

Witness Name: Nina Douglas

Statement No: WITN1644001

Exhibits: WITN1644002 - 004

Dated: February 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF NINA DOUGLAS

I, Nina Douglas will say as follows:-

Section 1. Introduction

1. My name is Nina Douglas. I was born on GRO-C 1973 and I live at GRO-C
GRO-C.
2. My mother is currently living with me and I am living with my partner of 28 years. I have 1 estranged brother as well as children and grandchildren. I am currently employed in a family business.
3. I make this statement on behalf of my late father, John Cowen. He was born on GRO-C 1955 and died on 19 May 1991 from AIDS.
4. This witness statement has been prepared without the benefit of access to my late father's full medical records. If and in so far as I have been provided with limited records the relevant entries are set out in the medical chronology at the end of this statement.

Section 2. How Affected

5. My father was diagnosed with severe Haemophilia A as a young child in the 1960s, aged about 4 or 5 years old. I believe he was diagnosed following a bleed.
6. I remember my father used to go to the hospital to have Cryoprecipitate transfusions when I was really young. My mum always used to mention it which is how I remember the name.
7. Since my father was a toddler he was mainly treated at the Royal Victoria Infirmary (RVI) in Newcastle. He was mainly under the care of Dr GRO-D
GRO-D
8. My father's GP was call 'The Surgery' in 12 Portland Square, Carlisle, and he was under the care of Dr Jolly and Dr Hadshar.
9. I believe my father started receiving Factor VIII (FVIII) in the early/mid 1970s. I know he was administering FVIII at home in the mid 1970s as I recall walking into my father's bedroom when he was injecting FVIII and I was shocked as a young girl. I asked him whether he was a drug addict and he explained to me that he required this treatment because of his Haemophilia. He continued to self-administer FVIII up until his death in 1991.
10. My mother always used to reassure me and say it was fine that my father was injecting FVIII.
11. My father required FVIII each time he had a knocked or a bump, or for dental extractions.
12. Everything went downhill from the day my father attended a dentist appointment in the mid 1980s. Shortly after the appointment, he received a letter inviting the whole family to a hall in Newcastle.
13. We travelled and went into the hall like we were attending a conference and I remember there were lots of people that were standing on the stage with

microphones and speakers. This was when they announced that people who were treated with FVIII had contracted HIV and my father was one of them. My parents were shocked as my father did not even know he was tested for HIV at the time.

14. Everyone was upset and tearful and it was just so weird to be in a hall full of people crying. Everyone was asked to give back the stock of FVIII they had as well as the cards which recorded the dates and batch numbers of when they had FVIII. As people were returning them, their names were being ticked off the list.
15. I still remember what happened in the hall like it was yesterday. The way they communicated the news was absolutely terrible. We did not have a private consultation. My mother also remembers sitting next to a very emotional couple whose baby was infected with HIV. It was a horrible way for people to find out that they or their loved ones were infected with HIV and it should have been done on a one to one basis.
16. After reviewing his medical records, I found a letter to my father from Dr GRO- dated 3 July 1985 and it confirms that he is HIV positive. However, what shocked me about this letter was the way it was written to my father. It states the following: *"...I am afraid that your result from the General shows that you are HTLV III antibody positive. Please remember two things, firstly this must be confirmed by a more sensitive test, and secondly that if this is positive it simply fits in with everyone else's results...."*. The doctor made it sound as though it was normal for everyone to be infected with HIV. I do not know if my father received this letter and if he did, I believe he received it after he was told in the conference. A copy of this letter is exhibited at **"WITN1644002"**.
17. After my father was diagnosed, my father developed AIDS and was cared for at home. In the last 2 weeks before his death, he was moved to CI where he died in May 1991. We were not allowed to see my father after he died and the hospital staff told us that he needed to be "bagged up" as soon as possible

due to his AIDS. He had lived with the infections for 5/6 years before he died. I knew my father was poorly but did not realise he was ill enough to die.

18. In 2009, a man knocked on my mum's door and asked her to fill out a form as there was a possibility that my father also contracted Hepatitis C (Hep C) when he was alive. I believe this man was from the Skipton Fund. It was at this point that we found out that my father could also have contracted Hep C. No one ever contacted my mother again regarding my father's Hep C. However, after reviewing his medical records, I found a blood test result which states that he tested positive for Hep C in 1990. I was shocked when I saw this blood test result. The doctors knew my father tested positive in 1990. I do not believe that my father was told that he was being tested for Hep C and that the test was positive. The blood test also confirms that he was tested for Hep B and both Anti HBs and Anti HBc shows a positive result. This really upset me. I do not believe my father knew that he tested positive for Hep C. A copy of this blood test is exhibited at **"WITN1644003"**.

19. My father was also infected with Hepatitis B (Hep B). I reviewed his medical records and there is a blood test record dated back to the 30 September 1974 which confirms he was tested for Australia Antigen and the antibody was a weak positive. A copy of this blood test is exhibited at **"WITN1644004"**. This was later confirmed in a blood test that was done in 1981.

20. Neither of my parents received any information or advice regarding the risk of being exposed to the infections as a result of FVIII. After my father's death, my mother used to say that if my father knew of the risks, he would have never had FVIII.

21. I do not know if my parents received any information about the infections but I believe they did not. They were very lost when they heard the news that my father was infected. I believe that even my brother and I, as children should have been told about the infection. We were not even informed that there was a risk of transmitting the infection through my father.

Section 3. Other Infections

22. I do not know if my father received any other infections other than HIV, Hep C and Hep B.

23. I was always worried that my father might have had vCJD. He had problems with his nervous system so I believe this was a link to the vCJD. My father had a post mortem and I have been trying to get hold of the report, but I have been unable to do so.

Section 4. Consent

24. I believe my father was treated and tested without his knowledge and consent.

25. My father did not even know he was tested for HIV and so he did not give his consent to be tested. He was shocked about when and how he was told that he had contracted HIV. I believe that he had no knowledge that he was Hep C positive or that he had Hep B.

26. I believe he was definitely tested and treated without being given adequate or full information.

27. I do not know if he was tested or treated for the purposes of research.

Section 5. Impact of the Infection

28. My father suffered mentally as a result of the infection. My father used to compare his situation to a double decker bus coming towards you in slow motion and you do not know when it is going to hit you. My father just took it day by day after he found out about the HIV and did not know when he would die from it. He was very concerned and worried for us, his family, and what would happen after he passed away.

29. My father once told my mother that after he passed away, he wanted her to go out and meet someone else and get remarried. He used to ask my mother

to promise him she would do this but she always refused. To this day, she never met any other man and she is still very devoted to my father and wears her wedding ring.

30. My father started going out less and stopped having a normal life. He just became very down and he hallucinated a lot. His demeanour changed and he became a very different person. His happiness and cheerfulness disappeared but prior to the diagnosis he was a fun, jokey person, making everyone laugh.

31. My father also suffered physically as a result of the infection. My uncle told me that my father weighed 4.5 stones when he died. He lost a lot of weight and towards the end of his life in the last year, my mother had to help my father go to the toilet as he would wet and soil himself without even realising. He was always tired and it stopped him going out and about. Following the diagnosis of HIV, my father became ill gradually but in his last year his illness rapidly changed and deteriorated rapidly.

32. Both my parents were mentally and physically drained as a result of my father's infections. However, my mother did not give up on looking after my father.

33. I believe in the 1990 my father received AZT treatment for the HIV. This treatment had both mental and physical effects. Everything went downhill from this point and he became a funny greyish-yellow colour and became very poorly. His teeth went very bad, his hair fell out and he was completely out of energy. He got very confused at times which was strange. He also lost his appetite and he just wanted to eat soft foods. He stopped the treatment because of the above symptoms.

34. My father's infected status impacted on his dental treatment as he had to transfer from a private dentist to the RVI for his dental care.

35. Whilst my father was sick and poorly, my mother was looking after him and so I had to grow up quick at the time. I was looking after my brother a lot and took responsibility of him to take the burden off my mother. I had to make sure

I was not being a nuisance or anything which I know would have upset her. It was just such a sudden shock for me at the time that my father was not going to live long. It happened so quickly.

36. When we received the death certificate, my mother phoned the registrar and pleaded with them to take off the cause of death, 'AIDS'. My mother was devastated and did not want anyone to know my father died of AIDS due to the way the media portrayed it at the time. We always kept the cause of my father's death private and to ourselves.

37. On hearing about my father being infected with HIV, his mother (my grandmother) felt very guilty and heartbroken as she was

GRO-C

GRO-C

38. I was only 18 years old when my father died. I was shielded but it has still affected me and my mother and it still does. My mother never remarried and she gets upset when she receives letters from the Macfarlane Trust and the Skipton Fund.

39. My father worked up until the last year of his death. He used to work at the Cumbuland News in the printing room. He enjoyed his job and I believe he would have continued to work until retirement.

40. My education was heavily affected as a result of my father's infection and his death. Whilst I was in school, I did not learn anything because I was constantly thinking about my parents. I did not pass my exams even though I was really bright at school prior to all the problems.

41. My work life was also affected. I was working as a waitress just before my father's death and I started receiving warnings for not turning up to work on a few occasions.

42. Our finances were limited and my mother had to be careful once she realised my father was not going to be around for long.

Section 6. Treatment/care/support

43.I do not remember my father having any difficulties or obstacles in obtaining treatment, care and support as a consequence of being infected with HIV.

44.I do not believe that my father was offered any counselling or psychological support for the HIV and none was offered to me or my mother. I believe it would have definitely helped if the support was offered to us both.

Section 7. Financial Assistance

45.I do not think my dad received any financial assistance. I believe he was a party to the 1991 litigation claim for which he signed a waiver, but did not live long enough to receive the money. However, just after my father's death, my mother received a lump sum payment of around £60,000. I remember my mother and father had a big argument on the day about signing the waiver, but I believe he did sign it as he wanted to be sure that our family was going to be fine financial after he was gone.

46.I believe my mother received a lump sum payment of £20,000 from the Skipton Fund. I do not remember when she received it. I do know the application process.

47.My mother also receives monthly payments in the sum of £580 from Macfarlane Trust which later changed to EIBSS.

48.My mother used to get so anxious filling out the same thing in different forms as it kept reminding her of my father's death.

49.I did not receive any financial assistance as a result of my father being infected.

Anonymity

51. I do not wish to remain anonymous.

52. I do wish to give oral evidence to the Inquiry.

Statement of Truth

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

Signed..

GRO-C

Dated 27th February 2019.

MEDICAL SUMMARY

(This summary is not intended to be exhaustive but sets out key points in the records relevant to the Statement)

Virology Results

15.09.1977	Australia Antigen/Antibody: Negative
24.09.1979	Australia Antigen/Antibody: Negative
15.09.1980	Australia Antigen/Antibody: Negative
24.06.1985	HTLVIII Antibody: Positive
24.08.1981	HBs antigen: Negative
	HBs antibody: Positive
20.10.1988	HIV (HTLV III) Antibody: Positive MRC Trial
18.12.1990	HBS Ag: Negative
	HBs AB: Positive
	HBc Ab: Positive

Significant Entries