Witness Name: Sadie Riley
Statement No: WITN3419001
Exhibits: Nil
Dated: 15 October 2019

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF SADIE RILEY

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 5th June 2019.

I, Sadie Riley, will say as follows: -

Section 1. Introduction

1. My name is Sadie Riley and my date of birth is GRO-C 1970. My address is GRO-C West Sussex GRO-C. I am not married and I have been back at home living with my mum for the past two years.

2. I intend to speak about my mother Anne Riley, who has already provided a written statement to the Inquiry. (W0202) She was infected with

Hepatitis C virus ("HCV") as a result of being given blood transfusions after operations on three separate occasions.

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 had on her and our lives together. My statement is to be read in conjunction with my mothers because I am uncertain on dates. There are a number of memories that I have blocked out because I do not want to remember them. I have a brother called Dan, (W3420) and a sister called Angelina (W3494) I understand at the time of writing they have yet to make their respective statements.

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. In 1977 a cyst on my mother's ovary exploded and she bled internally for 36 hours. She was sent for emergency surgery on the 8 January and given a blood transfusion at Watford General Hospital.

6. I was 7 years old at the time and my sister, Angelina was only a baby. My father was still alive at the time and he stayed at home with the dog as she had a litter in the night. I was sent to my Nan's house, my brother to my Aunt's and that evening Nan, sadly passed away. I do not know why we were all split up and once again the family was fragmented. (I cannot remember whether this was during the first operation or the second)

7. In 1978 another ovarian cyst burst and Mum underwent a total hysterectomy at Watford General Hospital. She received a further blood transfusion.

8. Mum later had an operation to remove her gall bladder, but on reflection we surmise she was infected with HCV from the blood transfusion given for one of the ovarian cyst operations.

Section 3. Other Infections

9. Mum did not contract any infection other than HCV as a result of being given infected blood.

Section 4. Consent

10. I consented to be tested for HCV and to the best of my knowledge they did not test for anything else. The result was negative.

Section 5. Impact

11. I feel unprepared for this witness statement interview because I just wanted to put mum's illness to one side. I have found the process very upsetting. I knew that I would get upset and that is why I did not want to face it. This is exactly why I focus on each day and tend to look forward rather than back on my life.

12. I had not realised how much mum's illness had affected me until making this statement. The emotions were stored. Everything needs to be teased out of my mind. In my whole body I was shaking most of the time and I was emotional. The memories were buried deep.

13. My father passed away suddenly when I was 8 years old, only 6 months after my Nan died. I was 7 weeks without my mum after my father died because she had to sort out everything with the house we were moving into. As such I had lost my dad and then lost my mum for that period of time.

14. I am so glad that the medical professionals saved my mum when her ovarian cyst burst, otherwise I would have lost all three of the main characters in my life. Had she not received the blood transfusion my siblings and I would have been orphaned at a very young age and life would have been a lot different. It is a double-edged sword – whilst I am grateful that the blood saved her life, she has been ill ever since and I am disappointed and angry that she has had to suffer such evasive surgeries each time.

15. As a single parent, mum was always busy working, so I would help out with looking after my brother and sister. I would also prepare the dinners when she was out and do all of the housework and ironing. I just wanted to help her as she was the provider for the family and it made sense for me to help in the household.

16. I did struggle at school but I cannot say that I attribute that completely to mum's ill health – I experienced bullying a lot. I went to a Christian school from junior to senior, which I found rather hypocritical. I stayed with a Christian family whilst mum had her gall bladder operation and I only saw her once in 6 weeks. Not knowing if she was ok and being separate from her was hard. I would only have been 13 and I had to ask permission to use their phone to call mum. I would have liked to call her everyday. I did not like being separated from the rest of my family because we are all very close. The separation made our family life disjointed.

17. I wanted to be everything when I was younger – I had so many interests and always had big ambitions, but now they have dwindled to the point where I do not even know what I want to do with my life. I do not know where I see my future, as I feel rather lost at the minute.

18. At one point I wanted to join the RAF and become a female pilot, but my application was rejected, as I was too young. The prospect of traveling the world and joining the forces was exciting, but my views have since changed.

19. I went to Crawley College after school to study catering. I really enjoyed college but I could not afford to go back for the second year. I needed money at the time and was struggling to manage the course alongside three jobs. I had moved out of the family home and had to pay rent, so I went into full time work. Around the age of 21 I worked at a police station for a while.

20. My brother, sister and I have all moved in and out of the family home, but we were all living with mum when she had to sell the house in 2005. She could not cope anymore with the mortgage payments as her health was so bad and she had to stop fostering. Before selling the house, mum was struggling with fostering and this was one of the reasons why I moved back home.

21. At the time of the blood transfusions we did not know mum had been infected with HCV. Throughout my childhood I knew that mum was unwell but none of us knew what was wrong. She was initially diagnosed with Fibromyalgia in the 1980s and was not diagnosed with HCV until 2012 following a lengthy stay in hospital, where further tests were taken to find out the cause of illness. She was full of tubes coming out of her body. The symptoms of Fibromyalgia are very similar to HCV, so if further tests had been carried out earlier, her liver might not have been as severely damaged.

22. I was living in London at the time of mum's diagnosis, working for an events catering company. I did not have a car so had to get the coach up to Lincolnshire. I used her car whilst I was up there so that I could visit her in hospital daily.

23. Mum told my siblings and I in person that she had been diagnosed with HCV. It took the hospital 10 weeks to find out what was wrong. Mum was like a pincushion where so many tubes and wires had been inserted into her skin. She had jaundice, was as skinny as a rake and covered in

bruises from the daily blood tests she had to have. Mum had to tell the medical professionals how to take the blood from her due to the fact that her veins were very thin. It appeared that the majority of medical staff did not know how to take blood properly. I did not know what the virus entailed until I did some independent research. In some way I found it a relief that we finally knew what was wrong with her, but at the same time it was devastating news – the virus was so serious, damaging to the liver and she could die.

24. Within the same visit the medical staff came into her room dressed in full protection, in order to carry out further tests. Mum does not like needles and I could sense her fear surrounding further injections. This traumatised her and mum was particularly distressed; in turn this upset me having to witness it. To add more pain and suffering was unfair. I recall being tearful at this as it was not a nice feeling – I was sat there with mum and had no protection, whilst they were all gowned up. I tried to smile through this incident for my mum's sake. It was hard to comprehend at the time, as we did not know the severity of the virus and how transmittable it was. I do not recall anybody from the medical profession explaining to us what the diagnosis of HCV actually meant.

25. Whilst mum was in hospital she contracted clostridium difficile – a bacteria that infects the stomach. This was particularly distressing for both of us as she would mess herself and I would clean up after her. The hospital kept mum in pyjamas and every day I had to take them home to clean. It would have been easier if they kept mum in a gown – knowing mum had a virus and that I was handling her soiled pyjamas was not good hygienic medical practice.

26. Seeing someone that you love very much and care about in such bad health is hard, especially when there is nothing you can do to make them better – you feel useless. I struggled with the fact that I could not help or comfort mum. I hate hospitals, yet I had to visit them countless times for mum. I also found sitting in hospital with sick people surrounding your

loved one rather traumatic. Having to leave mum in there was hard, I felt like she was a guinea pig.

27. Mum was living in Lincolnshire at the time of the diagnosis and she was offered to have treatment at Leeds Hospital or Kings College Hospital. Kings was easier as the rest of the family were living in London and Sussex. Mum moved down after my sister Angelina found rented accommodation in GRO-C. It took a long time to find suitable home because of the dog and the fact that mum was receiving DSS, but my sister will cover this in further depth within her statement. We felt bad and guilty for moving mum down as she was happy in Lincolnshire and did not want to move, but Leeds would have been too far for us to visit her.

28. In 2014 mum was placed onto a 12-week treatment of ribavirin and sofosbuvir to clear the HCV. There was no interferon, as they knew it would not work for her genotype. I was not living with mum at this point but she was stressed, in terrible pain and could not relax. There was nothing I could do to relieve the pain or trauma – all I could do was make her food and drinks. I found it stressful and upsetting not getting her to eat properly, because I am into nutrition and I knew that she needed proper food whilst recovering.

29. It was horrible seeing her suffering and she became a different person to the mum I knew. Mum was good at putting on a brave face, but I knew she was not right. She lost her spark, her sense of humour and her happy go lucky attitude. Mum became forgetful and would talk gibberish – we would refer to this as 'liver brain'. Even now she is not the mother I had before she became ill. The ribavirin made her skin burn to the extent that she just wanted to rip it off and was constantly in and out of the shower. This added to her suffering whilst she was trying to recuperate and rest. I told mum to tell the doctors that she would stop taking ribavirin in the last few weeks because it was making her so unwell. She had the right to do so. Mum was a bag of bones by the end of the treatment.

30. The course of treatment did clear the virus and mum told us all herself that she was HCV free. On hearing this news, I was relieved that we had overcome another battle as a family. We knew then that she could qualify for a liver transplant, as this was not possible whilst she was still infected.

31. It was a waiting game finding a suitable donor that was compatible for mum. My siblings and I all have a different blood type to mum, so a part liver transplant was never possible. Whilst mum was waiting for a donor the severity of her illness became real. Visually she was not healthy at all – she was not our mum, but just a shell. It took 4 runs to the hospital before we found a suitable donor. This in itself was rather traumatic – having to travel into the hospital and wait hours to find out that it was not a match.

32. Fortunately I was self-employed so I had the flexibility to look after mum. To me family is always a priority over work and I did whatever I could to help.

33. On the night of the transplant I stayed with mum until she went down to theatre. I was full of mixed emotions. She was blue lighted to hospital as soon as they knew the liver was suitable. We finally had the go ahead and mum was well enough to have the operation. I did not want her to go in feeling nervous so I tried to have a laugh with her. Deep down I was worried I would not see her on the other side of operation, but I had the feeling that she would be fine. Although I felt that mum would not be taken away, there was still an underlying uncertainty. A fear that is constant to this day, she's not well now.

34. The hospital staff told me to go home and sleep because there was nothing I could do. I do not know how anyone could sleep whilst a loved one is having a serious operation, but I went home and waited by the phone until I heard any news. The hospital did keep me informed and phoned around 4am to say that the operation went well without any complications. I immediately tried to call my siblings but neither of them

answered the phone. I kept trying until I eventually got through to them. I remember being very anxious, as I had not seen mum yet.

35. As soon as visiting was allowed I went back to the hospital and arrived around the same time as my brother and sister. I was relieved to see mum, but it was a shock to see her all tubed up. She was bright spirited, but obviously high from the medication they had given her.

36. Mum is good at putting on a brave face, but after a couple of days I could see how much pain she was in.

37. Whilst she was still in hospital recovering from the operation, Mum suffered with clostridium difficile again and was put into isolation. The visiting hours were more flexible once she was in isolation. This meant that I could work longer hours rather than doing half days. As I was self-employed, if I did not work I would not get paid.

38. The nurses gave mum meal replacement shakes in hospital, but once she returned home I tried to encourage her to eat real food. The food in the hospital was undesirable and not nutritious. I would make healthy smoothies but she did not feel like drinking them because of the metallic taste in her mouth. The fact that I did not succeed in getting her to eat properly made me feel a bit of a failure. She lived on custard and ice-lollies – this was also hard to witness as neither have any nutritional content.

39. Even after the liver transplant, the postoperative appointments required my brother and I to take time off work to accompany mum on the train to the hospital.

40. During my early 40s I went travelling for around 18 months in Asia. I came back and was in the process of planning the next trip but then mum's health deteriorated. Had she not become ill I would not have waited as long before travelling again.

41. Once mum recovered from the virus and liver transplant I felt that I could go travelling in the Far East. I would not go before, as I did not want to be over the other side of the world whilst she was unwell. My life and travels were therefore put on hold. I initially went away for 8 months and then went back out for another 7 months. I face timed mum regularly whilst I was away, just so I could see her face and make sure she was ok.

42. My brother, sister and I were tested for HCV, but we did not tell mum until after we received the results. I was very resistant to having the blood test and I was the last one to have it done. I know that I had the test, but cannot recall where or when it was taken. I think it was taken at my local doctors surgery in London.

43. I think the results were given over the phone and we all tested negative. I was obviously relieved that none of us had contracted HCV – there was a high chance that we could have all been infected as we would have nursed each other at times and mum had been infected for decades without us knowing. My brother was particularly accident-prone so mum would have sorted out any cuts.

44. Of course my life would have gone down a different route had mum not been unwell. I think a lot of things would have been different if mum had not been infected with HCV and I would not be so scarred and traumatised by illnesses. I have grown up with an ill parent and at times had to deal with separation of the family.

45. I have never felt that my life has been disrupted as a result of mum's infection with HCV. I choose not to look at it like that, but in reality it has. My life has been full of insecurities surrounding my mum and such insecurities have been attributed to by a sequence of events including the loss of my father and Nana. This has robbed me of peace of mind over my mother's health – something I still have to this day.

46. I know that I have been affected by my mum's illness, but I did not realise how much I have stored in my body when I relive the memories. This realisation has become more prominent since I have started the witness statement process with you.

47. It is apparent that over the years I have suffered with stress, anxiety and depression over mum's illness and that has had a profound impact upon my life.

48. Mum's infection with HCV has made me look at medicine and life in a different way. I would choose not to have surgery and I would never go into a hospital if I did not have to. Due to mum's illness and the way she has been treated, I have an aversion against seeking medical advice and I have chosen not to have a doctor for the last 6-7 years.

49. Mum is still not right in my eyes. I would like to think that she will not be ill again, but I do not believe that. I still have a strong fear surrounding her health. My life is on pause at the moment – I do not want to commit to something, which would prevent me looking after mum if her health deteriorated. I feel that another organ in her body will fail because of all the medication she is taking – it is poison. It is another double-edged sword because she needs to take medication to stop her body rejecting her new liver.

50. Mum's infection with HCV has left me feeling angry and frustrated – I do not like the fact that she is on so much medication for the rest of her life because this can open up another avenue to her being ill again. For me this is a constant worry.

51. One of the tablets she takes (Azathioprine) has a possible side effect of cancer. She has already had lumps from her skin removed – three from her back one of which was cancerous, one from her ankle and one on her lip that were also cancerous. Her face was all swollen and bruised after she had the cancer removed. She had to have two procedures to remove

the cancer from her lip as they did not remove all of it the first time. I often wonder what is going on under the skin if cancerous lumps are manifesting on her body. She continues to regularly see a dermatologist.

52. Mum has always been fiercely independent, but I still feel the need to do a lot of things for her, so that she does not strain herself or make herself ill. I feel that I have a strong responsibility to look after mum, as she has no partner. My brother and sister have their own families so it is easier for me to look after mum. Perhaps this attitude is ingrained in my mind because I have looked after her for a long time. I could not live with myself if something happened to her and I was not there.

53. I would like the opportunity to travel more and settle down with a partner in a home of our own, but I will probably not have any children. I am getting too old for that now. I would also like to see my mum settle down with someone, so that she could enjoy life with someone.

54. Since Mum's witness statement was taken she is now on an inhaler because of the damage caused by the HCV. It saddens me that she has to have this further treatment.

Section 6. Treatment/Care/Support

55. I was never aware of any counselling or psychological support in relation to my mother's illness.

Section 7. Financial Assistance

56. I have never applied for or received any carer's allowance, as I do not like taking money from the state.

Section 8. Other Issues

57. I would like the Inquiry to achieve justice for people like mum, who have lost themselves through illness.

58. It also needs to be acknowledged that the contaminated blood scandal has had a knock on affect for family members.

59. I am angry at how such a huge failing in negligence has affected so many people. I am angry that my mum has had to suffer because she was given infected blood and I could have almost lost both of my parents.

60. To me it is logical that the blood would have been tested and screened before being used – I thought medicine is all about testing. Everything could have been prevented if the blood was screened – this is such a big mistake to make and so many people have suffered in consequence.

61. At this stage I do not think we can blame anyone for the use of contaminated blood – we do not know the person who authorised the use of imported blood and agreed not to screen it.

62. I do admire what the health profession can do and they did save my mum's life, yet there is a lot of misguided information and improper use of medication within the NHS.

Statement of Truth

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

Signe GRO-C

15th

Dated XX October 2019.