Witness Name: Samantha Burney Statement No.: WITN0731/01 Exhibits: WITN0731/02 Dated:

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF SAMANTHA BURNEY

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 19 November 2018. I adopt the paragraph numbering in the Rule 9 request for ease of reference.

I, Samantha Burney, will say as follows: -

Section 1. Introduction

- 1. My name is Samantha Burney. My date of birth and my address are known to the Inquiry. I am married to Chris and have three children.
- 2. I can confirm that I have chosen not to have a legal representative and that I am happy for the Inquiry team to take my statement.
- 3. I intend to speak about my father-in-law, Peter Burney, who was infected with the hepatitis C virus. In particular, the nature of his illness, how the illness affected him and the impact the illness had on our family.

Section 2. How Affected

- 4. I've been with my husband Chris, living with him and Peter and Christine, since I was 16. I have been a part of the family since then. Only 10 years ago we moved out but we still see them everyday.
- 5. Peter first got poorly in 2009 and he got really poorly, really quick. We were told that it was his lifestyle choices and that he was drinking too much alcohol. We would have a drink now and again at family meals, nothing too excessive so I couldn't understand that as he was only young.
- 6. He was in and out of hospitals in 2010 and we were told it all came down to alcohol excess. His liver was failing: he had ascites and it got to a point

where they couldn't drain him anymore as they were draining his life fluids as well.

- 7. At the end of 2010, we had a meeting with his doctor about his state. Even though he was very poorly, he was compos mentis, fine, very alert. Peter is a private person and would keep something like he was going to die to himself. When we had the conversation with the doctor, I thought they were telling us what Peter already knew. He was compos mentis so I thought they had told him. They said if anything were to happen, they wouldn't resuscitate him. They said he would be in a cabbage state and wouldn't be able to have a conversation. They said that, and we agreed if he got that poorly but we knew Peter was not at that stage yet. We went away, Chris and Christine were really distraught so we did not go and talk to him that day. I was upset as well but caring for them both. The meeting about the DNR happened right near Christmas and nobody talked about it because we thought Peter knew. We thought he wasn't saying anything about it because he didn't want to talk about it. The doctors were the only ones who had talked to us separately about it. It was a vicious cycle. It's only now that we are talking about it more. In relation to the DNR, I even think now that I should have said something.
- 8. For him to find it as well as if it was hidden from him, was terrible. I've looked at the DNR document and it says if the patient was composed mentions then that discussion could have been had with him. He was poorly but still able to make that decision. We thought, when that point comes, we will have another discussion with the doctor and talk about it then. And it looks so bad on us, because it looks like we agreed. We agreed that's what would happen if that was the case, but we weren't at that point. It wasn't a very happy Christmas, but it might have been the last one so we didn't talk about it.
- 9. Only in 2011 we found out he had hepatitis C. When he was told he had hepatitis C, no one gave us any advice about how to deal with it. Christine just thought it was part of his liver disease. She didn't tell the rest of the family until 2011.
- 10. You could tell as soon as he realised what was happening, he stopped everything with the kids. Wouldn't kiss them, share treats with them, he thought he would give it to the kids. It changed that whole relationship. It's a crying shame as if he'd died at Christmas then we never wouldn't have known. It's a horrible thing to think about, how it could have been had he died and us not knowing. It's never going to be the same as it was before, even though Peter looks good and is a force to be reckoned with, he's not the same. After 2pm Peter loses energy, he has to do everything before 2pm.
- 11. Still pretty raw. It's the "what if's". What if we would have known before? If we knew he had infected blood or hepatitis C, he would have changed his lifestyle and it wouldn't have got to this stage. For Chris, he doesn't like to talk about it because it brings everything back. It's affected all the family.

Peter will never be that person again. He was the breadwinner for the family. Chris has a driving school, and Peter helped run that. Then Chris was told his dad only had 2 weeks to live. What are you going to say to your two young girls about why their grandad has gone?

- 12. Peter has to have two scans every year and eventually it's going to turn into cancer. You have the build up to the appointment, the appointment itself and then the build up to the result. Eventually we are going to have to tell everyone this is what it is, hepatitis C. In my mind it's like AIDS you get it through needles, other things, you don't get it from doing nothing. How do you explain that to people? How do you explain that to your kids? We are just waiting to be told he has liver cancer. It's going to happen and it's horrible to think about it everyday. If he looks a bit off or a bit yellow, we get worried.
- 13. Since leaving school I've been a carer, caring for people with mental health problems. When he was in hospital, I used to care for him; cream his body, legs and shave him. I didn't wear gloves or protection to shave him. I didn't think I could catch it, just thought it was liver disease. If Christine's not here, I have to look after him. Preparing meals for when she's not here and make sure he has everything he needs.

Section 4. Consent

14. N/A

Section 5. Impact

- 15. Kids are pretty adaptable. They have just got used to not kissing granddad on the lips, sharing food with him. It's better now because I don't think they don't see the changes as much. Obviously if he's taken away from them from liver cancer, that would have a massive impact on their lives. They have grown up with him as babies, lived with him and come to his house four times a week.
- 16. Chris gets pretty upset about it. At the end of 2010, the same time as Peter got ill, his nanna died. He already lost a brother when he was young. So it was Christmas, his nanna died and then his dad was getting sick and told he had two weeks to live. A year later he had an accident. Peter provides a lot of support to the family. If I had to deal with Chris on my own, I would have become a lunatic. Chris is really angry about what happened to his dad, more than emotionally upset. We could have known at the very beginning in 2009, when he started getting sick.
- 17. Chris could have contracted hepatitis C, and then our kids could have got it. There are people out there who don't know they have it, people who died

and never knew they had it. No amount of money is going to bring back people's loved ones. They've still got the heartache, still got the pain.

- 18. In terms of stigma, we didn't mention it to really anyone in the family for a while because we were worried about what they would think. In terms of their reactions to the news, it depended on the person in the family. Everyone is fairly close family. If Peter died and we did not know that he contracted hepatitis C from the transfusions, everyone in the family would have thought, "what a selfish man to leave your family like that". He would have died with no dignity at all. That is one of the worst parts about it.
- 19. In terms of work related impacts, obviously Peter had to stop work but it also had an impact on Chris. Chris was a driving instructor, and he worked his own hours. If he didn't work, he didn't get paid. When Peter was really bad and in hospital around Christmas 2010, he pretty much had to stop working. He was back and forth from the hospital, and we had to get people to cover for him. As it was around the Christmas period, people were getting presents of driving lessons so it had a big impact on us because he wasn't getting paid for it. After the Christmas period, Chris was never the same. A year later, he had a car accident, which definitely had a big impact on his ability to work, but things had actually changed completely before then when Peter got sick.

Section 6. Treatment/Care/Support

20. No counselling or support was ever offered to us.

Section 7. Financial Assistance

- At Leeds Hospital, and Chris and his Dad were in the lift and saw the flyer for the Skipton Fund. Had to prove it with his blood transfusions.
- 22. I was not so involved in the applications for financial support. Chris and Peter sorted most of this out.

Section 8. Other Issues

- 23. I do think out of all this, they should make sure that everyone is aware. They should be going through people's medical records and contacting people if they have ever had any blood transfusions or blood products and letting them know that they may have been contaminated. There should be more posters, more awareness about hepatitis and infected blood, particularly at the GPs. There's awareness raising campaigns for bowel cancer, so why not this?
- I just hope they get justice for all the people, and for the families of those who aren't here anymore.

Statement of Truth

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

Signed _	GRO-C	
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Dated	28.1	.19	