Witness Name: William Anthony Spellman Statement No: WITN2978001 Exhibits: WITN2978002 Dated: April 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF WILLIAM ANTHONY SPELLMAN

I. William Anthony Spellman will say as follows:-

Section 1. Introduction

- My name is William Anthony Spellman and I live at <u>GRO-C</u>
 <u>GRO-C</u>
 <u>I was born on</u> <u>GRO-C</u>
 <u>I have 2 younger</u>
 sisters, Rhiannon and Fiona. I live with my fiancé and we are getting married later this year. I work in education; assisting universities to recruit international students.
- 2. I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 in respect of my late father, Dr William Spellman, born on the GRO-C 1943, who sadly passed away on the 28 July 2009, aged 65, as a result of Hepatitis C. I am aware that my mother Irene Ruth Spellman has also provided a statement and will be giving oral evidence.
- 3. This witness statement has been prepared without the benefit of access to my late dad's full medical records.

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Section 2. How Affected

- 4. My dad suffered from acute myeloid leukaemia when he was about 45 years old. He had chemotherapy and blood transfusions for this at the Queen Elizabeth Hospital in Welywn Garden City in 1989 and 1990. My dad contracted Hepatitis C as a result of one of these blood transfusions.
- 5. After he was diagnosed with Hepatitis C, he was mainly seen at the Royal Free Hospital for his liver problems from 1994. In 2004 he had renal failure and had most of his dialysis at Barnet Hospital but also occasionally at the Royal Free Hospital.
- 6. I am not sure how my dad found out about his infection or what information was provided to him. My parents never really wanted to speak to me about it. It was clear that my dad wanted to continue living a normal life.
- 7. I found out about my dad's infection by accident. This was because we had the same first name 'William'. In around 1996 a letter came through in the post addressed to 'William Spellman', so I opened it. It was a Hepatitis C support letter, and I quickly realized that it was actually addressed to my dad, not myself. I was around 16 years old at the time, doing my GCSEs. I asked my mum about it. I believe that she might have explained it to me, but my parents never wanted it to become the focus of our attention, consequently they never wanted to talk about it.

Section 3. Other Infections

8. To my knowledge, my dad did not receive any other infection as a result of being given infected blood products.

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Section 4. Consent

9. I do not know if my dad was tested or treated without his knowledge.

Section 5. Impact of the Infection

- 10. My dad was a very traditional and proud man. We enjoyed talking about football and had a typical father-son relationship. He was very content with what he had. He was a dedicated science teacher and he taught at the same school for many years.
- 11. My dad's health gradually deteriorated from when I was about 15 years old, over a period of 20 years and kept getting worse. He started to look unwell and he lost a lot of weight. As the disease progressed over a number of years his energy levels fell. He was in a constant state of exhaustion and he did not have any energy to do simple things around the house.
- 12. Some of his physical symptoms of Hepatitis C included loss of appetite, an enlarged swollen stomach and problems with his balance. We were all worried about him losing his balance and falling over but he refused a walking frame. At the very end, his brain got inflamed and he was not able to speak.
- 13. My dad tried to maintain a positive mentality throughout it all. However, in or around 2004, he started to develop serious problems with his kidneys, which affected him, both physically and mentally. He had to have dialysis from 2004 to 2009; 3 to 4 times per week, to remove excess water from his blood, which I believe was a direct effect of Hepatitis C on his kidneys.
- 14.1 recall an instance when Fiona was at the university in Leeds when Dad was admitted to the hospital with encephalitis and internal bleeding. We were told by doctors that he was not going to make it through that night. This was a very distressing experience for us all. Fortunately, he made it through that night, but

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passed away about 6 months after that. I attach his death certificate at exhibit WITN2978002.

- 15. When my dad passed away, to some extent it was a bit of a relief. The year prior to his passing was extremely traumatic for us all and I am not sure how much more he could take. I had prepared myself as best as possible mentally for him passing, because he was so unwell and we knew that it was inevitably going to come.
- 16. My dad had a couple of treatments for Hepatitis C, but they did not work. He also suffered from bad reactions to the medication. He developed clinical depression for 3 or 4 months after one of the treatments.
- 17.1 am not sure whether my dad's illness had any impact on any other treatments he had, if any.

Impact of my dad's infection on his private, family and social life

- 18. Prior to Dad's Hepatitis C disease progression, we enjoyed a normal upbringing, however, as his health deteriorated it had a huge impact on his private, family and social life (even if he was generally positive with a determination to carry on as normal). Dad's health was a factor in everything that we did as he needed to sleep for about 3 or 4 hours in the afternoon. We always had to have it at the back of our mind. We had to adapt to how he felt on the day.
- 19. As his health deteriorated, probably when his Hepatitis C started to progress, physically he was not able to continue his active hobbies, such as playing golf and squash.
- 20. Even before his dialysis he was not able to go on foreign holidays, as he could not get travel insurance. This had an impact on him mentally. I can imagine he

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might have felt aggrieved that we could not go on family holidays abroad. Instead, we went on holidays around the UK.

21. He kept up with friends as much as he could through social engagements. We always tried to ensure the illness had a minimal effect on his ability maintain close relationships with friends. I am not sure how much he shared about his condition, but I would imagine it was very little. My dad had a lot of very close friends who came to visit him and help out where possible.

Impact of Dad's illness on me

- 22. My dad was infected with Hepatitis C when I was around 7 years old, but I was not aware of it until when I was around 16. Nevertheless, I was aware that my dad was not well from the age of 11, but I was not aware of how or why. I remember when I was growing up, Dad had hospital appointments at 2 or 3 months intervals. I could sense from a young age that he was not 100%. It felt like he was living from one appointment to the next, hoping it was not bad news.
- 23. Aside from Mum, I was the first of the siblings to find out about his Hepatitis C infection, when I was about 16 years old. My sister Rhiannon found out some time after me, but our younger sister, Fiona, did not find out for a long time after us. I immediately felt a sense of panic. All of the material I read about Hepatitis C told of a very uncertain prognosis. I did not know what this would mean for Dad. The endless different scenarios, all of them seemed very worrying and we were never able to talk about our dad's illness or how we felt. I just felt I had to go on and to cope as best I could, given Dad's attitude was that he wanted to carry on as normal and not make a fuss.
- 24.1 do not remember speaking to my dad about his infection at all; he always wanted to just continue as normal; as if everything was fine. I would ask questions but it was clear that he didn't want to talk. I recall trying to speak to my mum about it once, but she adopted a similar stance as my dad.

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- 25. In the period from 2000 to 2003 I was studying at university, living away from home, so whilst I did not see Dad day to day his health was always a constant worry. I remember seeing my dad's heath deteriorating.
- 26. After graduating from university, I moved back home with my parents for approximately 2 years to look for work in London. Soon after I moved back, Dad was diagnosed with kidney failure, which was a huge shock to us all. Not only was Dad suffering with Hepatitis C, but now kidney failure with zero warning. A nightmare became reality. I knew that there was a terrible pressure on my mum, so I wanted to help. My mother and I took turns driving him to hospital on Saturday mornings.
- 27. For the period I was living at home from 2004 until 2007, I remember I was drinking excessively. I am not sure if that was to do with Dad but we were certainly all extremely worried and trying to cope in the best way we could. One of the causes of worry aside from Dad was Mum, as she had a hugely demanding job.
- 28. In 2007 I moved to London and lived with Rhiannon, however, I continued to drive back to Hertford every weekend or every other weekend to help out.
- 29. My mum also had to have **GRO-C** in around March 2007, so I tried to take over some of her responsibilities at home. I took Dad to his hospital appointments around this time as he was not able to drive long distances, especially for treatments. I was with him for quite a lot of the time; however, I never went in to the consultations with him as he wanted to do these on his own.
- 30.1 also started to develop stress-related problems during those last few years of my dad's life. I went to the doctor as I kept on waking up with night sweats, which lasted for about 2 years. I remembered that my dad told me that this was one of the first symptoms of his leukaemia (the treatment for which he had contracted Hepatitis C). However, after having tests done I was told by the doctors that it

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was stress and anxiety which were the cause. It was a relief being told it was not something more serious. However, I did continue to wake up with night sweats for many years.

31.1 am getting married later this year, and as with every milestone, I can't help but miss Dad. I am curious about what he would think of Sohanna. I am sure he would love her. I would have loved for him to meet her.

<u>Stigma</u>

32. We did not believe that a lot of people knew about the illness, so we preferred to keep it to ourselves. Our extended family did not know about it.

Impact on my family

- 33.1 believe that my dad's illness had the biggest impact on my mum. She had a very demanding job, as she had to support 3 children and care for her husband. Consequently, she had a lot of stress at work and at home. Mum coped admirably but was understandably anxious and on the edge and I do not think that she was able to sleep properly. Dad was still trying to put a brave face on it. As much as we worried for Dad, my sisters and I had a lot of worry for my mum's mental and physical health, as the stress and pressure she was under for a number of years was extreme.
- 34. From the age of 13, Dad would come home from work and sleep. As his disease progressed his energy depleted. My sisters and I would cook the family meals from Monday to Friday. My dad's health was gradually declining so he went from being proactive at home, to not being able to do anything at all.
- 35. My sister, Fiona, was the youngest and was also very close to Dad. She was home for a lot of Dad's illness as she did not go off to University until a few years before he died.

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Impact on my dad's work

- 36. Hepatitis C undoubtedly did affect my dad's career. He loved his job, but due to the chronic fatigue, despite wanting to carry on as normal, as the disease progressed, he could no longer fulfil his full-time role, which was something that was very upsetting for him and he found extremely difficult to come to terms with. He had to work part-time and he had to give up his position of responsibility. This was upsetting to him as he loved his job and the routine. Despite the decline in his health, he persevered working and carried on working until a few months before he died.
- 37. In reality we were fortunate that dad was not the breadwinner, and we coped well financially despite the decrease in his salary. However, as he was a very proud man and Head of Science at a school for 25 years, the illness affected his self-esteem, as he could no longer cope with the demands at the job.
- 38. As a by-product of this decrease of earnings, I believe this put more pressure on Mum; with the uncertainty. I believe it is perfectly feasible that if it was not for the pressure she was under, she may have made different career choices.

Impact on my work

39. The final stages of my dad's illness proved to be particularly difficult. My boss at the time was not supportive at all, and he was not willing to give me any time off work to help out at home.

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Section 6. Treatment/care/support

- 40. My dad had two Interferon treatments; the first started in 2002 and the second in 2006, however, neither of them proved to be successful. I am not aware whether any other treatment was available at the time, which ought to have been given to my dad but was not. I remember that my dad was always asking the doctors for treatments.
- 41. None of us were ever offered any counselling or psychological support. I believe counselling could have been of great help, particularly to our family, considering that we could not open up to each other about what was happening.

Section 7. Financial Assistance

42.1 am not aware whether my dad or mum received any financial assistance in relation to my dad's Hepatitis C infection.

Section 8. Other Issues

- 43.1 believe that people have to be held accountable and there are lessons to be learnt to make sure that nothing like this will ever happen again.
- 44.1 believe that there should be financial compensation, but in my opinion, it is more about getting to the bottom of what happened, how it happened and why. It is scary to think that the contaminated blood still infected people a number of years after it became known about.
- 45. My father lived for 20 years after he got infected; however, I know that there are many people who have lived for a much shorter period of time because of their infection. There could be many thousands of people out there who are affected by this tragedy to this day, some of whom are not aware of how or why they are unwell.

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Anonymity

46.1 do not wish to remain anonymous.

47.1 do not want to give oral evidence to the Inquiry.

Statement of Truth

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

Signed	GRO-C		国力にないいないですから
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Dated	03/06/19.		と同語に
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