Witness Name: Christine Burney
Statement No.: **WITN0730/01**
Exhibits:
Dated:

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF CHRISTINE 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, Christine Burney, will say as follows: -

Section 1. Introduction

1. My name is Christine Burney. My date of birth and my address are known to the Inquiry. I am married and have two children. My eldest son passed away when he was 19 years old. My younger son is 37 and married with three children.

2. I can confirm that I have chosen not to have legal representation and that I am happy for the Inquiry team to take my statement.

3. I intend to speak about my husband, Peter Burney, who was infected with the hepatitis C virus. In particular, the nature of his illness, how the illness affected me, the treatment received and the impact the illness had on my family and I.

Section 2. How Affected

4. Peter was infected with hepatitis C from blood transfusions either in 1975 or 1986. We were together then and I don't remember any risks being explained to us.

5. We were just getting on with our own life when Peter started becoming a little bit poorly in 2009. So I told him to go to the doctors, and he wouldn't at first but eventually he did. The GP did routine blood tests, and told him to cut down on drinking. When he went back to the doctor, his liver enzymes were higher than ever. At this time, my Mum was very poorly, she was living here

and I was taking care of both of them. Peter's stomach was distended, and he couldn't go to work. He had to have it drained. He went into hospital in June/July 2010 and just got sicker and sicker. He could still shower and get out of bed. Sometimes you had to push him in a wheelchair, but only when his stomach was really bad.

6. At no time did they tell us it was hepatitis or explain how he got it. He was put on a ward with alcoholics so he thought that's how he got it. Dr Das, who not a nice doctor at all, never even looked up from his notes while he was talking to you. I was also looking after my Mum at this time. She was in the same hospital.

7. He was in and out - he would get a little bit better then the fluid would build up again. In 2010, it was just visiting, visiting, visiting at the hospital. One particular day, Peter told me I had to get tested for hepatitis C. I just related it to his liver being poorly. I got checked and I was fine. We were still doing the daily routine - going to hospital then going home.

8. His consultant went on holiday, then Dr Ahluwalia came to Peter's room one day around December 2010. He asked me, "has Dr Das ever spoken to you about Peter's illness?". I said "No" and he asked to see the family for a meeting. I told my son, Christopher that we had a meeting with the doctor. So me, Sam and Christopher went. There was a secretary taking notes. Dr Ahluwalia said to us, "Peter's very very poorly, and we don't expect him to survive". And we're sort of looking at each other, and obviously it's breaking my heart. He went on to say "and in these circumstances, we put a DNR against his name". So I'm crying, screaming. Christopher was crying and he ran out of the room. The doctor went and got a nurse; I asked what I was going to tell Peter and she said to wait until we'd all calmed down a bit. They never asked us to sign anything. The doctor told us he needed to get to the MRI, a liver specialist hospital. I asked how long it would take and they said a couple of weeks. Within 4 hours he was there. A couple of the family had come down because I had told them. He was wondering what was going on with all the family there, he thought they were coming to visit my mum who was in the same hospital. He wasn't even yellow, was talking to us all, making jokes. The day after my mum died. Talking to the funeral fellow, I was telling him that it might be a double funeral. Peter was gutted he couldn't come to the funeral. We buried my mum on 27 December 2010. Peter was too poorly to come.

9. In January 2011, Peter pinched his file and called me and asked me "what's this about the DNR". We had always discussed what we wanted to happen in that situation, and we said we don't want to be a cabbage. He went absolutely berserk. I told him: we're not doing away with you yet and he calmed down. When he went back in January for the TIPPS - the doctor told him that he wasn't going to do it because his vitals/signs had come up a little bit. None of the doctors ever spoke to me about the DNR again. I thought because he'd improved that they'd take it off his file, but they never did.

10. He had to sign an alcohol free thing in the June 2010. Back in July 2010, Dr Das asked Peter about whether he had had any transfusions, injections, tattoos, gay sex. But he never explained why he was asking. Then it was just appointments. Nothing was discussed until March/April 2011 about hepatitis C. There was no discussion of risk to family members, lifestyle changes. There was never a mention of his hepatitis C. We just thought you got it because your liver was poorly. There was no connection made to the transfusions.

Section 3. Other Infections

11. N/A

Section 4. Consent

12. Nothing at all was explained about the liver tests and the test for hepatitis C.

Section 5. Impact

13. There has been lots of mental impacts - he's always been the provider. My son, Craig was born with disabilities so I couldn't work, I had to look after him. Peter's always been the breadwinner so that really really affected him. Watching a big strong working man become very depressed and wondering why. He would say to the doctors, am I ever going to get over it? We've never ever been sat down and explained about what will happen with the hepatitis C. He doesn't like me coming to the appointments now for the scans.

14. When he developed the encephalopathy, it was terrible, a nightmare. He was doing absolutely stupid things - ripping money up. I remember getting a call from a woman who asked who kept calling her phone, Peter he kept trying to phone people and was calling her. I told her that it was my little boy calling. Then there was the getting up in the middle of the night. He'd sleep for 10 minutes then get up and start running the bath. I didn't sleep in the room with him so I had an intercom, like a baby one, and I could hear him getting up. I'd hover around him. I saw him putting toothpaste on his razor. Sometimes I can still see bits of it now, when he forgets things - he was never like that before. He's always had a strong mind. They've told him that it'll never go away and that's really hard for him.

15. The first treatment was awful. Peter had to inject himself in his stomach every week. I remember going back to the hospital and doctors looking at his results and finding that his viral count was still high. I think he was on it for six weeks but it felt like three years. The doctors told us that the viral load was just getting higher and higher so they stopped the treatment. The second treatment was great though: he never had any side effects from that.

There is a mental thing to the treatments as well in the lead up to them: you wonder what it's going to leave him with and what it's going to be like. It was horrible.

16. Mentally it was very tough. Doctors told him he only qualified for the second treatment because he did not have that long to live. That affected him greatly.

17. For Peter, it had a big impact on his private, family and social life. He is such a strong man, so he just kept it to himself. He just did not want to go out or to have a social life. I don't think he even told his sisters or his brothers, but because of the DNR that was put against him, they found out.

18. Even to this day, it has a big impact on my social life. We go out for dinner but he cannot have a lot of salt so we are limited. We have found a restaurant that won't put salt in, but that is really it. We used to go on holidays three times a year, Chris was busy with his family so before we just used to take off. We cannot go on holidays together anymore because Peter's frightened and worried about getting an infection because he's platelets are so low. He's very bitter, we both are, but he's very bitter. Christopher is very bitter as well. In terms of my social life, I have been with Peter since I was 16 and the only person I could talk to was my Mum. I had friends when I was younger, but you become estranged from them once they start their own lives. I found it quite difficult because I did not have anyone to speak to when it got really bad for him. I have a sister in England and she was GRO-C at the time, and she had her own life. She was there for me, don't get me wrong, but you just don't want to burden anyone. That was one of the hardest things, supporting Peter but not being able to talk to anyone.

19. In terms of stigma; well we just did not talk about his Hepatitis C. Peter did not speak about it because of the fear of what it would be associated with.

20. Peter's illness was horrible for my son, Chris. He had already gone through losing his brother, then his nan, then he almost lost his father. Then he had a terrible accident in 2011. I was going through my own grief with Craig, and I was dealing with it myself. It did affect him a lot I think.

21. It impacted all of us in terms of the work and financial effects. My son Chris was a driving instructor then, and Peter used to help with that as well but then he had to stop. He got sick pay but it was nothing in comparison to what he was earning. I was not working so it did not affect my work.

Section 6. Treatment/Care/Support

22. No counselling or psychological support was ever made available to me. It most definitely should have been. Even now, I believe it should be.

Section 7. Financial Assistance

23. Peter found out about the financial assistance in a lift at Leeds Hospital. He and Christopher then got straight on it: Peter asked for his medical records back then because he knew that he would need them. He did all of the work applying for the financial assistance himself.

Section 8. Other Issues

24. It was a kind of trauma: you just want to forget. I think because I was going through quite a lot at the time with my mum, Peter and Chris, my brain just kind of shut down. Peter was in and out of hospitals for so many years: it was just an ongoing thing. You just try to forget.

25. I just want to get truth and answers from the Inquiry. If Peter was told years ago, if there was a look back program, he could have changed his lifestyle and stopped his suffering and treated a lot earlier before it got to this stage.

Statement of Truth

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

Signed GRO-C

Dated 28/1/2019