Witness Name: Naomi Robinson Statement No: WITN4040001 Exhibits: WITN4040002 - 5

Dated: 30 July 2021

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF NAOMI ROBINSON

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 11 February 2020.

I, Naomi Robinson, will say as follows: -

Section 1. Introduction

- 1. My name is Naomi Robinson. My date of birth is GRO-C 72. I live at GRO-C
 GRO-C 2. I am an Event
 Producer and live with my partner.
- I intend to speak about my late mother, Elaine Robinson, DOB GRO-C
 1944, who passed away on 3 September 2019, aged 74, from pancreatic
 and liver cancer.
- I can confirm that I have chosen not to have legal representation and that the Inquiry Investigator has explained the anonymity process to me. I am not seeking anonymity. I have not been involved in any litigation.

- 4. I can also confirm that the Inquiry Investigator has explained to me the 'Right to Reply' procedure, and that if I am critical of a medical professional or organisation, they will have the right to reply to that criticism.
- 5. I wish to acknowledge that naturally as time passes, memories can fade. I have been able to provide approximate timeframes for matters based on life events. However, these timeframes should be accepted as 'near to' rather than precise dates.
- 6. Blood tests shortly before her death showed that Mum had been infected with Hepatitis C (HCV), which had cleared at some point. The investigator and I have been through my mother's copious medical notes and found a letter, dated 15/07/2019 from Dr A Jackson, Consultant Clinical Oncologist, Royal Hampshire County Hospital Romsey Road, Winchester. SO22 5DG. To Dr Cribb, Alresford Group Surgery, which confirms this.
- 7. He writes: Second para. 'You also tested her at her request for hepatitis as she had a blood transfusion in 1979 after her youngest child was born who she subsequently breastfed and she was concerned over the risk of hepatitis c and transmission to her daughter following reading an article. Her blood tests as you may know suggest that she does have hepatitis c antibody but her hepatitis C RNA/viral load is undetectable suggesting that she has been exposed to hepatitis C virus but has spontaneously cleared it' Para later reads: 'She has never been on(sic) IV drug user and so there is not really any other plausible way she could have been infected with hepatitis C other than the blood transfusion in 1979' I produce this letter as Exhibit WITN4040002.
- This letter confirms my suspicion that Mum contracted the virus via the blood transfusion in 1979 and that chronic Hep C may have contributed to Mum's illness. This can never be proved. This statement focuses on the

- fact that Mum, like many others, was never contacted or offered a test after receiving potentially infected blood.
- My dad, Geoffrey Robinson, and my mother were married for 51 years and have three children and five young grandchildren.
- I intend to discuss the nature of Mum's illness, how it affected her, the treatment received and the impact it had on her and our lives together.

Section 2. How Infected

- I believe Mum contracted Hep C from contaminated blood used during a transfusion at the caesarean birth of my younger sister on GRO-C 1979 at the Royal Hampshire County Hospital.
- 12. There are no hospital records or blood batch records from 1979, but based on Mum's consistently healthy lifestyle, it is unlikely there were any other occasions she was exposed to the virus.
- HCV infections spontaneously clear in 10-15% of people. 80% of infections progress to a chronic stage and can cause liver damage over decades.
- 14. Nothing else in Mum's family history or lifestyle pre-disposed her to liver or pancreatic cancer. Her parents both lived into there 80's and my mum's older sister is still alive. I suspect chronic, undetected HCV may have caused Mum's liver and pancreatic disease.
- Mum was never informed or made aware that she could have received infected blood in 1979.

- 16. Mum first reported feeling ill during October 2018 with classic liver disease symptoms (weight loss, nausea, jaundice, upper GI pain, pale stools, dark urine).
- Throughout the following 9 months until her death, medical teams made no potential connections between Mum's 1979 blood transfusion and her illness.
- 18. Mum asked to be tested for Hep C in June 2019, two months before she died. By this point she was in the final stages of liver cancer. She had read an article that had made her think she may have contracted Hep C during the transfusion during her caesarean in 1979 and she was worried in case she'd passed it on to my younger sister through breastfeeding.
 See Exhibit WITN4040002.
- 19. With hindsight, it surprises me that it was Mum and not the medical teams who made a potential connection between her blood transfusion 40 years earlier and her illness.

Section 3. Other Infections

20. To my knowledge, Mum did not contract any other infections apart from HCV because of receiving contaminated blood, though this wasn't investigated.

Section 4. Consent

- 21. I do not know if Mum consented to a blood transfusion during her caesarean section in 1979.
- 22. I am aware that Mum asked to be tested for HCV in June 2019.

Section 5. Impact

- 23. In October 2018, when she first became ill, Mum was 73 years old. She had recently retired as dyslexia teacher. She had always lived a healthy lifestyle: never smoked and drank little alcohol.
- 24. Mum lived life fully. She enjoyed walking, pilates, cooking, playing the piano, singing in the local choir, going on holiday, cooking. She had just started painting she showed talent and was studying on an art course. Mum volunteered helping underprivileged local families with their children and often visited the local primary school as a volunteer reader.
- 25. Mum was not a 'do-gooder', she was simply a naturally, genuinely, instinctively kind and caring human who treated everyone she met with respect and dignity. She was loved by many. She was also very beautiful. One of my earliest memories is asking Mum if she was an angel. We were very lucky to have known her.
- 26. Mum loved spending time with her three children, five grandchildren, sister, and friends. She was happiest at the heart of her family. Her grandchildren were 10, 8, 6 and 2 when she died. During the last 10 months of her life, Mum saw much less of them. This was partly because she had lowered immunity and felt very weak. I don't think she wanted them to see her looking so ill or to remember her like that. Her grandchildren were very sad about this and struggled to understand why they couldn't see her more.
- 27. In May 2018 Mum had suffered severe bruising and a broken clavicle in a car accident. In the following months Mum and her GP put her aches and pains down to the crash. This may have slowed her cancer diagnosis. In late October and early November 2018 Mum went to see her GP several times with classic and rapidly evolving symptoms of liver disease. Her GP shared Mum's concerns about upper GI cancer and arranged for a '2WW' referral (two weeks) for further investigations.

- 28. Eight weeks after first visiting her GP, Mum was still awaiting a conclusive diagnosis and any treatment plan. During this time, her physical decline was catastrophic. She became increasingly jaundiced, lost weight rapidly and experienced constant pain and nausea.
- 29. A faster diagnosis and treatment plan could have made a big difference to Mum's physical and mental wellbeing. Knowing she'd had Hep C might have also helped the medical teams diagnose her and form an appropriate treatment plan.
- 30. Whilst the wait dragged on and her health deteriorated, Mum worked hard to keep her spirits up. She got up every morning, did her exercises and forced herself to eat, despite the smell and thought of food making her feel very sick.
- 31. Mum was uncomplaining about the lack of diagnosis, treatment plan and communication, though it caused all of us extreme anxiety. We all knew something was badly wrong. Mum had spent her life looking after other people and I don't think she knew how to put herself first and demand attention. I feel angry with myself that I didn't make more noise for her.
- 32. Mum became so ill that she was hospitalised between 14 and 21 December 2018. She ate little and mainly slept. I felt she was dying. She hadn't been communicated any treatment plan, or any conclusive diagnosis, though pancreatic cancer had now been listed on the notes at the foot of her bed.
- 33. Mum had the Whipples procedure on 8 January 2019 to remove the head of the pancreas, the first part of the small intestine (duodenum), the gallbladder and the bile duct.
- 34. She began to recover. She then began chemotherapy. She was very weak from combined stresses of the car crash, her illness and the operation. The chemo took a huge toll. She sometimes had to skip chemo

sessions or receive a lower dose because her white blood cell count was too low. In July 2019 she learned that the cancer had spread, and she died on 3 September 2019. Over the previous year she had suffered so much, with so much dignity.

- 35. It seemed unfair and inexplicable that Mum became so ill so suddenly after having taken such good care of her health throughout her life. We thought her illness was just very bad luck. Throughout her illness Hep C was not on the radar at all.
- 36. If Mum had known decades ago that she (had) had Hep C, she could have kept an eye on her liver and her health over the years. But she was never contacted. She didn't even know there was a possibility she may have been given infected blood.
- 37. This is what makes me feel most angry: at some point a decision was made not to do take the small, potentially life-changing action of contacting potential recipients of infected blood products. Why was this not done?
- 38. Having read other witness statements from the Inquiry, it is heart-breaking to read of the stigma, ill health and emotional fall-out that has wrecked so many lives. By comparison Mum lived a healthy, if too short life until her final year so any impact on our lives together that may have been caused by Hep C was relatively minimal.
- 39. Mum's good health and lifestyle may have minimised the symptoms of liverdamage or enabled it to go undetected until it was too late.
- 40. We will never know for certain if Mum's illness was caused by infected blood or if it played a part in her subsequent illness. But that isn't the issue. The issue is that Mum, like so many others, was never informed that there was a possibility she had been given infected blood and was thus denied the opportunity to seek treatment.

- 41. After my initial meeting with the investigator to discuss Mum's illness I wrote to the Records Officer Royal Hampshire County Hospital. The letter read as follows: My father, Geoff Robinson, and I have still not received any medical records for my mother, Elaine Robinson, following our attached request to RHCH, sent July. There should be records of scans from 2018 and records relating to a blood transfusion in 1979. If there are no records for blood transfusions in 1979, please supply records of plasma deliveries from that time using the batch# and donation date. This is part of the infected Blood Inquiry. My mother received a transfusion at RHCH on 18 October 1979. I produce a copy of this letter as Exhibit WITN4040003.
- 42. In response I received two replies, one letter dated 11th March 2021. Exhibit WITN4040004, and another letter dated 25th March 2021. Exhibit WITN4040005.
- 43. The latter being the more informative. In answer to my questions, this letter states: 'Please note, Hampshire Hospitals is unable to examine your mothers's records to obtain this data under the limitations of the Freedom of Information Act 2000. This allows public access to information held by the Trust regarding its activities as a public authority only. Therefore, personal records are excluded. Furthermore, the Trust follows the record retention schedules as set out in the Records Management Code of Practice for Health and Social Care (2016) As the record is above 25 years, this is not something we are able to provide as they no longer exist'
- 44. Re the Plasma deliveries they responded as follows: 'The Blood Transfusions department must legally retain the fate of all blood components for 30 years. This follows The Blood Safety and Quality Regulations 2005. Therefore, Hampshire Hospitals does not have any relevant records dating back to 1979. Plasma delivery records would also fall into the 30 year category in accordance with guidelines set by the Royal College of Pathologist: The retention and storage of pathological

records and specimens (2015) To conclude, we are unable to provide a response to this request because these records no longer exist'

45. The irony of their response is not lost on me. Had the NHS informed my mother earlier, that there was a possibility that she had received infected blood, she would have been able to gain access to her records. These records would have still existed and we would have been able to identify the relevant batch numbers. Because we didn't know Mum was infected and the time that has since lapsed, all the records have allegedly been destroyed.

Section 6. Treatment/Care/Support

46. Mum didn't know that she had been infected with Hep C until she requested a blood test 40 years after her blood transfusion. At this point she was dying of terminal liver cancer and it was too late for any treatment or support, and none was mentioned.

Section 7. Financial Assistance

47. No financial assistance is required or sought.

Section 8. Other Issues

- 48. I would like the NHS to 'own' its mistakes and the impact these had on so many lives. I would like it to acknowledge responsibility and be held to account, especially regarding the suppression of information, which could have helped victims become aware of and deal with their illness. The Infected Blood Scandal damaged people's health and subsequently robbed them of the opportunity to seek treatment.
- 49. I would like evidence that systems will be implemented to stop anything like this from happening again.

50.	I would like to see full recognition, apologies and compensation for the			
	individuals and families who suffered physical, emotional and financial			
	damage as a result of an infection from contaminated blood products.			

Statement of Truth

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

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	GRO-C	
Signed		