Witness Name: Janis Dickson
Statement No.: WITN3626001
Exhibits; WITN3621002-4
Dated: 9.12.2019

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF JANIS DICKSON

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 07 August 2019.

I, Janis Dickson, will say as follows: -

Section 1. Introduction

1. My name is Janis Dickson. My date of birth is GRO-C 1957 and my address is known to the Inquiry. I am a retired teacher. I live near Glasgow with my husband and we have two children. I intend to speak about my father, Alexander 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.

Section 2. How Affected

2. I am the middle of three children of Alex and Mary McArthur. I have one older sister, Sandra McKay (WITN3707001) and one younger brother,

Stephen McArthur (WITN3757001), both of whom have also given statements to the Inquiry.

3. My father died in August 2000 aged 69. His death certificate states that his cause of death was gastro oesophageal haemorrhage, myelofibrosis, a form of bone marrow cancer, renal failure and Hepatitis C. (See Exhibit WITN3626002).

4. Dad was diagnosed with Hepatitis C in 1992. Eight years earlier, in 1984, he received a kidney transplant, and my family believe that either the transplant 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. Then, in around February 1984, he became ill again and was always incredibly tired. At this time, my sister Sandra was married, but my brother Stephen and I were both living at home and I was recovering from a burst appendix. I remember that Dad would come home from work and fall asleep on the couch. I used to tease him for going straight to sleep and not offering to make me tea.

6. In April 1984 the doctors informed Dad that his kidneys had failed. One of his kidneys had stopped working in around 1977, although this had not been identified at the time, and now his second kidney had stopped working properly.

7. Dad had health insurance through his work and had been referred to a private hospital by his GP. The doctors said that there was nothing they could do. He was sent home to die. Four days later, after a visit from his GP, he was taken to the Western Infirmary and received dialysis. He was put on the transplant list in September and received dialysis from April until October.

8. In October a kidney became available. I received a phone call from Mum at around 7am in the morning with the news that one might be available. They were doing tests all day and it wasn't until 7pm that the operation went ahead. My sister Sandra gave birth to her first son GRO-C GRO-C

9. Although I do not know for certain that Dad received a blood transfusion during the operation, I believe it is highly likely. As far as I am aware, Dad was never informed of any risk of infection from the kidney transplant or a blood transfusion.

10. In fact, we were told by mum that dad had been reassured often that he was lucky and was receiving the good blood from America.

11. After the transplant, Dad got his energy back and returned to work. 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.

12. Dad had to take immunosuppressant drugs and did have a few minor infections over the next few years, which I believe is common. The biggest change was that he suddenly developed a sweet tooth, which he had never had before.

13. In 1992, Mum told me that Dad had been told that he had Hepatitis C, which was a really serious illness that couldn't be cured, and he was going to die. This was the second time that our family was told my father was going to die. Mum told me this when we were in the queue at the supermarket. I think she chose to tell me that then in public so that I wouldn't cry and she wouldn't cry.

14. I know that Dad was asked about how he might have contracted Hepatitis C. He had never had any major operations prior to the kidney transplant. Nor after, certainly up until the final years of his life, although I am aware that he had blood transfusions relating to his mylo-fibrosis from about the mid-nineties onward. He didn't have any tattoos and he

wasn't an intravenous drug user. He was very happily married, he was a church elder. He had all these questions put to him and I recall that he was really offended by them. They questioned my mother too although never offered to test her.

15. As far as I know, Dad was never informed of the source of the Hepatitis C infection. The only possible answer was that he contracted it through the kidney transplant or through a blood transfusion during the transplant operation.

16. My sister Sandra later saw in Dad's medical records that the doctors knew he had Hepatitis C in 1990, two years before they told him. The doctors never discussed this with him.

17. Our family wasn't given much information about the risk of transmitting Hepatitis C. We knew not to touch blood and bodily fluids for example, but not that we should have used separate towels and things like that. Mum would have told me if she and Dad had been told of any other precautions. As far as I am aware they were giving no information on how to manage the disease or what to expect but simply left to get on with it.

18. We were never tested for Hepatitis C. Mum was only tested after Dad died; she was negative. She had been looking after one of her grandchildren, GRO-C and Mum was frantic that if she had Hepatitis C GRO-C GRO-C

Section 3. Other Infections

19. 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, but I feel he must have been since he was tested for Hepatitis C. I do not believe that he suffered from any other illnesses that infection with HCV may have contributed to.

Section 4. Consent

20. 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.

Section 5. Impact

21. Dad didn't talk to us very much about the nature of his illnesses, his doctors' appointments or the medical advice he received, he tended to keep those things to himself. He most likely attended the majority of the appointments on his own and he would not have wanted to worry us.

22. As far as I am aware Dad never received any treatment for Hepatitis C. I understand that he was told that there was nothing that could be done. That is why mum told us he was expected to die. He spent a lot of time in hospital but I think that was more to do with his kidney than monitoring the Hepatitis C. I don't know if Dad ever had any investigations or monitoring relating to his liver. He was treated primarily at the Western Infirmary, at the renal unit, and later also went to Southern General for the skin lesions he developed in his final years.

23. While Dad's diagnosis wasn't something that we broadcast, I told some of my friends and I'm sure that my siblings did too. The infection was something that had been done to him so there wasn't any sense of shame about it, and it never caused us any problems socially. In any case, not that many people were even aware of Hepatitis C.

24. I remember that when I was attending a teacher training day there was a discussion about whether schools should be informed if a student had AIDs or HIV. I said that they shouldn't, there wasn't any need to

know because they shouldn't be treated differently, if any child was cut or bleeding the teacher should be taking the same precautions for all.

25. From the early 1990s onwards, Dad would become very puffy with water retention, and then very thin and fragile, and this pattern would repeat. He began to develop skins lesions, some of which had to be removed, including one from the top of his head which required a skin graft from his thigh.

26. 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 this was a few times a month, then fortnightly, then weekly. He started out driving himself to the hospital for the transfusions but soon he became too weak, and the family took over.

27. Dad continued working until he was around 65. I don't know if he informed his employer about the fact that he had Hepatitis C, he would travel to a different site each day so he wasn't in the position of someone working in an office. His work wasn't physically demanding and he started to scale it back towards retirement but I remember him still being drained when he returned.

28. Dad couldn't get travel insurance, and because of this and his poor health my parents had to stop travelling to France, which they used to do regularly to visit my mother's sister and her family. This was difficult for Mum as it reduced her contact with that side of the family.

29. 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. Mum nursed Dad herself, I don't think she was ever offered help from a visiting

nurse or another service. My siblings and I were working and had small children but helped as much as we could.

30. At one stage Mum had to go into hospital to have varicose veins removed, and I took over Dad's care during that period. He would often bleed and I was careful about washing his bedding.

31. In his last few days, Dad developed very low blood pressure and low potassium levels and was admitted to the Western Infirmary. At first, he was in a ward of four people, and the standard of care was very poor. For example, Dad's medication was a liquid which would solidify if it wasn't taken immediately. He was lying flat on his back and the nurses would just leave the medication for him without providing a straw, so it was almost impossible for him to drink it. None of the nurses tried to administer the medication whilst it was in a useable state.

32. Another man in the ward who was also on dialysis needed to have the plastic dialysate bags warmed up for him, and the nurses didn't do this. The man's wife was too scared to complain.

33. I was at work one day when I got a message that I had to get the hospital. By that time Dad was in a single room. I could see that he was leaking blood and the nurses weren't cleaning it properly, and if they did they weren't wearing gloves and protective clothing. Later, Mum put in a complaint to the hospital. They replied and apologised, and said the staff would be reminded about proper processes. Mum responded asking why they needed to be reminded to do their jobs.

34. During dad's last few HOURS, 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 hard for us to hear these celebrations while we were with Dad seeing the state he was in and knowing he was nearing death.

35. Dad died shortly after a visit from a minister who was a friend of the family. We weren't allowed to see his body following his death, the only reason we were given was the infection. When we saw the coffin it was sealed, and Dad was cremated which had been his instruction.

36. Mum fell apart a bit after Dad's death. It was very hard on her to watch Dad decline. They were very close and spent all their time together, and they had a great social and family life. Afterward, she sought psychological treatment and I believe she took anti-depressants. Later, when we were cleaning her house following her death, we found a whole lot of books on depression and self-help; she had put paper over the covers so we wouldn't know about them.

37. Dad had always dealt with the family finances, so that was something Mum had to take on. He had bought a former council house in the 1990s because he was concerned Mum wouldn't be able to pay rent when he died. Unfortunately, he was unable to get insurance to cover the mortgage because of his illness, so Mum still had to pay it. She later sold that house in order to be free of a mortgage and to create better financial stability for herself.

38. Dad was ill for a very long time and never really had the energy to play with his grandchildren. This was very hard for me to see as he was very family oriented and when my siblings and I were growing up he was a very hand-on dad would always play with us and take us on trips. As a result, my children don't have much memory of him, whereas they remember my husband's father who died in 1999, because he was able to play with them. The memories they do have are negative, about Dad being hospital or in bed at home.

39. What happened to Dad felt so unfair. Dad's brother lived into his 80s and so did his father, so he could have expected another 20 years. Mum died in 2019 aged 86. They should have had the chance to enjoy their retirement and their grandchildren. Dad didn't even get to meet his

last grandchild. He had to plan for Mum's future without him. When he had the kidney transplant it felt like a gift, and then when he contracted the HCV, it felt like it was all cruelly snatched away.

Section 6. Treatment/Care/Support

40. There were a number of occasions when Dad had difficulty obtaining treatment. For example, he developed the skin lesions and because of the Hepatitis C, he would be the last patient of the day.

41. I remember one occasion when I drove dad to an early appointment. After checking in he was called back to the reception desk and I witnessed him being told; "You can't go first because you have Hep C and the theatre will have to be thoroughly cleaned after you. You need to go last." While Dad was normally a very patient man he was very frustrated by this. He told the man to use a felt pen and write on the front of his file "Hep C" in large letters to stop this happening again. Dad said "I know I've got it, you know I've got it, the hospital gave it to me!" The man told dad he couldn't write "Hep C" on the front of his file because of reasons of privacy. This incident took place in a busy waiting room. We then had to wait several hours for dad to be seen. Dad had actually been given this early appointment by the hospital.

42. Things like this happened quite regularly. I rarely saw my Dad cry, but he was on occasion moved to tears about the way he was treated.

43. No one in my family was offered counselling or psychological support during Dad's illness or after his death. Nothing was offered direct to my father when he was diagnosed. Mum did seek some psychological treatment after Dad died, at her own initiative, so I'm sure she would have accepted support if it was offered.

Section 7. Financial Assistance

44. I feel that the way things were reported in Scotland was that compared to the rest of UK, everyone in Scotland who was impacted by infected blood received money, which wasn't the case – we didn't receive anything.

45. Mum made an application to the Skipton Fund but she didn't receive any money. Things were hard for my mother and father after the illness struck him down not helped by the many trips to different hospitals. In the latter years of his employment my dad had slowed down his rate of work due to his general fatigue and this meant less money being available. As mentioned, mum had to sell the house to discharge the mortgage with all the stress and strain that such an act involves. It is hard enough for younger people never mind a woman of her age on her own and still grieving the loss of her husband.

Section 8. Other Issues

46. Dad's experience made me much less trusting of the NHS. Before it all happened I just thought that doctors knew everything, and you should do what you're told. Now I'm much more mistrustful. I know that the individuals in the NHS are generally nice people, the problems are with the way the organisation is set up.

47. I feel like my family was continually treated unfairly: at the time of my Dad's illness, especially when we found out that the doctors knew of his Hepatitis in 1990 and did nothing! During the Penrose Inquiry, and then even more recently in my correspondence with my MP, which I will explain below.

48. The sense of unfairness was something that really affected Mum. She contacted the Scottish Haemophilia Society in around 2003, they were represented by Thompsons Solicitors and they referred her. Thompsons

began pursuing judicial review for our family and another two families in relation to deaths due to infected blood. (See Exhibit WITN3626003) However, this didn't progress, I think because of the Penrose Inquiry. Watching the Penrose Inquiry was very difficult, seeing people walking out in tears was devastating. I believe that Thompsons still has the medical records obtained during this period and this is where Sandra saw the notes that confirmed they were aware of dad's condition two years prior to diagnosis.

49. Mum would phone me in tears any time there was something about infected blood on the news. It would come up every few years and would be a very painful reminder.

50. In July 2017 I contacted my MP, Paul Masterton, via email to ask how we could be involved with the Infected Blood Inquiry. An intern in his office sent a very inappropriate reply with the typo 'Bloody Inquiry' as the subject, which I found shocking. Although I received an apology from the MP himself I was deeply offended by the wording. I didn't tell Mum about this because I didn't want to upset her. (See Exhibit WITN3626004). She had gone through enough.

51. I feel strongly that Mum was deprived of what should have been the best years of her life and died without any closure despite trying her best to get some kind of answers..

Statement of Truth

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

Signed GRO-C

Dated 9.12.2019.