Witness Name: Louise Merrigan
Statement No.: WITN5458001
Exhibits: WITN5458002
Dated:

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF LOUISE MERRIGAN

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 16 March 2022

I, Louise Merrigan, will say as follows: -

Section 1. Introduction

1. My name is Louise Merrigan. My date of birth is GRO-C 1975 and details of my address are known to the Inquiry. I am married and work in Human Resources. I intend to speak about my mother, Janette Patricia Merrigan, whose date of birth was the GRO-C 1957 and who sadly passed away on the 30th December 2012 aged 55. In particular, I intend to speak about the nature of her illness, how the illness affected her, the treatment she received and the impact it had on her, my sister and myself.

2. I am making this statement in conjunction with my sister, Alison Dyson, nee Merrigan. This statement represents a composite of both of our

memories of events and of our mother. We make this statement without the benefit of our mother's medical records.

Section 2. How Affected

3. Our father passed away when we were young, so our mum and our grandmother brought us up together. Mum moved with us from Northern Ireland to a small town in Bedfordshire when we were very young; 5 and 2 respectively.

4. Mum worked full-time for the NHS, first in elderly care and then as a mental health nurse - she worked in mental health for over 25 years, first on an NHS ward, then a secure ward and then in the community. She loved her work and could definitely be described as a tough cookie - she didn't scare easily.

5. While we were growing up, our mum was in good health. She suffered from occasional depression relating to our dad's death and later developed type II diabetes, but it wasn't until mum underwent surgery that her health deteriorated.

6. We believe that our Mum was infected with the hepatitis C virus (HCV) when she was sent into our local hospital in Bedford for a procedure relating to an ectopic pregnancy in January 1985. I'm not entirely sure exactly what procedure she underwent whilst there but I know she had a hysterectomy at some point but can't be certain when it was. We have records to say that on the 3rd January 1985, 2 units of blood were requested for surgery (WITN5458002). Later, she was put onto the maternity ward. I remember that Mum was threatening to discharge herself after a week of being in hospital because she was getting frustrated that they weren't getting on with it quickly enough.

7. I remember that afterwards, Mum couldn't work for a while as her job was very physical and she was in convalescent recovery. When she did recover, although she had physically recovered from surgery, both my sister and I remember that she did not recover emotionally for a long time. In hindsight, we realise that this was probably due to hormone imbalance following mum's hysterectomy. We both remember that she was much more emotional and that she had to go on HRT (hormone replacement therapy). Mum put on a lot of weight and tired more easily - she was definitely more tired than before the operation. Later on, we remember her suffering from brain fog.

8. Whilst we aren't sure why, we both remember that Mum went to her GP at Marston surgery regularly, subsequent to having had her hysterectomy. We remember that she had gastrointestinal issues that she would consult her doctor about. Mum also went through periods of depression and taking antidepressants. We always thought that Mum's depression was down to losing our dad, but we now realise that depression and brain fog are potential side effects of HCV.

9. We remember Mum's health being in steady decline following her operation in 1985 to her diagnosis of HCV in 2009. We also feel that she was let down by her GPs, who could have done more to diagnose her condition sooner.

10. In 2009, Mum was incredibly lethargic and suffered from unexplained tiredness and exhaustion. She was sent for a blood test at Bedford hospital. At first, it was thought she had cancer, but she was told following the results of the blood test that she had hepatitis C. When she was diagnosed, it was already very advanced - her liver was cirrhotic. Mum was told of her diagnosis completely out of the blue and we feel that it was delivered to her very matter-of-factly, all in one hit. She wasn't offered any treatment at that stage, but had a liver biopsy

and was put under the care of the gastroenterology team at Bedford hospital.

11. After her diagnosis and being transferred to the gastroenterology team under the care of Dr Anne Day, a consultant gastroenterologist who worked between Addenbrooke's and Bedford Hospital, Mum's care improved. This is mainly down to Dr Day - we strongly feel that Dr Day was one of the only doctors under whom Mum was provided with good care. Dr Day was fantastic not only with our Mum but also with us and was incredibly supportive of Mum's needs, which we didn't feel she received from any other doctor.

12. After Mum was put under the care of the gastroenterology team, although she wasn't offered any treatment immediately, she was offered interferon treatment in 2010. We are not sure which interferon treatment she was given, but it lasted for 6 months and ultimately was not successful in clearing the virus.

13. The 6 months of interferon treatment was incredibly difficult for our Mum and for us. It was a very aggressive treatment. We remember that her hair went from being straight to being curly. We feel that it was similar to some cancer treatments in terms of its impact on Mum - she was incredibly tired all of the time and developed encephalopathy, becoming very forgetful to the point where she was missing appointments. My sister and I used to have to leave work to make sure she was ok and we both remember having to call her on repeat to make sure she was responsive. Pans would burn on the stove because she would forget to take them off, and we remember that some roast dinners were cremated. She often forgot to eat meals. Mum was really young and was working full-time, until her treatment, with its debilitating side-effects started. She couldn't function, let alone work. It was like caring for an elderly relative even though she was so young.

14. Mum was by herself by the time she started her interferon treatment because our grandmother had passed away by then and my sister and I were living independently. It was completely impossible to get her any form of support from carers at home despite being in danger due to the side-effects of her treatment - all of Mum's care from her diagnosis onwards was provided by my sister and I. She lived for just 3 and a half years after her diagnosis.

15. Until her death, Mum was constantly in and out of hospital - we felt that she was constantly being pushed away. She would go in and would be treated for whatever immediate problem she presented with, but was always promptly rushed out and there didn't seem to be any effort to try and look into or treat the base cause of all the problems - the HCV.

16. We truly felt, and continue to feel, as though there was no joint-together care. More often than not, Dr Day and the gastroenterology team weren't informed that Mum had been admitted or discharged from the various wards. A few times, Mum was admitted onto the dementia ward. Other times, she would be treated for issues relating to her diabetes as her encephalopathy lead to blood sugar problems and then she would be discharged. It really felt to us as though they didn't want to hear the bigger picture and that the hospital wanted to solve Mum's immediate problem and then get the bed back. Towards the end of Mum's life, Mum couldn't take care of herself or her physical appearance despite being someone who used to take pride in her outward appearance and who we knew to be someone who would never have left the house looking unkempt if she could help it. Alison felt that she was made out to be some sort of vagrant at the hospital as she couldn't look after herself but the hospital staff attributed it to her ability to care for herself as opposed to her HCV infection.

17. Mum was put on the liver transplant list from 2012 onwards, which was advocated for by Dr Day. In hindsight, we don't think Mum would have been well enough to get through this procedure but there was a focus

on trying to get Mum as well as she could be. Not long before Mum died, we also had a conversation about expensive alternative drugs. We're not sure why it didn't happen, but it was quite close to when we lost Mum, so perhaps we ran out of time.

18. Mum passed away very suddenly on 30th December 2012. She had Christmas at home with us and had been a bit more present over the festive period. Mum had been so upbeat when I picked her up for Christmas. She always loved Christmas and always went above and beyond with presents. Despite this, she had been in hospital two weeks before and we strongly felt that she shouldn't have been discharged. It was very clear to us that she was having issues with fluid retention and fluid in her lungs. At this point she was so unwell that she couldn't control her bowel movements and couldn't take care of herself at all. Both of us remember having to put blankets down and put plastic bags around her legs so as not to get fluid on the carpets.

19. We managed to get community and district nurses coming in to help Mum shortly before she passed away. It was a nurse who found Mum on the day of her death.

20. We are not sure exactly what was listed on Mum's death certificate but believe it to have been hepatitis C, cirrhosis and something relating to her kidneys.

Section 3. Other Infections

21. We do not believe our mother suffered from any other infections as a result of the blood she was given in 1985.

Section 4. Consent

22. To the best of our knowledge, we cannot recall any requests of consent, but assume that Mum would have had to consent to her operation in 1985.

Section 5. Impact

23. Mum had had no life from the point of her diagnosis in 2009 onwards. She couldn't work, couldn't leave the house and wasn't truly cognisant.

24. At the time of Mum's diagnosis, our grandmother was still alive, but she passed away 10 months after Mum's diagnosis. Mum was an only child with no extended family to speak of - it was just our mum and us following our grandmother in death, so this was a devastating loss for us.

25. Mum had a strong, core group of friends and work friends who used to do things together all the time. Although they were mainly work friends, Mum had a group of friends from the local village too. Friends stopped asking Mum to do things after her diagnosis because she became 'unreliable'. Mum was open about her diagnosis but friends lost touch as she wasn't able to go out and see them. One friend became her carer following our grandmother death but by the time she was really poorly, there was no one really checking on her. We believe had been suffering from cancer, she would have been supported completely differently by her friends, and would even have received better care from doctors and healthcare workers.

26. We couldn't go away together because of Mum's health. Every time we would have something booked and would look forward to it, it wouldn't happen.

27. Mum became a lot more reclusive and much less confident because of her swollen legs. She would even get a friend to go and buy her electricity for the meter.

28. Mum couldn't go to Alison's wedding because she was so unwell. Alison had to go to show her photos the day after the wedding. She was devastated, as were we.

29. There was constant anxiety between us sisters that Mum was alright and still alive. We both lived in South London and worked in the City and we frequently had to leave work to go and find her and check in on her. Thankfully, our employers were very flexible but we had to bear the cost both financially and emotionally. Every weekend, we would take it in turns to go and make sure the house was clean, to go and do a food shop and to look after Mum's basic needs as we could get no one to come in and help her or us. We wouldn't see each other as we were taking turns in looking after our mum. We would regularly receive calls saying that Mum was going into hospital and we would have to rush to her house in Bedfordshire to secure it and to pack Mum a hospital bag.

30. Mum was very vulnerable. She was prone to leaving the gas on and to forgetting basic things, for example. We had to rely on her neighbours even though they weren't completely trustworthy. We tried repeatedly to get Mum into a retirement flat nearer to where we lived but couldn't as she was too young. We just could not get Mum the care she needed when she required it. If we did manage to secure someone to come in and check in on Mum, they would care for her until Mum started improving then would leave her again until she got worse. This happened over and over. We have to stress that the community team let her down, her GP let her down and the hospitals she attended let her down.

31. Financially, Mum was also very vulnerable - her sick pay from work had ceased and I helped her with applying for benefits in the end. It was all so challenging. I discovered that Mum was in some serious arrears with the council for utility bills from looking through Mum's post. The Housing Association were great when they found out but the council were steadfast in demanding vast sums of money from Mum. I persevered with the system but this took a huge toll on me emotionally and in terms of time. I truly don't know what Mum, or anyone in Mum's position, would have done if I hadn't been able to help and I struggle with this. She just couldn't cope with things mounting up with her illness. Cruelly, Mum received back-dated benefits a week before she died.

32. Mum died when Alison was pregnant. Alison found out about her pregnancy two weeks after Mum died. She never got to meet her grandchildren, or even know that they were on the way.

33. We both feel as though Mum's death wasn't inevitable - she died very suddenly. If we had been listened to, she might have been alive longer. There was no joined-up thinking or consistency of care for Mum and it always felt like an uphill battle to advocate for Mum's care and be listened to by medical professionals.

34. Losing our mum to hepatitis C has been so difficult and we are very angry about it. Mum didn't meet her grandchildren. Most of our friends still have one or more of their parents. We will have no reference point with our kids as Mum isn't here. Mum won't be able to be there for the milestone moments in our families' lives.

35. Around the time Mum passed away, we were both considering moving back home. Mum had lost hope, we feel, and maybe if she'd known about Alison's pregnancy that would have been the hope she needed.

36. Mum had never participated in intravenous drug use or drugs more generally, barely drank, had never had hospital treatment abroad, she had no tattoos or promiscuous sexual exploits. On the form sent to the Skipton Trust the doctor who was helping her fill it in must have filled in the entry about GRO-C as it is not her handwriting. She was constantly subjected to judgement and stigma because of this disease, even from doctors and medical professionals.

37. We still feel stigma and judgement about Mum's infection to this day. We are reticent to tell our friends or employers, for example. We are quite a private family and tend to gloss over our parents' deaths when people ask. Only our partners and our mum's friends know about Mum's infection. This is mainly out of a fear of judgement - we don't want to tarnish mum's reputation and want to preserve and protect her legacy. When Mum died, we asked for donations to the Liver Trust and people assumed she'd died of liver cancer. We didn't think that people would donate to the Hepatitis C Trust. When we fill out medical questionnaires or are asked questions about family history, we feel we get judged as soon as we open our mouths. You have to quickly explain through the judgement. We feel as though no one really accepted that Mum was given hepatitis C. I don't think anyone's ever really believed that Mum didn't drink etc - everyone thought it was her own doing. It was only Dr Day who put things together - she was the one who looked at Mum's records and put two-and-two together about Mum's operation and source of infection.

38. Mum's hepatitis C infection affected her hugely mentally. She had been a strong, powerhouse, happy-spirited, hilarious person but became a shell of a person with her infection. She was terrified of dying. She wasn't really living, just existing, and was in tears nearly every day that we spoke to her. We tried to keep her positive and upbeat but it was very difficult to keep her that way.

39. When Mum died, the police came to my door to notify me. It was such a shock and the whole situation was hugely traumatic for me. We wouldn't have dropped her home after Christmas had we known. Mum didn't want to bother doctors or hospitals until things got really bad, but even when she did, she'd be turned away. When I told Alison, we all went to Alison's house. Mum was taken to Bedford Hospital. We made the journey up there as I wanted to see Mum before she was taken to the undertakers but we were left waiting at the hospital for hours and I didn't think I was able to see her, so we left after a while. An autopsy was performed and I was told by the Coroner's Office that she had died in her sleep. I also wasn't allowed to see Mum at the funeral directors'.

Section 6. Treatment/Care/Support

40. It wasn't hard to get access to care and treatment for Mum once she was under the care of the specialist gastroenterology team and Dr Day. However, the rest of Mum's care - from her GP and her general hospital treatment was awful and so isolated. It's difficult to describe it as care - rather a lack of care.

41. We strongly feel that having hepatitis C affected Mum's care and created a fear that people caring for her didn't want to deal with her. Mum was treated like a leper - healthcare workers bagged up everything she had come into contact with and some cleaners didn't want to clear up her room, for example. Some carers, when we managed to get some in, would come in and assume that Mum was an alcoholic. Mum's GP was hugely reluctant to come and undertake home visits and Mum felt like an inconvenience. On one occasion, her GP Dr GRO-D turned up when I was there with his headphone on, displaying a complete indifference to his patient. Mum faced so much

judgement and a complete lack of respect - we felt that she was blamed for her infection.

42. There were times when Mum had gone into hospital and soiled herself. It was assumed that it was her own fault, her own lifestyle. We knew our Mum to be a powerhouse, strong, independent woman who was incredibly conscious of her own cleanliness. She worked incredibly hard and all of her friends loved her. She was the epitome of someone who would always do the right thing. Seeing her be reduced by the healthcare system was incredibly difficult. We feel as though we lost our Mum way before she died.

43. Mum was never offered support mentally or psychologically, and neither were we. There definitely should have been more support for Mum from a mental health standpoint, especially given her history of depression.

Section 7. Financial Assistance

44. Mum did not receive any financial support or receive any financial advice, apart from being signposted to the Skipton Fund by Dr Day. Mum didn't want to push for financial assistance until I encouraged and helped her to.

45. Mum did not benefit from any hepatitis-C related trusts or schemes. Dr Day made Mum aware of and filled out the form for the Skipton Fund when Mum needed it most. However, the application for the Skipton fund was denied. Mum was worn down so didn't want to reapply. She was so worn down by improper treatment that nothing would have happened without us - she just didn't have the fight left in her to do it.

46. With my help, Mum successfully applied to receive EIBSS and qualified for a relatively high amount of support but she was in so much debt that any payment would go to paying off her debtors. Mum was in arrears of about £3000 to £4000 to the water provider, for example. She was also in arrears with her council tax, short term loan companies and with credit card repayments. We ended up having to pay around £8000 in debt collection upon Mum's death.

47. With EBISS, Mum would have been given bulk loans and a regular income. She didn't get round to being able to access her pension on account of her age.

Section 8. Other Issues

48. We are fiercely proud of our Mum and want to preserve and protect her legacy.

49. At the conclusion of this Inquiry, we would like to know what's moved on to prevent something like this happening again in the future. To this day, we are furious about the judgement of nurses and healthcare professionals that our Mum endured and would like to see that people suffering with infections such as hepatitis C are treated with respect and with dignity going forward. We would also like people to be held accountable for this scandal. We lost our Mum so young to an infection that she was given. Had Mum been given better holistic 360-degree care, she might have still been here today or at least lived a better life when she was alive. There needs to be a better, joined-together approach in the way that our healthcare system approaches care. Families of patients should also be listened to much more. Lastly, we hope that following this Inquiry, anyone who is still suffering as a consequence of the infected blood scandal receives better all-round care and support and stops being punished for an illness that isn't their fault.

Statement of Truth

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

Signed GRO-C

Dated 25/10/22