Witness Name: Catherine Joyce Donnelly
Statement No.: WITN2122001
Exhibits:
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INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF CATHERINE JOYCE DONNELLY

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

I, Catherine Joyce Donnelly, will say as follows: -

Section 1.

1. My name is Catherine Joyce Donnelly. I prefer to be known as Joyce. My date of birth is the GRO-C 1937. My address is known to the Inquiry. I am a widow and living alone, I have family that live nearby and far away and I am currently in good health. I intend to speak about my late husband Thomas John Donnelly's infection of hepatitis C. He was known as Tom. In particular, the nature of if his illness, how the illness affected

him, the treatment received and the impact it had on him and our lives together as a family up until the point of his passing on the 28th February 2017.

Section 2. How Affected

2. I was married to Tom in 1961 and went on to have and raise 4 children with him. Tom was historically referred to as being a 'bleeder' and then to be given the label of suffering from haemophilia. Tom was infected with hepatitis C at some point in the 190s or 1980s by receiving infected blood products. He was diagnosed with this in 1991 and he and I continued to live with the disease up until his passing on the GRO-C 2015 from a cerebral haemorrhage.

3. Tom suffered from haemophilia A. He was considered to be mild/moderate in severity. He was officially diagnosed with haemophilia when he was an adult. Tom was born in 1935. As a child, he was referred to by the doctors as a 'bleeder'. He was not given the haemophilia label until he came to Glasgow from Dunoon in his early 20s. He was diagnosed by the Royal Infirmary Glasgow. I have his medical records and he is referred to in them as being mild/moderate, however 10 years before he died, he was considered severe because there were antibodies detected in his system, feeding on the Factor VIII in fact he had no resistance at all at this point, his clotting factor just didn't exist at that time and the doctors at the Royal Infirmary, Glasgow, had to find products to counter act this. I don't know if this was part of the hepatitis C or a separate matter but it was quite worrying.

4. Tom received Factor VIII. Prior to receiving this, he was getting transfusions in the late 1960's until Factor VIII, the great 'saviour drug' was introduced. According to the form that was completed for the

Skipton Fund, he was receiving Factor VIII concentrate, and cryoprecipitate.

5. Tom was under the care of the Haemophilia Unit Royal Infirmary; Glasgow (RIG) this is where he would go for most of his procedures. He had a few minor operations done at Gartnavel Hospital Glasgow. He was registered with Radnor Street GP Surgery, Glasgow, under the care of Dr Harrison. Tom would always receive a product before an operation or procedure was done elsewhere, so for example, he was under the care of Gartnavel Hospital Glasgow, latterly in his life for wet macular degeneration, which required injections to his eyes. Before he went to Garnavel Hospital to receive these injections he would always have to visit the RIG to receive his products beforehand. He was under the care of Professor Lowe at the Royal Infirmary, Glasgow.

6. Certainly during the 1970s and 1980s he was receiving the infected products. Tom was in and out of hospital with a lot of dental problems and as a matter of course, he would receive a product as a matter of procedure before anything else was done. He also had problems with anal abscesses as well. Any procedures or bumps and bruises etc required him to receive a product as routine.

7. Symptoms of hepatitis C, tend to take a long time to emerge once someone is infected, however for Tom, symptoms appeared very quickly after the treatment in the mid to late 1980s. He ultimately had to take early retirement due to the symptoms he was exhibiting. Tom self-diagnosed himself as suffering from ME because of his acute depression and chronic fatigue. He had been tested when the first haemophiliacs died in the mid-1980s when he was tested for HIV and he was told then that he was HIV negative, but there were still haemophiliacs dying. He was retested and latterly he was told that he had hepatitis non-A, non-B. Prior to this he knew that he had all of these symptoms and he couldn't function properly at work. As it was

building up, he couldn't look for promotions at work, he couldn't even do the job. He was a lecturer for English and I used to hate having to phone his employer and say that he wouldn't be into work that day because he couldn't leave his bed. It was very difficult to put this into words. When you are phoning someone into work, as sick, it is difficult to get the point across that he is in bed and he cannot get up. That does not make sense to people. They would wonder, is it flu? A tummy upset? It wasn't anything like that, it was chronic fatigue, which he suffered from the rest of his life.

8. In 1991 I was working full time at that time, so I wasn't with him when he found this out. I would presume it was the doctors at the Haemophilia Unit that told him. I can't recall details of how I found out about the infection, but what I can recall is that Tom took the news badly. Tom was a highly intelligent man, 3 years after his death, I still find pages and pages of notes, about what he has written about the condition. He would be writing, about what they were doing, what they should be doing, what they might do about it. He was very bitter about the whole thing. In the 1980s when we first knew there was something certainly wrong, he was very bitter. He said that it was the Government's fault, which I believe as well. Tom said they knew what they had done, they knew who was involved and it was up them to do something about it. He refused to apply to Skipton at first. The nurses at the Haemophilia Unit, would ask him, have you applied to the fund and Tom would say "*It is not up to me, it is up to them*" the nurse at the unit said to him, "*That's not going to happen Tom, you are going to have to apply*". Eventually he did and he received £20,000. He was very reluctant to do this though as he felt the onus was on the government to do something about this, as they had sanctioned the whole thing in the first place by buying in the infected blood.

9. When he was told he had hepatitis, this was a disease of the liver and that they would monitor his liver and at some point he would get cancer of the liver. It was a liver disease. They never said anything

about chronic fatigue or the acute depression and all the other aches and pains that he had, things that people now know are associated with the condition were never mentioned. It was just purely; "this will damage your liver and therefore you must give up drinking. If you continue to drink you will be contributing to your early death."

10. I would imagine that Tom would have asked being the person he was, whether they didn't know is another matter. They knew what was going to happen at the end with the liver cancer, but possibly there were not aware of the side effects that came with it and it was the side effects that Tom had for 30 years. He lived in day in and day out with all these other side effects that were crippling.

11. Well I think information should have been provided in the 1980s. It was 1991 when the whole thing came out, they knew they could have made it public in the 1980s in my opinion, but I believe they were trying to keep a lid on it. Tom's medical records interestingly start in 1992 and it was the same with the GP records. I went to the GP and requested them, they told me no, they don't keep the records and I would have to go to the health board. I went to the health board and they told me, the GP would have to make a request, the GP did that, the GP then got some medical records, went through them, sent me a couple, but again, they start in 1992. I have never received a full explanation as to why this is. I wrote to Gartnavel Hospital and said, 'These records are incomplete' because he had been a patient at the Haemophilia Unit from the 1960s, they just didn't reply. I have filled in a mandate for Thompsons Solicitors to try and get the records. I know people who have been told that their records are kept for medical research or their records just aren't there anymore. When I phoned the health board, they told me that they only keep records for 3 years after a patient's death, however she went to look and confirmed that the records were still there. But she didn't say the records from 1992 are still there and that was what I received. The information I am keen to get, the 1970s and 1980s doesn't appear to be there, at least to

me. I would like the Inquiry to look at, why do Tom's records only start in 1992?

12. I have no view. I accepted what Tom told me that he had a liver condition that was severe.

13. I have no idea about what information Tom was given about the risks. I was not given information. The staff at the Haemophilia Unit were lovely, the girls there, couldn't' do more for their patients and if I wasn't working I would take Tom up. They always made a point of asking how I was, because they knew how Tom was. They were very caring.

Section 3. Other Infections

14. Tom was at risk of Variant CJD. There was a risk factor. He was told if had to have any surgery that the equipment would have to be destroyed. It was the RIG that told him about this. It was another one of those things. He used to think, how long did he have, he certainly had his liver tested and a lot of tests periodically conducted, he would question if he had months or years to live, what was going to ultimately happen to him. His whole experience crippled him, he had no social life at all. He put a lot of thought into his condition. I am not aware of him ever having surgery.

Section 4. Consent

15. Nobody said this product could cause him problems. The factor VIII was a saviour to his problems, that was the way it seemed at the time.

16. Tom wouldn't allow for that to occur.

17. I don't know who had full information, but I don't think the doctors had the full information, they did their job.

18. I don't know if Tom would fall under this category but I have heard that haemophiliacs were a popular group of patients to test on but I don't know

Section 5. Impact

19. Catastrophic, it destroyed his life, he was a brilliant man and a very social man, it took the social aspect out of his life, as he wasn't to drink, so he didn't go to the pub, so the social aspect of going out and meeting people and having a drink was denied to him, so he didn't go out. He spent the rest of his life at home basically. I took early retirement and I would suggest things that we could do together, but because of the chronic fatigue he would say, I would like to, but I can't. I would try to arrange a holiday and he would say I don't feel up for it, I would try and persuade him and say, you would like it when you got there, but he just wouldn't. Hepatitis C was a very significant factor for the rest of his life. It dictated what he could and couldn't' do. He didn't want people in the house to visit him either. He couldn't have people to visit him, he couldn't stand it. He liked our daughter Roisin to visit but he would request that she came alone without her own children. He couldn't manage the mass of people. Tom used to be an extrovert, he was an actor. There was 3 in the marriage, there was Tom and I and hepatitis C, and hepatitis C dictated would could or couldn't happen. In retrospect it had a big impact on me. We couldn't go on holiday, the other thing was, we couldn't have workmen in the house. If I said, we should get something done about a part of the house, he would say "*Are you trying to make me feel worse than I already feel*?" The thought of it would set him back a fortnight. It would involve someone coming into the house, making a lot of noise and he just couldn't cope with that. Therefore, not a thing was done to our house until he died. My son pointed out to me at one point, "*Do*

you realise the state your house is in". I said "*Yes I do, but I can't do anything about it*", I would have had to put him in respite.

20. There were a whole lot of things that were not recognised at the time, but his mobility was affected, he had red palms which is a sign of the hepatitis C, gradually breaking down his system. Towards the end of his life, the last 5 years of his life, he was taking a lot of spontaneous bleeds including some from his ear.

21. It was a gradual deterioration of his system. He had a different outlook in the 1980s and his abilities, that was when he took early retirement with the reduced pension that came with it. Tom's liver was enlarged, but it was not to the point he had developed cancer. Hepatitis C is not on his death certificate; haemophilia is with the cerebral haemorrhage. His death was sudden; I wasn't in the house when it occurred. It will be one of the biggest regrets for the rest of my life. It was a Friday when he had the haemorrhage. I look after my grandson on a Friday. On this day he phoned me at lunch time and was talking about making a pizza. He said in this phone call, that he didn't want our grandson to come up to the flat as he didn't feel well, so I didn't bring our grandson up there, which I usually did. When I came home in the evening, I found him on the floor. He was unconscious then, I have neighbours who are doctors, who I called upon for help and he was taken to hospital after a wait of over an hour for an ambulance. Tom died at 2am in the morning of the 28th February 2015.

22. Tom refused treatment. He was offered interferon, but he asked the nurses how it would make him feel. They warned him it would make him feel worse and his response was "*I can't imagine feeling any worse*" so on that basis he refused.

23. I don't know if dentists would have treated Tom because of his haemophilia, he only went to the RIG for dental work. His care was

really mainly done at the Royal Infirmary Glasgow and a few other procedures were completed at Gartnavel Hospital.

24. Tom was deprived of his social life, it deprived him of mixing with his friends, it deprived the family because he couldn't be bothered with them. Our first grandchild, who is 25 now, got the best of him, he would spend time with him, I think this shows a level of tolerance that he lost over time, he just could not tolerate children. I began to wonder if he could even tolerate me at times, he did not want people and noise and he had to have his own space, his own things around him. He took solace in books and cryptic crosswords. It wasn't that he didn't like his children, it just became a case that he didn't care if they didn't visit and he didn't want the grandchildren visiting. It is hurtful to people, they don't understand. We had two girls and two boys. I felt the girls understood better, I felt that the boys thought their dad was just a bad tempered bugger, which he was, but it wasn't his fault, he couldn't control it. That's what happened to him. Our youngest grandson has fond memories of his Grandpa making good potato scones. Tom would write poetry and wrote poems for his grandchildren which they have kept. They have good memories of him but there was no rollicking or fun to be had. You could never be sure that he was going to turn up to any social event.

25. I took early retirement because I thought we could have more time together, but anything I proposed, he refused. I thought I can't just sit here all the time I would go mad. He couldn't' stand me doing the hoovering, he didn't want me to move his papers or his books. I couldn't do anything and thought I was going to go mad, so I started to do supply teaching. I remember saying to people, this was my social life, which they thought was amusing, but it wasn't, it was a social life for me. If I could get out for a while, I didn't mind going back, but I couldn't spend my whole life at home with someone who was so depressed and so fatigued he couldn't' do anything. It sounds callous but my own GP said, "No you have to look after yourself as

well or you are going to go the same way". I wasn't working full time, but I was in and out which broke up my days. When Tom declined social events, I would also decline to attend social events. I did tap classes and other classes to go out in the evening, to socialise with people. Tom didn't' want to create a social life, he didn't want to face people. I was very resentful of the situation, Tom was a member of the Haemophilia Society in the 1980s, he stopped going to the meetings because he couldn't sit through them and listen to people "burbling" on as people often do in meetings. After Tom died I joined the Scottish Infected Blood Group and started going to meetings as I feel somebody has to be held responsible. Someone knew, it wasn't right and they let it go on. Gerry Malone was a lawyer in Glasgow and was in Margaret Thatcher's Government. He said "if they hadn't had the treatment at the time, they would have died." So more or less what are you complaining about. People knew and they have to be held to account. People have very strong emotions about the whole thing and the more you hear, the more upsetting it becomes.

26. Only in the past few years, have people even asked "is this what Tom had?" People were never quite sure what was wrong with Tom, we didn't move the type of circles where stigma existed for hepatitis.

27. Tom applied for early retirement on the grounds of ill health in 1990. He didn't want to retire but he knew he couldn't continue. He was missing too much. He worked at Clydebank Further Education College.

28. There was no impact on my own working life. I was a school teacher and I live near to the school. I retired in 1997 and I have retired every year since then, but last summer I finally decided that this was enough now and I am devoting my time to the Scottish Infected Blood Group and this Inquiry.

Section 6. Treatment/Care/Support

29. There wasn't any support unless he needed treatment. The Unit were supportive as far as they could be. Psychological support was not offered to Tom as far as I am aware, and not to me. The nurses would enquire after me but it was superficial. I think I should have been offered psychological support, it is happening now, but it has been a long time in the making. As time went on, Tom would have probably refused psychological counselling. Maybe not in the early days but as the disease progressed, it wouldn't have mattered. Psychological support would have benefitted our children though. We never sat down and discussed it as a family, it would have given them an outlet.

Section 7. Financial Assistance

30. We were aware of the Skipton Fund through conversations with the nurses at the haemophilia unit and the media in the 1980s. Tom refused to apply originally, he believed that the government should have contacted him, however the nurses told him that that wasn't going to happen. So he did apply.

31. Tom was awarded £20,000 from the Skipton Fund. He never received anything else. As a stage 1 widow, I received £30,000 from the SIBSS, which I am on the panel for, in December 2018. Stage 1 widows have been overlooked up until now. For me there shouldn't be a stage 1 or 2. Chronic or advanced, if you have hepatitis for 30 years you have the effects that is it. As hepatitis wasn't on Tom's death certificate it wasn't categorised as stage 2, it was stage 1 and there was nothing being done for stage 1 widows. The Haemophilia Society and the SIBF were fighting this and we got this recently. I am also getting 75% of what the stage 1 infected are receiving, which works out at about £14,000 per year. About £1,100 a month. A hard fight.

32. The process was straight forward, it was just a case of filling out a form and handing this to the consultant to complete.

33. As a group we have been fighting for the stage one widows. There is one individual who is classified as a stage zero. Skipton wouldn't accept her husband had died of hepatitis C so she has had nothing. My son once said to me, that he thought I was spending too much time on this and I said to him, no I am speaking for the people who can't speak for themselves.

34. I had to fill in a form that said that Tom was severely affected by hepatitis C. The SIBSS had a form that asked if you were severely affected, moderately affected or negligibly affected.

35. Through the societies I have learned that some people have been in dire straits. This didn't' happen to me as Tom got it, in his 30s. He already had a job. I know people who have grown up not having that security or the financial background that he had when he first got infected. There are a whole lot of people who are a lot worse off than we were. Other people have lost their jobs, and had nothing to fall back on at all.

Section 8. Other Issues

36. I certainly will follow the Inquiry and go back down to London when the relevant time comes. I will also provide Tommy Leggate with the file that Tom kept about his experience, and if there is anything that would be relevant to the Inquiry I will pass it onto Thompsons Solicitors.

37. Thompsons are recovering Tom's medical records, and I will be given the opportunity to review these.

Statement of Truth

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

Signed GRO-C

Dated March 26th 2019