

Witness Name: HOWARD JAMES NEIL SMITH  
Statement No: WITN1780001  
Exhibits: 0  
Dated: FEBRUARY 2019

## INFECTED BLOOD INQUIRY

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### FIRST WRITTEN STATEMENT OF HOWARD JAMES NEIL SMITH

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I, HOWARD JAMES NEIL SMITH, will say as follows:-

#### Section 1. Introduction

1. My name is Howard James Neil Smith. I was born on GRO-C 1949 and I live at GRO-C Cambridgeshire GRO-C. I am retired and I have three children, three stepchildren and six grandchildren.
2. My mother, Constance Mary Smith (born on GRO-C 1914) was infected with the Human Immunodeficiency Virus (HIV) from contaminated blood products. My mother died of 1 a. renal failure, b. Myocardial Infarction c. Diabetes Mellitus 11. Factor VIII Inhibitor Haemophilia H.I.V. (Human Immunodeficiency Virus) Infection on 20<sup>th</sup> December 1992, aged 78.
3. My brother, Michael, has given his own Witness Statement to the Inquiry (Witness Number WITN1529001).

4. This Witness Statement has been prepared without access to any of my mother's medical records.

## **Section 2. How Affected**

5. My mother developed Von Willebrand's disease in adulthood. She was a long term type 1 diabetic. We were told that she had developed Von Willebrand's disease having been left on the same insulin for over 30 years. My mother's Von Willebrand's was severe. Her arms, legs or any impacted area would fill with blood given the smallest knock and this would take weeks to drain. She also suffered from nose bleeds which had to be managed given her condition.
6. My mother was treated at the Royal London Hospital Haemophilia Centre on the Mile End Road under the care of Dr Colvin.
7. My mother was treated with the Factor VIII product made by the Armour Pharmaceutical Company in mid 1987. My mother was diagnosed as being infected with HIV within weeks of treatment.
8. My mother was staying with us in GRO-C near GRO-C in GRO-C when one night her hand slipped on some clothes put on a chest of drawers and she fell breaking her hip. We called the ambulance service and having told them of her Von Willebrand's disease, and, by the time the ambulance arrived, they had instructions to take her straight to The Royal London Hospital.
9. I went to GRO-C (where my parents lived) to collect my father and then on to the hospital. By the time I arrived and met a doctor, we were told that my Mother had been put in traction and that as bleeding could not be controlled there was no possibility of operating to repair my mother's hip. There was also suspicion voiced by the consultant involved that there was internal bleeding at the site of the break (although there was no visible sign of this 12 hours after the fall).

10. Two days later we were told that there was in fact internal bleeding, however, there was a potential way that it could be stopped using a refined blood product called Factor VIII which the hospital was trialling on mothers with bleeding problems after giving birth. Dr Colvin stated that he had been able to get some of this product, by twisting all arms and begging favours, to use on my mother. If it didn't work there was no further outlook for her other than death. We readily agreed to the Factor VIII being used.
11. About a week later we were told that the Factor VIII had worked and the bleeding stopped and that now all she had to do was survive another four weeks in traction in a hospital bed without getting sores or pneumonia.
12. Some weeks later, when we were discussing my mother's discharge and rehabilitation, Dr Colvin spoke to me and my father informing us that my mother was HIV positive from an infected batch of the Factor VIII
13. No advice was given to us beforehand about the risk of my mother being exposed to infection from Factor VIII. Dr Colvin led us to believe that he was doing us a great service in sourcing the product for my mother. He told us that my mother would not survive unless we tried the treatment (as the only option).
14. The information provided to help us understand and manage the infection was inadequate. Dr Colvin spent about half an hour with us discussing the management of the infection and risk of infection to others and gave us some literature (photocopied sheets) to read before being called away. Dr Colvin told us that provided we wore gloves (and no gloves were provided) and made sure that no body fluids from my mother came into contact with an open wound, we would be safe from infection. At no time was the serious and fatal nature of the infection explained. We saw Dr Colvin a number of times before my mother was

finally allowed to come home but have no memory of any other in depth discussion. We were not given any adequate information until *at least* six months after a subsequent move to Warboys by a new/local GP there.

15. Unbelievably, Dr Colvin told us about my mothers HIV infection in an informal *'stand up meeting in a corridor'* and only when it started to become apparent that my mother might actually survive her broken hip. I recollect the meeting as being in parts (but of a total duration of no more than half of one hour) with Dr Colvin and one of his assistants because Dr Colvin was 'called away' – which in hindsight was appalling given the nature of the situation. In hindsight I believe the manner in which we were told to have been Dr Colvin wanting to down play the seriousness of the matter.

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

16. I do not believe other infections were received as a direct result of being given Factor VIII but it was very evident that treatment for my mother's other ailments were affected. I remember being told that a procedure on her leg was to be carried out on the ward and not in theatre as they could not afford to down time whilst it was disinfected. Their inability to cure the ulcer may well have been caused as a result of the reduction in her immune system by HIV, further impacting on her suffering.

### **Section 4. Consent**

17. My mother was treated with Factor VIII without adequate or full information. We did not know that there was an issue with the Factor VIII product before my mother was tested for HIV. It would appear that the Factor VIII was being trialled at the hospital for the purposes of research.

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

18. My father was immediately compelled to take early retirement from work in order to look after my mother. He had a long term alcohol problem.
19. Within a year I moved home to the **GRO-C** in Cambridgeshire and had lengthy discussions with my parents, local doctors and Addenbrookes Hospital before moving my parents to the same village. I think it had become common knowledge in **GRO-C** that my mother was infected and my father was getting unwanted and unwarranted attention in the pub and in the village.
20. It was only in discussion with my GP in **GRO-C** that, for the first time, I really understood the dangers of HIV and the potential for infection. I had two children at primary school 100 yards from their home who we had to educate them in the do's and don'ts of being with Granny without telling them what was going on. Even though tactfully handled this had an immense impact both on the children and my parents. As a family we had to be totally aware especially when mother was around the children.
21. From the time my parents moved, they never stayed away from their home except to visit my brother, and the most noticeable effect of my mother's HIV infection was the reaction of hospital staff when my mother attended hospital for treatment of her diabetic illnesses (going blind, ulcers etc).
22. I believe that both my parents were stoical in their outlook. There is no doubt that the stress of caring for my mother had a major detrimental effect on my father and his drinking problems which became significantly worse although focused on home. He was a primary carer who was there on duty from 7.00 am until 8.00 pm. Whenever he was unable to cope, he would telephone me and this obviously caused increased stress on both my work and home life.

23. I believe my mother's health was further complicated and compromised by the significant deterioration in her immune system. My mother lived with HIV for 5 years without developing into AIDS. Her Death Certificate states that her cause of death as 1a. renal failure b. Myocardial Infarction. c. Diabetes Mellitus. 2 Factor VIII Inhibitor Haemophilia H.I.V. infection. My mother had no treatment for HIV other than her routine GP visits. Nothing by way of treatment was offered to her by the Royal London Hospital.
24. My mother was acutely aware of her condition and could naturally become depressed particularly at the futility of her situation – you need to remember that there was a lot of horrific publicity about HIV at the time but she always tried to put on a brave face. There is no doubt that her infected status had an enormous negative effect on any treatments she required from hospitals to dentists.
25. My mother's social life ended when she was infected and my parents had to move to **GRO-C**. She never went out except to visit my brother in Scotland or me at home. Visitors to the house were discouraged with the exception of my children who would go and see her for an hour after school once a week. I would try to see her daily. Before this happened she had been gregarious and outgoing being involved in voluntary groups especially raising money for the riding for the disabled.
26. My mother's infection took a major toll on my father who was the primary carer. We all became very aware of the potential for full blown AIDs developing and the nightmare that was going to be. This took a toll on all of us especially my wife who was suffering from **GRO-C**. No member of the family escaped the impact.
27. The stigma was not an issue within the community as no one knew the true situation with the move to **GRO-C**. My mother became housebound and my father moved away from his friends. This led to him drinking at home in the

evenings. My wife and I never discussed my mother with anyone unless it was essential. Whenever I told anyone about my mothers situation I could actually see him or her taking a step back putting space between us it gave a horrible feeling. To be fair this still exists in some way today when we mention the situation – people have a natural inbred caution even now.

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

28. I cannot speak highly enough of the local surgery and Dr David Warbrick Smith who was our GP. Their care was second to none. This made the way in which the other NHS staff who dealt with my mother more obvious in that they were clearly and frankly frightened of the HIV, which resulted in her minimal levels of treatment.

29. No counselling or psychological support was made available.

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

30. My mother had a conversation with Barbara, Michael's wife, in which she mentioned that she had received a nominal sum from what we think may have been the Terrance Higgins Trust. She did not say how much she received. What she did say, however, was that she might have been one of the few women infected and that those males infected had conversely received a very substantial sum of money - thousands of pounds - on the basis that they needed sufficient funds to support themselves and their families; and, she was just a woman and felt discriminated against.

31. We do not know very much about how any finance matters evolved. What we can recall is that our mother put one thousand pounds into savings accounts for each of her six grandchildren. It is almost certain that any money received was

used in providing for her personal support as our father was no longer in employment – we believe there was no carers allowance at that time and if there had been they would both have been very reluctant to claim. No funds were evident at the time of her death.

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

32. There are no other issues.

### **Anonymity**

33. 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.

### **Statement of Truth**

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

Signed

GRO-C

Dated

22<sup>nd</sup> February 2019.