Witness Name: Sinead Moore
Statement No: WITN2656001
Dated: 12th April 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF SINEAD MOORE

I provide this statement in response to a request under Rule 9 of the Inquiry rules 2006 dated 12th December 2018. I adopt the paragraph numbering in the Rule 9 request for ease of reference.

I, Sinead Moore will say as follows:-

1. Introduction

1. My name Sinead Moore. My date of birth is GRO-C 1980. My address is known to the Inquiry. I'm married with two children; two boys. GRO-C GRO-C I've had to stay at home to look after him.

2. My daddy has severe haemophilia A as well as dementia. We care for him at the family home.

3. I'm the first girl in a family of seven children.

2. How Affected

1. My daddy was born with severe haemophilia type A. He attended the Royal Victoria Hospital in Belfast in Northern Ireland and Altnagelvin Hospital in Derry. He also attended the City Hospital in Belfast and was under the care of Doctor Elizabeth Mayne.

2. From his medical chronology I can see that he was given various blood products from the late 1950's until the early 1980's such as Hameophil, Kyrobulin, Profilate and Cryoprecipitate. He was also given plasma and a blood transfusion. To my knowledge he was given contaminated blood products in 1982 during his home treatment. The only reason I know about this is because of the information provided in his medical notes.

3. He was first diagnosed with hepatitis C (HCV) in 1992 and then hepatitis B (HBV) a few years later but Daddy's medical notes state that he was showing signs of abnormal liver function form as early as 1986.

4. My daddy only confided in me a few years ago that he had been infected when I questioned him on it. He didn't tell me initially that he had been infected with hepatitis B and C. He only told me that he had been given bad blood. I was told not to tell anyone. His medical notes don't mention him having been informed about his infection by the doctor. As far as I'm aware he wasn't spoken to about anything.

5. No advice was given about the infection or any of the risks surrounding it. That's what angers me the most, the lack of information. He would have been pushing his body to the limit with travelling back and forth to the hospital; which was on his own a lot of the time as well. He would have to go on the train to the hospital and it was so far away.

6. My mammy wasn't told until I told her. She actually said to me that Daddy just had a bad infection. However, the way he said it to her was that it wasn't that bad and that it could have been a lot worse. Daddy was innocent; he believed

everything he was told without question. Whatever the doctor told him he would just believe.

7. When he eventually found out he had the infection he was told not to tell anyone. He received an information request slip asking him if he wanted more information about his condition. My daddy ticked the box but the doctors later made out that he hadn't asked for anymore information which was untrue.

8. My mammy has never been tested nor myself or my siblings. This is even though me and my younger sister were born around the time he contracted the infection. Daddy was drinking a lot at the time I was born. It is possible that this was his way of coping with the loss of his brother from hepatitis C though infected blood. It also could have been to numb the pain because he knew he had the same liver infection through infected blood.

9. **GRO-C**

3. Other infections

1. The only thing I know is that my dad was sent a letter in regards to him being at risk of vCJD. I went to the hospital appointments with him and as far as I know he wasn't offered any treatments for it. I remember telling the rest of the family that he had stopped eating red meat because he was afraid of getting mad cow disease.

2. Daddy's doctors said about 10 or 12 years ago that he had dementia. Three and a half years ago he started to show signs of this. But I have doubts that he has dementia as I think it could possibly be vCJD. I suspect this as a result of reading articles on Google on a vCJD website and seeing my dad's symptoms. Also, the doctors only saw him two or three times when they were supposed to be examining him twice every six months so it makes me wonder how they can be so sure.

3. The doctor told me alone that my dad had dementia before telling me to tell the rest of the family. This whole situation has made me think that they knew all along.

4. He found out he also had hepatitis B in 1995.

4. Consent

1. My daddy was definitely treated and tested without his consent. There was no consent in the treatment he received or didn't receive. Around 2001-2002 I would have been going to the hospital with daddy. I was there with him and consent was never mentioned.

5. Impact

1. Mentally, I think it just finished him off. He started drinking quite a lot. I think that my mum and dad's relationship fell apart and they even started sleeping in separate bedrooms. They were arguing a lot. I remember that my daddy would go out and not come home. My four older brothers would have been 14, 15, 17 and 18 at the time. They just thought that my mum and dad weren't getting on.

2. My mum couldn't understand why he was pushing her away. She just thought that it was their marriage coming to an end and that she had lost her husband.

3. My dad became very bitter about gay people at one point which we couldn't understand. GRO-C GRO-C GRO-C I think that my daddy's views about gay people were largely to do with the media.

4. I remember that before the treatment my parents and their families would always go out for social gatherings but they stopped all of that after my dad's diagnosis. He would then start going out on his own and not even socially. He would drink throughout the night. His relationship with my mum got really bad.

5. In regards to stigma, we weren't aware of it at the time so I can't comment too much on that. However, I can understand why my daddy felt he had to hide his situation, especially considering the time period in which he was infected.

6. I know my dad was very concerned about the health of me and my own children. I didn't tell him I was pregnant until I was seven months along. When I had my son I was told there was a high chance of him having haemophilia. I remember my daddy crying over the phone when I told him. For a while he couldn't even look at me.

7. He was very protective of us all. He didn't want me going to my university lectures while I was pregnant. This was because I was a carrier of haemophilia and he worried about how the stigma of the contaminated blood would impact on me and my son. He was worried about how people might look at me. When he was born, he even refused to let me take my son out sometimes. I couldn't understand why he was so against some of the things me and my siblings did, but then again he's lost two brothers through contaminated blood. He doesn't speak about this though.

8. He hated having to tell anyone that he had haemophilia. If he had a bleed and had to use a wheelchair he wouldn't leave the house. He was embarrassed if anyone saw him struggling to get in and out of the car. I think that a lot people knew he had haemophilia but he seemed to want to believe that people didn't know.

9. I can't explain how bad it's been for me and my family. He's my best friend and I've gone to every appointment with him since I found out. Daddy only told me around 9 or 10 years ago and upsets me that I couldn't be there for all those

years and couldn't do anything to help him. I can't get my head around how he went through it all on his own. Daddy did try to convince me not to get involved in the Infected Blood Inquiry because he knew that I would struggle with the guilt.

10. My dad is bedridden all of the time. He's also lost his eyesight. It's hard to ask him what he thinks about his situation because you can't get a conversation out of him. He doesn't talk to me much about it and I don't know how to talk to him anymore. It hurts me that he has no trust.

11. Daddy had to stop working as a Publican. This was because he couldn't stand for very long. His joints were too bad. I remember that he got into a lot of debt. My mum thinks this is because he was always drinking. They ended up having to re-mortgage their house. Because he couldn't work he became so angry which lead him to drink more.

12. I would say that for me, my schooling was affected. It was sometimes hard to focus on my education because mum and dad were fighting all the time. Life was changing so much.

13. Daddy's infection impacted the relationship between me and my mammy. Me and my dad had a close bond so I was always on his side. He was the one I turned to talk about things. She couldn't understand why this was as he was always out drinking. At the time I didn't understand why she was always on daddy's back. I would say that in the last 11 years our relationship has repaired.

14. Dad's infection has also had an impact on my relationship with my husband. We've had to look after him in our family home. My siblings and I will usually take in turns to look after him.

6. Treatment/Care Support

1. Daddy started treatment in 1994 although I'm not sure if it had a positive lasting effect. I do know that the negative impact of the treatment was awful; he couldn't walk. As I mentioned, about 10 or 12 years ago the doctors told my dad that he had dementia. I actually think that their improved treatment of Daddy was their way trying to compensate as they knew how things were going to go in the future for him. They knew how older men would have the same type of problems on the treatment.

2. There's been no support given to my mum. She hasn't even been tested. She's been left to deal with everything by herself.

3. When Dad was in the hospital last November he received a letter from the hospital to give to his GP informing him that he was asthmatic and had arthritis. This was actually the first time in years that had acknowledged that he had hepatitis C. I believe that the only reason that they finally acknowledge it was because the family had started asking questions.

4. I'm not aware of his liver ever being scanned. I know that his liver should have been scanned every six months but that it hasn't been scanned in over 17 years. The doctors at this point are unsure about the extent of the damage.

5. No counselling or psychological support has been offered. I've spent a fortune on counsellors over the years.

7. Financial Assistance

1. My daddy received £20,000 from the Skipton Fund. I recently found that that he should also been getting a monthly payment. The social worker thinks that the reason he didn't get the monthly payment is to do with data protection because of the fact he had hepatitis C. To be honest it's not even about the money it's about getting to the truth.

2. I was the only one who knew where the money came from. He told me not to tell the rest of the family where the money had come from. This is when I found out about him having been infected. I believe that he was embarrassed to have received the money in the first place. It was instilled in him that money received from others was bad money which he later passed on to me and my siblings. He especially hated having received what he considered as blood money.

3. He didn't keep the money for himself, he distributed amongst his children. He told us to do something nice with it.

8. Other Issues

1. I would like to see those responsible held accountable especially Doctor Mayne. What she did and was allowed to get away with truly disgusts me. He put her on a pedestal and even gave her a cheque. She let the family down massively. Her betrayal has put a massive strain on the family.

2. There's a letter from Doctor Mayne saying that daddy was quite a strange man and not very intelligent. My daddy was a self-conscious man who read a lot of books, so her saying this angers me. After I was born my mother suffered from GRO-C and Doctor Mayne suggested that GRO-C GRO-C It's just awful especially as she was like a mother to me and my family.

3. In the last couple of months we've been collectively asking Daddy's Consultant's questions about what happened and how, but they seem reluctant to answer them. They don't pick up our calls. I told Doctor GRO-D that I'm not asking you as a doctor but as a human being.

4. What has happened to my daddy has impacted the way I treat GRO-C GRO-C GRO-C

5. I had a conversation with my dad about the infected blood and he couldn't even remember telling me about it. He told me that the doctors had told him not to tell anyone about the bad blood. This is how they tried to cover everything up, by keeping patients quiet. I don't know how they can sleep at night. There's no way that this is just a coincidence.

6. We missed out on so much and it breaks my heart. There's no talking to him about it. It's unbelievable that up until quite recently I wasn't aware he had hepatitis C. Daddy had to go through it all by himself. I believe it's time the truth came out.

Statement of Truth

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

Signed GRO-C ....

Dated 12-4-19