

Witness Name: SHARON ELIZABETH WILLIAMS

Statement No: WITN1632001

Exhibits: 0

Dated: MARCH 2019

## INFECTED BLOOD INQUIRY

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### FIRST WRITTEN STATEMENT OF SHARON ELIZABETH WILLIAMS

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I, SHARON ELIZABETH WILLIAMS, will say as follows:-

#### Section 1. Introduction

1. My name is Sharon Elizabeth Williams. I was born on **GRO-C** 1978 and I live at **GRO-C**
2. My father, Peter Williams (born on **GRO-C** 1943), was co-infected with the Human Immunodeficiency Virus (HIV) and the Hepatitis C Virus (HCV) from contaminated blood products. He died from an intracranial hemorrhage on **GRO-C** **GRO-C** 1994, aged 50.
3. My mother has given her own Witness Statement to the Inquiry (Witness Number WITN1654001).
4. This witness statement has been prepared without the benefit of access to my father's full medical records.

## Section 2. How infected

5. My father had severe Haemophilia A. He was diagnosed with the disorder from the age of 13 months and suffered with it throughout his life. He was an only child and no-one else in the family was known to have it.
6. My father was treated at the Liverpool Haemophilia Centre at the Royal Liverpool Hospital (Roald Dahl Centre) under the care of Dr McVerry and Dr Mackie.
7. My father suffered frequent hemorrhages in his joints. This caused damage to many of his joints and he suffered from chronic arthritis.
8. I understand that my father was first given the Factor VIII (FVIII) treatment in or around 1979. Before having the FVIII treatment from the Royal Liverpool Hospital, he was apparently bedridden after having a bleed. The treatment was regarded by my parents as a welcome improvement in terms of my father managing his condition. He used the product up until he died. After becoming infected, he was told that the product was safer to use than previously because it was, by then, heat treated.
9. We moved from North Wales to GRO-C in the spring of 1985. My father's care was transferred to the Sheffield Haemophilia Centre at the Royal Hallamshire Hospital Sheffield. At that hospital, my father was told that he had tested HIV positive. My understanding is that my father had been infected with HIV the previous year.
10. My father was then diagnosed with HCV some time in the early 1990s. Towards the end of his life, he contracted an HIV/AIDS related illness (pneumonia) and subsequently died on GRO-C 1994, aged 50, after a cerebrovascular accident (as stated on his Death Certificate).

11. My understanding is that my parents had no information or advice beforehand about the risk of infection from FVIII.

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

12. My father received no other infections that I am aware of.

### **Section 4. Consent**

13. I do not know whether or not my father was tested without his knowledge and consent.

14. In terms of treatment, my father said that he felt like a guinea pig as they tried various drugs on him.

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

15. I was just 6 or 7 years old when my father was told that he had HIV. My brother, Vernon, was 14 years old and my sister, Hayley, was 8 years old. I do not remember anything specific but, even though I was young, I knew something was wrong. I picked up on things that were said in our household and I later became aware of the issue of HIV/AIDS through the media. As time went on, I began to worry. I then asked my mother "Has my dad got that?" and she confirmed that he had.

16. My mother and father attended a lot of hospital appointments and were often out. My siblings and I had to care for my father when my mother was out working. I remember my father's stitches breaking after he had a liver biopsy. I will never forget it. My mother was at work and Hayley and I did not know what to do. My

father was bleeding all over the bed. We phoned for an ambulance and then called my mother. We were traumatised.

17. When I was 12 years old, we moved from [GRO-C] to [GRO-C]. I went to secondary school in [GRO-C]. Knowing that my father had HIV made me feel dirty. The subject was taboo and we did not talk about it outside of the family. I remember one day confiding in a friend at school and she told someone else. Before I knew it, I was being asked by other pupils whether it was true. The concern was meant kindly but the attention was unwelcome. I was in tears and being asked "Oh my God, are you alright?" I was close to my father and very protective of him. HIV/AIDS carried a lot of stigma. It was being associated with being gay. It made me unhappier than I was that people knew.

18. Before long, we moved again (to another part of [GRO-C]). My father struggled to cope with the diagnosis and needed a distraction in his life, moving home was one such distraction. Moving about was disruptive for us.

19. As a teenager I did not understand. It was a difficult time for me. I detested his illness so much. I could not bear to be around it. My father suffered with so many nasty health related issues. He suffered with heart burn and had ulcers in his mouth. He was coughing up blood and being sick. Towards the end of his life, he was on liquidised food and had lost a lot of weight. He was skin and bone and looked a funny colour. My way of dealing with it was to remove myself from it. I started to stay out/away from home as much as I could. No child that loves their father wants to see him in that state but I am left with a lot of guilt. Being the youngest, my father and I were very close. I believe that I was his favourite. I now realise that he must have been worried about me. The side effects of my father's treatment coupled with his depression also changed him. He became short tempered and would fly off the handle for very little reason. From my perspective he was always angry.

20. My father had always been a strong man but he was in effect dying. I failed my GCSEs having achieved grade B results in my mocks. I felt lost. There were no concessions on compassionate grounds. There was no counselling and/or support offered to us. We were no longer a normal family. My father used to enjoy taking the three of us to football matches to watch our team, Wolves. That had to stop as he could no longer walk and no longer drive because he became too tired. I could no longer ask friends home. He was in a lot of pain and he became very strict and paranoid. He used to enjoy me combing his hair and keeping him company watching TV together. All that stopped. There was nothing we could do together to share between us.

21. My father's death was traumatic. He was unconscious when I got to the hospital after his brain haemorrhage. I was there when they turned the machines off. Our whole family was affected. It broke us apart. Hayley had a bad asthma attack and died the following year. I attribute her death to her grief and distress. She really did pine for my father when he died. I firmly believe that had my father still been here today, my sister would be here too.

22. I dropped out of college and was not working. My mother was struggling financially and none of us were thinking straight. We were all grieving. I was at loggerheads with my mother and brother. I was homeless for a while, sofa surfing and sleeping on the floor of a friend's room in shared accommodation. My relationship with my mother and brother is still strained to this day.

23. I went on to have children at a young age, trying to reconstruct the family unit that I miss so much. I had my first child at 18 years old and another when I was 20 years old. I have been left with massive attachment issues. I also suffer with depression and I am on medication to help with this.

24. My father never saw me get married and meet his grandchildren. Like Hayley, I suffer with asthma. The absence of my father on my wedding day, culminating in

the mention of my father during the speeches, resulted in me having an asthma/panic attack. An ambulance had to be called as I felt like I was being strangled.

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

25. My father was given different medications and treatments, some for the purposes of research. He felt like he was treated like a guinea pig.

26. No counselling or psychological support was ever made available to me. When he died there was not enough support for the family.

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

27. My father received two ex gratia payments through the MacFarlane Trust.

28. My parents had a mortgage and my mother had to downsize after my father died. My father wanted to set some money aside from the MacFarlane payment to be put towards the cost of my (and Hayley's) Wedding.

#### **Section 8. Other Issues**

29. I am seeking accountability. The knock on effect on the lives of so many affected people is immeasurable.

#### **Anonymity, disclosure and redaction**

30. I do not wish to apply for anonymity and I understand this statement will be published and disclosed as part of the Inquiry. I am willing 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

13/5/19.