Witness Name: Margaret Dalgity
Statement No.: WITN2111001
Exhibits: **none**
Dated: 23rd November 2018

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF MARGARET DALGITY

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

I, Margaret Dalgity, will say as follows: -

Section 1. Introduction

1. My name is Margaret Dalgity, my date of birth is GRO-C 1959. My address is known to the Inquiry. I am a retired Company Director. I intend to speak about my brother William (Billy) Cannon's infection of hepatitis C. I will, for the remainder of this statement, call him by his shorter name of Billy. I will describe in particular, the nature of his illness, how the illness affected him up until his death on 10th February 2013, the treatment received and the impact it had on our lives as his family.

Section 2. How Affected

2. My brother had no prior condition. In 1986 he had a stomach ulcer that was bleeding, which resulted in him being admitted to Bangor Hospital

in West Lothian where he received, over an 8 day period, several transfusions of whole blood. I believe, from information in his medical records, that during at least one of those transfusions, he was given infected blood. He received around 11 units of blood over an 8 day period.

3. He received whole blood through several blood transfusions. He received the blood because of a bleeding ulcer in his stomach. He had vomited blood at home and was admitted to hospital with very low haemoglobin levels, which therefore meant he needed to have an immediate transfusion.

4. Billy was under the care of Bangour Hospital in 1986 for a bleeding ulcer. From 1986 until 2010 he was in excellent health and had no problems that required medical attention from a hospital. He was treated until his death by the Western General Hospital in Edinburgh, the Royal Infirmary Edinburgh and St John's Hospital in Livingston. In January 2013 he was also treated briefly at Dumfries Royal Infirmary, towards the end of his life in February 2013. I do not know the details of his General Practitioner. This information will be available from my sister in law, Linda Cannon. I do not know the specific details of the doctors involved in his care when he was given the blood transfusions, or those involved in his subsequent care in 2010 onwards. Again, my sister in law Linda Cannon, will provide these details. She is providing her own statement to the Inquiry.

5. Billy received the infected blood via whole blood transfusions over an 8 day period in 1986.

6. Other than the bleeding ulcer in 1986, Billy was healthy and had no health issues until 2010. In early 2010 he began to suffer from severe lower back pain and around his hip. At that time, he went to his GP. His GP told him it was sciatica and he prescribed painkillers. That was

around January or February 2010. Around March he went back to his GP, still complaining that his back was really painful. He was again prescribed more painkillers. By April he was using a walking stick to get around. He returned to his GP and was referred for physiotherapy, for which there was a six-week waiting list. In May 2010 he attended his first physiotherapy session and was told he needed an x-ray, and then he was advised, as a result of the x-ray, that he needed a replacement hip.

7. He was told to continue with physiotherapy until he could get an appointment with an orthopaedic specialist. His physiotherapy sessions were once per month so Billy, because of the pain that he was in, paid for additional private physio sessions, the details of which I will cover later in this statement.

8. In July 2010 at his monthly physiotherapy session the therapist noted that Billy could hardly walk into the waiting room. She examined Billy's spine, noted that something was wrong and referred him to the Western General Hospital in Edinburgh to have an immediate x-ray at A&E. By 6pm that day Billy had been admitted to hospital, had the x-ray, followed by a CAT scan and by 9pm was told that there was a tumour on his spine that needed to be operated on. He was told the operation would take place on the following Monday morning. However the doctors then decided that further investigations were required as they could not determine the primary source of the cancer.

9. After 17 days in hospital and 11 days waiting for results, he was told that he had stage 4 Non-Hodgkin's lymphoma and the tumour on his back had wrapped itself around his spine, which was causing the pain. At that time doctors told him that whilst there is never a good cancer, NHL was treatable and that he would fully recover. However, further tests carried out over the same four week period confirmed that the primary source of his cancer was in fact in his liver.

10. Billy was due to start treatment at the Western General Hospital in Edinburgh in August 2010. He was scheduled to be admitted on a Friday

afternoon and was told his treatment, because of the advanced stage of the cancer, would last three weeks.

11. During his pre-admission checks a nurse asked him if he had any infections. Billy said no. A while later a doctor then approached Billy and asked him the same question. Again, Billy said no. The doctor then told Billy that he would come back and speak to him later on when the ward was quieter. Several hours later the doctor and nurse came back, took Billy and Linda into a side room and explained to them what his treatment would entail, how the chemo would be administered and the potential side effects of it. He told him that the treatment would be aggressive because the cancer was aggressive. Then the doctor asked Billy if he was aware that he had hepatitis C.

12. Billy said that he was not and the doctor then told him that he had found this information on Billy's medical records from 1986, and that it had been lying dormant in his system. He told him that the chemotherapy treatment may flare up the hepatitis and if this happened, they would need to stop the chemotherapy, treat the hepatitis and then recommence the chemotherapy.

13. Billy again told the doctor that he had been unaware of this and had never been told by anyone that he had the infection. The doctor then told Linda that she would have to be tested for hepatitis C as Billy may have infected her.

14. There were two consequences to this information. Firstly, Billy had been told that he had contracted aggressive stage 4 liver cancer and then he was told that he had hepatitis C, He had no idea what the implications of having hepatitis C were. He vaguely knew about hepatitis, and vaguely associated it with drug users and the gay community, but he had no idea how or when he could have contracted it. Secondly he was absolutely devastated that he may have infected Linda. Linda was not offered a test by the hospital, nor was she offered assistance in making an appointment for the tests, the results of which took an agonising five

weeks to come through; several weeks after Billy started his own gruelling treatment.

15. Billy and Linda were told that having just had a bombshell dropped on them that his treatment would be deferred until the following Monday. The doctor sent them home for the weekend and told them to come back on the Monday morning. I don't have the details of the doctors involved at that time. My sister in law, Linda Cannon will have this information. I found out about Billy's condition via telephone call as I was living in England when he was diagnosed.

16. Information about hepatitis C was provided by the Consultant Oncologist at the Western General, Hospital in Edinburgh who was treating Billy. Other than the original discussion where he was told that he had hepatitis C and its impact on his cancer treatment, Billy was given no further information. All further discussions and information given were focused around his cancer treatment. There was no indication of the seriousness of the infection, nor of its potential impact on his life expectancy. The only comment made was that the chemotherapy could activate the dormant infection.

17. Adequate information was not provided. All of the information provided to my brother related to the cancer treatment. The focus was all about treating his cancer first and then deal with the hepatitis C at a later date, unless the hepatitis C flared up. Their view was that if the hepatitis C flared up then the chemotherapy would be halted, the hepatitis C would be treated and then chemotherapy would recommence. At no time was any information given about the possible consequences of the hepatitis C flaring up.

18. Billy had stage 4 liver cancer. It was very aggressive and he was given a very aggressive course of treatment. At that time all of the focus was on treating the cancer. He underwent 21 sessions of chemotherapy in the initial three-week period of treatment. The strength of the treatment was such, the nurses administering the drug, questioned on multiple

occasions whether or not he was being given the correct dosage. He reacted badly to the treatment and was admitted to intensive care on 2 occasions, eventually being put into an induced coma to try to allow his organs to rest. He was in isolation during this period, with only my sister in law being allowed to see him. Instead of spending 3 weeks in hospital, he remained there for 4 months, in both intensive care and high dependency units. The whole period for our family and my sister in law in particular, was horrendous. My brother was never given adequate information on the hepatitis C infection, how it is contracted, how or if it is treatable, the potential consequences of the infection on him, his wife, his life or his livelihood.

19. Information should absolutely have been provided to my brother earlier. It should have been provided when the NHS, its suppliers, and the various UK Governments became aware that they had infected people. It was their responsibility to contact those people who received blood products and/or whole blood transfusions. My brother was diagnosed with liver cancer in 2010, 24 years after he received infected blood. The relevant authorities knew over thirty years previously that people had been given infected blood yet they did nothing. No one from any authority ever contacted Billy to either inform him that he may have been infected or, more importantly, give him the opportunity to be treated for the infection.

20. The so-called "Look Back" exercise undertaken by the NHS was completely inadequate. There was little or no effort made to carry out the exercise properly. My brother never moved from the village that he lived in and he never changed doctors. He was perfectly contactable. There was no excuse for it. If the relevant authorities had done their job properly and contacted people, my brother would have certainly taken treatment. By the time my brother was diagnosed with stage 4 cancer, his immune system was already weakened.

21. My family argues that had he been told at an earlier date of the hepatitis C infection, he would have taken treatment and he may not have contracted liver cancer. We argue that the cancer was a direct result of his liver being damaged by the hepatitis C that lay untreated in his system for 24 years. Had he not had hepatitis C we believe he would not have contracted liver cancer. His immune system was compromised by the hepatitis C. Even if he had contracted some form of cancer, his body had it not been compromised by the hepatitis C, would have been stronger and would have been able to fight. As it was, because his immune system was compromised by the chemotherapy, his white blood count never increased to a level that would have enabled treatment for hepatitis C.

22. My family was horrified at the way in which the confirmation of the infection was communicated to Billy and Linda. He had just been told that he had stage 4 liver cancer, not the 'treatable' NHL and then he was told that he had hepatitis C; a fact known but not disclosed to him since 1986, and that he may have infected his wife; the latter delivered as a throw away remark. It was appalling.

23. Given that Billy was never told that he had hepatitis C he was never given any information about the risks of infecting others. The only information given was in 2010 by way of a throw away remark by the same doctor who informed my brother that he had been infected.

Section 3. Other Infections

24. Billy was a healthy and active man. There was nothing at all wrong with him. He didn't smoke, he drank very little, he was a keen golfer and lived a normal life. He ran a very successful restaurant for many years and then a 14 room guest house in Dumfries. His job was very manual. He was an active, healthy man until 2010.

25. My brother went on to develop liver cancer in 2010, our family will argue, as a direct result of being given infected blood in 1986 from which he contracted hepatitis C. Had he not been infected he may not have developed cancer. Had he been told and treated early enough for the hepatitis C infection, his immune system would not have been compromised and his body, even if he then did contract cancer, would fight it. My brother is dead now as a direct result of him being given infected blood. He was not given the opportunity to be treated for the hepatitis C following infection, and because of this, he was not given the opportunity to fight for his own life.

Section 4. Consent

26. I don't believe he was treated without his knowledge. Billy was given blood for a bleed and recovered. I believe he was tested at some point for hepatitis C without his knowledge though.

27. He was not treated without consent, but he was tested, at some point for hepatitis C, without his knowledge

28. Billy was not given full and adequate information when he was given the transfusions. He was not warned that there was a risk of infection or that the blood was contaminated. If he had been, he would have challenged it. He was not given the option.

29. I do not believe that Billy was tested for the purposes of research.

Section 5. Impact

30. Billy was devastated to learn that he had been infected. He was a typical stoic Scot who did not show very much emotion. The only time I saw him in tears when he was ill, was when he talked to me about the fact that he may have infected Linda. He felt he had put her in danger. During the period that he was being treated in 2010 for the cancer, he was too ill to

be aware of what was going on. He was sleeping about 22 hours a day, he was on a cocktail of powerful drugs, he spent time in an induced coma, he had pneumonia, was in an oxygen tent in an isolation ward. He had little or no awareness of what was happening. Linda carried most of that burden. We, as his family, were all frightened that he would not come through it, but it was Linda who was affected most of all, and on a daily basis.

31. After the cancer treatment, Billy's immune system was further compromised. He became really susceptible to infection. Before he was ill he would barely take paracetamol, but after treatment, a common cold would floor him. He fought general ailments to the end of his life without complaint. Before he became ill, Billy was 5ft 11in tall. Afterwards because of the tumour on his spine, he was about 5ft 6in tall. This was because his spine had become curved by the tumour. It could not be removed because it may have paralysed him. He had limited mobility, having to endure the humiliation of a mobility parking pass as he could not walk long distances. He also had to have his bathroom adapted to accommodate a wet room arrangement, as he had difficulty stepping up into a shower cubicle.

32. Billy was diagnosed with stage 4 liver cancer in 2010. At the same time, he was told that he had hepatitis C, which he had contracted in 1986 but was not informed of, from transfusions of whole blood. He died on 10th February 2013 from liver cancer and hepatitis C. He was 57 years old.

33. He was treated in 2010 with chemotherapy for the liver cancer. The liver cancer was declared inactive in 2011 following treatment. He was never able to receive treatment for the hepatitis C as his white blood count never reached the required levels to commence treatment. He was told in 2012 that even without the treatment for the hepatitis C, he had a life expectancy of 10 years, meaning that treatment was not urgent. He was further told, that a new less invasive drug would be made available within

a few months, that he would be treated with. He was never offered the new drug.

34. In July 2012 Billy had a 'routine' scan and was told his cancer remained inactive, but that he still could not commence the hepatitis C treatment because his white blood count continued to be too low, and that the risk of infection from the treatment (because of its effect on the immune system) was too high for his body to sustain. In December 2012 he attended a further appointment which included a further scan. He was not given the results of the scan, nor was he contacted by the hospital.

35. In late December his condition deteriorated and my sister in law contacted the hospital for an early appointment for him, which was given to take place at the end of January. She asked for, but was not given, the results of his scan. She was told there had been a mix up because of holidays and that his results would be in the post. In early January my brother was so ill, Linda took him to Dumfries Royal Infirmary which was where his then business was located. He was admitted as an emergency patient

36. That evening the doctor at DRI after having contacted the WGI in Edinburgh for Billy's medical records, told them that the scan taken in December had shown that the cancer had returned, had spread and was inoperable. They sent him home to die. On return to Edinburgh, after great effort, he was given an appointment to see a Consultant Oncologist who confirmed his condition. They apologised for the way in which they had been treated and told him nothing further could be done. My brother asked to be treated with a lifesaving drug. Sorafenib, which was not available to NHS Scotland patients, but which was available in England.

37. He and our family, offered to pay for the treatment as we knew it had proven success rates. He was told that his condition was too far advanced, so his request was denied. He was also told that had his condition been identified four months earlier he would have been eligible for treatment. When we asked why he was given scans at six monthly

intervals and not three months, which would have identified the cancer's return, we were told that it was standard procedure. Again, my brother was denied potential lifesaving treatment because of NHS 'protocol'.

38. My brother was denied access to both Sorafenib, for his cancer and Ribavirin for the hepatitis C, both of which are proven drugs.

39. The cancer treatment he received prolonged his life, for which we are grateful, but which nearly killed him several times. The impact of having cancer stayed with my brother. It was always there in his everyday life. He was never given any treatment for the hepatitis C. It held him hostage to the end of his life.

40. The tumour on Billy's spine gave him significant pain. Although the physiotherapy that he received under the NHS gave him some relief, he felt the need for additional treatment, so he also paid for private therapy. He attended a sporting injuries specialist near to his home in Edinburgh. When he was diagnosed with hepatitis C he was told of the need to disclose his condition, which he did. When he did so, the physiotherapist refused to treat him. He told Billy that he could not take the risk of treatment him because of the risk to his business, his reputation and his other patients. He said his concern was that if Billy had a cut, or a break in his skin then he, the physio, may get hepatitis C or that his patients may get it, from the broken skin. The ignorance was incredible. Billy was humiliated. This is one example of the reaction of some people, that infected victims have to endure.

41. Billy's life, as he knew it, ended when he was diagnosed and treated. He never fully recovered enough to undergo the treatment for hepatitis C and his body never recovered from the chemotherapy. Prior to becoming ill. Billy was a very keen golfer, he ran a successful and demanding business, and he had a strong, active social life. After he became ill, he had to leave the running of his business to his business partner, who subsequently stripped it and took it to bankruptcy after Billy's death.

Linda had to give up work to care for him, he could no longer play golf and their social life became almost non-existent.

42. My sister in law lost her husband, her business and her livelihood as a result of the situation. It has been like a horror story for her.

43. Billy was my elder brother. I am married and live in England, but I was very close to him. Our family has been devastated by the nature of his death and the way in which the NHS, its suppliers, its representatives and successive UK Governments have behaved. They have joint and several responsibilities for the deaths of some three thousand people, and the destruction of tens of thousands of lives, including my brother's life. The emotional impact on our family and all of the other families affected, is beyond description.

Section 6. Treatment/Care/Support

44. Other than the assistance provided by MacMillan, no other support was forthcoming from the NHS or any other authority. Billy paid for additional physiotherapy sessions which, after he disclosed the hepatitis C infection, ceased because of the providers fear and ignorance. He was never offered the cancer drug Sorafenib, because it was not available in NHS Scotland, nor was he offered treatment for the hepatitis C because his body was not considered strong enough to endure the side effects of the drugs that would be used. Any other care and support Billy and Linda received were from family and friends.

45. No counselling of any description was offered to Billy, Linda or any other family members.

Section 7. Financial Assistance

46. Linda discovered, through a family friend, that a trust fund had been set up to assist victims and their families. It is a charity fund named, The

Skipton Fund. She contacted them via the internet and then by telephone to establish if Billy was eligible to receive assistance, and how to apply. No information regarding the trust or its function was provided by the NHS or any other authority. I do not know exactly when Billy and Linda were informed of the existence of the Trust, only that it was some time after his discharge from hospital.

47. I believe Billy qualified for an initial lump sum of £25,000 and then a second lump sum because he was categorised as final stage, which meant he was dying. He also received a monthly payment of around £1,200 which ceased when he died. Linda was then simply left with no husband, no income and no job.

48. Billy was very unhappy with the process of applying for financial assistance, and in particular because it was done through a charity. The forms were long and complex and required his consultant's signature before submission. When Billy approached his consultant for her consent she retained the forms because she was unfamiliar with the Trust and its purpose, had never seen the forms before and was uncomfortable with the level of payment that Billy was applying for, commenting that £25,000 was a lot of money. To which my brother responded that it was not a lot of money for his life. A process that was already complex and difficult was made worse by the complete lack of knowledge by NHS representatives.

49. There was a complete absence of information or assistance from all the relevant authorities. He received no information at all, that assistance may be available. He had to rely on family and friends to discover that the Skipton Fund was the correct charity and then he had to go through the whole application process independently.

50. There are various preconditions when making the application to the charitable funds. There is a pecking order defined by a degree of illness which dictates the level of payment and assistance available. My brother was defined as a grade 4 candidate; terminal, which meant

he qualified for the highest payment. By its very definition it is a terrible process.

Section 8. Other Issues

51. I have no further documents to provide to the Inquiry.

Statement of Truth

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

Signed GRO-C

Dated 24th Febr. 2020