

Witness Name: SHAYNE DELGLYN

Statement No: WITN1642001

Exhibits:WITN1642002

Dated: JANUARY 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF SHAYNE DELGLYN

I, Shayne Delglyn, will say as follows:-

Section 1. Introduction

1. My name is Shayne Delglyn. I was born on [GRO-C] 1978 and I live [GRO-C]
[GRO-C] Berkshire [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 sister, Tara Wooldridge, have given their own Statements to the Inquiry (Witness Numbers WITN1183001 and WITN1614001 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.
7. My father was treated with Factor VIII (FVIII). I refer to **Exhibit WITN1642002** being copies of my father's treatment record.
8. My father told me that he had HIV when I around the age of 11. He told me and Tara together and used the word 'AIDS'. He told us one evening, watching television in the living room. He said "I have AIDS" and then he impressed upon us the importance of keeping it to ourselves. He said words to the effect "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."
9. There is evidence within my father's medical records that he was first tested HIV positive as early as April 1985. I do not believe my father was aware that he had a diagnosis of HIV in 1985. He told us that he had HIV in late 1988 or 1989 and only knew that he had it for about a year prior to that.
10. We as a family kept my father's diagnosis a secret. Tara and I did not even tell our school friends. Everyone knew about HIV/AIDS at that time and there was a lot of playground AIDS related jokes bandied around.

11. 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. I was with him when it happened. We were in the car driving home and we were probably only about three miles away. My father told me that his vision had gone and that he could barely see the road in front of him. I had to talk him home. It was a frightening experience.
12. My father was never the same after the brain haemorrhage. He could not work and had trouble reading because he could not focus on anything written. My father then became very ill and in what would have been the very end of 1992, he was told that he had chronic liver disease and HCV. 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, Tara and I) received them. It is however clear from my father's medical records that my father had tested HCV positive and had chronic liver disease some time prior to 1989/90.
13. My mother, Tara and I believe that the doctors were aware of risk of contamination to my father from his FVIII treatment before he was infected. He trusted the doctors and should have been warned of the risk and/or given safe treatment. My father should have been informed of his HIV and HCV diagnoses as soon as he was first tested positive.

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 and his death had a huge impact upon me. Up until then I had wonderful memories of my father. He was a happy go lucky, joker. When he was dying, he was so sick and he suffered. He had no psychological support. He knew that he was dying and he was not ready to go. We were powerless to help him. It was too late for him to have a liver transplant. He was told that even with a liver transplant he would still be unable to work and have to claim benefits.

17. My father's death took a long time to hit me. I always expected him to walk back through the door. His death hit me in a big way the following September (1994) on holiday with my mother. I really felt my father's absence. I broke down and cried.

18. I have had a drug addiction problem that I did not initially associate with my father's death. However and since I began counselling, I have revisited memories and details about the last months of my father's life that I have previously tried to shut out. I have remembered things that are psychologically hard for me to deal with. I wanted to remember him the way he used to be. There is a lot I had previously blocked out. My counsellors have also noted that the relapses I have had in the past have been in June (the month of my father's death).

Section 6. Treatment/Care/Support

19. My father needed counselling. Nobody in the family was offered counselling before or after my father's death. I am currently having counselling in relation to my drug addiction issue.

20. I went to my GP around 2 or 3 years after my father's death for an HIV test. No-one offered me testing and/or counselling. I had to ask for the test myself. My sister and I have trust issues with the medical profession.

Section 7. Financial Assistance

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

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

Section 8. Other Issues

23. 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 to 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.

24. My father was not a drinker. My father developed chronic liver disease through HCV, not alcoholism, and through no fault of his own.

Anonymity, disclosure and redaction

25. Whilst I am not seeking anonymity, I would like my address redacted before publication. I understand this statement will be published and disclosed as part of the Inquiry. I wish to give oral evidence at the Inquiry.

Statement of Truth

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

Signed GRO-C

Dated 16-02-2019

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 Matthews 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*)