

Witness Name: JENNIFER ELIZABETH JONES

Statement No: WITN1312001

Exhibits: 0

Dated: DECEMBER 2018

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF JENNIFER ELIZABETH JONES

I, Jennifer Elizabeth Jones will say as follows:-

Section 1. Introduction

1. My name is Jennifer Elizabeth Jones. My date of birth is 1979. I live at with my husband and my son, aged 10 months. I am by occupation a University Lecturer/Health Visitor.
2. My father, , was co-infected with Human Immunodeficiency Virus (HIV), Hepatitis B Virus (HBV) and the Hepatitis C Virus (HCV) from contaminated blood. He died from pneumocystis pneumonia (PCP) on 1991 at aged 45. This witness statement has been prepared without the benefit of access to my father's medical records.

Section 2. How infected

3. My father, , was born in 1945. He was diagnosed with severe Haemophilia A within days of his birth. He was

circumcised because of a problem passing urine and would not stop bleeding after the circumcision. His younger brother (my Uncle [GRO-B]) was also diagnosed with haemophilia at birth.

4. My father was treated at the Royal Hallamshire Hospital, Sheffield under the care of Professor Preston. He was treated with Factor VIII (FVIII). He found out that he had contracted HIV in February 1985. It transpired that he had actually been infected with HIV two years before he was told of the diagnosis. He was diagnosed with HBV and HCV a couple of years later and had problems with his liver as a result.
5. I do not believe my father to have been warned of any risks associated with FVIII treatment.
6. My father appeared on television on [GRO-B] and also a programme hosted by [GRO-B] to talk about the issue. He was very angry about it. My uncle did not tell his children about my father, he had been infected with HCV and did not tell his children. My brother, [GRO-B: B] and I were aware that my father was infected with HIV. Our parents were open and honest about what was going on.

Section 3. Other Infections

7. I do not believe my father to have been infected with anything other than HIV, HBV and HCV.

Section 4. Consent

8. I do not know whether or not my father was tested without knowledge and consent. My mother has told me that all patients treated with FVIII and their relatives were called in for a group meeting towards the end of 1984. They were told about the issue and that there was a strong possibility that they and their partners would be infected. When my father was told he had tested

positive for HIV in the early part of February 1985, he was told that they would also test the blood samples they had kept over the previous three years. My father gave his consent on that occasion. Positive test results for HIV were identified from samples taken over the previous two years.

Section 5. Impact of the Infection

9. The impact of the infection on our family was huge. My mother was a health visitor. She had to wait for a significant period of time before finding out whether she too had been infected by my father. That waiting period for her was painful. At the practice where she worked, she had to use a toilet designated for her own personal use and had to wash her crockery in a different sink to her colleagues.
10. I was just 7 years old when I was told Dad had HIV. [B] and I were still at primary school. My father was very vocal about how he was treated and, as stated, went on television to raise awareness. Our friends knew my father had HIV and we endured taunts that our father is 'gay' and has 'AIDS'. We were made to feel like we were very different to everybody else. The neighbours knew too. It was a very bad time for us. When [B] moved up to secondary school he kept it to himself. He hid it because it was shameful for us. [B] has not really dealt with the death of my father. I find it hard as a sister watching him over the last ten years processing his grief as he has become a father himself.
11. Our parents' marriage broke down the year after my father was diagnosed. My father instigated the break up. He had made contact with the Secretary to the Haemophilia Society ([NOT RELEVANT]) and started spending a lot of time with her. She was 16 or 17 years his junior. He married her in [GRO-B] [GRO-B] [NOT RELEVANT]. [NOT RELEVANT]. She had a great deal of inside information in relation to haemophilia and contaminated blood. My mother would never have left my father with a terminal illness. Our parents were not happily married at this

time, according to my mother, however she was not planning to leave my father and has said it was not her intention to take away his children at this time in his life.

12. My father received a lump sum payment from the MacFarlane Trust. With the help of the MacFarlane Trust he set up a separate trust fund for me and B with what I now believe to be half of that money. I am uncertain as to the exact fund my father received, I have tried to find this out but I am not sure.

13. My parents had a reasonably good relationship (it was not an acrimonious break up). Conversations when the marriage ended centred round my father's health and the plans my father had to ensure that B and I received our inheritance when he died. He told my mother that he had seen a solicitor about a making a Will. Ultimately my father told my mother he had written his own Will with a pack from the Readers Digest.

14. I was 11 years old when my father died in GRO-C 1991. NOT RELEVANT

NOT RELEVANT

15

NOT RELEVANT

NOT RELEVANT

16. My father's Will was never found after he died and [NOT RELEVANT] applied for Grant of Representation on an Intestacy basis. The entirety of my father's estate fell to her on that basis. [NOT RELEVANT]

[NOT RELEVANT] My father had purchased a set of Encyclopedia Britannica books to gift to me and [B] on his death. He had personally inscribed them with the family name. He wanted us to have them as an educational gift to remember him by on his death. [NOT RELEVANT]

NOT RELEVANT

17. The impact my father's illness and subsequent death has had on me has been huge. Before reaching the age of 12, I had experienced my father openly and publicly speaking about his HIV status with all the associated stigma of that time, the breakdown of my parent's marriage and my father's death.

18. I was aware my father was dying and for a long time we were waiting for it to happen. My parents thought if my brother and I were more aware of what was happening, we would deal with it better. He went into a coma when he developed PCP and we knew that was the end. It was traumatic.

19. I have named my son [GRO-C] after my father. I could not have contemplated having a child with haemophilia after what has happened to my family through my father receiving contaminated blood. I had [GRO-C] in order to ensure that [GRO-C] was born free of haemophilia. I would not consider having a daughter as a carrier of haemophilia and this was our express wish only to have embryo's that did not have the haemophilia gene [GRO-C] [GRO-C]. We only have one child and [GRO-C].

We will not conceive naturally despite wishing to have more children so that we do not pass on this condition.

Section 6. Treatment/care/support

20. I do not believe that any counselling was offered. My brother and I did not receive any counselling. I believe counselling would have been helpful, particularly for my brother.

Section 7. Financial Assistance

21. Payments to my father were made by the Skipton Trust and the MacFarlane Trust as detailed at paragraph 12 above.

22. Professor Makris at the Royal Hallamshire Hospital, Sheffield has been helpful in assisting me with an application to the Skipton Trust for a Stage 2. The payment would have been useful to me and [B]. I wanted to use my share to fund the IVF I needed. When I informed Skipton that [NOT RELEVANT] is next of kin, the successful application was unable to be processed at the final stages as my brother and I are not deemed next of kin.

23. [NOT RELEVANT]

[NOT RELEVANT] There is a large sum of money for my father in the Skipton Fund we are unable to access. [NOT RELEVANT]

[NOT RELEVANT]

Section 8. Other Issues

24.

NOT RELEVANT

25. I would hope that the Inquiry acknowledges the vulnerability of those infected with a recommendation that financial payments and future claims for compensation are redirected to the right people

NOT RELEVANT

NOT RELEVANT

Anonymity, disclosure and redaction

26. 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 am willing to give oral evidence to the Inquiry if required.

Statement of Truth

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

Signed..

GRO-C

Dated.....

13.12.2019