

Witness Name: Frances Paula Sloan

Statement No. WITN3356001

Dated: 2nd January 2020

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF FRANCES PAULA SLOAN

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 26th June 2019. I adopt the paragraph numbering in the Rule 9 request for ease of reference.

I, Paula Frances Sloan will say as follows:-

1. Introduction

1. My name is Paula Frances Sloan. My date of birth is GRO-C 1954 and my address is known to the Inquiry. I am married and I am the mother of five boys and one girl.
2. I wish to make a statement on behalf of my father, James Cousins who was born on the GRO-C 1922 and who unfortunately died on GRO-C 1986. He died as a result of becoming infected with hepatitis C. I recall that he was buried on Father's Day.

2. How Infected

1. My father James Cousins was a mild haemophiliac but bled as a severe haemophiliac. He would often suffer from regular spontaneous bleeds but didn't let this get him down. He always had a smile.
2. Sometime between 1958 and 1960, I don't recall the exact date, my father suffered a perforated ulcer and spent a lot of time in the Royal Victoria Hospital, Belfast. On this particular occasion he was in hospital for about a year. He was very ill on admission to hospital and it was thought by Dr. Carroll the family GP that he was not going to survive. At this time he was treated with plasma and blood.
3. There was then a second admission to the Royal Victoria Hospital six months later because my father had started to spontaneously bleed internally. To my knowledge, he was again treated with plasma and blood as there were no other treatments available at this time.
4. When my father eventually returned home after the last admission, he still went back and forth to the Royal Victoria Hospital with various further bleeds. Practically every day my father would suffer a spontaneous bleed. He was treated with Cryoprecipitate and then later with Factor VIII. This carried on for years and continued for the rest of his life.
5. My father died at the age of 63. Until that time, I believe he had been the eldest haemophiliac in Ireland. Although he was told by the doctors in the early years that he was not expected to reach the age of 18.
6. My brother Martin and I learnt how to home-administer Factor VIII to my father because my mother could not bring herself to treat him. She was too afraid she would hurt him. However, at no time during the training were we informed of any danger or risk involved in administering Factor VIII. We assumed it was absolutely safe.

7. My father became immobile in or around the 1970's, so it was arranged for him to have hydrotherapy treatment with Mrs. Cavern at the Davey Hill Hospital, Newry. The hospital was much closer to our home than the Royal Victoria.
8. My father would still regularly attend the Royal Victoria Hospital for blood tests and would stay in hospital for maybe two nights on each of these occasions. It meant shorter stays for him in hospital.
9. I believe that it was around this time (1970's) that my father became infected with hepatitis C. I remember the nurses wearing aprons and rubber gloves before they would touch my father. However the nursing staff didn't seem concerned about protecting the family in this way. I would often change my father's bedding and help him with his personal care, but I was never advised to wear gloves or an apron for my protection.
10. My father was not aware that he had become infected with hepatitis C but the signs were all there. His skin was yellow and he suffered with abdominal problems.
11. My father did not drink and never touched alcohol. I recall an incident when my father was in hospital. The nurse tried to persuade him to drink a small glass of Guinness to help increase his iron level, but my father went mad and told her he wouldn't drink it.
12. The knowledge that my father had hepatitis C became apparent after he had died. Although without my father's medical records we cannot be sure that he did not know of his infection. Due to the length of time since his death, the records have been destroyed.
13. Quite by chance, my sister Donna attended an appointment with Dr. Gary Benson, Consultant Haematologist at the Royal Victoria Hospital

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 At the appointment Dr.

Benson discussed the circumstances surrounding my father's death and suggested to her that the family contact the Skipton Fund.

3. **Other Infections**

1. I am not aware of my father becoming infected with any other infection than hepatitis C.

4. **Consent**

1. I think there is a good possibility that my father was treated without his knowledge and consent. My father was not the type to ask the doctor questions. He would have just trusted the doctors' judgment and accepted whatever treatment was prescribed to him.
2. I am sure that my father wasn't given any information regarding his treatment. If he had been, he would have felt that this was important and would have wanted to discuss it with me.
3. My mother was not aware of my father's treatment or of any information in relation to it.

5. **Impact**

1. After my father died, my mother was left with the children to look after. Donna, my youngest sister who was only 14, (who had a particularly close relationship with my father), my brother Anthony and my elder sister Kathleen (who also still lived at home and was expecting her first child). Donna and Anthony were both studying for their exams at the time my father died.
2. My mother didn't tell my brother and sister that my father was dying because she didn't want to distract them from their studies and upset

them. Donna was a bright girl but needed to work hard on her studies. She wanted to become a nurse. To this day, Donna has not forgiven us for not telling her our father was dying. She blamed all of us but particularly my mother for not telling her. She felt aggrieved and upset at not having the opportunity to say goodbye to our father.

3. Anthony took our father's death really hard. When he found out that our father was dying, he went to the hospital to see him. When he saw the poor condition of our father, he was extremely upset. He said "that's not my daddy". He then ran out of the hospital. After seeing our father in hospital, Anthony would go to a field close to our home and spend long periods of time there. He took our father's illness really hard.

4. In the early years, whilst working as a Seamstress I met and married Damien. He is the love of my life. We started about making a life for ourselves. We have six children; five boys and one girl. Two of my boys were born with haemophilia

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5. My two sons became infected with hepatitis C as a result of contaminated blood products. My son Martin has also made a statement to the Inquiry telling his story of how he became infected.

6. When my father was dying, I remember having to break the news to him that I was pregnant when he was in hospital. It was very upsetting for both of us.

7. Something that has stuck with me through the years was the colour of my father when he died. He was yellow.

8. After my father's death, my mother felt so lonely, she missed him dreadfully. My father was the "lynchpin" of the family. A big void has been left within the family.

9. After my father's death, Dr. Mayne's team at the Royal Victoria Hospital asked my mother to arrange for the family and close relations to go to the hospital for "genetic testing". This also included my **GRO-C** **GRO-C** was asked to go along as she had been staying with the family for a long period of time.

10. We all went to the hospital and were tested but none of us ever received any test results or further communication from Dr. Mayne or her team. Even to this day, we do not know what the results were or why we were really being tested.

11. I have always been aware that I was a carrier of haemophilia but eight years ago I was diagnosed as a haemophiliac.

12. **GRO-C** We have been aware that we are carriers all our lives but we did not know we could be potential haemophiliacs. We have since realised that female carriers are sometimes referred to as mild haemophiliacs.

13. **GRO-C**

14. Kathleen has two boys and one girl and Donna has a boy. **GRO-C**
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15. In the early years it was very hard to keep my boys safe. I recall the doctors telling me not to let Martin go out to play with the other children in the street, which was hard considering we lived on a Council estate with lots of young families. It would break my heart to see him standing there watching the other children playing but knowing he could not join in with the fun.

16. As it was so upsetting to see Martin stand and watch the other children, as parents, we took the decision to let him join in with the other children, but he suffered lots of bleeds as a result.
17. When either of the boys had a bleed it meant a two and a half hour journey to Belfast to the Royal Victoria Hospital which was effectively in the middle of a war zone at that time in Northern Ireland's history. The fact we didn't own a car didn't make it any easier.
18. We relied on good neighbours and the ambulance service to take us to appointments or for hospital visits. The boys spent long periods of time in hospital in the early years. It sometimes felt that they took it in turns to need hospital treatment. One or the other would be in hospital after suffering a bleed.
19. Life at home whilst the boys were growing up was chaotic. Both boys were very active and as a consequence there were many accidents, bumps and bleeds. It became impossible to hold down a full time job and care for them at home.
20. In 1995, Damien and I were informed by the doctors, that the boys had received a 'bug' in their blood. We were told that it was nothing to worry about as it would not cause them harm. We were told that the boys didn't need to know about the 'bug'. I have a lot of guilt around this meeting as we never questioned what we were being told and I have very little recollection of the details of what was, in hindsight, one of the most important meetings of my children's lives.
21. Later, in adulthood, Martin got married and moved out. His brother had formed a long term relationship with his girlfriend and both of their lives appeared to be taking shape and progressing as they should. Then came the news that the 'pioneering' treatment, Factor VIII, championed

to us as a 'miracle' was poison, and I was the one who had administered it!

22. Martin was informed about his infection with hepatitis C in around 1996/1997 when he attended a routine appointment with Dr. Mayne. At that appointment he told her that he was intending to get married. Dr. Mayne said in that case, she needed him to make a further appointment with her and that he should attend this appointment with his fiancé. Martin did this and it was at that appointment that Dr. Mayne explained to Martin and his fiancé of his infection with hepatitis C. Martin will explain in more detail about this appointment in his witness statement to the Inquiry.

23. I am unsure as to when and under what circumstances Martin's brother was told of his infection but I believe it would have been around the same time period as Martin.

24. The boys were advised by the doctors not to panic. The medical staff played it down a lot and it didn't seem like a big deal at the time, but then shortly after came the awful Interferon treatment.

25. My son Martin will cover the affects of this treatment in his witness statement to the Inquiry.

6. **Treatment/Care/ Support**

1. To my knowledge, my father was treated with plasma and blood in the early years and thereafter with Cryoprecipitate and Factor VIII.

2. I believe it was around the 1980's that Factor VIII became available. We were told that it was a 'miracle treatment' and 'pioneering'. They used the word 'pioneering' over and over again, and in effect, it was. Prior to the Factor VIII treatment the boys were both treated with what the nursing staff called 'Edinburgh High Potency' treatment.

3. While this treatment was not a cure, it meant that there was a possibility of my father and my boys being able to spend much less time in hospital and much more time at home.
4. When the boys received their treatment for hepatitis C they both became very agitated and depressed. The constant shivering, sweats, rashes and pains. It was so awful to watch. They were so sick at times I was afraid that I could lose them. But eventually, with the great grit and determination that they have both shown through the hard years after a couple of attempts with the treatment, they both cleared the virus.
5. Martin will explain the types of treatments he received in his statement to the Inquiry.
6. My father did not receive any psychological support and neither did the family in relation to my father's infection or the boys becoming infected.

7. **Financial Assistance**

1. My brother Jimmy applied and corresponded with the Skipton Fund and the family eventually received a payment. I am unsure of when that was, but it would have been within the last 8-10 years. My mother had passed away by this time, so she knew nothing of the payment. She should have been entitled to this to help her.

8. **Other Issues**

1. When my father was dying, we were told he had cirrhosis of the liver. We found this information strange as my father had never touched an alcoholic drink in his life. Cirrhosis was not put as cause of death on his death certificate but we had no cause for suspicion. We had absolute trust in the staff at the Royal Victoria Hospital.

2. I wish to know what Dr. Mayne knew about the hepatitis C virus and when did she know.
3. I feel responsible and guilty as I helped to put this poison into my father and my two small sons' bodies and I did this time and time again.
4. Whilst I was aware of the blood products which contaminated both of my boys and the difficulties caused to them, since becoming adults and clearing the virus, I was no longer reading any material connected to haemophilia or the extended community. I was so unaware and ignorant of the storm that was raging around this scandal and I feel so much shame of my ignorance. It wasn't until I went online and found groups such as Factor8 that I realised the extent of what my boys had been hiding away from me. I know they were only trying to protect me from the reality of their infection.
5. From the internet I have read some of the heart breaking stories of the losses that people have suffered. So many of these families have been hit so much harder than my family. I found myself crying for all the people I had never had the pleasure of meeting in their living years. To all the infected and affected, I send my love and my prayers.
6. I also read of some of the potential cover ups. It made me question some of the information I was given over the years by clinicians.
7. I feel so let down by the doctors I trusted over the years. It has destroyed my trust in the medical establishment and politics. It has changed me, and that hurts a lot. I believe they took my happiness away.
8. I have become very sad and low with the guilt that I played a part in my father's death and my boys becoming infected. After all, I was the one

treating them. My boys had come through so much in their lives, they didn't deserve this.

9. Whilst both of my boys hepatitis C is classed 'undetectable', I fear even if it is not in my day, the infection may come back and wreak havoc on them as I have witnessed with so many others in this brave community.
10. One of my sons in particular has helped me with preparing my statement to the Inquiry. Some observations from my family in relation to the change in me personally are explained below.
11. Within my family I was considered a very strong individual. The issues I faced and dealt with in my life appeared to be like 'water off a duck's back'. I just got on with things. My family believe that this woman has disappeared.
12. They have become aware that my mental health has suffered terribly as a result of the guilt I feel that I infected my boys and killed my father. My family try to convince me otherwise but I cannot shake off the feeling of guilt.
13. My family feel that my health has spiralled downward. They can see a woman who was once, a very social and active person turn into a person suffering from ill-health, depression and feeling extremely sad. They try their best to console me but the feelings of guilt are too strong.
14. No-one from this community should be left feeling like this, they have no guilt, but it seems that the ones who do have blame, also have no conscience.

Statement of Truth

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

Signed.... GRO-C

Dated..... 2 / 1 / 2020