Witness Name: Roseleen Kennedy
Statement No.: WITN2177001
Exhibits: WITN2177002-013
Dated: 17th March 2021

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF ROSELEEN KENNEDY

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 5th November 2018.

I, Roseleen Kennedy, will say as follows: -

Section 1. Introduction

1. My name is Roseleen Kennedy. My date of birth is the GRO-C 1965 and my address is known to the Inquiry. I am employed as a teacher and have been teaching for 32 years. I intend to speak about my mother Eileen O'Hara who was born on the GRO-C 1930 and passed away on the 7th May 2003 from hepatic failure. I will speak in particular about 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 as a family.

Section 2. How Affected

2. My mum was the kindest person, everybody would say it. She'd been used to illness because she'd been ill for a while, so it actually made

her very patient. She was so kind and so gentle and everybody, and I mean everybody, loved her. No matter who they were. That's just the sort of person she was. I have 3 siblings, two sisters and a brother, I'm the oldest. My father was Archie O'Hara. Dad died six months to the day before Mum. My dad died on the 7th November 2002 of lung cancer and my mum died on the 7th May 2003. They got married in 1962 and were married for 40 years.

3. My mum had multiple blood transfusions over the years. Referring to evidence that SNBTS provided to the Penrose Inquiry (PEN0001356) she had a blood transfusion during a caesarean section on the 31st March 1972 receiving two units of blood. She received one unit of blood on the 28th November 1979, and 5 units of red cells on the 5th June 1985 along with a possible unit of plasma. On the 24th July 1991 she received one unit of FFP and on the 16th October 1991 she received 5 units of red cells A detailed summary of the transfusions that Mum received was provided to the Penrose Inquiry as PEN00010032 from SNBTS. She was tested in 1990 and that was a negative test but it was a false negative. It was first generation testing so that's where the false negative came from. It was concluded that she had clearly been infected by 1990 so the fact she tested negative must have been wrong. Penrose concluded that it was likely 1979 when Mum was infected because of the state of her liver. The assessment of her situation in Penrose was that she was either infected in 1972 or 1979 however the evidence tended to give weight to the date of 1979. It was admitted that it was not possible to know the date of infection for sure though,

4. Early in her life, mum developed rheumatic fever, which left her with problems with her heart. This ultimately led to her requiring heart surgery in 1985 at the Royal Infirmary, Glasgow. I am not aware who the surgeon was, but I know that her Cardiac Consultant was Dr Dunn.

The surgery was a heart valve replacement and my mother was given a mitral valve from a pig. To my knowledge there were no complications with the surgery and I know she was given a blood transfusion as part of this surgery, this is not mentioned in the summary of the operation however. I exhibit this as **WITN2177002**. She was in hospital for a short period and made a good recovery.

5. Mum worked part time between 1980 and 1990 as an orderly in the Haematology Department at Stobhill Hospital, Glasgow. She stopped working in 1990 after she turned 60 and soon after she became unwell, breathless and tired. She went to her GP, Dr Davda at Springburn Health Centre, Glasgow, who carried out some blood tests. It was noted then that she had raised LFTs. I exhibit a letter dated the 6th September 1990 as **WITN2177003**. She was going there for several months, and when we spoke she would always talk about how the doctor kept telling her she was drinking. Mum very rarely drank alcohol, only a small glass of wine on very special occasions, which she never finished. She was getting increasingly upset and felt as though she was being treated like an alcoholic. The GP eventually told her there were problems with her liver function tests.

6. Mum was referred by her GP to the Royal Infirmary in relation to her mitral valve operation where she discovered that she needed another heart valve. She went to these appointments on her own. She went to a lot of these appointments by herself because she understood the language they used. She'd been ill since she was a child so she knew what they were telling her. My sister, Annette Macdonald, who is a nurse, went to some of the later appointments with her. She never used words like LFTs when she told us about these appointments, she just kept saying that her liver functions were off. She probably talked about those things with my sister. Around this time she began suffering from

bowel problems as well and was referred to a gastroenterologist, who I understand she only saw once. I exhibit a letter to Dr Davda and Dr Morris dated 5th November 1990 as **WITN2177004** that discusses this and then talks about potential historic blood transfusions and testing for hepatitis.

7. Mum was due to be admitted to hospital for heart surgery in July 1991, but she put this off as I was getting married in October. She ended up being admitted two days after my wedding which would have been 14th October 1991 and had the mitral valve replaced with a metal one. During her admission to hospital, she was in intensive care. My sister Annette recalled that mum was given a blood transfusion.

8. Mum appeared to keep well and recover from this second heart surgery. I gave birth to my daughter in 1992, and my mother looked after her from when I returned to work until June 1995. Mum had to stop caring for my daughter then because she was not keeping well. She had fluid retention in her legs and her abdomen also appeared swollen. She was pale looking and she was very tired and had to have naps in the afternoon. She felt nauseated and lost her appetite, she didn't look jaundiced though. She went to see her GP, who was then Dr Millburn of Springburn Health Centre Glasgow who then referred her onto Stobhill Hospital Glasgow for an ultrasound scan.

9. The ultrasound scan indicated that there was evidence that was suggestive of cirrhosis. I exhibit a letter dated the 19th October 1994 from E H McLaren to Dr Davda as **WITN2177005**. In her next review in March 1995, in a letter from E H McLaren, he advises that she had antibodies for hepatitis C which may have been the cause for her cirrhosis. I exhibit this as **WITN2177006**.

10. After the scan, Dr Millburn informed her that one of the issues they wanted to check was lymphoma. They wanted to do further tests because they thought there were nodes around her liver. I exhibit a letter to Dr Davda from F G Dunn dated the 10th May 1995 as **WITN2177007**. She knew that this was quite serious. We thought it was lymphoma at first just because that's how it was presenting itself. She had a lot of internal bleeding. After thinking it was lymphoma initially, they started talking about her liver, that's where the investigations went after that. Dr Millburn is an absolutely fantastic person. He gave her his mobile number so she could call him anytime, he was brilliant. He had obviously seen her quite a lot and he knew her well. That's the kind of person she was. That he would give her his mobile number to phone him anytime day or night.

11. She was referred to a gastroenterologist and admitted to Stobhill Hospital Glasgow in approximately July 1995 for a liver biopsy and bone marrow test for lymphoma. After testing, she was advised that her bone marrow was normal, but confirmed cirrhosis. I exhibit the findings as **WITN2177008**.

12. I think mum was shocked by her diagnosis, it was the last thing she thought she could have. We were all shocked, we didn't understand it. We started looking into hep C after mum was diagnosed, trying to find out more about it. Mum would read newspapers and cut articles out that she found. With mum, everything she'd had, she'd overcome it. She always thought, I've got this now, what do I do to keep myself healthy? What do I do to make this better? Having had so many illnesses, that was just her attitude. She immediately changed her diet. She did everything you possibly could do to keep herself healthy.

13. She really struggled with the swelling/fluid around her stomach it was really uncomfortable, she couldn't wear her usual style of clothes, she

couldn't wear anything unless it was elasticated at the waist or loose fitting. That was hard for her because she was quite glam and she couldn't wear anything like she did before. She was quite thin before and this swelling developed over time, it was painful for her. Her stomach stretched because of it.

14. When my mum and my sister found out about her results she wasn't given any information, not even a leaflet. I didn't see a leaflet until I was at the Penrose Inquiry. It was like they were saying you've got it, deal with it. It's not that my mum and sister didn't ask questions or ask the right questions. They had both worked in hospitals so they knew what to ask. The only thing my mum told was to talk to her GP and even he didn't know much about it. My sister did some research for her, that's how we got our information. We got nothing, not a single bit of information from the hospital. Nobody told her it could have been from a blood transfusion. We had to do our own digging, that's when all the stories were coming out about American prisoners being the source of some of the blood. At that time those stories were everywhere. She got all of her information from news reports and newspapers and latterly the internet, she was looking for anything that would help her.

15. My sister Annette was working in Stobhill Hospital, Glasgow as a nurse at this time and she asked to speak to my mother's doctor. The doctor told my sister that as well as the cirrhosis of the liver, my mother had hepatitis C. My sister asked the doctor if the hepatitis C had caused cirrhosis of the liver and the doctor said that it was a possibility that she had contracted hepatitis C from a blood transfusion. My sister was present when the doctor gave Mum her diagnosis. The doctor played down the hepatitis C and gave the impression that it was a common infection. It came as a relief to us, because at the time we knew nothing about hepatitis C and our fears had been focused around the possibility that Mum had developed lymphoma. My mother was not advised by the

doctor to be careful about passing on the virus and not warned at all about secondary infections. Even though she was on Warfarin for her blood, which made her more at risk from bleeding. She was not offered any support or further information, not even a leaflet. As family members, no one ever made contact to suggest that we should be tested for hepatitis C. Not even my dad or my sister Annette who lived in the same household as my mum. It was not until after Mum's death that I approached my own GP to ask for a hepatitis C test. At no point were we made aware of any services or support for families.

16. The doctor my sister Annette had initially spoken to suggested that she phone the Scottish National Blood Transfusion Service, which she did. A female doctor from the SNBTS told her that there was nothing they could do as my mother had been given the blood in good faith. "Given in good faith" was a phrase that came up a lot. It was like they were saying it saved your life at the time, it has repercussions now, but we didn't know that, end of discussion. The SNBTS were pretty rubbish, they were only interested in covering it up. She also said that because my mother had cirrhosis of the liver there was no treatment that would be effective. This call probably took place in 1995.

Section 3. Other Infections

17. I'm not sure she was ever tested for other infections other than hepatitis C.

Section 4. Consent

18. It's possible that when they took blood from her that they didn't tell her what they were doing. At that time, no one really knew what hepatitis C

was, outside of what you hear about drug addicts. I feel that if they'd asked to take her blood that she would have said yes.

19. Mum was never told about there being a risk of infection from her blood transfusions. She would have agreed to have the transfusion, but she wasn't given full information about the risks involving hepatitis C at that point.

20. I don't know if mum was ever part of any testing or treatment for research but she was certainly never asked.

Section 5. Impact

21. Mum asked about possible treatment for hepatitis C at every medical appointment she attended. Every time mum asked about treatment she was told that there was no treatment they could offer her as she already had cirrhosis of the liver. I exhibit a letter dated July 1996 as **WITN2177009**, a letter dated November 1996 as **WITN2177010** and a letter dated February 1997 which I exhibit as **WITN2177011** to illustrate she was consistently deemed as being an inappropriate candidate for treatment. She always asked about where she got hepatitis C from and eventually doctors started saying that it was likely that she got it from a blood transfusion in 1985.

22. From the time my mother was told she had hepatitis C until she died she asked every medical person she saw about treatment for the hepatitis C and she was always told she wasn't suitable for treatment.

23. Mum always coped well with ill health and always did as the doctors said and advised, but she found having hepatitis C very difficult. Mum hated having "hepatitis C risk" stamped on the front of her medical

notes, she was embarrassed about it. She knew that hepatitis C was an infection which was generally associated with drug addicts. Having worked in Stobhill Hospital herself, she knew a lot of people who were working there and was worried they might find out about her hepatitis C status. She felt this should have been inside her medical notes and not on the front so that people who weren't caring for her could not see.

24. The only clinics which mum attended were the Warfarin Clinic (she had been on Warfarin from the second heart operation), the Diabetic Clinic (she had been insulin dependent for a number of years prior to her death) and Dr Dunn's yearly cardiac clinic yearly. I noted she developed diabetes in 1990 which I understand can be linked to hepatitis C. I exhibit a letter dated 10th May 1990 as **WITN2177012.** She was never referred to any specialist in relation to her hepatitis C and was not referred to a liver consultant. She also attended her GP when she wasn't feeling well. Even though she was injecting herself with insulin twice daily, she was never given any type of special bin or special uplift for needle disposal. It was ultimately my sister Annette (and not the NHS) who warned the family not to use the same nail clippers, tweezers, pierced earrings, etc. as mum due to the risk of hepatitis C transmission. After we found that out my mum started using separate bathrooms, separate everything. It changed things for her. My sisters and I were always round at mum's trying on her earrings and plucking her eyebrows to cheer her up but all that had to stop.

25. From 1995 onwards mum's symptoms worsened. She was tired, weak, had a very pale pallor and a thin face. She also had symptoms of fluid retention and oedema in her legs and around her waist. She always dressed well and hated having to buy elasticated trousers and skirts to fit around her abdomen. She just slowly deteriorated. This

said, she was never depressed and still managed to walk around the town, although she was unable to carry things.

26. At that time my dad was diagnosed with a condition related to being exposed to asbestos from working in the ship yards in Clydebank. So during this time he was deteriorating as well. It was very difficult for him but he couldn't really help mum. At that time his health was worse than my mum's, there was nothing he could do.

27. My brother and sister and I did whatever we could to help. We were up to their house all the time, helped them get to hospital appointments and stayed over whenever they needed. My sister Annette had the biggest burden because she was a nurse, she could do more than us.

28. My sister Annette left home in May 2001 and my father was diagnosed with cancer in February 2002. He passed away on the 7th of November 2002. Mum was looking after my dad with support from the family. My other sister came back from England for the last three months of my dad's life to help out. Following my dad's death we never left my mother alone again.

29. My brother was getting married in April 2003 and my mother was planning on going to the hen night in March. However, in March she became very unwell. She had abdominal pain and was vomiting. Her GP carried out some tests and informed her that she had pancreatitis. She was admitted to Stobhill Hospital, Glasgow two days later and investigations were carried out as she was thought to have gallstones which were blocking the bile duct. A tube was put down her throat in an attempt to remove the stones but this was unsuccessful. When we arrived that evening for visiting we were very surprised and upset to

see Mum being taken from the ward to the High Dependency Unit. Her temperature had risen so high that it was causing great concern. I was later told that during this procedure an area near the bile duct had been "nicked" by a surgical instrument causing infection and her temperature to rise. Her liver then failed. She was moved to the High Dependency Unit. After a week or so she had recovered enough to be moved back to the ward. She even managed to get out for a few hours to attend my brother's wedding. My sister Annette and another friend of hers, who was a nurse, helped her with this. She had to have a lot of help but she went to the wedding and the reception. She had a photo taken of her with my brother and his wife and someone went and got the photo developed so she could take it back to the hospital with her.

30. However, a few days after this we arrived for visiting to once again find my mother very unwell. Her condition had deteriorated and she went into organ failure and never recovered. She was transferred to coronary care as it was felt the cardiologists should take over her care due to her past heart surgeries. The cardiologist came in to see her and said he wanted to move her to cardiology because he had a nice wee room for her on the ward. He was giving her a nice place to die. Where she was in cardiology was much nicer than in the ICU. They were able to set it up so that she had her own private space. She died on 7 May 2003. I exhibit a letter dated 9th May 2003 discussing the events that led to her death as **WITN2177013.** Ironically the cardiologist said at this time that her heart valve was working fine, it was her liver that was the main problem. I cannot recall the name of the doctor whose care she was under, however after speaking with my sister Annette, she recalls that it was Dr Goodfield.

31. My family are all very close, we see each other all the time. Losing my

mum left a big gap in the family. It was very difficult for the family losing her, everyone was so close to her. She was so wise and kind, she was good in every situation.

32. The night my mum died I was told to come to the ward the next day to collect the death certificate and that Dr Mark Petrie, would complete the death certificate and talk to me about it. My sister Annette told me to make sure they put hepatitis C as the secondary cause of death. When I got there the death certificate was already done. I asked the nurse why only "hepatic failure" and not hepatitis C was on the death certificate. She told me that that the doctor who had completed the death certificate wasn't available. Looking back, I wish I had pushed for hepatitis C to be on there. I know my mum's death was caused by hepatitis C but her death certificate doesn't say that. If Annette had been there she would have stood there until someone rewrote it. The staff had all been so good with us, I didn't want to argue with people who'd been nothing but nice to me.

33. Although my mother was regarded as a hepatitis C risk, few precautions seemed to have been taken in regards to cross-contamination. There was one day that was really scary where my sister had to go into the bathroom of my mum's room in hospital and mop up all the pools of blood coming out of her. My mother ended up lying in a hospital bed or sitting in a chair with her legs leaking fluid containing blood onto a blanket and incontinence pads. She was warning us not to touch the blanket. There was no attempt to alert visitors or other health service workers to the risks of cross-contamination and ultimately my sister Annette had to explain to the nurses that it wasn't safe.

34. Mum took the job as an orderly between the ages of 50 and 60

because she liked it. She liked the people and spoke to everyone. She worked in haematology taking blood from the blood bank to where it was needed. The walking involved in that role though made her exhausted. The last five years before she retired she was absolutely exhausted after work. She only worked 15 hours a week which was 5 hours over 3 evenings.

35. As mum already had a pre-existing heart condition, she couldn't get good life insurance. She had to get the insurance you see on TV, where they'll take anyone. The life insurance aspect can be a massive thing for some people who die from hepatitis C but that wasn't the case for my mum.

Section 6. Treatment/Care/Support

36. Mum was constantly asking about treatment options. There was no support offered by community nurses or social services. Nothing was offered, It didn't seem like it was an option she had. All the support she got came from the family.

37. Mum was not offered any counselling or psychological support. It if was offered, she would have taken it. She would have done anything that would have helped. When she was in diabetic clinic they gave her a diet plan to follow and she followed it exactly, that's just how she was. She did anything and everything, she was always looking for help and support.

Section 7. Financial Assistance

38. We found out about the Skipton Fund through their website. We initially missed the cut off date for the Skipton Fund but it was later backdated.

It used to be that a candidate had to have died after August 2003 and mum died in May 2003, but they changed that rule so were able to get £50,000 from the fund.

39. I don't remember it being difficult to apply to the Skipton Fund when we found out we could get the backdated payment. It was reasonably straight forward because we had a lot of evidence.

40. I've not heard about SIBSS, we didn't know that was an option this is new information I am being informed about now.

41. For us, the amount we received was more than adequate but I know that's not the same for everyone that was infected.

Section 8. Other Issues

42. I think the attitude of a lot of doctors was very dismissive. It was like they were saying you're lucky to be alive, what are you moaning about? I don't think that SNBTS were very forthcoming, they were very protective of their information. Even just the issue of tracing the source of the infection, they had no idea where the blood had come from. Even hearing that the blood had come from prisoners, things like that made my mum really upset. And it was a doctor that told her that in the early 90s before all those stories really came out in the media. I know that some of those stories are nonsense but I didn't know that at the time. It was a dangerous thing for my mum to be told. I think even when my mum had the blood platelets they knew it could be a risk. It was so concentrated and from so many different sources. I am extremely angry that SNBTS did not heat treat the blood they used until a year after England had started doing it, which put people at risk.

Statement of Truth

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

Signed GRO-C
Roseleen Kennefy (May 3, 2021 08:39 GMT+1)

Dated May 3, 2021

[redacted]