Witness Name: Janet Williams Statement No: WITN41130001 Exhibits: WITN4113002 Dated: March 2020

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF JANET WILLIAMS

I, Janet Williams, will say as follows:-

Section 1. Introduction

- 1. My full name is Janet Lorna Williams. I was born on GRO-C
 1949 and I live

 at
 GRO-C

 Worcestershire
 GRO-C
- My son, Stuart Gregg (born on **GRO-C** 1975), was co-infected with the Hepatitis B Virus (HBV), the Hepatitis C Virus (HCV) and the Human Immunodeficiency Virus (HIV) through contaminated Factor VIII (FVIII) blood products. Stuart has provided his own Witness Statement to the Inquiry (Witness Statement Number WITN1252001).

Section 2. How Affected

- 3. Stuart was born in GRO-C 1975, a healthy 9 pounds. He had a large haematoma on his forehead at about 9 months old after which he was diagnosed with Haemophilia A, although it was not in the family.
- 4. We were referred to Birmingham Children's Hospital (BCH) under Dr Frank Hill, Consultant Haematologist. I was told that haemophilia was controlled by injections of FVIII taken from blood transfusion donations. This replaced the missing factor in his blood. The prospect seemed excellent as all was controlled by a natural product. I was unaware that the British blood transfusion services had not had the money invested in them to enable the supply of all products.
- 5. The main products he received were from Armour Pharmaceuticals. Stuart was not a severe haemophiliac, he had approximately 2% clotting factor. That being said, he did spend a lot of time in hospital or going to be checked each day and receiving treatment.
- 6. On reflection, the amount of Factor VIII and the number of stays in hospital were very high for the type of bleeds he had. Up until Stuart was 8 or 9 years old, there were incidents when I raised concern with the hospital over Stuart's health. I felt that he showed symptoms of hepatitis but was told he tested 'non A non B' and was reassured by that. I later found out that there wasn't a test for HCV and that he was unwell with HCV from at around that time.

Section 3. Other Infections

7. We had an awful time when Stuart, as an inpatient with a bleed, was given a skin test for TB and had a violent reaction to it. We had not been informed that TB had been on the ward or that Stuart was to be tested and he was seriously ill in hospital for a few weeks and then had tablets and x-rays for 18 months.

Section 4. Consent

8. During Stuart's childhood years at BCH, treatment was administered by the clinicians without our knowledge or consent and the children were informed of their HIV status while as an impatient on the ward. I refer to Stuart's Statement for further comment in relation to absence of consent.

Section 5. Impact of the Infection

- 9. The AIDS crisis appeared in the newspapers and on the television. The media referred to haemophiliacs having AIDS and being infectious. At first, we (the parents at the Children's Hospital) thought we were all safe because we had been reassured by Armour Pharmaceutical representatives that their FVIII product was sourced from single donors and not pooled products. We later learnt that this was not true.
- 10. Time went on and fear grew. We did not know what was happening or what to expect. Over a period from talking to other parents, we realised that 100% of the boys at Birmingham Children's Hospital had been infected with contaminated blood products. On reflection, the knowledge that the blood was contaminated was there years before.
- 11. The boys were only expected to live for 18 months after contamination. It is impossible to list all of the difficult problems we had to deal with during those years; from caring for the boys and trying to retain normality in their lives; to the fear of anyone finding out and to receiving no professional help from doctors or dentists, government or solicitors.
- 12. The important part for me was for Stuart to have as normal a life as possible. He was a bright child and good at school before the HIV infection. He has good friends and a close family. Unfortunately his health is now quite bad and,

financially, life has been difficult for him. I have listened to Stuart's oral evidence and completely agree with the content of his Statement.

13.1 could expand further in my own Statement but prefer to refer to the content of Stuart's Statement and to refer to a transcript of my interview on 22nd March 2007 entitled 'HIV in the Family' exhibited to this Statement marked WITN4113002.

Section 6. Treatment/care/support

14. As a family no support or counselling was offered to us. Stuart although being unwell has had to research and even fight for basic treatment. Care and support was not there when it should have been for him.

Section 7. Financial Assistance

15. The basics of the Government putting in funds and setting up the Macfarlane Trust are known. We were encouraged to sign away future rights on the basis that the boys had a very short life expectancy and the money was needed to support them. I tried to pursue a claim with solicitors in Birmingham and Liverpool up until Stuart became of age at 18 but was told as an individual it was impossible for me to claim against an American pharmaceutical company.

Section 8. Other Issues

16. A complete injustice has been done to the haemophiliac community who have suffered terribly and are emotionally drained after the events of the last 35 to 40 years. The injustice is still not acknowledged.

<u>Anonymity</u>

17.1 do not wish to remain anonymous.

18.1 do not want to give oral evidence to the Inquiry.

Statement of Truth

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

Signed.....

Dated 15 August 2000.

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