Witness Name: Angelina Riley Statement No: WITN3494001 Exhibits: Nil Dated: 16th December 2019

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF ANGELINA TREVA RILEY

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 24 June 2019.

I, Angelina Riley, will say as follows: -

Section 1. Introduction

- 1. My name is Angelina Riley and my date of birth is GRO-C 1977. My address is GRO-C GRO-C GRO-C .
- I live on a barge with my long-term partner of 15 years and our three-yearold son. I am a self-employed variety performer and I also teach Yoga and Pilates in the local area. I met my partner whilst working on a cruise ship, I was performing and he was employed as a photographer.

- 3. I am the daughter of Anne Riley (W0202), who was a victim of the contaminated blood scandal. She was infected with the Hepatitis C virus ("HCV") as a result of being given blood transfusions after operations on three separate occasions. My mother has already provided a written statement to the Inquiry.
- 4. In particular, I intend to discuss the nature of her illness, how the illness affected her, the treatment she received and the impact it had on her and our lives together. My statement is to be read in conjunction with my mothers. I have an older sister, Sadie (W3419) and an older Brother, Daniel (W3420) who have provided their own statements.
- 5. 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

- 6. My father died when I was only 9 and a half months old so I have no memories of him. I feel that I absorbed a lot of the family's loss. I have an older brother and sister.
- Mum worked really hard to provide for our family and to give us the best in life. Through her hard work I was able to attend dance lessons.
- 8. My older sister Sadie had a lot on her shoulders to deal with as a child because she was 7 years older than me. She helped mum with us siblings when mum had a nervous breakdown. She missed out on a lot of activities that my brother and I were able to enjoy.
- 9. We lived in GRO-C until I was 8 and then we moved to GRO-C
- 10. From my understanding, a cyst on my mother's ovary exploded and she bleed internally. She was admitted into hospital and given a blood transfusion. This happened before I was born. It then happened a second

time after I was born and a second transfusion was needed. I do not know the exact dates and I was too young to know the hospital details. Through the transfusions she was infected with bad blood and suffered with severe health problems from that point onwards.

- 11. Please see my mother Anne's statement (W0202) for a comprehensive account with exact dates and hospital information.
- 12. A few years after the ovarian cyst procedures, mum had her gall bladder removed.
- 13. As the youngest child, I have no memories of mum being well and to me she has always been ill and suffered with her health for as long as I can remember. It was the norm for mum to be in pain, but she would always put on a brave face and try not to cry in front of us children.
- 14. I always felt that mum struggled, but I put this down to the fact that she worked a number of jobs at once and brought up her children on her own. I recall her always being fatigued and in pain.
- 15. I did not like to see her struggling so I would help out with the housework.I felt that she was always trying to please everyone and was doing things for everyone else. She burnt herself out.
- 16. At times mum would have flare ups of fatigue, bloating and chronic pain. These were the times when I had to do even more to help her. She was originally diagnosed with Fibromyalgia, but I feel that this term is often thrown about when the medical profession does not have answers for certain symptoms.
- 17. I do have a vivid memory of mum reacting badly to a particular medication as her back was so bad. I would have been around the age of 14 and I recall her shaking all over and unable to walk laying on the floor.

- 18. In 2012 mum was admitted to Grimsby Hospital because she had difficulty breathing. It transpired that her lungs had filled with fluid. Her health deteriorated very quickly. This created a lot of worry in the family and I found it hard to concentrate on my performing work. She was living up North at the time. Sadie and I had a house we had brought in GRO-C. It was a good three-hour drive to visit her in hospital.
- 19. After a number of weeks of testing, mum was diagnosed with HCV. We made the decision to move her back down to Sussex so that we could be close to her during the treatment.

Section 3. Other Infections

- 20. Mum did not contract any infection other than HCV as a result of being given infected blood.
- 21. The first of mum's blood transfusions happened before I was born, so I was tested for HCV not long after we found out about mum's diagnosis. It was a frightening time waiting, but the results were negative.

Section 4. Consent

22. Please refer to my mother's statement (WITN0202001) in relation to consent.

Section 5. Impact

- 23. I think mum told us herself that she had been infected with HCV. I did not know much about the virus at this point, but I had heard of it before and had some awareness that it was not good.
- 24. It was a bit of a light bulb moment when we found out about the HCV, because I had a gut feeling that something else was also wrong with her

all this time. I felt rather angry that no medical professional picked up on this before and by the time they did her liver was pretty much destroyed.

- 25. I kept questioning myself whether I should have done something different, asked for second opinions and followed my gut instinct that something was not right.
- 26. After the HCV diagnosis, mum was very worried about blood contact and she became paranoid about touching us. I could see that her spirit was being crushed and that she was dissolving away after holding everything in for so many years.
- 27. Mum was put on a course of treatment prior to the liver transplant, to clear the HCV infection. I do not recall the name of the medication, but I know that she was part of a drugs trial and that she was one of the fortunate patients because the medication was so expensive.
- 28. It was very impressive how the viral load of HCV dramatically decreased whilst mum was on the medication, although she did experience side effects of fatigue, headaches and dizziness. She was up and down for the entire time.
- 29. My siblings and I would take it in turns to meet mum in hospital and I still lived in **GRO-C** at that point. I know that mum found travelling up to London for treatment rather exhausting and she would often get the train up with Dan. I didn't like Mum driving so was always worried if she did.
- 30. Between the three of us, my brother, sister and I did the best we could to care for mum during throughout the treatment. We all had the underlying fear that we would also lose our other parent. This fear drove my action to do everything I could for her.
- 31. Whilst in hospital, mum contracted Clostridium difficile and this has affected her for a long time. The infection robbed her of freedom after the

liver transplant because she refused to go out. She did not want to venture very far because she was worried about having an accident. Mum became very depressed, reclusive and withdrawn.

- 32. At times she still has to deal with the effects of Clostridium difficile now, because she has no gall bladder. Mum has been instructed of certain foods to avoid.
- 33. Once the HCV was discovered the hospital started carrying out tests on mum's liver. I think either my brother or sister told me that she needed a new liver. I felt that I had to stay strong just as my mum always had been.
- 34. During moments like this I can take things on and process it later. I remember staying calm about the facts as I tend to deal with news as it comes and try not to get too ahead with myself.
- 35. It was a shock to find out about the condition of mum's liver. At this point we all thought that we could loose mum and the sense of losing a parent hit me again. I found this rather unsettling.
- 36. I remember taking mum nettle tea everyday into hospital because in my mind it was a way of giving her something good for the liver.
- 37. I was with my partner Craig when I found out mum required a liver transplant. He is very fond of my mum, so he was also very upset.
- 38. Craig and I had been talking about having children for a while and we felt the need to crack on with it as mum wanted grandchildren.
- 39. When mum was on the waiting list for a liver transplant, she was constantly on standby and there were a few false alarms. The whole process was stressful and it felt as though her liver was a ticking time bomb. I felt rather helpless during this period because I could not do

anything to improve the situation. It was a constant distraction in achieving everyday tasks.

- 40. It was nerve racking when she eventually went in for the transplant and we all felt a sense of relief when she came out of the operation.
- 41. The state of her old liver was awful, it was a grey, distorted mass and it hit us all how close it was to stopping completely.
- 42. I was very pleased with mum's recovery after the liver transplant and I could not believe how well she looked. The medical professionals at Kings College Hospital quickly got her walking so that she did not loose too much muscle mass.
- 43. My siblings and I went to visit mum in hospital as often as we could. I felt as though I also supported my brother and sister through this time, because we have different coping strategies. We all coped in our own way, but my brother tends to get easily stressed and my sister rather emotional and teary. The fear and powerlessness of losing our mum triggers loss from our Dad and other emotional traumas.
- 44. I was happy that mum finally had a new liver free of HCV, which meant that she had a new lease of life and new opportunities.
- 45. The anti rejection medication mum takes for her liver has a possible side effect of cancer. She recently had some cancerous lumps from her skin removed. This is very worrying but there is not a lot we can do.
- 46. I am aware that my sister Sadie is very resistant to the anti-rejection medication and she would rather mum found an alternative. I understand that Sadie wants the best for mum, but I'm not sure how realistic this view is? If mum does not take the medication her body may well reject the transplanted liver.

- 47. Mum is very strong willed and stubborn. She did not have a good childhood so she has always had a constant battle for survival.
- 48. It seems as though mum feels rather suffocated by Sadie. Sadie will be50 next year and I feel that she needs her own home. Her attention onmum is too magnified and she often puts a lot of pressure on mum.
- 49. Sadie's behaviour is driven by her underlying fear that we will loose mum. She had to deal with losing our father and grandmother as a young child and that has affected her. I feel that she really struggles with this.
- 50. Before the HCV diagnosis mum would often arrange gatherings and be the life and soul of the party. She was funny, loud and always a great host but she lost all of this confidence and became a shell of what she used to be. She loved socialising with people but she withdrew from this completely.
- 51. Due to her ill health, mum experienced bouts of bloating and then she would lose the weight very quickly. This had an effect on her skin and means that she looks a lot older than her age. Her stomach is also full of scars because of the numerous operations. Both have knocked her confidence and she is definitely not the lady she used to be.
- 52. I would like mum to find a partner and be happy, but she does not have the confidence to go out on dates. I think she is keen to have some sort of companionship and she needs to be loved and cared by someone.
- 53. After the transplant, mum was so low and would barely do anything. It certainly took her a few years to get over the operation. Now she is back making crafts and selling her work. It is nice to see her doing that again and using her creative skills, it feels as though she is finally coming out the other side.

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- 54. I feel that I have always carried my brother and sister, despite being the youngest child. Being that little bit younger, I could skim past some of the baggage they faced and this has supported me a little bit more.
- 55. I did used to place my father on a pedestal as a child, but in my own sub consciousness I have been blaming him for not protecting us as a family. When this realisation hit me, I found it overwhelming and discovered a lot of underlying anger and frustration within me. The loss of him not being there in my life came out and I sobbed for hours. Every Farther's day is a reminder of what I never had.
- 56. I have a very selective memory and only retain what I think I need to remember. Unlike me, Dan remembers everything so clearly and I really enjoy his retelling of our childhood. Maybe selective memory is a coping strategy?
- 57. My siblings and I had no father figure to look after mum throughout her ill health and it was difficult to see other people take advantage of her kind nature.
- 58. I know my siblings very well and we are all close. I try to be grounded and supportive with my family.
- 59. I do miss not being immediately near my family, but we are in regular contact and I try to see mum at least once a month.
- 60. My partner and I ended up in <u>GRO-C</u> because of his job, but it was my idea to live on the barge. I enjoy a nomadic lifestyle and I like to be different with ways of living. We previously lived in my VW transporter whilst I toured and performed and we also lived in some warehouses in North London.

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- 61. I would not be surprised if there was some judgement and stigma towards our family because of mum's HCV diagnosis. We are often looked at as the black sheep by our extended family.
- 62. Mum has experienced a number of dental problems since her diagnosis with HCV.
- 63. Mum has to pay higher insurance premiums because of her ill health.
- 64. The responsibility to find mum a home back in Sussex in 2012 fell on myself. I found it particularly difficult to find her accommodation because of her dog and due to her health conditions. On top of this I had to find a guarantor in the event that she could not make rent payments.
- 65. I asked my uncle if he would be mum's guarantor, as he has a very comfortable lifestyle but he declined. I recall it being a draining period because I was continually let down in my attempt to find mum a home. It was my partner's mother that helped us out in the end.
- 66. I had to really persuade the landlord to let mum rent there and I also had to arrange the logistics with the house move.
- 67. I do still worry over my mother's health and that concern will never go away, but I have learnt to live in the now and to be grateful of how well she has recovered.
- 68. Mum's health is still not good and we still do not know how long she will have because of the liver transplant.
- 69. Medical professionals still state that mum continues to suffer with fibromyalgia.

Section 6. Treatment/Care/Support

- 70. No one in our family was ever offered any counselling or psychological support in relation to my mother's illness.
- 71. We have just battled on as a family and we are not ones to ask for help because we are used to just surviving.
- 72. I do think that counselling could have guided my siblings and I in relation to mum's ill health. Losing a father meant that we lost some guidance and although mum did her best we had no male energy or father figure in our lives.
- 73. I have done a lot of transformational work and some cognitive behaviour therapy, alongside work with the Concord Institute. I find that this style of therapy helps because it focuses more on energetics, mind, body and nutrition.
- 74. The treatment mum received at Kings College Hospital, London was amazing. They looked after her well and she finally received the treatment she deserved. I am pleased that they took care of her and that she received a new liver, but everything came too late. Had they found out about the HCV much earlier, mum may not have needed a liver transplant.



Section 7. Financial Assistance

76. I found out about the Skipton Fund after researching online what financial support mum was entitled to. Up until this point I had been supporting

mum financially and it was stressful covering the cost of her house move. I started to acknowledge that we needed financial assistance.

- 77. I applied to the Skipton Fund in 2014 on my mother's behalf and we waited around a year to find out whether the application had been approved. It was very tough waiting this length of time and as a family we felt financially squeezed during this period. It was a long stretch of surviving.
- 78. The Skipton Fund required medical evidence that mum had been infected with HCV via a blood transfusion. Most of her medical records had been destroyed, but one of the documents left detailed the blood transfusions given. This proved vital in our financial assistance application.
- **79.** The application was approved and mum was granted a lump sum of compensation. It was a huge relief and I felt good to have helped mum receive the money she was entitled to. The lump sum certainly gave her a bit of a spark and became a financial safety net for her. She continues to receive a monthly sum of money.
- **80.** My mother Anne Riley (W0202) has detailed the amount of financial assistance she received in her statement.

Section 8. Other Issues

- 81. I would like the Inquiry to ensure guidelines are put in place so an error like this will never happen again.
- 82. It is very disappointing that the NHS administered infected blood to patients, but if mum did not receive the blood she would not be here now.
- 83. Victims of the contaminated blood scandal should receive proper compensation. My mother should receive an amount of money so that she

can live comfortably, maintain her health and enjoy activities that she has missed out on because of receiving infected blood.

Statement of Truth

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

Signed	GRO-C
Dated	16.12.19