Witness Name: Sandra McKay
Statement No.: WITN3707001
Dated: 7/2/2020

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF SANDRA MCKAY

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 22 August 2019.

I, Sandra McKay, will say as follows: -

Section 1. Introduction

1. My name is Sandra McKay. My date of birth is GRO-C 1955 and my address is known to the Inquiry. I am a foster carer and retired podiatrist. I live near Glasgow. I am divorced from my husband and we have two children. I intend to speak about my father, Alex McArthur, who contracted Hepatitis C following a kidney transplant. In particular, the nature of his illness, how the illness affected him, the treatment received and the impact it had on him and our lives together.

2. I can confirm that I am not legally represented and I do not require access to the anonymity process. I am the eldest of three children of Alec and Mary McArthur. I am aware that both my younger sister Janis Dickson (See WITN3626001) and brother Stephen McArthur (See WITN3757001) have provided statements to the Inquiry.

Section 2. How Affected

3. My father died in August 2001 aged 69. His death certificate states that the cause of death was Myelofibrosis, a form of bone marrow cancer, renal failure, Gastro Oesophageal Haemorrhage and Hepatitis C.

4. Dad was diagnosed with Hepatitis C in 1992. Eight years earlier, in 1984, he received a kidney transplant, and my family and I believe that either the transplant organ itself or a blood transfusion that he received during the operation was the source of the Hepatitis C infection.

5. Dad first began experiencing lethargy and other symptoms in 1977 and doctors were not able to diagnose the cause. In early 1984 he became unwell again, I remember him being exhausted all the time. In April the doctors informed Dad that his kidneys had failed.

6. Over the summer of that year doctors conducted various tests and tissue typing but didn't find anything abnormal about his blood. Dad was put on the transplant list in around August or September 1984 and shortly afterwards, in October, a kidney became available. The day of the operation GRO-C That's why I remember it so well. GRO-C Dad had the transplant and I wasn't allowed to visit him at first GRO-C GRO-C

7. As far as I am aware, Dad was never informed of any risk of infection from the kidney transplant or any blood transfusion that may be associated with it.

8. Dad had to take immunosuppressant drugs. Prior to that and the transplant he began Continuous Ambulatory Peritoneal Dialysis, which he could do at home. At first, he got his energy back and returned to work after a period of recuperation. He worked for an insurance company inspecting goods that were being exported, which meant that

he travelled to different sites each day rather than working out of an office.

9. After his initial improvement Dad started going downhill. He was very fatigued and started suffering with joint pain. The doctors looked into it and at first, they thought he might have had leukaemia. Various tests were conducted, including blood tests. He was never specifically told he was being tested for hepatitis.

10. He was diagnosed with Hepatitis C in 1992. I recall that he was told that it wasn't very serious, that he shouldn't worry too much about it. Mum was told that there was no danger of her catching it as it wasn't possible to pass it on. Very little useful information was supplied either about how to manage the infection or what to do to keep our family safe. We simply weren't told we needed to take any precautions.

11. Much later on I saw Dad's medical records when they were obtained by our solicitors, and they stated that doctors knew that Dad had Hepatitis C in 1990, fully two years before he was told! This was never discussed with him. Why? Who makes that type of decision? He may have been able to adjust his lifestyle or do something medically to fight the infection and that may have prolonged his life

12. As far as I know, Dad was never informed of the source of the Hepatitis C infection. He never had any major operations prior to the kidney transplant. He didn't have any tattoos and he wasn't an intravenous drug user. He was very happily married, he was a church elder and only drank alcohol on rare occasions. The only possible answer was that he contracted it through the kidney transplant or through a blood transfusion during that operation.

13. Shortly after having the transplant Dad saw something on the television or in the paper about infected blood, and I recall him he saying he hoped he hadn't had the 'the bad blood from America'. How ironic as Mum later

told us that he had received a blood transfusion during the transplant containing blood from that was sourced from America.

14. Our family members were never tested for Hepatitis C. The offer was never made but surely it should have been, at least for mum. She was only tested years later when she was looking after one of her grandchildren, GRO-C Mum was concerned that if she had Hepatitis C GRO-C GRO-C. Mum had to arrange all that by herself.

Section 3. Other Infections

15. As far as I know Dad didn't receive any infection other than Hepatitis C. I don't know if he was tested for HIV. I don't know what effect the HCV had on his kidneys and the medicines he took in later life but it can't have helped.

Section 4. Consent

16. I believe that Dad was tested for Hepatitis C without his knowledge or consent, as I understand his medical records show that he tested positive two years before he was informed. As far as I am aware he did not know that he was being tested for Hepatitis C in the blood test that led to his diagnosis.

Section 5. Impact

17. Dad never spoke to us in much detail about his illnesses, or about doctors' appointments and things like that. He mostly kept things to himself. I think that he told Mum some of it, but not all of it.

18. As far as I am aware Dad was never offered any treatment for Hepatitis C. I believe that at the time there was nothing available. I

don't recall if there was every any testing or monitoring relating to his liver. He did have an enlarged spleen, in fact I recall mum saying that one of the doctors said it was the largest in the West of Scotland. He was treated primarily at the Western Infirmary, at the renal unit, and later also went to Southern General in Glasgow for treatment for the skin lesions he developed.

19. From the early 1990s onwards, Dad became fatigued and frail. He gradually lost the strength in his legs and feet and suffered from peripheral neuropathy, the loss of sensation in his hands and feet. He felt the cold really badly and had repeated bouts of gout, something which was a new condition that had never affected him before. He began to develop skins lesions which were painful and unsightly. Some of them had to be removed, including one from the top of his head which required a skin graft from his thigh.

20. Dad developed Myelofibrosis in around 1995, possibly as a consequence of the immunosuppressant drugs he took following the kidney transplant. From that point he began to receive regular blood transfusions. At first, he was able to drive himself to the hospital but eventually he became too weak to drive so my siblings and I would take him.

21. Dad stopped working when he was around 65, at about the same time he stopped driving. Mum couldn't drive so Dad used to drive her everywhere. Before he stopped driving, he used to take her to the shops and then sleep in the car while she was shopping because he always so tired. He would wear a big sheepskin jacket and a hat because he was so cold. On one occasion, when he was sleeping in the car, a passer-by was worried that he had passed away in his sleep, and the police were about to break the car window when he woke up.

22. My parents used to go on holiday every year and stay in a caravan but Dad became too unwell to do this. He couldn't get travel insurance,

and because of this and his poor health they also had to stop travelling to France, where my Mum's sister lived, so Mum could no longer visit her.

23. Over time Dad lost his social life. He was a football referee and played golf and tennis and he was on the community council. He was heavily involved in the church, he was church elder and a Sunday school superintendent. All of that was curtailed when he lost the energy to participate; at the end he couldn't even attend church services. I don't believe the fact that Dad had Hepatitis C caused him to lose any friendships, but he wouldn't have told us even if it had. He was a very sociable person and it would have hurt him inside having to give up what had been a very active way of life. His deterioration was also a big loss to the local community.

24. From around a year before his death Dad was essentially confined to his bed. The house that my parents were living at the time was two levels, with the living room and bathroom downstairs and the bedrooms upstairs, so a bed was moved into the living room for Dad.

25. Mum nursed Dad herself, she didn't have help from a nurse or any other agency other than early on when Dad began dialysis. At one stage, when Mum had to go into hospital to have varicose veins removed, my sister Janis took over Dad's care. That is the way my Mum wanted it.

26. Mum didn't like leaving the house for too long and wouldn't leave at all unless someone was with him. Dad couldn't get up by himself to get to the bathroom. My father-in-law used to go and sit with him so Mum could go shopping.

27. Dad was back and forward to the hospital all the time, which meant a lot of driving for all of us. There was a petrol shortage at that time and I remember I never used to let my tank get below half full in case I had to rush to the hospital.

28. In the last few days of his life Dad was admitted to the Western Infirmary and in my opinion the standard of care was poor. One instance related to his medication. He was lying flat on his back in bed and the nurses wouldn't give him a straw so that he could drink his medication, which would start to solidify if wasn't taken straight away. He couldn't sit up to take it and got no help from them so why couldn't they provide a straw. Once it solidified it lost potency.

29. On one occasion Dad was put in a special hoist so that he could be moved from the bed. It should have been operated by two people but a nurse was operating it alone and Dad was dropped onto the concrete floor. Luckily, he wasn't too badly hurt.

30. Dad was then put into a single room and by this stage he was skin and bones and had sores that were constantly weeping blood. He was being given continual blood transfusion and the bed linen was often saturated with blood. One nurse came into to clean it up and didn't wear a gown or gloves, I was shocked that she wasn't conscious of the risk of infection, not just to herself but to other patients. When another nurse came in who was wearing the protective clothing, we asked if that was the normal practice and she said yes. Later, Mum put in a complaint to the hospital. They replied and apologised, and said the staff would be reminded about proper processes. But isn't that what they are taught in the first place?

31. On the day he died, we could hear a group of nurses outside the room celebrating one of their 21st birthdays. Apparently, it was a tradition that when a nurse turned 21 she would be thrown into a bath of cold water. It was quite raucous and it was hard for us to hear these celebrations while we were with Dad, bearing in mind his state at the time.

32. The day Dad died mum got a phone call about 12 noon and we went up to the hospital and stayed there all afternoon and into the evening.

In the early evening, my siblings left and I went about half past nine. Mum stayed, and a minister came to visit Dad. Not long after the minister's visit, a nurse came into the room and said to Mum, "I think he's gone" – Mum hadn't realised. The staff asked if Mum wanted to phone us to come back and she said that she'd call us in the morning. The staff said that if we didn't come tonight we wouldn't see Dad, he would be zipped up in a bag and sealed in a coffin because of the risk of infection. Mum didn't want us to come back again that night, so that was it. Later Dad was cremated, which had been his instruction.

33. I remember just before Dad died Mum was crying because she knew she would have to move as the house was on top of a hill and it wasn't practical to stay there in dad's condition. Dad couldn't get life insurance or any insurance on their mortgage, so eventually Mum had to sell the house because she couldn't make the payments. Dad had money saved up for his funeral because he couldn't get a policy to cover it.

34. Dad's grandchildren can only remember him being unwell. They don't remember him being a 'proper' grandfather, they missed the experiences that other children have. They just remember him sleeping in the bed in the living room. They also missed out on quality time spent with their grandmother too. Mum used to come over to my house every Wednesday to see my sons, but over time her visits got shorter and shorter because she was so worried about getting home to Dad.

35. Looking back, in his last two years, Dad had no quality of life and neither did Mum. He would sometimes shout at Mum and blame her for his situation and then get really upset because he knew it wasn't her fault. It was just the pure frustration of his situation. He should have been in the prime of his life having had the good fortune of the transplant yet here he was just as badly off as before.

36. Mum effectively lost her reason to live after Dad died. Her life had been taken up by caring for him and now there was nothing. She was sleeping all day and staying awake all night. There were two things that saved her. She started babysitting one of her grandchildren during the day, which was a really good thing for her. And a family friend started a new job in Glasgow and moved in with her, which meant there was someone home every night cooking dinner. Together these gave her purpose and possibly the feeling of being needed again and it took the pressure off the rest of the family.

37. Mum started taking anti-depressants shortly before Dad died, as a result of his illness rather than anything else, and she was on them until was around month before she died in 2019, almost 20 years. After her death we found discovered some books she had on depression, she had kept them in paper covers so we wouldn't realise. As far as I am aware she never used such medication in her earlier life.

38. Dad was about the age I am now when he became bedridden. His life was either lying in bed or going to the hospital. It's so hard for me to imagine that kind of life at this age when you should have so much to look forward to.

Section 6. Treatment/Care/Support

39. When Dad had his skin lesions treated or went to the dental hospital he was always the last patient of the day.

40. I know Dad was frustrated by the way he was dealt with by the staff who looked after his skin lesions, because the same thing would happen again and again. He would be asked to come in first thing in the morning, but then, when the staff looked through his notes and saw he had Hepatitis C they would tell him he'd have to wait until the end of the day, because they had to do a deep clean of the equipment. He told them to

put the information on the front of this file so it wouldn't keep happening, but they said they couldn't for privacy reasons. This really upset him.

41. Removal of the lesions was always painful because Dad could only be given a limited amount of anaesthetic, I'm not sure if this was due to the Hepatitis C, his kidney or the immunosuppressant drugs he took.

42. No one in my family was offered counselling or psychological support during Dad's illness or after his death. He was certainly never offered any counselling at the time of his diagnosis. Mum eventually sought psychological treatment of her own after Das passing.

Section 7. Financial Assistance

43. I don't know if Mum applied to the Skipton Fund or any other assistance fund. If she did, she didn't receive any payments.

Section 8. Other Issues

44. I don't blame the NHS as a whole for what happened, there was a group of people somewhere who were making the decisions that led to people contracting Hepatitis C and HIV. I don't want to tar the whole service with the same brush because they've also done a lot of good.

45. I think that even at the time of Dad's transplant in 1984 I was aware that there were concerns about the safety of blood transfusions. After the birth of my son a few days after Dad's operation I was anaemic and the doctors were considering a blood transfusion. I remember thinking I didn't want one because there was something at the back of my mind telling me there was a danger attached to it.

46. In around 2003, Mum was represented by Thompsons Solicitors as part of a judicial review relating to tainted blood transfusions. She had to sign a form stating that she wasn't seeking compensation and I

didn't think that was right, because she was entitled to it. Nothing came of it and I recall that they decided to go ahead with another family who had a better chance of success. It was during this period that I saw my father's medical records which had been obtained by Thompsons and to which I referred earlier in this statement.

47. I have signed a consent form for the use of my statement and I am aware that this will only be submitted once my written statement is signed and completed.

Statement of Truth

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

Signed GRO-C

Dated 7/2/2020