

Witness Name: JACQUELINE TOMKINSON

Statement No:WITN2807001

Exhibits:0

Dated: March 2019

## INFECTED BLOOD INQUIRY

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### FIRST WRITTEN STATEMENT OF JACQUELINE TOMKINSON

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I, JACQUELINE TOMKINSON, will say as follows:-

#### Section 1. Introduction

1. My name is Jacqueline Tomkinson. I was born on the [GRO-C] 1959. I live at [GRO-C] West Yorkshire [GRO-C] I am currently retired.
2. I am writing this statement on behalf of my husband, David Stephen Tomkinson. David was born on [GRO-C] 1959 and he sadly died on the 12<sup>th</sup> April 1987, aged 28. David is the father of my two daughters, Rebecca and Helen.
3. This witness statement has been prepared without the benefit of access to my late husband's medical records.

#### Section 2. How infected

4. David was diagnosed with severe Haemophilia A when he was two years old after he bit his tongue. He was taken to St James Hospital, Leeds, where he was under the care of Dr McVerry and Dr Swinburn

5. David was initially treated with Cryoprecipitate before his treatment was changed to Factor VIII. He was then treated with Factor VIII all the time, in hospital and at home. He bled a lot as a child so he had to attend a special school known as Welburn Hall School. I believe David received the infected products sometime in or around the mid 1980's. I am unsure whether his mother consented to the change in treatment, or whether the risks associated with the Factor VIII was discussed. David was infected with HIV as a result of being given contaminated blood products.
6. In 1985 David received a letter advising if there was anything unusual about his health to get in touch with the hospital. As David had a rash on his body he made an appointment to see Dr Swinburn. During the appointment Dr Swinburn examined David and took some blood tests. We waited about 4 weeks and then David and I returned to see Dr Swinburn and Dr McVerry for the test results. It was during this meeting they confirmed that David had HIV.
7. After we found out about David's HIV status I was also tested. I was 3 months pregnant at the time. I asked if I needed a termination, but I was advised not do anything until I had my results back. Fortunately, my test results came back negative.
8. David was not given enough information to help manage the infection. I do not think any treatment was discussed at this point either. David was just having a lot of blood tests and they were monitoring him carefully.
9. I believe information should have been provided to David sooner. When the doctors were aware of the risk of infection, they should have discussed this with David, but they did not.
10. When David was informed about his HIV status the doctors told us we had to use protection if we had intercourse. We were also told David had to have all his belongings separated from ours and, if he had a bleed or cut himself I could not help him.

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

11. David was also infected with Hepatitis B Virus which I found out after he had passed.

### **Section 4. Consent**

12. David was tested without his knowledge, consent and without full or adequate information.

13. I believe David was experimented on as Dr Swiburn and Dr McVerry tried David on lots of different drugs leading up to his death. David also often said he felt like he was being used as a guinea pig.

### **Section 5. Impact of the Infection**

14. Almost immediately after David was diagnosed his health deteriorated. He suffered with depression and anxiety. When he found out he had HIV he broke down and cried. He was frightened about infecting our elder daughter Rebecca, our unborn child Helen, and also me. He was a really jolly, outgoing, cheeky guy, but behind closed doors it was hard. David was withdrawn and down. Some days he would cry and I would have to get his Mum and Dad to come over to try and talk to him. He was so frightened of dying.

15. David could not tell anybody about his infected status. He eventually told his parents and brother, however, he could not tell his friends. I did notice a massive change in him as soon as he was diagnosed and over time he became quieter and quieter. It was heart breaking to see.

16. David was very healthy before he was diagnosed with HIV. When he found out he was infected and put on all sorts of different drugs, his health deteriorated rapidly and within a year and a half he was dead. He had a lot of illnesses that resulted from the HIV such as, flu, pneumonia, and cold sores.

At the time the doctors were not aware that these were as a result of the HIV, they just said they did not know why he was not recovering. David also had to have his spleen removed, blood transfusions, and lumbar puncture.

17. Furthermore, David was diagnosed with non Hodgkin lymphoma in 1985. They only told him he had non Hodgkin lymphoma in the neck, but they did not tell him how bad it was. It was upsetting for David, but he tried to put a brave front on in front of everyone. However, when it was just us he would break down. David had chemotherapy and radiotherapy in order to treat this non Hodgkin lymphoma. This was not easy given he had just been diagnosed with HIV.

18. David and the doctors had many arguments about the treatments he received; David was refused drugs to slow the HIV because they denied he was ill and ignored his symptoms when he tried to explain. They changed his drugs on numerous occasions and treated him like a guinea pig.

19. David was sick from the treatment he received. He would get rashes, have hot flushes, and he lost his appetite resulting in him losing a lot of weight. He would start to pick up a little, but then they would put him on some other drugs and he would be back to square one. It was so sad to see. I could see him wasting away in front of my very own eyes and I felt helpless.

20. David was treated like a leper. He was put in wards that were entirely disposable; this involved plastic cutlery, crockery, bed sheets and clothing. He was ignored and treated deplorably. Everyone would dress up as if he was contagious. The disposable room was not kept private either, so everyone could see David from outside. David was conscious that everyone knew he was isolated because of his condition and the stigma attached to it.

21. He would burst in to tears every time he saw the AIDS advert on the TV as he was so frightened of the stigma.

22. We kept quiet about David's infections at the insistence of St James's Hospital as David and I previously worked there. The hospital did not want a medical circus and the hospital being put into the spotlight. David was taking time off from work so when people started to ask questions, he said he was not attending because he was a haemophiliac. They did not know the truth.
23. We had no support from the NHS Trust and we were constantly reminded that the media would turn against us. As a consequence, David's death was swept under the carpet.
24. When David was told that he had HIV I broke down and cried because I thought I would have to terminate my unborn baby, Helen. David also worried about me and we stopped having sex because he was so frightened about passing it on to me. It was always at the back of our minds, he always said he could cope living with HIV, but he would not if he passed it on to me
25. We almost lost our family home, I had to rely on family members to help us pay our mortgage and look after my children whilst I worked and nursed my dying husband. We applied for income support, but it did not come through until after David died. We struggled financially as we did not have enough money to live off. We went to the bank when we found out David was dying, as we were in arrears, my father in law explained David only had days to live, so they put everything on hold. I was working at the time at St James Hospital and I had to take time off work to care for David which had a massive impact on our finances. I only worked 16 hours a week, but I still had to take time off as he needed looking after. This was mentally and physically draining for me, I would randomly break down and cry.
26. When David died I asked Co-op funeral care if I could see him. They said unfortunately his body had gone back to St James's Hospital as he had an infectious disease. This was said in front of everybody. After this I rushed to St James's to tell my boss what happened because I did not want the press to know. They told me what was discussed could never leave that room because it would be 'difficult for them'.

27. I had to go through so much paper work to see David again before the funeral. I did get to say goodbye, but they kept telling me I could not touch him. I had to put a mask on which was ridiculous because I nursed him for several months before he died. I kissed his forehead and said goodbye. That was it. That was the last time I saw him. I was not allowed to have him buried; he had to be cremated, which was against my wishes.

28. I saw the registrar and he told me David died of full blown AIDS. I could not believe it. Prior to this, I asked Dr McVerry if the HIV had developed into AIDS and he said he did not think so. Eventually Dr McVerry confessed that he thought David was developing AIDS, but he was not told of this. This was sometime in or around 1987.

29. I tried hard to carry on the best as I could, but David's infection and death affected me and our children. I was being a mum and dad in one. My eldest daughter still suffers from the trauma of David's death. At six she had counselling as she became withdrawn and developed selective mutism. As a result of David's death she has anxiety that has continued into adulthood. My youngest daughter was only 18 months old when her father passed away.

#### **Section 6. Treatment/care/support**

30. We got no support. David was just treated like a leper. They did not even treat him like a human being.

31. David did not receive any counselling or physiological support. I think both of us would have benefitted from counselling.

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

32. In 1992 the MacFarlane Trust wrote to me and I received £46,000. Rebecca received £7,000 [GRO-C] The children's money was put into Government funds. This was through the High Court.

33. I was made to sign a waiver, but I did not understand what this was for or the implications.

34. The process was lengthy. I had to send off David's death certificate and they wanted to know about my finances. I had to produce a lot of paper work before I received the financial assistance.

**Section 8. Other Issues**

35. I keep up to date with the contaminated blood news. David and I were also part of the Hemophilia Society Group, but I am no longer a member.

**Anonymity, disclosure and redaction**

36. I do not wish to remain anonymous. I understand this statement will be published and disclosed as part of the Inquiry.

37. I do not wish to give oral evidence

**Statement of Truth**

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

Signed. GRO-C

Dated 21/03/2019