Witness Name: **Nicola Burton**
Statement No.: **WITN0710001**
Exhibits: **Nil**
Dated: **17 July 2019**

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF NICOLA BURTON

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 13 May 2019.

I, Nicola Burton, will say as follows: -

Section 1. Introduction

1. My name is Nicola Burton. My date of birth is **GRO-C** 1966 and my address is known to the Inquiry. I am a Director of Financial Operations. I currently live in Wisconsin, USA, where I have lived for 17 years, with my husband Robert (Bob) and our two daughters.

2. I intend to speak about my mother, Irene Milne, and her infection with HCV which she contracted in 1984 when she was given a blood transfusion in the UK. In particular, I will go into detail about how she discovered she was infected and how the illness caused liver cancer, as well as the treatment she received for the cancer, and how the illnesses ultimately took her life. I will also speak about the impact it had on her and our family.

3. My older sister, Judith Clarke (W0709) has also provided a statement to the Inquiry.

4. I can confirm that I have chosen not to be legally represented and that I am happy for the Inquiry team to assist me in writing my statement. The Inquiry team has explained anonymity and I do not require any information to be kept private.

5. My husband, Bob, was also present at the interview with the Inquiry team.

Section 2. How Affected

6. In 1984, I began my first year at Nottingham University. My sister, Judith, was also at Nottingham University in the year above me. It was during this first year at university that both my parents were involved in a car accident.

7. Mum was driving them home from Edinburgh to Sheffield following a funeral of my mum's aunt. The accident occurred near Alnwick, close to the Scottish border when a driver, who was over the legal alcohol limit, smashed head on into my parents car, while on the wrong side of the road. Mum was taken directly to Newcastle General Infirmary due to her severe injuries. Dad was taken to Alnwick hospital which was more local. The driver walked away from the accident unharmed and received only a fine.

8. Mum was taken to Newcastle General Infirmary; I understand this hospital closed in November 2010. She had many broken bones and her injuries were serious. She had broken her back, her chest bone and also her neck. It was at this hospital that she had the blood transfusion and received blood products. She must have lost a lot of blood, although I am not aware of how much blood she was given.

9. My uncle called me to tell me about the accident. Later that night I got a bus up to Sheffield from Nottingham, and was then given a lift to Newcastle General Infirmary. When I arrived, the nurse warned me that it would be shocking, and it was. It was horrible.

10. From what I remember, she was already hooked up to machinery, and was drifting in and out of consciousness. I recall that when she came to, she mentioned that she had broken a nail. Mum was a very strong independent person who didn't like to be fussed about. We used to call her 'Lady Irene'.

11. I stayed overnight and then went to see dad, who was still in Alnwick Hospital and not too badly hurt. Once dad was released, he stayed in a hotel near Newcastle Infirmary to be close to mum.

12. Mum was in hospital for 4 months. She had to lie totally flat on her back and couldn't really move at all, as treatment was focused on resetting the broken bones. I believe she was only on an IV for a few days.

13. Mum was finally released from the hospital in March 1985 and went back to Sheffield. For several months after she had to wear a brace which supported her head and went down to her waist. Her broken bones eventually healed, although she had a broken toe that they didn't set properly. She had a couple of surgeries to correct this. No blood transfusions were needed during these operations.

14. I missed a lot of university that year as my sister and I were constantly travelling up and down to help dad and to visit mum. Transportation was always an issue - I was only 18 years old and although I had a driver's license it was a problem to hire a car. It was very expensive to do so. My sister Judith did not drive. My dad had suffered from a stroke in 1982 and mum had become his primary care-giver.

15. Over the next couple of years mum had many medical issues such as leg swelling, rashes, ulcers, lupus, vasculitis and sepsis. Before the accident she didn't have these problems. She had been very healthy. After the accident she has problems walking and also couldn't use her hand very well, she had to change to driving an automatic car.

HCV Diagnosis

16. Just before I moved to the US in 2001, mum was told she had HCV. She was told flippantly, as if in passing about the diagnosis by her local GP in Stannington, Sheffield. As if to say, 'Oh yeah, you've got this disease.' She was told it was nothing to worry about and that there was no treatment available and that she should just carry on as normal.

17. The doctor told her that the HCV was a result of the blood transfusion/products she received after the car accident, as we always spoke about it as 'something else the drunk driver gave her'. In any case, I am not aware of any prior surgery or illnesses that would have required her to have a blood transfusion.

18. After the diagnosis, no information was provided to help understand or manage the infection. At no point was she told to watch her alcohol intake in order to take care of her liver. She continued to give blood regularly. She also didn't receive any warning that HCV could lead to cirrhosis or liver cancer.

19. We also didn't receive any information about the risk of infecting others. She was never told that she needed to inform her dentist or other medical professionals of her HCV status. If she had been told to do this, she would have definitely done so. She used to be a Health and Safety Officer so was always very conscious of being rule-compliant. Mum was also very open about information she was given about her health, so she would also have shared this information with us if she had been told anything.

20. There was a time when mum came to visit my family and I in the US and while she was here she went and got her ears pierced with her granddaughters. Looking back now, I am aware of how risky this was, but she was never told of the risks of doing things like this.

21. Further down the line, I was at my own doctor's appointment where I was asked about my medical history. I told them that my mother had HCV and they said that I needed to be tested straight away. They seemed shocked that I hadn't already been tested. My test was negative but, to my knowledge, the rest of my family have not been tested

Section 3. Other Infections

22. To my knowledge, my mother did not receive any other infection as a result of being given infected blood, other than HCV.

23. Although she did not receive any other infection at the time from the blood transfusion/products, she later developed cirrhosis and liver cancer as a result of having HCV. I will discuss this in more detail under Section 5 of this statement.

Section 4. Consent

24. I was super close to mum and we spoke frequently about her medical issues so it's likely that I would know about any medical information she was told by professionals. It is my understanding that mum was not tested for HCV without her knowledge. I do not know if she had or was tested for HBV and she never mentioned HIV, so I do not know if she was tested for that.

25. When mum was later diagnosed with liver cancer she was told that they had been monitoring her for cancer, as HCV often turned into liver cancer. This angered her, as she had no idea that HCV could lead to liver cancer, and also because she had no idea they had been monitoring her. Mum had been told there was nothing to worry about in relation to HCV. It's almost as if there was

a conscious decision on the part of the medical professionals to sweep it under the carpet. They didn't want to open a can of worms that they would then have to deal with.

Section 5. Impact

Physical and mental impact

26. In November 2010, mum and I had been on holiday in Dubai. It was very soon after that trip that I heard from my mum, telling me that she had been diagnosed with liver cancer. As mentioned in Section 4, we had no idea there was a possibility that she could get cancer as a result of having HCV, so we were both in shock. The doctor told her that they had caught the cancer early because they had been monitoring her for it.

27. The cancer was initially treated with chemotherapy. I went over to the UK to take her to her first chemotherapy appointment at St James Hospital in Leeds. At that first appointment, she saw how ill other people looked and was devastated. She said, 'this is my life now.' Surgery to remove the tumor or a transplant were not options. Different trial treatments were also tried.

28. Unfortunately I was only able to stay in the UK for a couple of weeks at this point. Both Judith and dad didn't drive and mum couldn't drive herself so it was hard for her to get to treatment, especially as she had appointments in Leeds, Sheffield and Manchester. She tried a patient transport ambulance service, but this meant she ended up having to wait around for long periods. My sister accompanied her to appointments often by train, which was very hard on them both.

29. Initially the chemotherapy started to work, but it wasn't long before the cancer started to spread and the tumors got bigger. Mum then started a cancer trial in Manchester, but the side effects of this were bad, and she didn't like having to hang around all day. She was seeing doctors in Sheffield, Leeds and Manchester. On advice/discussions with her doctors and family she stopped treatments as they were not proving to stop the growth of the tumors and

making her quality of life unbearable. She thought there was no positive reason to continue. This really angered dad as he thought she was giving up, and he desperately wanted her to get better. But mum just wanted to enjoy the little time she had left. Judith and I accepted mum's view, but dad continued to struggle with it.

30. She suffered a lot physically from the cancer and treatment for it. She lost her hair and her body would swell up. She was in a lot of pain and always sick. She also went yellow. Mum also lost her quality of life and her independence.

31. In June 2013, mum suddenly got much worse. Judith had called me to say that mum had bleeding varices, which was caused by cirrhosis of her liver. Mum had been out to drop off dad at a lunch, and she was driving home by herself when she started vomiting blood in the car. She had managed to get home but couldn't quite open the door. She collapsed at the door and set the security alarm off. The neighbours found her unconscious on the doorstep and called for an ambulance. By this point she had lost a lot of blood. After hearing the news from Judith, I got a flight straight away back to the UK.

32. Mum was put in the liver ward in the Northern General Hospital, Sheffield. She never went home went home again after this. She found this ward very distressing as it was full of alcoholics and she felt like she didn't belong there. There were a lot of violent people asking for alcohol, which scared mum. She didn't feel safe and I asked the nurse if she could move wards as there was a particular woman that frightened her. They were not able to and was she felt she was being blamed for bringing it on herself. She kept saying "I do not belong here" referring to the alcoholics she was sharing the ward with.

33. As mum was the primary care giver for dad, and I had to return to the US, we had to find a place for dad to stay. We found a retirement home in Loxley for dad which was hugely expensive, but at least he was safe and being taken care off.

34. The doctors told mum that she wasn't fit enough to go home. At this point we decided we needed to sell the house as dad was also not well enough to live there by himself. Mum also decided told she shouldn't drive anymore. This was hard for her as she felt like she was losing her independence. She leased the car they had, so I had to spent a couple of days cleaning the blood out of it, which was everywhere, it was a very upsetting task. We had had some discussions about how unwise it was to be driving when she was that sick. She was really hard on herself, and felt terrible that she could have caused an accident and hurt someone else. I left for the US but came back again a few weeks later.

35. One day while I were visiting mum, a doctor came to mum's bed, pulling the curtain for privacy, and told us that the cancer had spread to her lungs and that we now needed to start talking about hospice care. I remember mum saying, 'He's finally killed me', referring to the drunk driver that caused the car accident.

36. At this time, and for the last 6 months of her life mum became very confused. After her cancer diagnosis we used to call her confusion 'chemo brain'. I recall having a phone call with her at some point, and after hanging up the phone thinking that she wasn't really there.

37. Judith and I now had to find a place for mum to live. We were given no guidance as to what we should be looking or who we could contact for mum. Judith and I drove around Sheffield looking for a place for her. Ultimately we needed a place for both of them as we wanted them to be together; they had been married for 50 years. We also couldn't afford to keep dad in the home he was currently at. We eventually found a place with 24 hour care and tried to make it as homely as possible for them with photos and knick-knacks. They ended up in separate floors of the home – but at least they were together. We also installed a phone for them in her room so they didn't have to use the general one, I talked to mum every morning until she wasn't able to hold the phone anymore. Mum's care was paid for by the NHS, but dad's wasn't.

38. At the end of 2013, I went back again to the UK with my family for Christmas. We had planned to bring both mum and dad to a hotel, but we only managed this for one night as mum had deteriorated. They both had. Mum was now incontinent and her skin was bright yellow. She was also constantly cold so had to be wrapped up all the time. I stayed in her room with her overnight. She was so unwell, it felt as if she was just holding on for us so she could say goodbye, as she knew we were coming back for Christmas to see her.

39. My family and I went back to the US and had only been back a week when I got a call from the nurse at the home to say mum wasn't doing well and only had a few days left. I went straight back to the UK. Mum passed away on 12 January 2014.

40. Although mum was given treatment for liver cancer, she was never offered it for HCV. This is what upsets me the most. Treatment for HCV was available, and she was never offered anything. The cancer could have been prevented. Once she was diagnosed with cancer, her HCV was never mentioned again, not even during her autoimmune appointments. It's as if it was swept under the carpet. Looking back now, there are symptoms that she had that could be attributed to HCV, although we didn't realise at the time. The doctors didn't look at the HCV symptoms that she was having, but instead treated all her other supposed illnesses.

Stigma

41. Neither mum nor we felt there was much stigma attached to her HCV diagnosis because we were told by the doctor that it wasn't a big deal. She also didn't appear to be suffering from it. She had been diagnosed with both lupus and vasculitis, but we never related any of these symptoms to HCV. The doctors did not discuss any of these symptoms could have been related, even though they were aware of the HCV diagnosis.

42. After she developed liver cancer, that's when the stigma started. When talking about the cancer she never really told anyone about her HCV diagnosis as she never thought anything of it. Doctors also rarely seemed to join the dots

between HCV and liver cancer, so there was a sense, even from nurses, that she had brought it on herself, as liver cancer is often associated with alcoholism. She felt she had to explain to people that she wasn't an alcoholic. Although she would have a drink, her liver damage definitely wasn't caused by alcohol.

Impact on private/family and social life

43. Mum always remained positive through the ups and downs, even during the times she was really struggling with her health. She never complained about her health or the situation she was in. She volunteered with the Samaritans, which helped keep her sanity. Mum was a really wonderful person. She continued to work as a health and safety expert in the civil service after the car crash, but took retirement just after her HCV diagnosis. She remained self-sufficient. She was never not able to do anything and was always able to get herself to treatment until the liver cancer diagnosis.

44. Two years before the car accident, dad had a stroke and retired on medical grounds. After the stroke, he was still able to get around, but he had lost a bit of movement in his arm and leg, so was no longer able to drive. Mum became his primary care giver. When mum became so sick, she was no longer able to care for him, and as mentioned earlier in the statement, dad had to be put into a home.

45. Before the cancer diagnosis, we used to travel a lot as a family and mum would often visit me and my children in the US. I moved to the US on 8 April 2002 when my daughters were 5 and 9. I had always had a very close relationship with my mum, and mum was also very close to the grandkids. My daughters know her as 'Grandma Sheffield'. When she retired in 2002 she would come and visit us 2 or 3 times a year for up to a month at a time, and in the summer to she look after the kids. She also used this time to take a bit of a break from looking after dad and take some of the burden off herself.

46. After the cancer diagnosis, mum could no longer travel. In June 2012 my eldest daughter graduated from high school and my mum had booked to come over to the US to attend her graduation ceremony. But she was too ill to come and had to cancel which was devastating for her. She had been unable to get travel insurance so she also lost some money.

47. My daughters' education was very important to mum, she always asked about their achievements and their lives. My grandfather had been the type of man who believed women should stay at home so when mum had wanted to go to university, he dismissed it, saying it's not for women. Mum pushed my sister and I to go to university because she couldn't, and she was so supportive of the all of her granddaughters, encouraging them to go to university and always made them feel special.

48. It has been hard for my daughters. At the time when mum was so ill, they were too young to be burdened with what was happening to her, but old enough to understand. Even though she lived far away from the girls, they remained very close. She used to say, 'If you can see the sun, we are together. We are under the same sun.' My eldest daughter is getting married in the summer and at the bridal shower recently, her younger sister gave her a pin with suns on it to represent Grandma Sheffield. It's very upsetting for us all that mum had missed getting to see her granddaughters get married.

49. In August 2013, we had a family holiday to Majorca booked, my family, my sisters family and my parents had planned to go. When it came to it, mum's health had deteriorated fast and was, again, too ill to travel so both our parents stayed at home. We decided that we would still take the trip anyway as mum insisted and would have been offended if we didn't go. It was hard because they should have been there with us. Their absence was very much noticed.

50. Before mum got sick, I used to go back to the UK occasionally, but not very often because of my work and family responsibilities. Our parents would alternate Christmas between Judith and I, as it was easier for them to travel because they were retired. They used to travel a lot. I have taken them to many

different places on vacation such as, Florida, Missouri, Canada and Las Vegas. But since the diagnosis I had to leave my family at home to travel back to the UK 8 times between 2011 and 2014. I had to take a lot of unpaid leave and at one point had to take a month of unpaid leave. The cost of travel was expensive as it was often booked last minute and it was hard to determine how long I needed to be in the UK for. But I didn't have a choice.

51. I felt guilty that Judith had to do most of the work, as she lived much closer to our parents. Dad's health had started to go down hill too. He was 10 years older than mum and was not coping well with mum's illness. He needed a lot of attention and was completely reliant on my sister to look after him too. He was bad on his legs so couldn't walk very far and I'm not sure he could feed himself very well. I felt guilty that I wasn't there more often.

52. During the period after mum was taken to the hospital for the last time, Judith and I had a lot of hard decisions to make quickly about mum and dad's care, and selling the house. It was a real challenge to find a care home for dad. We tried social services and even care homes for cancer patients but they couldn't help. Dad could still walk and microwave a meal but he couldn't talk very well. After the stroke he couldn't pronounce words properly and he had a heavy Scotish accent which meant he wasn't easily understood. If people couldn't understand him, he would just speak louder, which didn't actually help.

53. During this time we also had to clear out their house so it could be sold. It was heart-breaking as there was a lifetime of stuff that no one wanted; they had lived in that home for 30 years. They had a study full of books that we tried to give to book shops, but no one would take them. Mum would have been devastated if she's known that her precious things were being thrown away.

54. I struggled a lot, I remember there were many evenings I was on the phone to my husband, Bob, and breaking down, which was rough for Bob too. He had a lot to deal with because his sales job required him to travel a lot. But while I was away in the UK he also had to take care of the children, who were grown up but teenagers so not independent.

55. When mum passed away, dad went downhill. He fell apart and at that stage was completely dependent so had to stay in the nursing home. He even had to have help showering. It's so upsetting because if mum was alive and stayed healthy he wouldn't have had to go to that nursing home. Dad passed away in September 2017 a very angry man.

Section 6. Treatment/Care/Support

56. Before the cancer diagnosis, no treatment of any kind was offered to my mum. Much later on after being diagnosed with HCV, mum did her own research and discovered that there were treatments for HCV available which were not mentioned at the time of diagnosis. One doctor told her that treatment has bad side effects, implying it better not to have had it. At one point mum was very angry about this because she should have been offered this and allowed to make her own decision. Had we known about it, dad would have also encouraged her to take the treatment. Having gone through this all now, it's so wrong that she wasn't offered treatment. The cancer and her ultimate death could have been prevented

57. After the cancer diagnosis mum used to go to St Luke Hospice once a week for crafts and activities. This wasn't so much support, but more of a reason to get out of the house.

58. At no point have any of us been offered counselling or support.

Section 7. Financial Assistance

59. We first found out about the Skipton Fund after mum had been diagnosed with liver cancer in 2011. One of the doctors mentioned there was a fund for people who had been infected with contaminated blood. I was in the UK at the time and went online to find out more about it. The application deadline was approaching, but I had to come home to the US, so I had to leave it to Judith to fill out.

60. The application required mum's medical records and product numbers, which we didn't have. Judith contacted Newcastle Hospital but was told Newcastle Infirmary had closed down. Judith was given multiple reasons as to why she couldn't be given mum's medical records. First she was told they were in a warehouse. Then she was told that this warehouse had burned down. She was also told that it was past their retention period. There were many excuses. Owing to the lack of information we could provide, our application was initially rejected, as we couldn't provide enough proof. There was an accusation from the Skipton Fund that mum's lifestyle was to blame for her illness.

61. We appealed this decision. As part of the appeal, Judith and I both wrote letters explaining that mum hadn't had multiple sexual partners or used intravenous drugs. We were essentially writing a character reference on her behalf. The appeal was also supported by medical records provided by the family doctor which showed that mum hadn't had any other blood transfusions.

62. The appeal was accepted and mum received an initial lump sum of £20,000. She then received a monthly payment until she passed, although I am not sure how much this payment was.

63. The whole process of applying to the Skipton Fund was a challenge. It was a difficult process made even more difficult by other people, with no one to actually help us. It felt as if they were doing everything they could not to pay. Without Judith's help, there is no way mum would have been able to do this application, she was not in the right place mentally. Dad would also not have been able to have helped.

64. The payments stopped when mum passed, which was at a time when dad really needed financial support. Aside from mum's Skipton Fund payments, as a family, we have not received any other financial support.

Section 8. Other Issues

65. While sitting down to write about what we have been through, I realised how tough it is to think about. During the period when it was all happening, we just did what we had to do to get through it. We always blamed the drunk driver that caused the crash, who walked away from the accident unharmed and received only a fine, but in fact it was the contaminated blood and treatment she received, or lack of it, that actually killed mum. They could have treated the HCV, but there seemed to be a conscious decision not to. If the treatment didn't work for her, then that's fine. But at least they would have tried and we'd know that everything that could have been done, was done.

66. I feel guilt about not having done something earlier but we just didn't know. But we should have known more! In the early 2000s we didn't question doctors, we just assumed they had taken in the whole picture and done what was best for mum. I will always feel guilty for living so far away from mum in the US.

67. Now that the contaminated blood scandal has come into public view, I expected the government to have worked in a different way. They should put their hands up and admit their mistakes, as they knew what was going on with contaminated blood and they haven't done everything that they should have done.

68. The NHS has let patients down, which has led to the death of many people. We know accidents happen and that people may not always make the best decision, but I feel that those who are responsible have chosen not to act, when it is these people who need to take responsibility.

69. I do not have the names of mum's doctors or her medical records, but Judith, who has also provided a statement, does.

Statement of Truth

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

Signed GRO-C

Dated 19/7/19.