

Witness Name: Luke Smith  
Statement No.: WITN0226001  
Exhibits: None  
Dated:

## INFECTED BLOOD INQUIRY

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### WRITTEN STATEMENT OF LUKE SMITH

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I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 9 November 2018.

I, Luke Smith, will say as follows: -

#### **Section 1. Introduction**

1. My name is Luke Smith. My date of birth is GRO-C 1986 and my address is known to the Inquiry. I am married with two children and I am employed in a company as a Risk and Insurance Analyst.
2. I intend to speak about my mother's infection with Hepatitis C virus ("HCV"), which she contracted as a result of being given transfusions of contaminated blood after she gave birth to my sister.
3. In particular, I intend to discuss the nature of her illness, how the illness affected her, the treatment she received and the impact it has had on her and on the rest of my family.
4. I confirm that I have chosen not to be legally represented and that I am happy for the Inquiry team to assist me with my statement.

## Section 2. How Affected

5. My mother was given infected blood through a blood transfusion at Doncaster Infirmary in 1982 following the birth of my older sister [GRO-C]  
[GRO-C]
6. From what I have been told my father consented to my mother's blood transfusion.
7. My mother had [GRO-C] my sister, and to the best of my knowledge she had not received a blood transfusion before my sister was born.
8. [GRO-C]  
[GRO-C] when she was pregnant with me she had no abnormal medical issues and her pregnancy was fine, she was often at the hospital for regular check ups.
9. I remember that for years, my mother had an unexplained illness; I recall periods of my childhood when my mother was ill suffering from headaches or collapsing and fainting. I recall the doctors being unsure of what exactly was causing her illness but advising her to rest. Generally, after a few days of bed rest, my mother would feel better. I cannot say whether this is from her receiving contaminated blood or not.
10. Throughout her life, my mother has been a blood donor and would regularly donate blood. Of course there were times where she was unable to donate due to not enough blood flow or collapsed vein.
11. Before my seventeenth birthday, my mother attempted to donate blood. It was during this donation that someone from the blood donation centre identified an abnormality with her blood sample. It was from this attempted blood donation that Hepatitis C was then diagnosed.
12. Prior to her diagnosis, my mother would have undertaken testing at Doncaster Hospital. I recall that she had many tests to try to explain the

abnormalities in her blood and to deduct what she had. It was after this testing that she was diagnosed with Hepatitis C.

13. I don't know how or exactly when my mother was diagnosed but I do know that it was before my sister's wedding in 2003.
14. I remember this time as a very traumatic and difficult one for my family. There were lots of questions that went unanswered, like how my mother contracted Hepatitis C or when did she contract it? The biggest difficulty for my family, in my opinion, was the unknown of it all as none of the doctors had any explanation for my mother's diagnosis. Additionally, I can recall the unknown of the possible treatment to cure it.
15. Shortly following my mother's diagnosis, I recall my father having to be tested for Hepatitis C; all the tests were negative.
16. As the doctors did not know how my mother was infected, they deduced that since she had a blood transfusion in 1982 this was the most likely cause of infection. As I was born in 1986, the doctors advised my mother that I would also have to be tested. At this point, I forgot about what was happening to my mother and I started to concentrate on what was happening to me.
17. Around 2003, I was tested at Sheffield Hospital and I was given the all clear. I recall that I did not completely understand what I was being tested for.

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

18. To the best of my knowledge, aside from my mother being infected with Hepatitis C, I am not aware of her contracting any other infection as a result of being given infected blood.

### **Section 4. Consent**

19. To the best of my knowledge, my mother always consented to being tested and treated for Hepatitis C.

20. From what I know and remember my mother received all necessary information about Hepatitis C and the treatment she received. I believe this was because she was employed as a full time School Teacher and she needed to know how to prevent infecting anyone else, especially her students.
21. The doctors told her that she could infect others through sexual intercourse.

### Section 5. Impact

22. From what I have witnessed over the years, my mother was not only physically but also mentally impacted from her diagnosis. In turn, her physical and mental state has strongly affected both my family and I over these years.
23. Following the treatment, my mother has been cleared from Hepatitis C however, but what does remain, are the emotional scars from her diagnosis, treatment and life following the diagnosis.
24. I know that my mother's diagnosis has consumed her thoughts and conversations. To this day, I cannot have a conversation with her without her Hepatitis C diagnosis coming up. My family and I consciously try to focus on positive moments to curb her reverting back to talking about her diagnosis. We have had to adapt as a family to try and be positive as my sister and I want our mother to have good and happy memories.
25. From the moment when my mother's blood was first flagged as having an abnormality during a blood donation and up until she was finally diagnosed, her life was full of struggle.
26. Over the years following my mother's diagnosis I have wondered how is it possible, considering that she was a blood donor, that she has not been diagnosed sooner. I wonder whether the doctors were actually screening the donors. I often think about how long it took for her blood to be flagged as

having an abnormality or what would have happened if she had not been a donor.

27. In order to come to a diagnosis, I recall that my mother was asked many questions about her lifestyle; this included questions regarding whether she had any tattoos, unprotected sex with partners other than my father or whether she ever took drugs. My family and especially my parents are very religious and to be asked these questions was a psychological trauma.
28. I don't remember how my mother was told of her diagnosis. In the period of "unknown" and until her diagnosis, my mother was frustrated with the medical staff as there were no answers to any of her questions. There are still times in these days when my mother does not want to see any medical professionals. She doesn't trust them anymore.
29. Looking at my situation, during the period of "unknown" and throughout the period when my mother underwent the treatment, I definitely felt the stigma. During this time, the doctors were unsure of where my mother's infection came from or how she was diagnosed. Now she is happy that she has been cleared of the Hepatitis C but that period has been was a traumatic time for all of us. I can only describe this time as an emotional roller-coaster.
30. In times that were supposed to be joyous or during family occasions, my mother's diagnosis overshadowed every event. For example, my mother was diagnosed before my sister's wedding and finished her treatment in the months leading up to my wedding. So I recall her being quite ill at both weddings and still now she associates those events to pain and sufferance. She has more than once mentioned during a conversation "I found out about the infection before your sister's wedding" and "I was being treated for it before your wedding". This is very unfair and sad as those special moments of celebration have always been remembered and associated by her to something horrible and traumatic.
31. At the time of the diagnosis, my mother was working as a full time school teacher and she was keep on questioning the doctors whether she had to

disclose her diagnosis to her employers. This caused her more uncertainty and she did not know how the school would react to her condition.

32. My mother is a private person and she thought that if she had told the school about her diagnosis they would have to put out a statement that one of their staff members had Hepatitis C. I can recall her debating whether to tell the school or not, and because some school head teachers were aware and other teachers not, she was worried that she may not be able to teach anymore. This uncertainty and unanswered questions not only affected my mother psychologically, but all our family.
33. Considering that now I am a parent too, if I had been one of her students' parents, I think that I would have wanted the school to disclose that one of their teachers had Hepatitis C. If I had found out that the school knew of a teacher's condition without putting a statement out, I would have been furious.
34. I can recall my mother being worried that, because she did not know for so many years that she was infected, she was afraid that she may or may not have infected someone else. I can see that she carries guilt of her ignorance during that time: the fear that a student could be infected is haunting her.
35. I have been asked whether Hepatitis C had an impact on my mother's professional life. My mother always wanted to teach and had completed the relevant educational requirements for her to be a teacher prior to her diagnosis. She did not stop teaching post diagnosis but she did have periods off work sick, through the treatment and to the best of my knowledge her career was not impacted.
36. After her diagnosis, I recall my mother taking extra precautions to the point of always having plasters and latex gloves in her handbags to make sure she was able to attend to any of her students.

GRO-C

GRO-C

37. GRO-C  
GRO-C I can see the hurt my mother carries knowing that GRO-C when she delivered my sister it led to her having to have a blood transfusion, and then being diagnosed with Hepatitis C.
38. My mother is the type of person that takes on someone's burden as her own; this has been heightened since her diagnosis. For instance, I was diagnosed with Malignant Hyperthermia when I was younger. This means that I have a severe allergic reaction when given certain medications. For example, I cannot be put under general anaesthesia. This is hereditary from my father's side, however when I was diagnosed my mother took that on as her own burden.
39. When there are pregnancies in my family, whether it be my sister or my wife who were expecting, my mother would not say congratulations until the birth of the child. In the case of my sister's pregnancy, GRO-C  
GRO-C my sister also had to have a blood transfusion. This, understandably, triggered my mother's emotions as she was infected following the birth of my sister through a blood transfusion.
40. During my wife's pregnancy with our eldest child, my mother was constantly worried about the pregnancy and our child's birth. During labour, our child was in a breach position GRO-C For the entire pregnancy and when she visited us at hospital she kept on apologising even before congratulating my wife and I.
41. Nowadays, my sister and I talk to our mother mainly about her four grandchildren. We are very conscious of her becoming negative as she gets into a cycle and she forgets who is around, even if the grandchildren are there. My sister and I both do not want to subject our respective children to these conversations as they are all getting older and they are beginning to

not only understand what is being said, but they are starting to repeat what is said.

42. I recall when I went to university and moved out of home for approximately three years, that I would not ask my mother much about her health. Firstly, I did not want to pry as she is quite a private person. Secondly, during our conversations I tried to be positive because I knew that otherwise she would go into a downward spiral.
43. As I mentioned above, my mother is a private person and has only told her extended family and friends of her diagnosis on a need to know basis. For example, at my wedding my mother told her brother, my uncle, about her diagnosis and treatment; she looked quite unwell and had to explain why she looked sick.
44. Even though there was a gap between her diagnosis and the treatment, my mother has told me that this time was filled with uncertainty and she never processed the whole thing herself in order to be then able to tell those around her. Despite that I have to say that in general, I did not see much of a change in her social life.
45. Personally, I recall having to tell my then girlfriend and now wife that I had to be tested for Hepatitis C and disclose to her my mother's diagnosis. This was difficult in itself as I had to relive my mother's diagnosis and my testing.
46. My parents and I attend different churches however both communities are interlinked. When GRO-C I attend church we avoid asking our community to pray for our intentions regarding my mother and her health as I do not want anyone going to her and openly asking her about her diagnosis or health in general.
47. My sister and I try not to dwell on my mother's diagnosis and I cannot speak for my sister but when we talk about it, I feel like she is in the same boat in regards to our experience as our stories are quite similar. With regards to my father, he often talks to me about being the one who consented to my



mother receiving the blood transfusion treatment. I think there must be some underlying guilt and I can see the pain in his face. I cannot imagine what he is feeling; if my wife had to go through what my mother has been through, I have no idea how I would have coped with it.

48. It was only in about 2016 that my mother shared with me that at that time the doctors wanted me to be tested at an STI clinic. My mother told me that she refused to allow the doctors to refer me to the clinic because of the shame surrounding the situation. This is another example of my mother taking on the burden of those surrounding her to try to protect them from difficulties.
49. With regards to the Inquiry, I can see that this has again affected my mother. When the Inquiry was first announced and it was said that witnesses would be asked to present evidence during the hearings, my mother was worried that she would be called to submit her evidence. To this day, only those within her family and friends that need to know of her diagnosis have been informed. She is afraid of the stigma and shame associated with Hepatitis C but she wants to tell her story because the Inquiry needs to know what happened.
50. When she receives medical letters or forms in the post, she will phone me to discuss them, and these types of discussion can be endless. In preparation for making my statement I showed my mother some notes and the initial Expression of Interest form that I submitted to the Inquiry. This gave her an understanding of how her diagnosis has affected me and after reading she apologised that she was a bad mother for potentially exposing me to Hepatitis C and for having to help her post diagnosis. She carries a lot of guilt and shame with regards to this.
51. When the Inquiry started, my mother started to attend some support groups related to the Inquiry in her local area. Following the first meeting she attended, she came back to say that other people have suffered more than she has. She has said that she is not ashamed of what has happened, but is afraid of the stigma if she brings it up.

52. To the best of my knowledge, my mother has never had any dental care issues nor has she been treated differently.
53. To the best of my knowledge, I do not believe my mother has been given anti-depressants and I do not think she has been depressed but she has the guilt that weighs down on her. I do recall her mentioning that she has had trouble sleeping [GRO-C]
54. Recently, [GRO-C] was admitted to hospital and they took him there by an ambulance. One of the paramedics had some tattoos on his arm, and whilst attending to [GRO-C], my mother reacted quite badly. I think that in her mind, those people with tattoos, have been exposed to potential Hepatitis C infection and she did not want [GRO-C] to contract the same infection. Later, she asked my wife if she behaved irrationally and my wife explained to her that because of her history it was a reasonable reaction. However, someone else would think it unreasonable not knowing her history.

#### **Section 6. Treatment/Care/Support**

55. I remember that there was a six or seven year period from diagnosis until treatment. I cannot recall why there was this gap – I do not know whether it was because her doctors were trying to figure out the best way to treat her or whether treatment was unavailable to her. I recall that my mother started the treatment about seven months prior to my wedding; this would have been approximately in autumn 2009.
56. During this period, I remember my mother's emotional sufferance. I think it was particularly related to the fact that she was given a 50/50 chance of the treatment working.
57. To the best of my knowledge, my mother was treated at Sheffield Hospital with treatment lasting approximately six months. I cannot recall what her exact medicines were but what I am aware of is that the doctors explained to

her everything she had to do. I recall her doctor telling her that the treatment would affect her body similarly to a chemotherapy treatment does.

58. I recall her losing most of her hair and having to hide the effects with big hats. At my wedding she wore a large hat; my family had to explain to guests why my mother was so frail and sickly looking, as many people did not know what was happening.
59. But it was not until summer 2010 that she received her results saying she was clear of the Hepatitis C.
60. To the best of my knowledge, neither counselling nor psychological support were made available to my mother. In hindsight, my mother would have benefited and appreciated some external support.
61. I cannot recall if I was offered counselling nor whether it was suggested that I should seek counselling or psychological support. Considering I was so young, I am not sure whether it would have helped or not.

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

62. To the best of my knowledge, my mother has not received any financial assistance from any of the Trusts and Funds set up to distribute payments.
63. I recall my mother receiving a reimbursement for her funeral plans.
64. My mother is a private person and has not been involved with neither campaigning nor litigation regarding infected blood.

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

65. In regards to the Infected Blood Inquiry, I just want to support my mother which is why my family and I are providing these statements.

66. I hope to have answers to the questions we have had over the years including whether the hospital knew that they were giving my mother infected blood during her blood transfusion.
67. Additionally, whenever she donated blood, did the people at the blood donation centre know something but never flag it with my mother?
68. Both my family and I hope to have some sort of closure and I hope that it will help my mother in closing this chapter in her life.

### Statement of Truth

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

Signed                       
                    GRO-C

Dated 17/4/19.