Witness Name: Sarah Gough
Statement No:WITN1246001
Exhibits:WITN1246002-3
Dated: January 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF SARAH GOUGH

I, Dr Sarah Gough, will say as follows:-

Section 1. Introduction

1. My name is Dr Sarah Gough. My date of birth is GRO-C 1974, and I live at an address known to the Inquiry.

2. I make this statement in relation to my father, Christopher Gough, who was born on GRO-C 1942 and contracted HIV, Hepatitis B (HBV) and Hepatitis C (HCV) via contaminated Factor VIII treatment. He died of AIDS on 10 February 1995, aged 52.

3. My mother, Eileen Gough, sister, Caroline Gough and brother, Dr Nicholas Gough have all been affected by my father's death. I have been asked by the other members of my family to provide this statement on their behalf. Where information provided is not within my own knowledge it is based on what my mother has told me.

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. Christopher was diagnosed with severe Haemophilia A when he was a young boy. He suffered from spontaneous bleeds into his joints and muscles because of a Factor VIII deficiency.

6. When he was young there was no specific treatment for Haemophilia other than bed rest and analgesia. This meant that his joints were very badly damaged and he had severe osteoarthritis as a result in his later years. Despite this, he worked full time as a Chartered Accountant and was a fantastic father to me and my siblings.

7. From the age of 4 he was treated at the Haemophilia Centre at the Churchill Hospital in Oxford. He was living in GRO-C but travelled to Oxford for treatment as it was the nearest Haemophilia Centre. At that time Dr Charles Rizza and Dr James Matthews were responsible for his care. In later years his care was managed by Dr Paul Giangrande.

8. When Factor VIII became available it revolutionised Christopher's treatment. He had multiple infusions from the 1970s (when Factor VIII concentrate first became available) until his death. The products he was treated with included Kryobulin, Factorate, Koate and BPL FVIII 8Y. These were administered intravenously in the event of a bleed, usually at the Churchill Hospital but also, in later years, by my mother at home.

9. My father was co-infected with HIV, HBV and HCV due to the use of contaminated Factor VIII which was imported into the UK.

HIV

10. In the mid 1980s there was a lot of concern amongst the haemophiliac community about HIV infection. My mother recalls that my parents got most of their information from the television rather than the hospital.

11. There is nothing in my father's medical records about the risk of infection and my mother does not remember it ever being discussed with her or my father.

12. In May 1983 a letter was sent to my father from the Haemophilia Society on behalf of Professor Bloom who was the Chairman of the Haemophilia Centre Directors. This was to reassure patients that the cause of AIDS was unknown and although cases had been reported in American haemophiliacs, there was no proof that this was due to an infective agent within blood products. Professor Bloom did not feel that the treatment programme should be altered. A copy of this letter is now exhibited at **"WITN1246002".**

13. My father's pathology records confirm that he first tested positive for HIV in the summer of 1985. I believe that the first tests for HIV were very unreliable and had to be repeated multiple times.

14. On 1 October 1985 my father was telephoned by the hospital and told that he was HIV positive. He was naturally devastated. My mother cannot recall him being offered any additional support at the time of his diagnosis.

15. I believe it was inappropriate for my father to be told his test results over the phone.

16. Some time later he called the hospital to ask for further information about the potential routes of transmission etc.

17. **GRO-C**

18. There are no records in the medical records I have obtained which record him being informed of his HIV diagnosis. I believe that this should have been recorded and I am not clear if there is no record because it wasn't recorded or because his records are incomplete. There is nothing written about what

information was given to him or what support (if any) was offered to him and the family. I find this particularly odd and shocking that such a clearly significant clinical event was not documented. There is also no letter from the hospital to his GP informing his GP of the HIV test result.

19. In February 1986 my father received a letter from the Haemophilia Centre asking him to return a form choosing one of three options:

a. He had been told his HIV results
b. He had not been told his results and DID want to know
c. He had not been told his results and DID NOT want to know

This was so that the Centre could ensure its records were "correct." This implies that the Centre did not know which of its patients had been told this life changing test result and I believe it is indicative of a complete failure in communication between the medical team and patients around an extremely sensitive topic. I also find it concerning to think that there were patients who had not been informed of their results and who may therefore have unwittingly passed the infection to their partners.

HCV

20. It is clear from my father's medical records that the hospital knew he had tested HCV positive in February 1992 if not earlier. My father was only informed of this diagnosis in December 1994. On this occasion he was told of his diagnosis face to face at a routine clinic appointment so he had the opportunity to ask questions and discuss the implications of his infection. However, there was still a significant delay in him being informed of the test results.

HBV

21. The medical records suggest that there was evidence my father had had an HBV infection as early as 1982. This was never specifically discussed with him.

Section 3. Other Infections

22. I am not aware of any other infections that my father may have been exposed to.

Section 4. Consent

23. It is clear that my father was tested for HBV, HCV and HIV multiple times. I believe that the hospital was routinely testing viral serology. He was consented for the HIV tests.

Section 5. Impact of the Infection

24. After his HIV diagnosis on 1 October 1985 my father remained physically well for the first few years aside from his usual bleeds and severe osteoarthritis related to his Haemophilia.

25. However, his mental health was significantly affected by his HIV diagnosis. He felt that the diagnosis had ruined his whole life and he felt guilty about the effect his HIV would have on the family. He was terrified that news of his diagnosis would leak out and the family would suffer.

26. He also worried terribly about whether he would be able to carry on working and earning money to support his family.

27. He contemplated suicide and saw a psychiatrist on several occasions. He was prescribed antidepressants and remained on these intermittently for the rest of his life.

28. His physical deterioration started in September 1992 when he was admitted to Oxford with Pneumocystis pneumonia which was an AIDS defining illness. He was started on AZT which was the AIDS treatment regime at that time.

29. He continued to slowly physically deteriorate over the next few years with symptoms related to HIV and also side effects from the treatment. He had ongoing fatigue, diarrhoea, oral thrush, seborrheic dermatitis and post herpetic neuralgia after a shingles infection.

30. In January 1995 he became confused and started falling over. He was admitted to Oxford and investigations showed he had cerebral lymphoma. He was discharged on 3 February but rapidly deteriorated and he died at home on 10 February 1995 with all the family present.

31. We were fortunate that we were supported by the family GP who was excellent. We never received any input from palliative care despite my father's very poor prognosis.

32. On the day of his death we were visited at home by the Coroner's officer from Salisbury because there was concern about what to put on my father's death certificate. As he had contracted HIV via contaminated Factor VIII there was a suggestion that he had been unlawfully killed and we were told there would need to be an inquest.

33. Following discussions between our GP, the Coroner and the Churchill Hospital it was decided that the death certificate should read:

1a Cerebral Lymphoma
2 Haemophilia

34. This meant that AIDS was not even mentioned on the death certificate even though this was what led to my father's death. It was very distressing for us, as a family, to have to go through this process when we were grieving. The fact that they failed to record AIDS on the death certificate made us feel like there was something to be ashamed of and just added to us believing that there was a cover up.

35. My parents were devastated by my father's HIV diagnosis. Before his diagnosis he was living a full life despite his Haemophilia and he was then told that he had a terminal condition as a result of the treatment he had received. My mother used to give him his Factor VIII treatment at home so she was left with the guilt of thinking she might have been the person who injected him with the contaminated Factor VIII.

36. Although my father lived asymptomatically with HIV for several years my parents lived with the constant worry that every cold signified the start of AIDS.

37. In the 1980s there was a significant stigma associated with HIV fuelled by the distressing Government adverts that were around at that time. My parents were very concerned about anyone finding out about my father's HIV status and my mother remembers being advised by either our GP or the doctors at Oxford not to tell anyone. At first they told no one at all. Then, over time, they told a few family members/close friends. A couple of these supposed "friends" never spoke to my parents again after finding out.

38. We lived in a small town and many people knew that my father had Haemophilia. Some people put two and two together and surmised that he was infected. My mother remembers people crossing the road to avoid us and can remember parents not allowing their children to come round to our house to play. My mother also heard stories about people with HIV having bricks thrown through their window and was worried that something like that might happen to us.

39. During the late 1980s we were invited to Florida to stay with family. We were not able to go because HIV + individuals were not allowed to enter America.

40. Neither of my parents were able to obtain life insurance because of my father's HIV positive status. My father continued to work as an accountant until the last few months of his illness although he increasingly worked from home.

41. When my father died I was only 20. My siblings were 18 and 15. We were all in full time education. His death had a significant effect on all of us. Concerns about the stigma surrounding AIDS meant that we could not really talk about it outside the family and even our closest friends didn't know that he had died from an AIDS related illness. His illness and death certainly impacted on our mental health. Some of us were able to access support from our place of education.

Section 6. Treatment/care/support

42. My parents were not offered any counselling or support at the time of my father's diagnosis. My father later saw a psychiatrist as set out at Paragraph 27 above.

43. Neither I nor my siblings were offered any support via the NHS when our father died.

Section 7. Financial Assistance

44. After my father's HIV diagnosis my parents took legal advice about taking action against the NHS for infecting him with HIV. In the end the legal costs were too high for them to consider pursuing this particularly as they knew that my father's ability to earn was likely to be compromised by his illness.

45. In 1990 my parents were given an ex gratia sum from the Government. The letter they received at the time made it clear that this sum did not represent compensation.

46. In May 1991 my parents were awarded a settlement by the MacFarlane Trust as a non litigant. My father had to sign a disclaimer stating that he would not take any further legal action in order to receive the money. A copy of this disclaimed is exhibited at **"WITN1246003".**

47. When he died my mother received some further money to help with funeral costs and while my siblings and I were in full time education my mother received financial assistance from the MacFarlane Trust.

48. My mother then received a further payment from the Skipton Fund regarding my father's HCV infection in 2011.

49. My mother then found out, by chance, that she might be eligible for some more financial assistance after she heard a report on the news in 2017. The MacFarlane Trust was about to be merged and renamed the Business Services Authority Infected Blood Support Scheme. She rang the scheme which had no record of my father at all. She had to re-provide all the evidence which included his death certificate. As his certificate did not put AIDS as the cause of death (or indeed mention it at all) they refused her application. I had to request a letter from the haematology department at the Churchill to explain the situation. I do not understand why they didn't have the records from the MacFarlane Trust.

Section 8. Other Issues

50. My father had his life cut tragically short due to contaminated Factor VIII. He never got to see his children grow up and develop careers. He never got to meet his grandchildren. He is never far from our thoughts, especially as some of his grandchildren also have Haemophilia.

51. Thankfully, genetically modified Factor VIII should mean that infected treatments are a thing of the past. However, it is important that the Inquiry hears stories like my father's, however difficult it has been for me to tell, to ensure this type of medical catastrophe never happens again.

Anonymity

52. I do not wish to apply for anonymity.

53. I am happy to give oral evidence at the Inquiry if required.

Statement of Truth

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

Signed. GRO-C ....

Dated 19/1/19