Witness Name: Mrs Anne McInnes
Statement No.: WITN2674001
Exhibits: NONE
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INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF MRS ANNE MCINNES

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

I, Anne McInnes, will say as follows: -

Section 1. Introduction

1. My name is name is Anne Murray McInnes. My date of birth is GRO-C 1951 and my address is known to the Inquiry. I'm retired now but prior to this I have had a number of jobs including being a lab technician in the haematology department of Edinburgh Royal Infirmary hospital from 1973 to 1975. I left this job to have a family and thereafter went into industry to a company that makes food ingredients. I am giving a statement in relation to my late husband John Kirk McInnes, known as Kirk, who was born on GRO-C 1951. 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 Infected

2. My husband was self-employed throughout his life. He missed a lot of schooling due to being confined to bed with bleeding episodes. He was a very intelligent person who was unable to reach his full potential due to his illness. He was however very knowledgeable about a lot of subjects and was well read. After leaving school he went to college and did a business course. After college he was employed in the office of a large engineering business but sometimes he was unable to go to work due to his illness and was dismissed after six months. His parents had a drapery business and he went to work with them. This was much more flexible employment. His parents eventually decided to give up their business and my husband had to find another way of supporting his family. He opened a pet shop and was very successful for a number of years. However it was heavy work, involving having to carry heavy bags of foodstuffs and equipment and through time it became more difficult for him, so he trained as a driving instructor and continued to do that until his death. Kirk passed away on GRO-C 2011. We were married for nearly 39 years as we had been married in September of 1972. We had two children. Lisa was born in GRO-C of 1975 and Gregor was born in GRO-C of 1977.

3. Kirk suffered from severe haemophilia A. He was diagnosed around the age of 18 months and at that time there was no treatment available. If he had a bad bleed he would have whole blood and then that moved onto plasma and then cryoprecipitate. All the treatments he had were essentially to give him Factor VIII.

4. When I knew him at first he was on plasma. He was treated at Edinburgh Royal Infirmary by Dr Howard Davies. At that time there was no motorway to Edinburgh from our area and the journey to hospital took around an hour and a half. If he had plasma for a bleed it would generally be two

bottles and it would take around two hours for each bottle to be transfused. Then the journey home. It took nearly all day to have treatment for a bleed and involved someone having to drive him to hospital and home again.

5. Kirk was treated at Edinburgh Royal Infirmary from a young age, originally he was treated by Dr Davies, and when he retired it was Professor Chris Ludlam. They were the consultants that dealt with haemophiliacs during that time.

6. When Kirk was younger he could have several bleeds in a week or sometimes go for a month without a bleed involving a trip to or a stay in hospital each time. Sometimes he could be confined to bed for weeks at a time. As treatment progressed from plasma transfusions (pre1970's) to cryoprecipitate (1970's) and then factor VIII concentrates (1977) he was eventually able to treat himself at home from 1976. This meant he could have treatment as soon as a bleed started, resulting in fewer severe bleeding episodes and much less time needed in bed or off work.

7. When I worked in the Haematology lab at Edinburgh Royal Infirmary we tested blood samples of haemophiliacs taken either when they were in hospital or attending regular out-patient clinics. There was a list of haemophilia patients who had Hepatitis B and non-A, non-B hepatitis kept in a drawer in the consultant haematologist's office, and when the blood samples arrived at the lab we would check the list and mark the samples for special handling if the patients name was on that list. In my time in the department my husband's name was not on that list. He was unaware that a list existed. To my knowledge none of the patients on that list were aware that they had hepatitis. At no stage did we tell people on that list that they had non-A non-B and I'm not aware of anyone else in hospital telling people at that point that they had non-A or non-B hepatitis.

8. I recall that at one stage patients and their families were all called into a meeting at Edinburgh Royal infirmary about HIV. The medical team explained that there were a number of patients who had been infected with

HIV and if the patients attending the meeting wanted to know if they were one of these they should make an appointment to speak with the consultant. This would have been in the early 1980's I think.

My husband's attitude was get on with life and don't let things get you down in terms of his haemophilia. He saw the advances in the treatment of haemophilia as progress. It was a long time after this that my husband found out about his hepatitis C and this would have been in 1992. He was told the general risks about blood borne viruses but he was told not to worry. It would have been Dr Ludlam that told my husband. I believe he was told that there was a risk that this could be passed on to someone else but it was not a major health issue. He never explained at that time that you could go on to develop cirrhosis and other liver damage. The doctors were very vague and basically mentioned the risks of passing on the infection and how to take precautions about passing on Hepatitis C to partner. Our children were quite young at the time so it was very difficult to explain the circumstances to them.

9. My husband felt he had to be very secretive. Hepatitis C was seen as a similar infection to HIV by the media and people panicked and thought that people with hepatitis C were going to die or pass on the infection. At the time, it was associated with gay men and drug addicts. The fact my husband worked with the public made things difficult. We did not want customers to find out, for fear that this would affect his business.

10. I do not think adequate information was given when my husband was diagnosed. I think around 1992 was about the time he found and was at that time he was offered interferon treatment. This was a trial to which he had to consent and was treatment with Human alpha interferon (Rofiron). At that time he was on interferon for 6 weeks but had to stop due to side effects. In August 1995 he participated in another trial of Interferon and Ribavirin but had to stop in October due to having side effects. In October 1996 he participated in a further trial of Viraferon and Ribavirin which was stopped in January 1997 due to worsening of his blood results.

11. In terms of the advice given to my husband, I think generally it would have been on a routine clinic visit and he would normally go himself and he would come home and relay certain aspects he was told, to me.

12. In terms of cross contamination, he was told not share toothbrushes and to not have unprotected sex. We were basically told to stay back if he had any outward bleeds. It's hard to know if this advice was sufficient because it was perhaps all they knew at that time about transmission of hepatitis C. I believe it was all played down.

13. I believe they did say fairly quickly that a blood product may have caused this. My husband was very suspicious of Chris Ludlam. I remember him trying to persuade my husband sign consent forms for clinical trials. I believe Dr Ludlam would try and wear my husband down about things like this. There was something very suspicious about him. I do not know what this form would have been for.

Section 3. Other Infections

14. My husband was infected only with hepatitis C.

Section 4. Consent

15. I do not recall anyone saying aloud that they were going to test my husband for hepatitis C. I believe he must have been tested when he went for a routine assessment clinic to take blood as part of his treatment for haemophilia. They must have been testing for hepatitis C. I do not think they ever told him that's what they were testing for at any point. I believe around the time of his diagnosis (1992), I was given a test for hepatitis C and this came back negative. From my husband's medical notes I have found that blood samples from him were marked high risk from around 1986, suggesting that the clinicians new at that time that he was infected with Hepatitis C. Also some of these blood samples were marked for storage.

16. Professor Ludlam coerced my husband into trying some new blood products, from the US.

Section 5. Impact

17. I believe when my husband was initially diagnosed he was concerned but not panicked. He was a very positive person. I don't think he knew the full implications of the condition. My husband was very strong mentally and very happy-go-lucky. He was full of fun. I think he just thought what was done was done. Since I knew him I do recall him having reactions blood products which involved flulike symptoms and skin rashes. I also recall him feeling cold and shivering. He suffered from aches and pains. I believe he was just told by medical staff to get on with things.

18. My husband was pushing himself all the time and had a heavy workload; the pet shop involved lots of heavy lifting. He would not give in and I only recall him being hospitalised with these twice.

19. Kirk was put on interferon within a year I believe of when he was diagnosed. I believe this was when interferon was first made available. I think around 1993 was about the time he was offered interferon treatment. This was a trial to which he had to consent and was treatment with Human alpha interferon (? Rofiron). At that time he was on interferon for 6 weeks but had to stop due to side effects. In August 1995 he participated in another trial of Interferon and Ribavirin but had to stop in October due to having side effects. In October 1996 he participated in a further trial of Viraferon and Ribavirin which was stopped in January 1997 due to worsening of his blood results.

20. I have a friend who has documented events. Her husband is a haemophiliac. She worked in haematology GRO-A GRO-A She would have had more access to policy and documentation than I had.

21. I think my husband may have received interferon first, then later treatment with Ribavirin and Interferon. Before he had his liver transplant I recall having another treatment but again I do not remember the name of this.

22. I believe that my husband was given whatever was available but he was never able to complete a set of treatment.

23. My husband managed to persevere with treatments for varying lengths of time but never managed to complete a full course due to the side effects.

24. My husband did not feel well when he had the treatments. He had no energy and suffered from fatigue. He got down but not depressed. I believe he did fine it quite difficult. He may have had a bit of brain fog but it didn't affect him greatly in any mental sense. I think he would mostly get fed up about it. I recall treatment exacerbating his flulike symptoms. He was never bedbound and would not give in to things like that. He spent so much time in bed as a child that he did not want to do this again. He would sleep lot but he would do things like fall asleep on a chair.

25. I do not believe there was any difference in the treatment my husband received because of his hepatitis C diagnosis. His dentist was aware of his condition but this did not change anything. I do recall that at one stage that he did have detached retinas and had to wait to have surgery at the Eye hospital in Edinburgh. He had to be last patient for treatment each time because of this condition. This was quite inconvenient for him but this was done by local anaesthetics so there was no nil by mouth or anything like that.

26. In terms of family life, it is hard to sort of divide this into different sections. We already had to plan our lives around his bleeds. Due to his haemophilia, Kirk could not play with the children physically a lot in case he had a bleed. It was our "normal" life so it's hard to define what's normal and what is not, as my normal may be different from yours.

27. I believe family life was impacted by treatments. At no time we were ever told about the risk of having the treatment and of any side-effects. My husband was never able to play football or other physical games with the children.

28. When my husband was on treatment for Hepatitis C (interferon etc) he could not go anywhere or do anything. We did not tell the children at the time that he was diagnosed in case they said to other children and were Kirk having hepatitis C.

29. Kirk had difficulty walking, with his knees and ankles being damaged by bleeds into the joints over the years, so they just thought that he walked funny to begin with.

30. In terms of our social life, we were very sociable and socialised together. Kirk would go to the pub with his friends to play dominoes and things like that. When Kirk was on antiviral treatment, he was not fit to socialise. He was not able to do anything other than go to work and come home and sleep. Our social life went back to normal a few months after the treatments stopped.

31. In terms of the stigma, we did not share Kirk's condition with lots of people, only very close friends. We did not want it to impact on any of our friendships. As I said Kirk, was working with the public so we were also worried about people's perceptions of hepatitis C. Hepatitis C seemed to sort of almost be on a par with HIV in people's minds. We were afraid of the risk of people assuming the worst about hepatitis C.

32. In terms of the impact on our children, I believe our son feels that it did have an impact on his upbringing but my daughter is much more of a private person and doesn't talk about these things. I do not believe that my husband's condition and treatment had any impact on the children's school

performance. As I said my husband was the sort of person to just get on with things and did not make a big issue of it.

33. In terms of my husband's work, he did own a pet shop and this did eventually get to be too much for him while he was on treatment. I think my husband's haemophilia was responsible for stifling his earning capacity quite early on in his life. He missed a lot of schooling as well because of treatment. He was not an academic but he certainly was intelligent andwell read. At one stage he did a business course at college. He told me that when we was younger he got sacked from his first job in the late 1960s because he had been off work several times due to having bleeds and needing to go to hospital. Following this he went into the job with his family and as I said took over the premises as pet shop which was a real struggle for him. He felt he had to make it work because he had started it. We opened a shop in Falkirk and it did quite well financially. Other people saw the success of this and opened up in competition. The competition got to be too much, and Kirk decided to retrain as a driving instructor. He started this in 1986 to 1987 and did this until he passed away.

34. Kirk was diagnosed with cirrhosis 1999 I believe, and this was a progressive thing. He then had his liver transplant in 2003. The medical staff did say that the cirrhosis was a result of his hepatitis C.

35. Kirk had a tumour on his liver and this was cancerous and related to his hepatitis C. He was assessed for suitability and put on the transplant list. After 10 weeks on the list he was called for a transplant but when he was in theatre for the surgery the donor liver was found to be damaged and so the transplant didn't go ahead at that time. Eventually in December 2003, after waiting 10 months, he had the transplant. After the transplant the surgeon told me that if Kirk had had to wait any longer the transplant wouldn't have gone ahead as the tumour in his liver would have been too big. I remember that he got home on Boxing Day and then had to go back into hospital because he was not well. He got a blood transfusion and then was much improved. At this point his viral level was undetectable. When

he had the new liver he didn't have haemophilia symptoms for the first time in his life as the liver had come from someone who did not have haemophilia. This was the first time in his life that he was free to live without the fear of a bleed happening.

36. We had a grandson who was born three weeks before the transplant and he was able to do all the things with him that he was never able to do with his own children. After a period of time the Hepatitis C became detectable again.

37. I believe that Kirk wasn't too concerned about this as he thought he was going to be quite old before it started affecting him again. After the transplant, I recall that he went regularly to the liver clinic. They kept regular checks on him and checked his blood. The main focus was on making sure that the new liver was functioning. He would have blood tests, ultra sounds etc.

38. In April 2011, he started getting really tired. He really wasn't feeling great and he thought he put on weight as he had swelled up. He kept phoning the liver transplant team but they would not do anything until, one weekend I had to take him to Edinburgh Royal Infirmary. I took him to the transplant ward. They admitted him and did lots of tests and they didn't know what is was. His legs were weak, and he could not walk.

39. Kirk was in a room with three other patients in the hospital while investigations were carried out. One day the consultant came in and said that he had secondary cancer and they didn't know where the primary cancer was. He had cancer in his lungs and adrenal glands. There was some mention of a blood clot on his aorta. All this information was imparted in a room with other patients and their visitors listening. They originally said that it was unrelated to liver cancer but then after a couple days said it did originate from the tumour in his own liver. At no time did he see an oncologist. Dr Ludlam and the Haemophilia centre team attended from time to time in an advisory capacity. Kirk asked how long he

had to live and they said 2- 3 months. Kirk passed away 10 weeks later. He was sent home on a Friday in a private ambulance without any medical support, just the ambulance driver, and there was no care package put in place to help over the weekend. The ambulance reversed to the top of our driveway and made Kirk walk in. He was devastated by his physical condition at this point. 10 weeks later Kirk died in a hospice.

40. After the transplant Dr Ludlam continued to see Kirk on a regular basis although he no longer needed treatment for haemophilia. He attended the liver clinic regularly to monitor his liver but at no time did they ever investigate whether the original tumour had spread. He never had any scans to check for this. They were only interested in the transplanted liver. After Kirk's death Professor Ludlam met with me and suggested I talk with the transplant consultants about the circumstances surrounding Kirk's death. Professor Ludlam offered to come with me to deal with this but I said I could not deal with it at that time.

41. After a while I did feel capable and sent a letter to the liver team. In this letter, I set out my concerns about the way we were treated in the hospital and the fact that they hadn't investigated the possibility of a tumour having spread. I got a letter back admitting that they hadn't looked after my husband properly, in terms of investigating the cancer post transplant and the lack of privacy and the way we were treated in the hospital. Professor Ludlam retired from his post and so I was unable to contact him further about this matter.

42. My husband died in a hospice and I got the death certificate. The day before the funeral a doctor from the hospice phoned me and said that a doctor from the Haemophilia Centre had contacted her and suggested that a post mortem should be carried out. This wasn't possible but an amended death certificate was issued from the hospice. I believe this was to add hepatitis C as a contributory cause of death to the death certificate.

Section 6. Treatment/Care/Support

43. I believe treatments were offered as they became available, when they did not work it was quite difficult. I do not recall any counselling or support being offered during Kirk's diagnosis of Hepatitis C or at any point subsequently. I do not know if he would have benefited from it. I think until his cirrhosis we weren't really aware of the consequences of his infection. I believe he would have benefited when he was diagnosed as having cirrhosis. I remember him having to go into hospital for a week to see if he was a candidate for a liver transplant. Part of this assessment was with a psychiatrist, and also benefits people who said that he was not entitled to any benefits.

Section 7. Financial Assistance

44. I believe we found out about the Skipton fund through the haemophilia society. My husband was quite active in the haemophilia society while he was alive. I believe when he was stage-1, he got £20,000 and then at stage-2, he got £25,000 I think. Later we then got monthly payments that amounted to around £12,000 a year. I believe we only got three payments of this before my husband died. I was not involved with the actual writing of the form to get any money through Skipton but I believe my husband did say that it was a form and I do not recall him having any difficulties applying.

45. I believe the second payment came automatically. The haemophilia unit or haematology unit may have had something to do with it. I think the second payment may have been around the time of my husband's transplant.

46. I do not recall receiving any money from the Caxton fund at that time. I did however find out that widows could apply for a winter fuel allowance which I got twice.

47. I don't really have much of an opinion on Skipton. I would say that it was an inadequate amount, although it was welcome. Considering the circumstances of infected people, it was a pittance.

48. I got some fuel payments from Caxton after my husband's death but nothing while he was alive. I think it someone at haemophilia Scotland that told me about this. I recall it being an easy process but I do not remember much detail.

49. I have now applied for the widow's allowance through the SIBSS fund. I found this to be an easy process. This was quite straightforward.

50. The amount of money I get is certainly enough to allow me to stay in my family home which I may have struggled to do without this payment. No amount of money is enough to compensate for what has happened. I'm just glad the Scottish government has been more generous than the UK government in the amount of money they have given.

Section 8. Other Issues

51. Both my husband and I gave statements to the Penrose inquiry. This was a total waste of time. I believe a woman came to our home. I did not sign up immediately to this current inquiry but I did once I saw the opening statements. At no point did I really fully consider litigation. Dr Ludlam was keen to help at one stage to pursue something but then he retired. I found some disturbing references on the internet to things he had been involved in and accused of. There were suggestions that he had used his patients as guinea pigs in research projects but I'm not sure how true these accusations are. My husband was always suspicious of his motives.

52. I believe some of these allegations were to do with the fact that he had a group of patients who hadn't been infected with hepatitis C signed up to a drug company that were in the process of eradicating or trying to eradicate HIV and Hepatitis viruses from their products. I don't know if my husband

was involved in any of these, but he was involved in trials which Dr Ludlam was conducting on more than one occasion.

Statement of Truth

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

Signed GRO-C

Dated 02/04/19.