

21/04/2022

Witness Name: Mr Matthew Hughes

Statement No: WITN4061001

Exhibits: Nil

Dated:

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF MR MATTHEW HUGHES

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006, dated 27 January 2020.

I, Matthew Hughes, will say as follows: -

Section 1. Introduction

1. My name is Matthew Hughes. My date of birth is **GRO-C** 1984. I reside at **GRO-C**
GRO-C I have been in a long-term relationship with my girlfriend for four years, and I do not have children. I have been employed as a Data Analyst for around ten years, working in the heavy logistics and the freight industry.
2. I intend to speak about my mother Judith Margaret Swift's infection with HIV, after she received a blood transfusion during childbirth in 1984. In particular, the nature of how my mother had learnt about her infection, how the illness had affected her, and the impact on my family, including my father and sister, and

our lives thereafter. My mother's date of birth is GRO-C 1952, and her date of death is 14 August 1994.

3. My sister Laura Margaret Selman (**WITN0960001**), and my father Paul Hughes (**WITN4060001**) have also provided a witness statement to the Infected Blood Inquiry ("IBI").
4. I can confirm that I have chosen not to have legal representation and that the Inquiry Investigator has explained the anonymity process to me. I am not seeking anonymity as I wish for my story to be known in full.
5. The Inquiry Investigator has explained to me the 'Right to Reply' procedure, and I understand that if I am critical of a medical professional or organisation, they will have the right to reply to that criticism.
6. I have today, 03 November 2020, signed a consent form for the use of my statement, and I am happy for this to be used in conjunction.
7. I have constructed this statement without access to my mother's medical records.
8. I was only ten years old when my mother passed away. It is only recently that I was made aware of the true facts surrounding my mother's infection and the cause of her death, through conversations with my family. Therefore, I wish to acknowledge that I have only been able to provide approximate timeframes for matters, based on life events, and through such conversations. These timeframes should be accepted as 'near to' rather than precise dates.

Section 2. How Affected

9. As previously stated, I was only ten years old when my mother passed away. I was led to believe that she had died due to a form of cancer. I also remember someone mentioning Leukemia, but as I was so young at the time, I did not question the cause. I believed what I had been told.

10. However, it is only recently that I have gained a full understanding of what happened to my mother with regards to the true cause of her death. Since the Inquiry started my sister Laura always said she wished to provide a witness statement on behalf of my mother, and give her a voice.
11. It is my sister's actions which had recently prompted by father and sister to sit down with me and have a conversation surrounding the cause of my mother's death.
12. My father explained to me that my mother was a haemophiliac with Von Willebrand's disease. Therefore, when she gave birth to me on GRO-C 1984 at King's College Hospital, Denmark Hill, Brixton, London, ("King's") she suffered a serious bleed where she lost a lot of blood during the birthing process. It was at this point that the doctors in charge of her care had decided that due to the magnitude of the blood loss, there was a serious risk to her life. Urgent treatment was required and she received it via a blood transfusion.
13. A year after my birth, in 1985, King's contacted my parents. My mother was told that they had just become aware that there was an issue with regards to the safety of the blood she had received during her blood transfusion in 1984.
14. I assume that she had undergone a number of tests for infections such as HCV, HBV, HIV, and it was as a result of these that she was told she had tested positive for the presence of HIV.
15. As she was contacted by Kings regarding the issue of safety surrounding the blood transfusion she had received in 1984, the family believe that this was the cause of her HIV infection.
16. My father had told me that it was at this point that my mother was sadly given a life expectancy of eight to ten years. After this, our lives became focused on learning to live with and manage her infection thereafter.

17. As I was so young at the point of my mother's death in 1994, I cannot pass comment on whether she was provided with any information to help her understand and manage her infection either at the point of her diagnosis in 1985, or thereafter. I also cannot pass comment on whether this information was considered adequate.
18. In the spring or summer prior to my mother's death in 1994, I distinctly remember going on a family holiday to Mallorca, Spain, with my mother, sister, and father. We were having such a great time, when all of a sudden, one day, my mother became extremely ill. I was told that she would be okay, but it was such an upsetting and scary time for me to go through seeing my mum, who meant everything to me, the way she was.
19. Even before this point, I had begun to notice that there was something not quite right with regards to my mother's health. However, after this, it reaffirmed that there was a serious problem. She was flown home for treatment at hospital not long after.
20. When we came back from our holiday in Mallorca, both my mother's appearance and her health took a turn for the worst. She became really skinny, she started to lose her hair drastically and her complexion quickly became very pale. She also had one black eye, and the other was completely blood shot. I can only describe her appearance, as though she looked something like she was forty or fifty years her senior – as if she had aged very rapidly. It was as if she was no longer herself in some ways. It was a real visual blow for me.
21. After our holiday, and until mother's death in August 1994, she was unable to do much around the house, certainly not the things which she was once able to do. She was pretty much bed bound in our family home thereafter.
22. Two or three weeks before her death, she was put into an induced coma in our parent's bed at our family home. At that point, it was not a matter of if, but when as she did not have many days left to live. It felt as if every night would be her

last night, so, we would say our goodbyes every night just in case whilst we were able to.

23. On the day of her death, on 14 August 1994, my father came into my bedroom and sat on my bed with his hands crossed. At that moment I knew there was something wrong. I was told that my mother's health was not getting any better and that she would probably not survive the day. My mother passed away a couple of hours later.

24. Before the undertakers came to get her body, I can distinctly remember standing in the corner of my parent's room, quietly and still, just staring at her bed. It felt like it was still my mother, but at the same time, she was no longer here, it was just her body. This was the first time I had seen a dead person, and I did not know how to react, I just froze. To this day, this is still a clear image which is burnt into my memory.

Section 3. Other Infections.

25. I cannot pass comment on whether my mother was infected with any other infection or infections other than HIV, as a result of the blood transfusion she received in 1984. I also do not know whether she was tested for the presence of any other infection. I was very young when my mother was diagnosed with HIV, so I was not made aware of this fact.

Section 4. Consent

26. I cannot pass comment on whether my mother provided fully informed consent when she had received treatment or testing, either before the point at which she was diagnosed, or after this point. I also cannot say whether my mother would have been given adequate and full information when treatment or testing was carried out. I was only one years old when she was diagnosed with HIV. I was not made aware of this fact thereafter.

Section 5. Impact.

Mental/Physical Effect.

27. My mother's HIV diagnosis had a great physical effect on her, especially in the last few years of her life. Her hair had started to thin considerably, and she had become so skinny, that she started to look gaunt.

28. I can remember one incidence when I was growing up, I was sitting on my mother's bed in her bedroom chatting with her, and watching her brush her hair. After a while, I started to notice that as she was brushing her hair, large clumps were coming out. Once she realised, she suddenly put the brush down. I had this feeling that something was obviously not right. I immediately asked her what was wrong, and she simply shrugged her shoulders and gave me an excuse which did not really make sense. As I could feel that she was really sad about what had just happened, I did not question this further, as I did not want to upset her.

29. In the last two years of her life, she was not as mobile as any other person her age. However, as she had a knee cap replacement when she was younger, which affected her ability to get around, naturally, at the time I had assumed she was slowing down because of this. In reality, this is more likely to have been a result of her infection taking its toll on her body. It would have been so obvious if it were not for that.

30. I was so young when my mother passed, so I was not aware of the mental effect it had on her. If there was any mental strain, which there must have been, she never let it show as far as I was concerned. I am sure she did her utmost to protect my sister and I.

Treatment

31. Due to my age at the time when my mother was diagnosed with HIV, I cannot pass comment on the treatment, if any she received as a result.

Impact

32. As my mother was taken from me when I was only ten years old, I have since felt that I was robbed of getting to know her. I was just getting to the age where I was starting to become more inquisitive about what my parents were like as people, not just as parents. It was always so difficult to think that I missed out on having a proper mother and son relationship, and because of this, I have always felt a mixture of being both desperately sad and angry.
33. Whilst my father did not tell me about my mother's HIV until recently, I believe this was an attempt to shield me from the complexities of the truth. He did not necessarily conceal or hide the truth from me, he just did not correct the narrative which I had already assumed surrounding the cause of my mother's death. He also tried to do everything he could to protect me by not opening my eyes to the dark side of my mother's illness.
34. He told me that after the point of my mother's death, it was never discussed as he did not think there was ever an appropriate or convenient time where he could bring it up. In the past, when I was growing-up, I was always so reluctant to bring up my mother's death with my father. I could see how much he battled with his emotions as he was so struck by her death. I did not want to upset him, so I did not ask. Looking back, I think a part of him died with her but he couldn't show it as he had us children to think about. Rather than worry about myself and how I would be affected, I was scared for my father and my sister. I did not feel that my family would fall apart, I was just worried how they would cope without her. I just tried to look out for them as much as I could.
35. When I found out that she had contracted HIV as a result of a blood transfusion she received during my birth, I was in shock. However, in reality, this explained a lot to me, and had joined a lot of dots surrounding my understanding of what happened to her. It also shone a different light on my memories with her. My memories growing up were bitter-sweet. Happy moments were slightly fractured by a temporary distance from my mother, and I can only imagine this is because of what was she was going through.

36. Whilst my mother was still alive, I cannot say there were many incidents where I can say that I was impacted by her infection. It is not necessarily because my mother was not impacted by her infection. She was greatly affected, but instead, I believe this was down to my parent's ability to just put on a brave face and get on with life. It is a credit to my parent's ability to shield us from the reality.

37. My mother used to take three to four trips to the hospital yearly. As she was a haemophiliac, I assumed that these trips were not out of the ordinary as she would be receiving treatment. However, on reflection, she could have been going to the hospital for her infection. At times, it was as if the truth was camouflaged from me as I was so young.

38. When my mother passed, we would stay with my grandparents or my close neighbours three doors down. Within four or five years of my mother, all my grandparents had also passed away. I wonder what impact it all had on them? They were not particularly old but it must have been difficult having to deal with youngsters at that time of life, especially for my mum's parents on top of the loss of a daughter.

39. It is hard to admit that as I lost my mother so young, this toughened me up for when my grandparents died. No one should get used to death, but in reality, I have had my fair share of death surrounding me. It is a foot note you take away from these experiences, which go on to affect you later on in life.

40. I did not suffer any depression or stress disorders as a result of my mother's death. I was lucky in that respect.

41. I do find it difficult to open up to people, other than my sister, father, or my girlfriend about most things. I am no longer willing to discuss sensitive information with others, aside from these three people. I do believe this is as a result of losing my mum, as I lost the primary person I discussed my problems with. Mum was always that person, and thereafter, I kept things to myself.

Maybe this would explain why in many ways, I feel I do not want to tell people things as I do not want to burden them with my problems.

42. When my mother died in the summer of 1994, it was in the middle of the school summer holidays. When I went back to school in September 1994, I had changed primary schools. I can remember being in the classroom on my first day, when the Head Master came into the room and asked to see me. He then took me to his office, where we talked about my mother. At the same time, my teacher told my classmates what happened to my mother.

43. When I returned to the classroom, people were being so nice to me, by giving me space and helping me with my school work. After this, I found it difficult to talk to my school friends about my mother. Whilst it has been such a long time since her death, I still find it difficult to talk about her, and I am a bit quiet when people bring her up.

44. I cannot say that my mother's death had an effect on my education or work, as from recollection, at the time I just took it in my stride. As a child you grieve in a different way – I had an overwhelming sense of loss but I kept it to myself, for when I was alone, hence the reluctance to talk about her with others.

45. Alongside myself, my mother's death had a massive impact on my father. Between twelve or eighteen months after I was born, both of my parents were made aware after that my mother was given ten years left to live. To be told that your wife is going to die is unimaginable. It is also must have been hard for mum to comprehend that she had a death sentence hanging over her head, and that she would not be there to watch her children grow up. In the end, they did their best for myself and my sister, whilst having such horrible news in the back of their mind.

46. My father has always been a great father. He was always keen for myself and my sister not to feel that we were being controlled. He was very patient, and gave us freedom as we were growing up.

47. He would usually travel for work as he was in the logistics trade. However, after mum's diagnosis, he would try to travel as little as he could so that he could be around. He always tried to be more active and engaging with us, so that we were aware that he was there for us. He did try to say if we needed someone to talk to, we could come to him. I did not think I needed to discuss it, and I contemplate what it meant for me on my own.
48. Alongside myself and my father, my sister was affected by my mother's death. My sister was and still is a very strong and intelligent individual. When mum was diagnosed, and it was more visible that she was ill, she started to pivot towards keeping an extra eye out on me. It was almost as if she took on a more mothering role from that point onwards, to in effect, keep me between the lines. I can recall that my sister was also more driven for me to become more independent. It may have been as a means of preparing us for what was going to happen with mum in the future.
49. Myself and my father are not religious. However, my sister found faith on her own, around one or two years after my mums passing. I cannot say for certain whether she found faith as means of coping with her death, or any other means.
50. I do not believe that mother's death had an impact on my sister's education. She did have moments of outburst of tears and sorrow in the presence of her friends when talking about her home life sometimes, but that is totally understandable. She was lucky to have a supportive group of friends around her.
51. I cannot say that myself or my family experienced any effects relating to the stigma associated with HIV. I did not know anything about AIDS or HIV at the time of her death, and it was not mentioned. It did not cause me any problems.

Section 6. Treatment/Care/Support

52. I cannot pass comment on whether my mother faced difficulties in obtaining care and support for her HIV infection as it was not something I would have been aware of.

53. I do not recall myself or my sister having been offered counselling or psychological support after my mother's death. However, I can imagine we did, but I cannot say this as fact.

54. I know my father was offered counselling. I can remember one occasion when the counsellor came to our house. I came down the stairs and saw my father sobbing on the sofa. It made me feel really sad at the time to see my father in that way, but I suppose it was good that he was able to get his emotions and thoughts off his chest.

Section 7. Financial Assistance

55. As I was ten years old when my mother passed, I cannot pass comment on whether my mother received financial assistance as a result of her HIV. I was also not made aware of this fact thereafter.

Section 8: Other Issues

56. When I was told that my mum had contracted HIV as a result of a blood transfusion she received during my birth, as I've mentioned I was shocked. In fact, I was deeply saddened. You think; "Why my mum?" How did it happen? Objectively her infection is a massive thing. However, for our family, it almost became a way of life after a while.

57. I have been quite lucky in reality, as I have friends and family support. My father worked wonders to keep it together both physically and mentally. I do not know how my mother and father processed the thought for ten years that my mother

was going to die. It is important that we give my mother a voice and have her story heard.

58. Three years ago, my father had a heart attack and the National Health Service ("NHS") saved his life. They can do great and wonderful things, but in the same instance, I now think that they actually took my mother's life. They provided the circumstances in which she contracted HIV, which later, took her life. It is damning to think of the NHS in this way, as the institution is priceless, but I suppose that is how it is. It is as simple as black and white. If I am honest, it has shaken my faith in the NHS.

59. I think my mother's passing demonstrates that people should give blood. It is such a necessity. It was not her fault – nor those treating her, that the blood she received at the time should not have been in circulation. I now believe that I should look to become a blood donor to help others who find themselves in my mother's position.

60. It is mine and my father's understanding that the blood given to my mother during her transfusion was contaminated with HIV, and ultimately, this came from prison inmates. Then again, you can never be sure.

61. I do not know the core reasons behind why and what happened with regards to the Contaminated Blood Scandal. However, it is devastating to know that it was not so much a genetic role of the dice which determines things such as cancer, but actually a decision, an error, made through human interaction which was responsible for my mother's death.

62. I would hope that nothing like this would never happen again. My heart goes out to the families and individuals both infected and affected as a result of this Scandal.

Statement of Truth

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

Signed

GRO-C

Dated

21 / 04 / 2022