

Witness Name: SUSAN DELGLYN

Statement No: WITN1183001

Exhibits:WITN1183002

Dated: JANUARY 2019

## INFECTED BLOOD INQUIRY

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### FIRST WRITTEN STATEMENT OF SUSAN DELGLYN

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I, Susan Delglyn, will say as follows:-

#### Section 1. Introduction

1. My name is Susan Delglyn. I was born on  1953 and I live at   
 Berkshire
2. My husband, Michael James Cox (born on  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 7<sup>th</sup> June 1993 aged 48.
3. My son, Shayne, and daughter, Tara, have given their own Statements to the Inquiry (Witness Numbers WITN1642001 and WITN1614001 respectively).
4. This witness statement has been prepared without the benefit of access to Michael'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. Michael had severe haemophilia A. He was diagnosed when he was about 18 months old. He told me, at that age, he had a fall and a stone became embedded in his forehead. When the stone was removed, his forehead bled profusely. Michael's parents had not heard of haemophilia beforehand. At that time, Michael was referred to as 'a bleeder'. Michael told me that he had an unhappy childhood. He wore a padded suit at school that caused chafing to his skin. He was the target of bullies and missed quite a lot of schooling.
6. Michael was treated with cryoprecipitate when he was young. He spent a lot of his childhood in hospital. When I met Michael in 1971, Factor VIII (FVIII) was available but Michael had to go to the haemophilia centre. A couple of years after we met, home treatment became available and Michael was taught how to inject himself with FVIII. Michael, on occasion, struggled to treat himself and, occasionally, Dr Watson came to our home to treat him. Michael had FVIII on a regular basis, when he needed it. I refer to **Exhibit WITN1183002** being copies of Michael's treatment record.
7. Michael was treated at the Oxford Haemophilia Centre at the Churchill Hospital under the care of Dr Rizza and Dr Matthews. Dr Giangrande took over Michael's care in the early 1990s.
8. Michael was not provided with any information or advice beforehand about the risk of being exposed to infection from blood products. We were told by the hospital that FVIII was bought from the USA but at that time FVIII was a huge advance in treating bleeds and no-one had heard of HIV/AIDS and HCV.

Michael never thought that using FVIII treatment could be fatal. If he had, he would not have taken it.

9. In or about 1988, Michael was told that he needed to be tested for HIV and he was then told to return to the hospital to collect his results. It was then that they told him he was HIV positive. When he came home and said that he was HIV positive he had what seemed like a huge dark cloud over him. We were in shock. Everyone knew about HIV/AIDS at that time and we knew we had to keep it a secret from everyone including the children. I made Michael promise not to tell the children. I did not want them to be burdened (as we were) with the worry and stigma.
10. My recollection is that Michael was told that he had HIV in 1988. However there is an entry in Michael's medical records that Nurse Mary Fletcher (whom I assume to be identified as initials MF) visited me at home on 20<sup>th</sup> November 1987 to discuss HIV and take a blood test from me. If that entry is correct, it may be that Michael was told of the diagnosis in the latter part of 1987, not 1988. Michael's medical notes also record that Michael was first tested positive for HIV in April 1985. I am certain that Michael was not told he had HIV back in April 1985 and/or any time sooner than the back end of 1987 or early 1988. We had three consecutive annual family holidays abroad between 1984 and 1986 and I am sure Michael was not aware of his infected status at that time.
11. When Michael was called in to the hospital to provide blood for an HIV test in 1987 or 1988, he was unaware that he had already been tested (positive) in April 1985. It is clear to me that the positive test result was withheld from Michael by the doctors responsible for his care. Not only did the doctors owe Michael a duty of care, they placed his family at significant risk from exposure to the same virus.
12. The only information and advice we were given about the diagnosis when Michael was told was that we were not allowed to have unprotected sex and that

no-one should touch Michael's needles. We were not given any other information or counselling.

13. Michael was never aware that he had HBV. I only found out that Michael had HBV when Tara, Shayne and I obtained Michael's medical notes and records in 2018.

14. Michael did not know that he had HCV until around 6 to 8 months before he died. He became very unwell and we thought at that time that the HIV infection had taken hold and had developed to AIDs. Michael was not given any advice about managing and/or treating HCV. His chronic liver disease was too far advanced for treatment by then.

### **Section 3. Other Infections.**

15. I am not aware of any other infection Michael contracted as a result of being given infected blood products. As stated, Michael and I did not know that he had HBV before we obtained his medical notes and records in 2017. We did not know that he had HCV until 6 or 8 months before his death and we were not told he had HIV for more than two years after diagnosis.

### **Section 4. Consent.**

16. I believe Michael to have been tested for a number of infections without his knowledge and consent. Michael was used to the hospital taking blood. He was led to believe that his blood was needed to test for inhibitors.

17. Michael's medical notes and records are not complete. A lot of information is missing. However it is clear that Michael was tested for HBV as far back as the 1970s. He knew nothing about the positive diagnosis let alone the testing. The

doctors were aware that Michael had HIV and HCV for a long time before Michael was told.

18. When Michael was diagnosed with HIV, Nurse Mary Fletcher took blood from Michael on a regular basis in our home. She also took blood from me to test for HIV. I was impressed at the time believing that Michael and I were being given special care. Dr Matthews, from the Haemophilia Centre, was so lovely to us and Michael thought so highly of him. We thought at that time that the FVIII being contaminated with HIV was an accident that could not be averted. It then felt like I had been hit by a steam train when I learned through news reports that the risk of contamination was well known but the treatment was given to haemophiliacs anyway. I believe haemophiliacs like Michael were used as guinea pigs and it is particularly hard for me to understand why because the doctors appeared to be so nice.

### Section 5. Impact

19. Michael's HIV diagnosis placed our family under tremendous strain. I did not tell anyone including my family. Michael told his close family members including his sister and his father. Michael's father had Alzheimer's and I do not think he fully understood.

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20. Michael was not good at keeping secrets and about a year after being told he had HIV, he told the children. I was upset and cross. I did not want them burdened. Tara was just coming into her teens.

21. Michael was devastated by the diagnosis. He was treated with AZT drugs and his health held up reasonably well given the poor prognosis. We began to think that the HIV was not going to develop to AIDS. In 1990/1991 Michael developed

oesophageal varices that needed lazering. We did not know that Michael had HCV at that time.

22. A short time after the lazer treatment, towards the end of September 1991, Michael had a brain haemorrhage with devastating results. He had problems with his vision and cognitive functioning. Michael was an electrical wireman and we ran our own electronic business but Michael could no longer cope. He would look at a diagram but would not be able to remember how to read it. The business folded and I took a job at Tesco working at night to try to make up our lost income whilst continuing to care for the children. The haemorrhage completely changed Michael's personality. He had always been a joker and a happy go lucky person but he became moody and progressively depressed. It put a massive strain on us. I felt I could no longer communicate with him on any subject without it drawing a negative response. If I asked him what he wanted for tea tomorrow, he would say 'if I am even here'. I no longer knew him as the man I married and a distance opened up between us that we both felt.
23. Michael then became seriously ill, 6 to 8 months before he died. He was very bloated, yellow and constantly cold. He lost his appetite and couldn't hold anything down when he tried to eat, he suffered with grey coloured diarrhoea and looked noticeably unwell. It was only then that the doctors told Michael he had HCV and chronic liver disease.
24. Michael had bouts of encephalopathy and had to have albumin injections into his liver. I recognised the changes in Michael every time it happened and got him to the doctor. Michael was not ready to die. Tara was pregnant and he was desperate to hang on until the baby was born but unfortunately that did not happen. Michael suffered a slow, tortuous death. He often broke down. He knew he was dying. There was nothing we could do but watch him slowly die. He would have had a quicker, more dignified death without pain if he had died when he had the brain haemorrhage.

25. It was however clear from the speed in which Michael deteriorated and died that his liver disease was well advanced. In failing to tell Michael sooner about the HCV, he was deprived of the opportunity for treatment. I promised Michael that I would be with him when he died. He was admitted to hospital on a Thursday and died four days later on the Monday. I had lent one of our two cars to Michael's brother and my other car ended up with a flat battery when I heard from the hospital that I needed to get there straight away. Whilst I was getting the battery changed with the help of a neighbour I received a second telephone call telling me that Michael had passed. The deep sense of guilt I have at not fulfilling my promise to Michael has never left me.

#### **Section 6. Treatment/Care/Support**

26. The lack of support available was awful. Nobody in the family was offered counselling. Tara and Shayne have suffered psychologically; Tara with an eating disorder and Shayne with a drug addiction.

#### **Section 7. Financial Assistance**

27. Michael received two lump sum payments through the MacFarlane Trust of £20,000 and £60,000 respectively.

28. Michael also had monthly payments from the MacFarlane Trust of between £250 and £280. This included a mobility allowance and a allowance to meet our monthly mortgage repayments. Without this we would not have survived after Michael's brain haemorrhage. The MacFarlane Trust continued to provide a monthly payment to me after Michael's death until the children reached the age of 18.

29. I received the Skipton Trust Stage 1 and 2 payments of £20,000 and £50,000 respectively in 2011.

## Section 8. Other Issues

30. I refer to the letters from Dr Trowell to Michael's GP in the 1990s as cited in the Chronology to this Statement. I had not previously seen these letters and was unaware of their existence and content until we obtained Michael's medical notes and records. Michael very rarely consumed alcohol. He was not a drinker. I am in no doubt that Dr Trowell fabricated the reports of alcohol consumption that she attributes to Michael.
31. Michael and I worked together from home. We ran a very successful electronics business. We had young children to care for and did not really have anyone we felt we could ask to babysit if we were minded to go out. Our social life was non-existent. Michael and I did not drink at all at home except for the odd glass of wine at Christmas. The alcohol in the house remained untouched from one year to the next.
32. We rarely went out. We probably only went out on our respective birthdays and to visit friends in Reading, perhaps every three months or so. When out for a meal on our birthday, Michael might have one glass of wine (a bottle between us was too much) or a soft drink and an Irish coffee at the end of the meal. When visiting our Reading friends Michael might have a couple of whiskey and cokes. That is the full extent of Michael's alcohol consumption and he would never have risked his driving licence in any event.
33. I do not remember Michael ever mentioning a 'Dr Trowell' to me. He has never consumed beer and/or bottles of spirits at Christmas or any other time. I can honestly say that in 22 years of marriage I have never seen Michael worse for wear through drink. I am angry and appalled that Dr Trowell has perjured herself and tainted Michael's name in the process. Moreover, initial MF/Mary Fletcher appears to collude with Dr Trowell in alleging that Michael reported as having 'drank a bottle of whiskey straight off'. Michael developed chronic liver disease



through HCV, not through alcoholism. He was not told that he had HCV. His liver functioning was not monitored and the HCV was left untreated. I am very keen to give oral evidence to the Inquiry on this matter.

**Anonymity, disclosure and redaction**

34. 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 Michael'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*)