Witness Name: Roisin Donnelly
Statement No.: **WITN2124001**
Exhibits: **WITN2124002-008**
Dated: 26th November 2018

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF ROISIN DONNELLY

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

I, Roisin Donnelly, will say as follows: -

Section 1. Introduction

1. My name is Roisin Donnelly. My date of birth is the GRO-C 1961. My address is known to the Inquiry. I am currently working as a Non-Executive Director for several different companies. The companies are Just Eat PLC, Bourne Leisure and Holland & Barret. I am living at home with my husband Robert Hughes and our three daughters. I intend to speak about my father Tom Donnelly's infection with hepatitis C. The genotype of his hepatitis C infection is not clear from the medical records to which we have access. In particular, I intend to speak about the nature of his illness, how the illness

affected him, the treatment received and the impact it had on him and our lives as a family together.

Section 2. How Affected

2. My father was born on GRO-C 1935. He died of a stroke in 2015. My father had haemophilia A. His condition was considered at times to be mild at times to be moderate. I exhibit a letter dated 16 April 198k from my late father's medical records as **WITN2124002** and a letter dated 22 June 1983 as **WITN2124003.** To my knowledge, he was diagnosed when he was at university in the 1950's at Glasgow University. He had tooth problems which led him to seek treatment. The doctors were unable to stop his bleeding and this led to his diagnosis. His records suggest that he was treated in March 1967 for a possible duodenal ulcer with bed rest rather than operative intervention, oral iron, whole blood and plasma for bleeding after a dental extraction in December 1961 and lyophilised plasma when he was knocked down by a car in August 1971. In any event by the 1980s it appears that he did not require a great deal of treatment, only for dental extraction or for minor surgical procedures (see letter dated 16 April 198k at page 98 of medical records). He appears to have been suitable for treatment with DDAVP in such situations (see letter dated 22 June 1983 referred to above). He was treated with cryoprecipitate for bleeding after a dental extraction in May 1985. None of the correspondence in his medical records over his period indicate that there was ever any discussion with him about infusion risks associated with the products which he received. They seem to suggest that he was just given the treatment and that the doctors decided what it would be.

3. My father received treatment regularly for a number of problems related to his haemophilia. Historically he had issues with his dental procedures and problems with this stomach. I am aware of conversations of my mother, Catherine Joyce Donnelly that he needed stomach surgery in the 1970's due to an ulcer. The hospital at Glasgow Royal Infirmary also at this point did

blood transfusions on him. He received 14 pints of blood. In the 1990s he was treated with factor VIII concentrate and was on home treatment.

4. My father was always under the care of Glasgow Royal Infirmary Haemophilia unit throughout his life from the point of diagnosis to his death. My father knew the Glasgow Royal Infirmary team very well. If he had any issues he would head straight there every time. I do not know the names of the doctors involved in prescribing the blood products to him. His records mention Professor Kennedy and Dr Lowe. I know that the doctors in the haemophilia unit came and went throughout his life but I do not recall their names. My father's GP was Radnor Street Surgery, Glasgow. He saw several GPs there.

5. I am not aware of my father ever being given information about the risks associated with infection from receiving the blood products. As I said, his records do not appear to indicate that he was. I am a carrier of haemophilia. What I can remember is when my father talked to me about the risks of how infection can be caught. This was in the 1980's that he spoke to me about this. This was at the time when there was a lot of information in the media about the risk of HIV. My father started to hear that haemophilia patients were catching HIV and he was tested for this sometime in the 1980s. I do not know the exact date. I do not know if he asked for a test. I know that he was worried about the risk that he was infected with HIV as he told me this. I had a very close relationship with my Dad and he did talk to me. I moved to Newcastle in 1984 and we had regular phone conversations.

6. This test came back negative and then I believe he was told that the products from this point were safe. I do not know which doctor told him this, I believe it was a doctor at Glasgow Royal Infirmary. Apart from this I have no awareness of my father ever being given information before he received a product about the risk of getting an infection from it.

7. My father was infected with hepatitis C, which was known as hepatitis non A non B at the time he was diagnosed. My father would regularly go to hospital, for check-ups and tests. I don't know if he was told by his GP or Glasgow

Royal Infirmary about his infection. I note that in a letter to his GP dated 7 January 1992 Dr Lowe recommends that he should be tested for hepatitis C. I exhibit this letter as **WITN2124004.** He may have been tested at that time. A further letter dated 1 August 1994 states that he has tested positive for antibodies to hepatitis C and it is said that he had had a full conversation about it with Dr Lowe and that he was aware that a percentage of patients would go on to develop chronic hepatitis over the years. It says that he was counselled about alcohol, blood and sex. I exhibit this letter as **WITN2124005.**

8. Prior to being diagnosed he had developed chronic fatigue syndrome and he had developed severe depression in the 1980s and 1990s. That could be connected to his hepatitis C infection. I do not recall exactly when this started. I do know that it meant he was unable to work as a lecturer at Clydebank Technical College and that he changed as a father. He had 4 children, Simon Donnelly, Mark Donnelly, Siobhan Donnelly and me. He was very active when I was younger; he was an amateur actor as well. He was very social and full of energy and creative and he never stopped, but by the mid-1980s he was housebound, exhausted and extremely depressed. Before he was diagnosed with the hepatitis, he was showing a lot of symptoms. For example, he was sick a lot, and very tired. When he was diagnosed he was very depressed. He described it to me that he felt like he had been given a death sentence. He took early retirement in 1992 as a result of his symptoms.

9. I don't know what information was provided to my father at the point of diagnosis other than what his medical records state. My father just said that he was only given very limited information. He told me that I had to be careful donating blood and I had to be careful at home to minimise the risk of spreading the infection. The information that he did take away from the conversation with the doctor was that it was a killer infection.

10. I don't believe the information provided to my father was adequate. Hepatitis C was new at that point. The doctor said he had it and that he was at severe risk of liver problems in the future, but they couldn't say when this would happen or how severe it would be. He was told that at some point he would

likely develop liver disease, which in the 1990's was not treatable and was a fast killer. He was already extremely depressed because he had been so ill before they had diagnosed him. I believe very limited information was made available to him. In the end, he did not develop the liver cancer or advanced liver problems and he lived until 2015. I don't know how much doctors knew at the time.

11. My father was diagnosed in the 1990s. My siblings and I did not want to ask questions about the infection because it appeared like no one knew what was going to happen. Situations would occur when family would visit and we would have no idea if we should have separate towels and glasses for everybody. My overall view though is that information was extremely inadequate when the family was left with many questions.

12. I think information should have been provided earlier. He should have been told of the risks before he received the products. The doctors should have spoken to other family members about the risks, especially my mother. We used to donate blood in our family. After my father was diagnosed, my mother was told that she couldn't donate blood anymore, however no information was provided to the rest of us. We were just left to donate blood and get on with it. We were all speculating at how infection had been transferred to my father originally. It was extremely unclear. There was no information. Our family ended up researching matters ourselves. At that point the internet did not exist so research took longer. In the 1980s and 1990s there was a lot of information about AIDS patients in the media. Haemophiliacs were dying from AIDS and there was a fear that my father could have been infected with this. He was tested in the 1980's and was cleared of AIDS, as discussed in paragraph 5 above. As our awareness grew around the subject matter we worked out that he had likely been infected through the blood products. I am unable to recall a specific conversation with a doctor that spelled this out, but I do recall conversations in the past that made this clear to us, but I could not give specific details now. My father should have received a lot more information and mental support.

13. I believe my father should have also been provided with mental health support. My younger sister Siobhan was still living at home at the time and she was provided with no information or support. She should have been. I could donate blood after this, but I always had to tick a box that indicated that I related to someone who has hepatitis. I ticked the box and I would always have to answer the question of what the nature of my relationship is with that person. That was emotional and it made me nervous. I was worried I would be turned away and refused the option of donating blood. Our whole family donates blood because of the family connection to haemophilia. My mother always thought that she could donate blood to help my father and keep him and others alive, but she was denied this option. That made her feel bad and made her feel like she was infected herself.

14. I don't believe my father was given any adequate information about the risk of spreading the infection, but my mother can describe this better than I can. My father didn't want to talk about it at all.

Section 3. Other Infections

15. I don't believe my father received any infections explicitly but my mother may be able confirm. He was however advised that had been exposed to Variant CJD as well, and that there was a risk he may have contracted this but there was no test to confirm if this was accurate. I exhibit a letter from my father's medical records dated 20 September 2004 as **WITN2124006.** The effect this letter had on my father was immense. The effect on him was huge. It pushed him further into depression which he was suffering from already. He had gone from being a very active, social and creative father when I was younger to severely depressed and barely leaving the house.

Section 4. Consent

16. I do not know if my father has been tested without his knowledge. I suspect that he was as he was told of his results without having any explanation that the tests were being done.

17. I do not know if my father was tested without his consent, though I strongly suspect that he was.

18. I think that my father was treated without being given full or adequate information, as I set out above.

19. I do not know if my father has been tested for the purposes of research.

Section 5. Impact

20. Even before my father was diagnosed with hepatitis C there were effects of being infected. Before diagnosis he changed from being an extremely creative writer, artist, actor and English lecturer, living a full on social life. Over the 1980s he changed to having no energy and a limited ability to work a full week. He didn't want people to go into our home anymore. He was a different person. After diagnosis this just seemed to get harder and harder for him. There was a huge physical impact on his health. He was already depressed when he was diagnosed. The whole thing was a life sentence. My father stopped having dreams for his future. Before he was always writing, planning and creating. He went from that in the early 1980's to in the summer of 1992 taking early retirement from work at the age of 57.

21. My father was diagnosed with depression but he did not want to take anti-depressants. He did a lot of research on depression and looked at the side effects, which led him to the decision that he did not want to take a further risk. He felt like he had been exposed to enough already and he did not want to risk any more problems. I didn't know if he was going to live to see my wedding in 1995. My father was also very frightened that his younger brother

Desmond Donnelly was infected as well. He worried a lot about his brother. Desmond had multiple cancers and passed away in 2009/2010. This really caused my father an immense amount of worry and stress. It is hard to express how frightened my father was that his brother had hepatitis C as well. My father had 4 children of his own but he went from being an outgoing happy parent to not being able to bear more than 1 grandchild at a time visiting him. He used to ask us every time we went to visit him, did we have to bring all the grandchildren. He just couldn't bear it. He loved his grandchildren dearly he just couldn't handle the noisy, busy, environment that children bring. He did not have the energy.

22. My father was diagnosed with ME in the 1990s as well. Years later, I have learned through reading on the internet, that ME symptoms are likely from the hepatitis C. It was a life destroying condition with absolutely no mental support.

23. My father had the risk of variant CJD as I describe in section 3. He had chronic fatigue. He had physical pains in his joints and swollen ankles. He was worried about the colour of his hands and used this as a marker of the illness. He would watch how red his hands were becoming and decided in his mind that this was the ticking clock of the disease. His abdomen was swollen. He had to have his liver tested every few months. He was always worried about having liver cancer. He had very poor digestion and a lot of pain.

24. My father's hepatitis stayed at stage 1. He had a liver test every 6 months and his readings stayed acceptable, but his liver function did test towards the high risk end. His liver also did get larger, but it never developed into stage 2 or cancer. Ultimately his liver did not deteriorate enough to reach stage 2. He had a stroke in 2015. He was at home when he had the stroke and suddenly passed away that night in the Western Infirmary, Glasgow. It was quite a significant bleed on the brain that he had. It was also sudden and unexpected. I am glad that he did not have years of suffering from cancer. The exact time he passed away, I suddenly woke up and I felt something touch my leg. Then the next morning I found out he had passed at that time.

25. My father refused treatment of Interferon when it was first offered to him. Ribavirin was not available at that time is my understanding. If it had been available, he may have refused that as well. When Interferon treatment was offered, there was not much information. However, the doctors were explicit about the side effects of treatment. He was told this was something that could stall the development of the infection but there would be severe side effects. My father was unwilling to take the risk for something that was unproven to work. He was told it may help with the liver but there would be massive side effects that may make his overall health much worse. My father said "*I can't feel worse than I already do*" and he refused the treatment. He was very concerned that the treatment would adversely affect his depression even more than the infection which had caused it. I exhibit a letter dated 19th December 1994 as **WITN2124007** and a letter dated 11th April 1996 as **WITN2124008.**

26. The greatest obstacle for my father at the time he lived through this, was the lack of mental support. Today there is more information and support for these types of infections. Back then there was nothing. Ironically the only time my father received counselling was when he was burgled in about 2000. Victim Support came out to see him and arranged for him to talk with someone. He appreciated this support.

27. I don't know if there were treatments available that were not made available to my father. I think mental health support should have been given, I can't make any other comments about the other treatments.

28. As my father declined the available treatment of Interferon, because of the side effect risk, there were no mental or physical effects of treatment.

29. I do not believe that his infected status impacted upon treatment for other medical conditions. My father attended a caring haemophilia unit. Every time he needed treatment for anything, he would go to the Haemophilia Unit at Glasgow Royal Infirmary. This included dental care. He was never turned away for anything. When my father travelled down to London to visit me, his

unit would write him a letter to show to St Thomas's Hospital in London, in case he needed to be seen for any reason.

30. The main thing that changed for my father was his social life. The infection changed his relationships with anyone he came into contact with. My sister Siobhan was still living at home when my father was diagnosed. She grew up with a very different father than I did. The father I grew up with was fun, creative and lively. The father she grew up with did not want to do anything but sleep and be alone. Because he was a carrier of haemophilia, he felt responsible that it was his genes that would have an impact down the generations. My three daughters knew that they had to be very cautious when they saw him. They knew he was ill. They knew not to jump on him. They were careful and considerate. He just didn't want them to play around him. Now they understand more about the infection. The impact on them has been to the point that they will think quite carefully about having children of their own. Because of the genetic risk there will be a chance their children have haemophilia and then their children could be exposed to something akin to hepatitis C in the future.

31. I never knew if my father was going to be OK. I remember the worries of my wedding. I never knew if he was going to be OK for it, I was questioning, this is my wedding, is he going to come? Is it fair to put him through this? Will he be able to give his speech? There are lots of moments that he has missed, baptisms, the children's birthdays, it was too much for him. There was too much travel involved. We were living in California in the mid 1990's. I would always think twice about phoning him or talking to him. I would even worry that phoning him was too much and I should leave him alone. I didn't spend enough time with him, I could have if he had been well.

32. There were no stigma problems at all with hepatitis C on our family. The stigma has never worried me. The only stigma I have seen is when I donate blood and the Blood Transfusion Service ask questions about my relationship with my father, when I tick the box that indicates I know someone who is infected. It may have been different if it had been HIV, but this was not applicable to our family.

33. There was a huge impact of my father's infection on my mother. She is intelligent creative and social. She compromised what she could do and she stayed my father until the end. My mother has lost 30 years of her life living with someone who had a big disability which had an impact on her. It was a large sacrifice what she did for him. My father was unable to go to social events and holidays and therefore she wouldn't go. The loss for her is immeasurable. My mother carried on working, doing everything for him. She was also living with the daily fear that his liver would just stop working and she would monitor his physical symptoms as closely as he did.

34. My father's work was as an English Lecturer at Clydebank Technical College. They never knew he had hepatitis C. They thought he was just tired due to his haemophilia. He was constantly phoning in sick. Eventually he did have to give up work. He had a discussion with work at some point, and he was given early retirement in 1992. He got a reduced pension and he hadn't paid his full National Insurance contribution so he was not receiving a lot of money for his pension.

35. My parents were fortunately financially OK to survive. Certainly however, he wouldn't have retired early if he could have avoided it as my father loved educating people. He had friends at work that were understanding and supportive. However I don't think those in charge at its work were. In fairness they did not know and from their perspective he was never there and would not turn up to work which was not helpful and when he did turn up he was no in a fit state to work. Eventually his employers and my father came to an agreement and he took early retirement. My mother took retirement as a primary school teacher at age 59 and then went back to work to support her family and has never stopped since. She always had the anxiety of whether there was enough money. My mother is now 81. She is still working as a supply teacher in primary schools in Glasgow.

36. There were no work or school effects on me relating to my father's infection. I felt guilty about not working in Glasgow. I did wonder if I should move to California. I did the job for 3 years and then came back to the UK.

Section 6. Treatment/Care/Support

37. There was no support. No one ever came to my parents or helped my mother with the numerous daily challenges she faced. There was no mental support, nobody ever came. If my father went into the Glasgow Royal Infirmary, Haemophilia unit, they would care for his needs and they were very caring and social. However no one came to him. My mother did manage though. She is incredibly strong and believed we should get on and do things ourselves.

38. There was no psychological support offered to anyone, not me, not my mother and not my father, not anyone in the family. My mother should have certainly been offered support and my father should have received this as well.

Section 7. Financial Assistance

39. I do not know when and how my father found out about financial assistance available.

40. I believe that my father received £20,000, a one off payment from the Skipton Fund, but I believe this is the only money he got. I don't know any more details.

41. I do not know the steps involved in applying for financial assistance.

42. I do not know if there are any difficulties or obstacles in applying for or obtaining financial assistance.

43. I do not know if there were any preconditions imposed on the making of an application for financial assistance.

44. The amount of financial assistance received is inadequate. We lost our father who was forced to live on a reduced pension and was struggling on with no prospects of success. There were no more promotion opportunities for him,

no more writing dreams. There was a lot more the NHS and government could have done to support the infected and the affected like my mother. People do not want to beg for assistance and that appears to be what the Skipton Fund was asking them to do.

Section 8. Other Issues

45. 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 29/4/19