became very susceptible to urinary tract infections. In particular, his behaviour and personality changed; the last 12 weeks were especially awful.

30. On 15 June 1991 my father had an operation on a salmonella growth on the back of his head in the Newcastle General Hospital, it was the only hospital that could handle a patient with AIDS. The operating staff were dressed in hazardous suits for the operation. He was then transferred to the Royal Victoria Infirmary in Newcastle where he stayed following the operation for two months, until he died on GRO-C August 1991. My father was only 39 years old, my mother a widow at 37 and I had lost my dad at 18 years old.

31. Even after he had died we were told to say goodbye quickly as he needed to be sealed in a hazardous bag and then sealed in the coffin. We are not religious and did not want him to be buried anyway, but we were told that burial was not allowed and that he would have to be cremated due to his infectious disease. It was very undignified and heart breaking.

32. My father's death certificate says he died of bronchial pneumonia and Haemophilia A. My mother recalls that she was told to put this as cause of death and that there would be no mention of HIV or AIDS.

33. My father did not really have contact with his side of the family other than his father, my grandad. His mam died when he was only 11 years old so it was only his father who was aware of his infection. My father had a younger cousin who had Haemophilia and HIV who we believe committed suicide because of his HIV. We do not see that side of the family very often.

34. My mother's parents and sisters knew of my father's diagnosis, along with their husbands, but this was never discussed. I am still in very close contact with a family who my parents met on a Haemophilia weekend and they knew as they were in the same situation. In total, very few people actually knew of my father's infection.

35. My father was able to work up until 1991. This was when he started to get particularly poorly and lost a significant amount of weight. His personality changed and I recall that the family we became close to, that I have just mentioned, came to visit in 1991 but my father was so awful to them. They understood that it was due to his illness but my father just became so different. This was also partly due to the growth on the back of his head which was also due to HIV.

36. I did painting and decorating for about 11 years. I also had a very understanding employer. They did not know why my father was really poorly but they knew he was dying in hospital and told me to go away and not to come back to work until I was able. This allowed me to spend as much time as possible with him.

Section 6. Treatment/care/support

37. My parents never received any support or care through my father's illness.

38. My mother had to ask questions as the doctors and hospitals were not forthcoming. She had to ask basic questions like *'is this full blown AIDS?'*, *'why is this happening?'* *'is this the end?'* and similar.

39. Neither of my parents received any counselling or psychological support; it was never offered.

Section 7. Financial Assistance

40. My mother cannot recall exactly about financial assistance however she says any information regarding it would have come from either the Haemophilia Society or the Haemophilia Centre.
41. My father had a monthly allowance from the MacFarlane Trust, it was not much but this ended very soon after he died on 15 August 1991. I am unsure of the application process as my father would have done it.
42. My father received an ex-gratia payment. I am not sure of the exact amount but it was in the bracket for married couples with a dependent child. The money was received in two lump sum payments. The final payment was received by my parents in the first few days of my father going into hospital. He was mentally unwell and he never knew that the payment had been received.
43. My father had to sign a disclaimer for this payment agreeing that he would not make any further legal claims.
44. My mother has always been dubious with the rationale of applying for financial assistance due to discussions with other survivors. She therefore did not apply for, or receive anything else.
45. Whilst I have received nothing, I did apply for financial assistance when I married and wanted to start a family. I had little faith in the NHS that something like the contaminated blood scandal would not happen again and I did not want a boy with Haemophilia as I had seen how much my father had suffered and how much pain he had been in almost constantly. I wanted genetic testing undertaken on GRO-C so that I did not have a boy with Haemophilia.

46. At the time, 1998, there was a type of GRO-C called GRO-C

GRO-C The closest place to have that was in St. Thomas's in London and the procedure had to be funded privately. My GP (who had also been my father's GP), was kind and funded the GRO-C drugs required and I paid for the actual procedure but this pre implanted diagnosis did not work.

47. I then applied to the MacFarlane Trust for funding of the whole procedure but they declined stating that because I was married I did not class as a dependant and that not wanting a child with Haemophilia did not fall into the specific criteria for funding as it was not a direct result of the contaminated blood scandal. I have a copy of this letter from the MacFarlane Trust that further stated that that they felt that *"having a child was a gift from God and not a woman's right"*.

48. I conceived naturally but following genetic testing at 12 weeks I had a termination at 16 weeks as the baby was a boy with Haemophilia. After this I tried again and had another natural conception, the baby was again a boy but thankfully he did not have Haemophilia. It was a very traumatic time for me, a very dark part of my life and I feel I am over protective of Charlie because of this. Thankfully he is a very healthy normal young man.

49. I understand that going through the procedures I did for a child was my choice. As my father was one of the first people involved with HIV treatment, I was one of the first to go through these issues too. Dr Peter Jones said some kind of procedure should have been put in place afterwards as more families are choosing this route when thinking about having children. I do not think I would have chosen what I went through but for Haemophiliacs being infected.

Section 8. Other Issues

50. My son, Charlie is now 18 and he is aware of what happened to my dad, his grandpa. As he got older he started asking what happened to his grandpa and I

have had to tell him gradually as is age appropriate. He can get very angry and upset about what happened and why he never got to meet his grandpa. This shows that the scandal does not end with the person who was infected. Even a grandchild that has never met his grandfather is affected. This shows just how far-reaching the implications of this scandal are. He sees my mother and me crying and upset when talking about it, even though it happened nearly 30 years ago and I still live it every day. There are seriously deep implications from everything that happened.

51. It is impossible for me to put into words or to express how the death of my father has affected my mothers, myself and my son's lives. I loved and still love my dad and to watch his life being so cruelly taken away has been extremely devastating. I found it so traumatising that I have memory loss from parts of my childhood so even some of my precious memories, which is all I have left have been stolen from me. It has now been 28 years since my dad died and I miss him every single day. I just want everyone to know how special my dad was and that, if it was not for this completely preventable tragedy, my mam would still have her husband, I would still have my father and my son would have known his amazing grandfather. Instead our lives have been broken and there will forever be a part of our family missing.

Anonymity, disclosure and redaction

52. 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.

53. I do not wish to be called to give oral evidence unless I can assist the Inquiry.

Statement of Truth

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

Signed. GRO-C

Emma Louise Frame

Dated: 10th October 2019