

Witness Name: MICHAEL GEORGE STEWART SMITH
Statement No: WITN1529001
Exhibits: 0
Dated: FEBRUARY 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF MICHAEL GEORGE STEWART SMITH

I, MICHAEL GEORGE STEWART SMITH, will say as follows:-

Section 1. Introduction

1. My name is Michael George Stewart Smith. I was born on GRO-C 1948 and I live at GRO-C. I am married with three children and three grandchildren. I am currently a full time Deacon in the Catholic Church (Vocational) with a retirement age of 75 years. My wife, 64, is the Owner of a Soft Furnishing Company.
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 renal failure on 20th December 1992, aged 78.
3. My brother, Howard, has given his own Witness Statement to the Inquiry (Witness Number WITN1780001).

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 and father lived for many years in GRO-C Whilst staying with Howard, my mother slipped and fell breaking her hip. Dr Colvin treated my mother in hospital for an internal bleed with the Factor VIII blood product. The product was being trialled at the hospital on mothers with bleeding problems after giving birth. It was the only option for my mother or she would die from the internal bleeding.
9. I was at that time living in Scotland. I was in close contact with Howard and my father and they kept me updated. About a week after treatment, I was given to understand 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.

10. Some weeks later I took a telephone call from Howard. He told me that our mother had been infected with HIV. When Howard and my father were discussing my mother's rehabilitation with Dr Colvin, they were informed by him that my mother was HIV positive from an infected batch of the Factor VIII.
11. Howard and my father were informed in a casual corridor meeting. We are unclear as to how my mother was told.
12. No advice was given beforehand about the risk of my mother being exposed to infection from Factor VIII. Dr Colvin said that my mother would not survive unless she had the treatment (as the only option).
13. There is no doubt that they were totally unprepared for what happened and no real information was ever provided by the Royal London Hospital. Correct and adequate advice should have been provided, in detail, before any procedures were undertaken in order for the patient involved and their family to make a judgement call. The NHS was clearly totally unprepared for managing HIV or chose not to reveal facts they were in possession of. Either the blood plasma being used had not been tested, which it should have been or was tested and a deliberate deception occurred or its being used is evidence of a cavalier and unconcerned attitude by those practitioners involved in taking risks with people's lives.
14. The subsequent information provided by Dr Colvin to manage the infection was basic and totally inadequate: 'Do not come into contact with body fluids; if you have a cut on your hands it is best to wear gloves'. The Royal London hospital staff was clearly unaware of how virulent the disease was and this serious aspect was down played when disclosing care requirements to the family. Gloves were never provided.

Section 3. Other Infections

15. 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

16. 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

17. 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.

18. Within a year Howard 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 believe 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.

19. During the main part of my mothers infection of HIV and decline, my family and I were resident in Scotland and the major aspects of care was undertaken by Howard.

20. My parents would come to stay with us each year and we tried to continue this practice. However with children aged 1, 3 and 7 years my wife became terrified that they would become infected or damage my mother in some way. When they came we set a dedicated room for them, and, as we were initially told that transference was only by blood, dedicated bathroom and towels etc., but supervising the children was a nightmare 24 hours a day. We did not intend to tell the children as they would not have been able to comprehend the situation. Ultimately, my mother was simply too infirm to visit.
21. I have been a life long blood donor in the 100's and was involved in a fracas in Edinburgh. Because Edinburgh was regarded as the AIDS capital of the UK in the late 80s/early 90s, I was tested for HIV. I was stunned when the Donor Centre explained the implications of this disease and the precautions required.
22. The biggest mental impact for my mother was coming to terms with the futility of her situation and of being so remote. No matter how carefully we dealt with the situation it was an emotional rollercoaster for my family and the sudden realisation that their loving and cuddly grandmother was infected and had to now remain distant from physical contact which was her choice.
23. When she was hospitalised I tried to visit every second weekend and, with my employment requiring weekend working, I became a remote father to my family.
24. Previously I spoke to my mother every weekend and she always tried to remain the same person. Social media did not exist in those days so our calls became so very important. As noted by Howard, mother became isolated. On the latter occasions that we travelled down to visit her it was like treading on eggshells and particularly stressful for the children who we told latterly of the diagnosis and going to school in Edinburgh knew the implications of her infection although we never mentioned them.

25. I was with my mother in the last day and hours of her life when her immune system had collapsed. Whilst any number of items might be written on the death certificate; her diabetes – now totally out of control, her leg ulcer infection increased exponentially, her gangrene – causing untold pain and discomfort ultimately she ended her life in the most horrific way. Whatever; we tried to conduct my last visit as normal discussing what presents she was looking forward to and how my wife was making chair covers for when she went home. It was only when I was leaving her room that she said ‘tell Barbara not to bother about the covers darling, all your happy thoughts are kind but worth nothing as I am not going to be here any longer and you know it’. As I passed the staff they told me they were making her as comfortable as possible and were now going to give her something to help her on her way. By the time I reached Scotland that evening, mentally distraught and worried, she was gone. It has taken many years to get over her unplanned loss.

26. 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 Howard or me and this obviously caused increased stress on both our work and home life.

27. 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.

28. 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 us in Scotland and to visit

Howard and his family. Before then, she had been gregarious and outgoing being involved in voluntary groups especially raising money for the riding for the disabled.

29. 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. Whenever I told anyone about my mother's 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

30. 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.
31. From the time my parents moved, they never stayed away from their home 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).
32. No counselling or psychological support was made available.

Section 7. Financial Assistance

33. My mother had a conversation with my wife Barbara 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.

34. 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


35. There are no other issues.

Anonymity

36. 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 

Dated 21.02.2019