

Witness Name: N J Gough
Statement No: WITN4109001
Exhibits: 0
Dated: 12th February 2020:

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF NICHOLAS JOHN GOUGH

I, Nicholas John Gough, will say as follows:-

Section 1. Introduction

1. My name is Dr Nicholas John Gough and my date of birth is [GRO-C]1979. I live in [GRO-C], Kent and my full address is known to the Inquiry. I am a full time medical doctor in the NHS and I write this statement in relation to my late father, Christopher John Gough (date of birth: [GRO-C]1942). He was a severe haemophiliac who contracted HIV, Hepatitis B (HBV) and Hepatitis C (HCV) from receiving contaminated Factor VIII treatment and subsequently died of Acquired Immunodeficiency Deficiency Syndrome (AIDS) on 10th February 1995, aged 52.
2. I was 15 years old when my father died; I learnt the details of and circumstances surrounding his death as he approached the end of his life or after his death.
3. This witness statement has been prepared by me without direct access to my father's medical records. However, my sister has also written a witness statement using his medical notes which I have read.

Section 2. How Affected

4. My dad had severe Haemophilia A (a genetic deficiency of Factor VIII – an endogenous clotting factor) which was diagnosed when he was a young boy. As a child, I remember the large bruises he frequently had all over his body and whilst independently mobile, he frequently used crutches to aid mobilisation due to the years of joint bleeds which caused arthritis affecting most of his large joints.
5. His condition was treated at the Haemophilia Centre at the Churchill Hospital in Oxford, UK, which was the nearest centre to where we lived in [GRO-C]. I remember we often went with him as a family so as to combine some of his medical appointments in Oxford as a kind of family day out!
6. The treatment for his Haemophilia was intravenous Factor VIII (derived from plasma) which he would either receive in hospital or latterly at home, given by my mum. I understand from my mum that dad had multiple infusions from approximately the 1970s when it first became available until his death. Factor VIII was not used prophylactically as it routinely is now but was used to aid coagulation after trauma or spontaneous bleeds.
7. My father was infected with HIV, HCV and HBV from contaminated Factor VIII. I understand that during the era he received this blood product, it was largely imported.
8. I simply don't know what information or advice was given to my dad about the risk of being exposed to infection as a result of receiving Factor VIII. However, my mum doesn't remember dad ever being made aware of such risks or being formally consented. Having spoken to my sister, who is also a medical doctor and who has read my father's medical notes and also submitted a witness

statement to this Inquiry, there is nothing documented in relation to consent and no consent forms. He tested positive for HIV in 1985, a time during which little seemed to be known about the disease. Much of patients' information about HIV was derived from the media rather than more trusted medical sources. (I appreciate reliable information about a relatively unknown virus was hard to come by at this time).

9. My understanding from my mum (concurred by the pathology results in my dad's medical notes) is that dad tested positive for HIV in 1985; a result which was given to him over the phone which is something I still find very hard to comprehend albeit in comparison with current practices in health care. My sister states there is no record of this telephone call or of communication with his GP of the result.
10. My sister also states that my fathers' medical notes contain a copy of a letter dated February 1986 (the year after my dad had been told his diagnosis over the phone) from the Haemophilia Centre in Oxford asking him to complete a form answering the following:
 - He had been told his HIV test results
 - He had not been told the result of his HIV test and *did* want to know
 - He had not been told the result of his HIV test and *did not* want to know

The implication is that the Haemophilia Centre was not even aware of which of their patients had been told the result of this life changing test!

Section 3. Other Infections

11. I understand the first HCV positive pathology result in my dad's medical notes was from February 1992. He was first told this in December 1994 according to my mum.
12. I understand the first HBV positive pathology result in my dad's medical notes was from as early as 1982.

Section 4. Consent

13. I do not know whether my dad received Factor VIII knowing the potential risks of receiving such a treatment. The lack of documentation or consent form in his medical notes suggests his decision was not informed. However, I also accept that in health care you often proceed with something in good faith and the dangers of so doing sometimes only become clear at a later date. The practice of consent may also have been different in the 1970-80s compared the current day. It may have been written consent wasn't routinely required for interventions such as blood/ blood product infusions in that era.

Section 5. Impact of the Infection

14. Physically, my dad remained relatively well during the early years post HIV diagnosis. He was able to work as an accountant and continued to be a fantastic husband and father to his three young children. He was frequently at medical appointments which to me was normal as I have many memories of dad involving hospitals as part and parcel of having Haemophilia.

15. In 1992 he became unwell and I remember he went to hospital with severe pneumonia (what I later learned to be *Pneumocystis pneumonia* – an AIDS defining illness). He recovered and started anti-retrovirals (AZT) and he was able to return to work but was increasingly troubled by physical symptoms of both AIDS and its anti-retrovirals including oral thrush, diarrhoea, fatigue and shingles and associated post herpetic neuralgia.

16. I understand from my mum that my dad's diagnosis had a huge impact on him mentally. Pre-HIV/HCV/HBV, dad was a worrier so found it very difficult to cope with not only having contracted a terminal illness, but one with such stigma attached.

17. I understand my mum and dad were advised by the doctors / GP not to tell anyone about his diagnosis. Indeed, my mum recalls telling a few close friends at the time who suddenly distanced themselves from our family and whom my parents never saw again. Many of my dad's friends / colleagues were aware he had haemophilia so may have concluded he had been infected which might explain a few instances where their children were not allowed to come round to play with my sisters and I when we were children. The Government advertising campaigns are still pretty shocking (which I appreciate was their point) to watch now!
18. He worried constantly that any symptom might signify the start of an on-going deterioration towards his death. He worried about leaving Mum without a partner and leaving his children without a father. He worried about his clients and letting them down (he was a self-employed accountant and ended up selling his business to a corporate firm of accountants as he was too unwell to do his clients work; a decision which he found really difficult as he felt he had let people down). I understand he sought medical advice to help with his low mood and anxiety.
19. Shortly after Christmas 1994, he was admitted to hospital with confusion and had a cerebral lymphoma diagnosed (AIDS related). He was discharged home for end of life care in early February and died on 10/02/1995.
20. I was 5 years old when my father tested positive for HIV and my parents made the decision not to tell me or any of their children in the beginning. I was told a few weeks before he died, my 2 elder sisters were told a few months before and 2 years before his death respectively.
21. In retrospect, I am pleased my parents '*lived a lie*' (as my mum describes it) as I am sure I would have been worrying about dad every time he caught a cold or was hospitalised when instead I simply assumed all his hospital admissions/ appointments related to his haemophilia which was something I had grown up understanding you lived with (and didn't die from).

22. As a teenager, I remember asking my dad about AIDS and haemophilia as the infected blood / HIV scandal hit the headlines. I remember him saying he was '*one of the lucky ones*' as he had not been infected and taking his word for it. Whilst my parents were simply protecting me. Keeping the truth from their growing children must have been difficult, especially about such a sensitive, stigma ridden topic. I myself now have young children, which adds another perspective to me about how difficult things must have been for my parents.
23. I remember, after dad's death, asking Mum if she was also HIV positive and not really believing her when she said no. I asked to see her negative test result before believing her.
24. I never talked about how my dad died with school friends; it was the stigma of HIV / AIDS that concerned me I think. Aged 15, I wasn't quite sure how my friends would react being in the transitional stage between teenage years and adulthood.
25. Twenty-five years on, HIV-AIDS is much better understood and the stigma has dwindled but I do now still think twice about being honest with people who ever ask. Depending on my judgement of the individual, cerebral lymphoma sometimes seems the safer, more acceptable diagnosis.
26. I was well supported by my school who provided access to a counsellor which I recall finding helpful being able to talk in a '*safe space*' to an adult. My dad died four months before my GCSE exams started. I was able to achieve my predicted grades which is I think because I used revising and focusing on work, rather than grief as a coping strategy, something I have done at other times since.
27. Whist I will always consider myself fortunate to have had a loving and caring father for 15 years I do still miss him and feel sad not to have had the opportunity to have got to know him as an adult and do things with him now that we both really enjoyed e.g. watching cricket together. It does make me frustrated to think that his death could have been avoided, however I also

appreciate these things are easily said in hindsight. I would like to think Factor VIII and other blood products were used with nothing but good intention and that once the risks/ consequences started to surface, things changed immediately. I am pleased the Inquiry will look to establish whether this was actually the case.

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 If something has been learnt from the experience of my dad and countless other haemophiliacs and those needing blood or blood products in the 1970s and 1980s I am glad they are the beneficiaries of it.

29. During my training as a junior doctor, I briefly worked in haematology and I remember the haemophilia consultant describing very poignantly (without knowing my dad had haemophilia or that he was dead) how a generation of his haemophiliac patients had simply been '*wiped out*' as a result of (what he described as) '*a total shambles*' and '*one of the NHS's darkest times*'.

30. Whatever the result of this Inquiry, I am not sure it will provide '*closure*' for me. I write this statement alongside my family to give dad a voice. Twenty-five years on I am not looking for an individual or government to blame. My dad would just wish the events surrounding the infected blood scandal were fully investigated so that any lessons can be learnt to ensure a similar catastrophe never happens to others again.

Section 6. Treatment/care/support

31. I don't recall my dad facing difficulties in obtaining what treatment was available for his HIV/HBV/HCV infection.

32. As described above, as a 15-year-old I received some counselling for about a year after my dad's death through my school. Some of what was touched on

was bereavement and some was my concerns of what friends might think of me if they knew how my dad had died.

Section 7. Financial Assistance

33. What I write below is information my mum has provided.

34. My dad and other people in similar positions looked into legal action against the NHS however they soon realised the legal costs would be far too much so they didn't pursue this.

35. They received an ex-gratia sum from the Government in 1990 which was accompanied by a letter making clear this was not compensation or an admission of responsibility for any of the events.

36. In 1991, they received a settlement from the Macfarlane Trust and my dad had to sign a disclaimer that he would not take any legal action in order to receive this money.

37. In 2011, my mum received a payment from the Skipton Fund regarding my father's HCV infection.

38. In 2017, my mum applied for and was awarded further financial assistance from the Business Services Authority Infected Blood Support Scheme (EIBSS).

Section 8. Other Issues


39. There are no other issues.

Anonymity, Disclosure and Redaction

40. I do not wish to remain anonymous and I would be happy to give oral evidence to the Inquiry if needed.

Statement of Truth

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

Signed.....  ..

Dated 12th February 2020