Witness Name: Simon Paul Francis Statement No: WTN1650001 Exhibits: 0 Dated: January 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF SIMON PAUL FRANCIS

I, Simon Paul Francis will say as follows:-

Section 1. Introduction

- My name is Simon Paul Francis. My date of birth is GRO-C 1968. I am married and live with my wife at GRO-C
 GRO-C I have no children.
- I make this statement as the eldest son of Derek Antoine Francis who was infected with HIV from contaminated blood. My father was born on GRO-C
 GRO-C 1946 and died on 19th November 1996. He was 49 when he died.
- 3. My father was married twice and had children from each marriage. I have 5 siblings, 2 brothers and 3 sisters.
- 4. This witness statement is based on my own personal knowledge and from information that I have been able to obtain from my grandmother, my mother and my uncles. It has been prepared without access to my father's medical records.

Section 2. How Affected

- 5. My father suffered from Haemophilia A, but I do not know the severity of it. I am told our family has a long history of haemophiliac sufferers and I believe my father was diagnosed from birth.
- 6. My father informed me that he was treated with Factor VIII (FVIII) blood products, but I cannot say when he told me.
- Throughout his life, my father was careful not to get injured and, for this reason, his bleeds were very rare. I can recall only two occasions when he was taken to hospital for severe bleeding; once in the late 1970's and once in 1984.
- 8. In the late 1970's, my father went to Kent & Canterbury Hospital because he had a tooth bleed. The bleeding would not stop and he had to go back to the hospital the following day. I do not know whether the dentist was aware that my father was a haemophiliac because the staff did not seem to know how to stop the bleed.
- 9. In 1984, my father went to St Thomas's Hospital in London to stop severe bleeding to his foot. My stepmother (Debbie Francis), who was married to my father at the time, believes the FVIII blood products that were used to treat him at this hospital were contaminated. However, she has no evidence to prove this.
- 10.1 believe my father kept Debbie regularly informed about his medical condition. I reasonably believe that my father discussed with Debbie the incident in 1984 and the treatment that he received at the hospital.
- 11. My mother is the one who told me that my father had AIDS. I am not sure in what year she broke the news to me but I think it may have been in and about 1991.

- 12.1 recall speaking with my father about his condition. This would have been after my mother told me in 1991. I remember my father saying "..you know I have HIV.. right?". I said "yes" and that was it. We did not discuss it any further. It was a very stoic conversation. We did not get emotional about it which perhaps was our way of coping.
- 13. I do not think my father fully understood the disease and the effect it could have on his life. Sometime afterwards, when he found out he would lose his life to AIDS, he found it difficult to come to terms with it.
- 14. I think my father felt closest to me out of all his children. Perhaps it was because I was the eldest and he lived close to me at the time. We did have a close connection and this bond became stronger when I began to visit him more towards the end of his life.
- 15.1 do not know if my father received any information or advice about the potential risk of being infected by contaminated blood. If he had, he would have been able to make an informed decision as to whether or not to take that risk. I do not think my father would have agreed to continue with such treatment if he knew it would lead to him losing his life.
- 16.1 do not know the names of the doctor or doctors who told my father that he had been infected with HIV. However, I do believe that these doctors did not inform him until long time after he had been infected.
- 17. The hospital's failure to advise my father meant, firstly, that close family members were being exposed to a risk that they ought to have known about and, secondly, my father may have chosen to live his life differently from the date of the infection to the date when he died.

- 18. My youngest stepbrother (Ben) was born in 1984. If my father had known he had HIV and about the routes of transmission, perhaps he and my stepmother would have decided against having a child.
- 19.1 do not know if my father was given adequate information to enable him to understand and manage the infection. He did not discuss much about his health with me. I think this was because he did not want me to worry about him. He took the view that everybody dies and the only difference with him was that he knew that it was going to happen soon and he needed to get his affairs sorted before his death.
- 20.1 do not know what information was given to my father about managing the infection. The fact that he tended not to discuss his infection with the family may be because the doctors did not give him much, if any, information about it. If they had done so, he may have discussed it with us.
- 21. The hospital did not inform the family that my father had tested positive for HIV. None of us really knew what was going on. I believe the hospital knew in 1984 that it was treating haemophiliacs with contaminated blood products. The hospital should have been transparent when treating my father, but it was not.

Section 3. Other Infections

22.1 am not aware of any infections other than HIV that my father may have contracted as a result of being treated with infected blood products.

Section 4. Consent

23.1 do not know whether or not my father was informed he was being treated and tested with FVIII products. I do believe that these were the only products on the market at the time to treat haemophilia. I also believe that these

products were contaminated and not safe to use. I do not think my father was informed of the risks of being infected from these products. If he had been informed, he is unlikely to have consented to being treated by them.

24.1 do not know whether my father was being tested for the purposes of research. It is difficult for me to say without reviewing his medical records.

Section 5. Impact

- 25.1 was a teenager in 1984 when I believe my father became infected with HIV. Apart from being a haemophiliac, his general health was good until he was treated with contaminated blood. He was employed as a telecommunications consultant and he was responsible for advising large companies how to set up business. At the time, he was single and his life was normal. His health began to decline rapidly particularly in the last 18 months or so before he died.
- 26. The physical effects of being infected with HIV did not manifest themselves until 1991. The infection did not affect any other part of his body and I am not aware of any other outward symptoms resulting from the infection. I am not certain of the psychological impact that the infection had on my father. When he was working, I would see him once a week or once a fortnight because he travelled to and from Paris, France.
- 27. My father was taking some medication in the last couple of years of his life to manage his HIV. I saw tablets in his bathroom cabinet and I assumed they were for his HIV. However, he preferred not to discuss his medication with me and neither did I ask him.
- 28.1 do not know if my father faced any difficulties or obstacles in accessing treatment or if there were other treatments on the market which ought to have been made available to him.

- 29.1 do not know of the mental and physical effects of the treatments he received.I do not know if the tablets he was prescribed were making him better or worse.
- 30.1 do not know if his infected status impacted upon his treatment, medical and/or dental care for any other conditions.
- 31. My father lost a lot of body weight in the last 18 months of his life and he struggled to walk. He looked very weak towards the end. In this period, he was physically and mentally unable to continue with his employment. He did not seek state benefits to support himself but lived on the money that he earned. He always kept details about his health to himself as he did not want it to be burden on the family.
- 32. In October 1996 my father suffered a stroke and was admitted to St Thomas's Hospital. He was given an individual room on Victoria Ward. He died approximately 6 weeks later. The cause of his death is listed as: I (a) Pneumonia, I (b) Acquired Autoimmune Disease, II. Haemophilia. We gave permission for the autopsy but were not made aware of any results.
- 33. My father left the family home when I very young and when he returned it took a long time for us to re-establish our father and son relationship. It took me several years to trust him again. When I found out that he was going to die due to AIDS, I felt like he was going to go away again and I felt he was going to abandon me again.
- 34. This was a difficult time for me, and I recall that we ended up doing our best to ignore his terminal condition. In hindsight, what we were actually doing was attempting to hide from the truth because we knew that we had to make the most of the remaining time together.
- 35. After my father passed away, his death hit me much harder than when he had left the family when I was a child. I found it incredibly difficult to bear.

- 36.1 work in the theatre industry. Even though my colleagues showed a certain amount of understanding and compassion, the stigma surrounding AIDS was very real.
- 37. When I told people my father had AIDS, I found it necessary to explain to them that he was not gay and sometimes this led me into complicated conversations about his haemophilia and contaminated blood products. For this reason, I tried to avoid talking about the cause of his death as much as possible.
- 38. My father's death had a very lasting effect on my brothers. We were all very close.GRO-CBen was only 12 at the time of his death.
- 39. My uncles and aunts have also taken my father's death badly. This is because my father was the focal point in the family, everyone admired him and loved being around him. After his death, everyone struggled to cope collectively. It broke the family apart. He had a very charismatic personality. He was intelligent and well informed. When that was taken away, everyone spun out of control. He was the person that everyone spoke to about their issues and when we lost him, everyone felt helpless. This still remains the case today.
- 40. My youngest brother's education suffered following my father's death. In the last 18 months of my father's life as his health deteriorated, Ben struggled to study. Apart from that, we found it difficult to pay for his school uniform.
- 41. I took the role of managing his estate as his executor and managed Ben's money up until he reached the age of 18. Losing my father in my 20s had a hugely negative emotional and mental impact on me but I had to keep working to help the family.

Section 6. Treatment/Care/Support

- 42.1 am not aware if my father faced difficulties or obstacles in obtaining treatment, care and support in consequence of being infected with HIV.
- 43.I believe counselling or psychological support was not available to him to help him deal with HIV infection.

Section 7. Financial Assistance

- 44. My stepmother believes that my father received a lump sum payment but she is not sure how much he received or when. She thinks that it may have been in the sum of £10,000.
- 45.As result of litigation, an offer was made to people who were infected from contaminated blood products but I would be surprised that my father signed any documents or accepted any payment.
- 46.I do not know whether my father applied for any financial assistance.
- 47.1 have no other observations about the various Trusts and Funds.
- 48.As an executor of his estate, I received £1,000 from the Macmillan Nurses Trust for my father's funeral expenses. I received no other payment. I think this was made shortly after his death. I did not encounter any difficulties obtaining this payment.

Section 8. Other Issues

49.1 am very frustrated about the length of time it has taken to begin exploring these issues. My main question is what happened at the point of infection and how my father was infected. The NHS has failed to provide our family with basic information about our father's death even though it is responsible for it. I feel as if the NHS has merely brushed all their mistakes under the carpet and this is not acceptable.

50.1 would like to know at what point the NHS knew about the risk of infection and when, if at all, it considered withdrawing the treatment knowing that it could lead those being treated to their death.

Anonymity, disclosure and redaction

- 51.1 confirm that I do not wish to have anonymity and that I understand this statement will be published and disclosed as part of the Inquiry.
- 52.1 do wish to be called to give oral evidence.

Statement of Truth

÷ .

11

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

Signed GRO-C

Simon Paul Francis

Dated (2 January 2019