

Witness Name: TARA ALLEN

Statement No: WITN1614001

Exhibits: WITN1614002

Dated: JANUARY 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF TARA ALLEN

I, Tara Allen, will say as follows:-

Section 1. Introduction

1. My name is Tara Allen. I was born on [GRO-C] 1976 and I live at [GRO-C] [GRO-C] Berkshire [GRO-C]. I have two children, a daughter aged 25 and a son aged 21. [GRO-C]
2. My father, Michael James Cox (born on [GRO-C] 1945), was co-infected with the Human Immunodeficiency Virus (HIV), the Hepatitis B Virus (HBV) and the Hepatitis C Virus (HCV) from contaminated blood products. He died from liver failure on 7th June 1993 aged 48.
3. My mother, Susan Delglyn, and my brother, Shayne, have given their own Statements to the Inquiry (Witness Numbers WITN1183001 and WITN1642001 respectively).

4. This witness statement has been prepared without the benefit of access to my father's full medical records. If and in so far as I have been provided with limited records the relevant entries are exhibited to this statement in the medical chronology.

Section 2. How Affected

5. My father had severe haemophilia A, diagnosed as a young child.
6. My father was treated at the Oxford Haemophilia Centre at the Churchill Hospital under the care of Dr Rizza and Dr Matthews. Dr Giangrande took over his care in the early 1990s. My son is also treated at the Oxford Haemophilia Centre and he was under the care of Dr Giangrande's.
7. My father was treated with Factor VIII (FVIII). I refer to **Exhibit WITN1614002** being copies of my father's treatment record.
8. I remember my father telling me and Shayne that he had HIV one evening as we sat on the sofa in the living room watching the television together. He blurted it out to us. He said "I have AIDS". I left the room when he first said it. I could not believe it. He said "You can't tell anyone. If you do, no-one will want to be your friend. No-one will speak to you. People think you can catch it drinking out of the same cup." I was at secondary school. I believe that I was 12 or 13 years old at the time.
9. There is evidence within my father's medical records that he was first tested HIV positive in April 1985. My father was not aware that he had HIV in 1985. He would not have been able to keep that information from my mother given the enormity of the diagnosis. When I was just 10 or 11 years old (I recall that I was still at primary school), I became self conscious about the hair on my legs. I took my father's razor and used it to shave my legs. It became something of a family

joke instigated by my father that he never had a razor that wasn't blunt. My father would not have allowed me to use his razor if he knew he had HIV.

10. My father was really worried about exposing me and Shayne to the risk of contracting HIV. He kept his needles away from us and would scream "get out, get out" at me if I happened to enter his room whilst he was injecting himself.

11. Everyone knew about HIV/AIDS from the newspapers and the tombstone TV advertisement. Shayne and I (out of fear of discovery and stigma) were the children that laughed the loudest at the AIDS jokes at school. My father had joint replacements and walked with a limp. I could not tell my friends that my father had haemophilia because of the HIV affiliation. That was difficult. Friends would ask 'what is wrong with your dad's leg' and there was nowhere for me to go in providing a truthful answer. My father having HIV became our family's 'dirty secret'. The fear back then was instilled within us. We thought my father was going to die.

12. In or around 1990/1991, my father had oesophageal varices and had to be rushed to hospital vomiting blood. In or around the Autumn of 1991 my father had a brain haemorrhage. He did not know that he had HCV and that he had developed chronic liver disease until 1993. My father's liver disease was, by then, far too advanced to be a sudden development. There are huge information gaps in my father's medical notes and records and none of the papers were in chronological order when we (my mother, Shayne and I) received them. It is however clear from my father's medical records that my father had HCV and chronic liver disease before 1989/1990. He was not told until around six to eight months before he died.

13. As stated, once he knew, my father was alive to the risk of infecting us with HIV. He was frightened about us coming into contact with his needles. My father should have been informed of his HIV diagnosis as soon as he first tested positive. He should also have been informed of the HCV diagnosis straight away

and given advice about the risk of infecting others (as well as treatment). Doctors have a responsibility to their patients' families. My father was vomiting copious amounts of blood in the car on the way to hospital with burst oesophageal varices. I was also unwittingly placing myself at risk every time I used my father's razor.

Section 3. Other Infections.

14. My father had HBV in addition to HCV and HIV. I do not believe that he ever knew that he had HBV. We did not discover this until we obtained my father's medical notes and records in 2018.

Section 4. Consent.

15. I believe my father to have been tested for infections without his knowledge and consent. Despite large gaps, it is clear from his medical notes and records that he was tested for various infections. If he had known about the testing, I believe that he would have enquired about the results.

Section 5. Impact

16. My father's HIV diagnosis had a huge impact upon me. As a young girl entering my teenage years, I had to come to terms with the fact that my father was terminally ill. There was no offer of support or counselling. I was frightened and confused and under a lot of stress in having to keep my worries to myself because of the stigma associated with HIV/AIDS. After my father's brain haemorrhage, my parents' relationship became very strained and my mother started working nights at Tesco. From the age of 15 years, I became my father's main source of support. I took on an adult's role. I was his best friend and confidant. By the time I was 16 years old I was pregnant and had dropped out of school. I spent a lot of time at home with him in the final months of his life, often

sitting up together into the early hours of the morning. He was very ill. He knew that he was dying and he would often break down. He was too frightened to go to bed and lent on me for psychological support. It grieves me that he had no professional counselling and support at that time. He also very much wanted to hold on until I had had my baby.

17. When my father died, it tore our family apart. I had a lot of anger towards my mother and felt that there was barrier between us for many years. I have had anxiety issues and an eating disorder over the years.

18. My daughter was born just **GRO-C** weeks after my father's death at the John Radcliffe Hospital which was where my father died. I was given my own private room with an en-suite bathroom as opposed to being in a communal ward with other mothers. I was just 16 years old and thought at the time that I was being granted a privilege because of my age. I remember my mother being pleased by it but I also remember feeling uncomfortable for a number of reasons that I could not then make sense of.

19. When the room was allocated to me and I was shown the bathroom, I was told that I should use that bathroom and no other toilet/bathroom at the hospital. I remember the nurses being very clear about that. It was a demand and not a request. Swabs were taken from the back of my throat to test for 'MRSA' but 'hepatitis C' was also mentioned as was my father's name. I do not remember much more except that I was treated differently there. With experience and hindsight, I believe I was placed in isolation for fear that I was infectious to the staff and other patients. I did not tell my mother. I mentioned the incident to my GP when I had my son at the age of 21 because it had played on my mind. I remember how unpleasant the swabs were and I also clearly remember the importance to the staff of me using the bathroom in my room and none other.

20. The memory of my own father's trauma has never left me. I no longer trust doctors. I do not visit my GP when I feel unwell unless absolutely necessary. When my son was approximately 3 years old, Dr Giangrande told me that the Haemophilia Centre were running low on (manmade) recombinant treatment and suggested my son have plasma for a while. I had a huge melt down, shouting that there was 'no way' they were 'putting plasma in my child'. Dr Giangrande tried to reassure me the plasma was 'now heat treated' and 'safe' and I said you all 'told my dad the same thing and it wasn't safe!' It was then agreed to give me some back up treatment and I held my son back from going to nursery school until the recombinant had been resupplied.

Section 6. Treatment/Care/Support

21. My father needed counselling. Nobody in the family was offered counselling before or after my father's death. Shayne is now having some counselling in relation to his drug addiction issue.

Section 7. Financial Assistance

22. I believe my father received a payment of capital through the MacFarlane Trust. My parents also received monthly payments from the MacFarlane Trust.

23. My mother has had Skipton Trust Stage 1 and 2 payments because of my father's HCV diagnosis and subsequent death.

Section 8. Other Issues

24. When I first obtained my father's medical notes and records, my mother had to put them away because I found them too (emotionally) difficult to read.

25. I refer to the letters from Dr Trowell to my father's GP in the 1990s as cited in the Chronology to this Statement and the clinical note dated 30th May 1990 bearing the initials MF whom I believe could be Mary Fletcher. I had not previously seen the references to alleged alcohol consumption/abuse therein and was unaware of their existence and content until after we had obtained my father's medical notes and records.

26. My parents are not drinkers. My father rarely consumed alcohol, perhaps just a glass of wine at Christmas. I never once saw my father drink a glass or bottle of beer. The alcohol in the house remained untouched from one year to the next. The reports that my father consumed alcohol as alleged are untrue. I have had my ear to the ground since the announcement of the Inquiry and attended the opening hearing in September. I feel that I need to represent my father. I have heard through others of false reports of alcoholism of those diagnosed with HCV. I am of course shocked and angry that false allegations have also been made about my father. My father developed chronic liver disease through HCV, not alcoholism, and through no fault of his own. I am very keen to give oral evidence to the Inquiry on this matter.

Anonymity, disclosure and redaction

27. 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. I would like 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... 17/02/2019

MEDICAL SUMMARY

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

This witness statement has been prepared without the benefit of access to my father's full medical records. .

- xx.11.1972 "Australian antibody detected" (*Clinical Notes*)
- 29.04.1976 "Australian Antigen negative, Antibody positive" (letter Dr GRO-D to Dr Inglis, Cumberland Infirmary)
- 23.02.1982 HBs antibody positive (*Pathology*)
- April 1985 Diagnosed HIV positive (see entry 25.06.1990 below)
- 31.07.1985 "Anti HBs Positive on 6.3.85, HTLVIII antibody positive" (*Virology*)
- 20.11.1987 "At home with wife. Discussed HIV. Using condoms. New supply given. Blood test from Susan for HIV" (*Clinical notes MF*)
- 02.03.1989 "Home.... Blood taken from Susan for HIV & HBs AB & AG" (*Clinical notes MF*)
- 28.02.1990 "He has been found to have abnormal liver function tests and certainly has signs of chronic liver disease with spider naevi and a palpable spleen.... He has a regular alcohol consumption which initially he merely indicated as 4 pints of beer and half a bottle of wine a week but it then became apparent that he had actually been given six bottles of spirits at Christmas, all of these are now empty! (letter Dr Trowell to GP)
- 06.04.1990 "Discharged from John Warin Ward I would appreciate an opinion from Dr Trowell re i) chronic liver disease, ii) diarrhoea (recent) iii) 4 yr intermittent symptoms of" (*Clinical Notes*)
- 30.05.1990 "Stopped alcohol since visit to see JT. Had the day off when he drank a bottle of whisky straight off" (*Clinical Notes MF*)
- 07.06.1990 "Viral screen HEP A, B, C Anti HBs detected (Nov 89), Not detected hep c - (+) in past" (*Virology*)

- 25.06.1990 "Chronic liver disease, cause uncertain" ... "at routine endoscopy appointment abnormal liver function tests and signs of chronic liver disease found on routine blood testing" "no previous jaundice and admitted to drinking 12-15 units of alcohol a week" "April 1985 diagnosed HIV positive" (*Arun Dhiman, Senior House Officer to Dr Trowell to GP, cc Dr Rizza*)
- 02.10.1990 "I have advised him to adhere to his diet and to avoid excessive alcohol ..." (*letter Dr Trowell to GP*)
- 27.09.1991 Brain haemorrhage
- 29.12.1992 "His advance liver disease, related to HCV infection and past high alcohol intake" (*Dr Lalvani, Registrar to Dr Conlon*)
- 05.04.1993 "Advanced cirrhosis secondary to hepatitis C...." (*letter Dr Wilkinson to GP*)