Witness Name: Peter Burney
Statement No.: **WITN006101**
Exhibits: **WITN006102**
WITN006103
WITN006104
Dated:

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF PETER BURNEY

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 17 August 2018. I adopt the paragraph numbering in the Rule 9 request for ease of reference.

I, Peter Burney, will say as follows: -

Section 1. Introduction

1. My name is Peter Burney. My date of birth and my address are known to the Inquiry.

2. 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. I am not currently working.

3. 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. My wife was present for my interview with Deirdre Domingo and Kate Meredith-Hardy on 23 August 2018.

4. In this statement, I intend to speak about my infection with hepatitis C. In particular, how I was infected, how the hepatitis C virus (HCV) has affected me, the treatment I received and the impact it has had on me and my family.

Section 2. How Infected

5. I was infected with hepatitis C through one or both of the two blood transfusions I received in 1975 and 1986. I was given two units of blood at Wythenshawe Hospital during my first transfusion after I was stabbed. I was 16 years old at the time. I received another two units of blood in 1986 at Withington Hospital during an operation on my kidneys. I have horseshoe shaped kidneys.

6. Before the transfusions, I was not told anything about the risks of infection. Nothing. I was with my wife from the age of 15 or 16 and she does not remember being told about any risks either.

7. I can confirm that I was infected with hepatitis C as a result of the blood I was given from my transfusions.

8. I found out I had been infected with hepatitis C in August 2010.

9. In Leeds Hospital in February 2011, I was told that I could not drink for life, but I had stopped drinking in June 2010 anyway. I had to sign a no alcohol agreement for life in order to be placed on the transplant list. I think they mentioned a few other things about the infection, like that I had to change my diet. I do not remember receiving much information about how I could infect my family, though.

10. I was never told that it could possibly be as a result of my blood transfusions.

11. I should have been given more information about my hepatitis C infection because I felt that my family was at risk. I changed the way I acted around them because I was afraid I could infect them by sharing food or cups or cutlery. My granddaughter would say, "Here Granddad, eat this cake" and I would have to say, "No thanks". We would keep things like toothbrushes separate. It had a massive effect; the impact on me can be reflected on them. My platelets were low so if I got a small cut I would bleed a lot. I also had itchy skin from my end stage liver disease and would bleed on my feet, arms and legs. My wife would have to clean the floor with bleach. The hepatitis C virus stays active for six weeks unless you bleach it.

12. Although I have since read my medical records and the history of my transfusions prior to 1991 is written all over them, the medical staff had convinced both me and my family that my condition was purely alcohol related.

13. As I mentioned earlier, I don't remember being given any information about the risk of cross contamination, and my family wasn't told either. Everything we learned was from websites: we managed it on our own, without help. It seems they had total disregard for the safety of my family, and only contempt for me. I was terrified I would infect them after I became aware of how easy it was to infect other people.

Section 3. Other Infections

14. I did not contract any other infections as a result of my transfusions.

Section 4. Consent

15. I was definitely tested for hepatitis C without my knowledge or consent. I was not told about my status even when the test came back positive. I was tested at Stepping Hill Hospital on 14 July 2010, and the results came back that I was positive for hepatitis C on 22 July 2010. I was not told until August 2010. I have those dates in my medical records. I believe when I was told it must have been in a way of, "Oh, by the way you have HCV". The enormity of HCV was never explained to me. I would have thought it was a complication of cirrhosis and a natural progression. I had no knowledge at that stage that it was a terminal condition. I was not told, and neither were my family, even though my wife attended every appointment with me as is documented in my medical records.

16. I was also treated for my condition without being given full information. Doctors were giving me diuretics, which were to treat my symptoms, but would not explain why I was being given them. When I was at the Manchester Royal Infirmary (MRI) around January 2011, I was given lactulose and I refused to take it. I asked the nurse what it was and she told me it was a laxative. I told her there was nothing wrong with my bowels but she told me to take it anyway. With hindsight I now realise that was to treat my hepatic encephalopathy.

17. A 'do not resuscitate' (DNR) order was put against my name while I was in Stepping Hill Hospital on 16 December 2010. I found out in January 2011 while I was having a scan with a view to getting TIPPS. No mention was made to me about the DNR. I was discharged on Christmas Eve, 24 December 2010, yet seven days before I was in such a bad state that they could not discuss this DNR with me. The DNR is signed by Dr GRO-D Senior Registrar under the consultant Dr GRO-D: he was not my consultant. It says verbal

consent was given by my consultant but it is not signed and dated. It also says the DNR was discussed with my next of kin and in the notes, it says DNR being considered by family. Where it asks if a review date is required it says no.

18. In January 2011, at the MRI, I saw the DNR on my file and I kept it so I could show my wife. I put it in a cupboard. A nurse came to my bed and told me that they had lost my file so they did not know whether or not to perform the surgery they had planned on me. I told her I had it and she snatched it out of my hands and said, "You have no right to read that". I said, "I have every right". She went off. My consultant came back in and said my scan was clear so I did not need the surgery. He went on to explain that none of the things he expected to see from the scan of my liver from an alcohol-related condition were there. There was good portal flow and no varices. Although he knew about my blood transfusions at that stage, he still did not tell me and I was still convinced I had brought the condition on myself.

19. I smelled something fishy and knew the DNR was questionable. What made me suspicious about my DNR was the fact that my medical notes never mentioned my HCV or my history of transfusions, though by that stage it was commonly known to the people treating me. I exhibit a medical note made on 16 December 2010 (**WITN006102**) which outlines my prognosis and conditions, however there is no mentioned of HCV. The second page of the note is written by a nurse, verifying my condition who was present in the room when the DNR was discussed with my family. Again there is no mention of HCV here. I also exhibit a handwritten letter from the same nurse who was present with my family when the DNR was discussed, to Dr **GRO-D** and Dr **GRO-D** (MRI) dated 16 December 2010 (**WITN006103**). The letter clearly states cirrhosis plus HCV, and requests that they urgently transfer me to the MRI as I was dying. I believe the doctor and nurse did not mention HCV in exhibit **WITN006102** because had I died and not been resuscitated, the DNR documents would have gone to the coroner, who would have registered my death as alcohol related cirrhosis. There would have been no mention of HCV on my death certificate. This is in keeping with the cover up where the UK has had a spike of alcohol-related cirrhotic deaths, where in the rest of Europe there has been a drop. People in the UK were drinking less alcohol but dying twice as fast from alcohol related liver conditions. Finally, I exhibit a letter from my GP in November 2013 after I asked him to have them remove the DNR from my file (**WITN006104**).

Section 5. Impact

20. The hepatitis C was debilitating physically and mentally.

21. Physically, I started getting really sick in 2009. I suffered from intense fatigue, itchiness, cramps and sometimes my whole body locked up.

22. In 2008, I remember someone said to me, "You look yellow". I thought it was the sun but I think that that was the onset of my liver issues. I went to my GP and had routine blood tests. He told me to cut back on my drinking. I started getting really sick and went for more checks at my GP in April 2009. My liver enzymes were raised. In 2009, I remember we went on holiday and I could not fly home because I was so unwell. I had to stay an extra week. I got home to my GP and he did more tests and found that my liver enzymes were higher than ever. I had a CT, which showed my liver was really damaged and I was sent straight to the hospital.

23. I did not sleep for eight months: I rested but I could not sleep. I became bloated from ascites as my liver failed: my abdomen was so big that I could not dress, shower myself, bend down or walk. I felt like a cumbersome lump. My ankles swelled and I kept getting pains in my right side. From July 2010 onwards, my stomach had to be drained numerous times: 10-15 litres of liquid each time. The drains were due to ascites build up, which is extremely dangerous. At first, they could just put a drain in, but as it kept refilling it then went into what they called 'pockets'. The best way to describe this is if you could imagine a mattress with all of its springs, the fluid went into the mattress springs. So the only way they could drain me was if they used a scan to find the fluid then drain the pockets. This meant that I sometimes had to have six or seven drains in one day. This process was extremely lengthy, extremely painful and extremely dangerous. Each drain inserted mean that I was open to infection. All of this could have been avoided if my GP had been more vigilant and checked the screen in front of him for my history, asked about other possible causes for my condition, e.g. transfusion, and not been so quick to pigeonhole me as an alcoholic. Was he just another pawn in the game, or simply negligent? Whatever he was, he created a massive delay in treatment, which nearly cost me my life.

24. In September 2010, I was admitted to Stepping Hill Hospital because my liver was failing. While there, I was put in a side room as they could see I was in terrific pain. One particular time I was laying in bed and I felt like I had baby's fists inside me, trying to punch their way

out. It was horrifically painful. All the way up my back on both sides cramped. I asked the team around me to give me something for the pain: they replied that there was nothing they could do. That reply to me was earth shattering. I was experiencing pain I could never have imagined: every part of my body was convulsing, I could barely talk. Each time my body trembled the pain got worse. I was crying out in pain. I remember being soaked in sweat, I was vomiting and I thought my head was going to explode the headache was that bad. That headache lasted for days. It was in the middle of the night and I was surrounded by doctors all looking at me: no one was helping me. I'm not saying they purposely withheld treatment. I have thought about this a lot. I don't think they knew what to do. Then again, I don't know what to believe. The above description is only one episode, but there were many others. I think at that stage they had decided it was all over for me, they knew why my condition was such, but they were blaming me for my predicament and telling my family the same. They certainly never mentioned contaminated blood. Not only was I dying, I was being robbed of my integrity.

25. I also became incredibly itchy: I could not stop scratching and itching. My wife would put bandages in the freezer and then put one on top of the other on my arms. When I became aware of my hepatitis C, I worried about the risk of infecting my family if I were to break the skin scratching but I could not stop. Itchy skin is a common side effect to end stage liver disease, as are many other things. I suffered from ascites, cramps, hepatic encephalopathy, jaundice, fatigue, anxiety and depression, confusion and many more.

26. On a weekly basis I get mad urges to eat, like a diabetic. I just have to get food in my mouth and sugar. It can happen at any time and the implications are massive. You have got to try and punch through but it is never far away.

27. Mentally, the hepatitis has had awful effects. I can wake in the morning and have my breakfast, sit on the sofa and I will feel like I've done a full days work, I would feel mentally exhausted. What you have to understand, this condition does not just affect me, it affects my wife as well. Sometimes I think it would be better if I was not here. This virus has stolen all of the last decade of my life and it is ongoing. Sometimes I really do wonder if I am only delaying the inevitable, but while I'm doing that I'm stealing what is left of my wife's life. If I was not here she could meet someone else, learn to live and laugh again. We have spoke about this and her answer is always the same, 'Don't be stupid'. But that does not take away the way I feel: I feel useless,

unable to provide, constantly fatigued and a burden. Why did they let it get this far? All of this could have been avoided with simple lifestyle changes. This whole thing, from my point of view, could have been avoided. It's a mess.

28. As a result of the hepatitis C, my liver began to fail and I developed hepatic encephalopathy in January 2011. There are only three stages of encephalopathy: the first is slight confusion, the second is more confusion and flappy hands, and the third is coma and death. I was at the third stage. My wife set up a bed downstairs for me when the encephalopathy symptoms became really bad. From what I can gather, at night time I would go to sleep for 5-10 minutes. I would wake up thinking I had been asleep for hours. Then I would start my morning routine: I would get in the bath and my wife would be hovering around. I wondered what she was doing. Then I would go somewhere else in the house and she would be right behind me. I would become agitated and ask her why she was there. This would happen four to five times a night. I remember her telling me one time, "Peter you're putting toothpaste on your razor blade to clean your teeth." I realised then that I had a problem. I could not turn the TV over, could not make a telephone call; I could not do anything. I always thought I had a really strong mind; that whatever happened, I would get over it with my mind. I still think I have a strong mind but I continue to get bouts of encephalopathy. Encephalopathy is a recognised brain disease, caused by a build-up of toxins in your body. In a healthy body, your liver dispels these toxins but my liver couldn't do that so the toxins started to attack my brain. On and off it sent me back to my childhood where I was totally dependant on others. Frightening is the word I would use to describe this condition. I can go into a room in my home and not know where I am or why I am there.

29. I have liver scans every six months. They are looking for changes in my liver. Liver cancer is a common cause of death for people with my condition as my body is constantly re-producing blood cells and there is more chance of a rogue cell getting in there and causing cancer. We generally get a letter with six weeks notice of a scan date. No one comments on the possible consequences of the scan, but it's plain to see that this letter has a massive impact on the whole family. During the scan, I try to glean information from the technician but they won't tell you (who can blame them), especially as they think they are dealing with an alcoholic who has brought his condition on himself. After the scan, the one thing I don't want is a letter asking me to go in and see them. I dread the postman coming for the next four weeks. This means that for well over four months of the year, me and my

family are living in fear of a diagnosis of cancer. This has been the case for almost the last ten years. As anyone will appreciate, this has had a massive psychological impact on me and my family. Take now as an example: we're heading towards Christmas and we are waiting for my last scan results which took place on 21 November 2018 (three days before my birthday). That scan took the edge off my will to celebrate my birthday and we now have Christmas around the corner. Again, what should be a time for preparation for celebration, instead is a time of uncertainty and trepidation. Unless you have lived this nightmare, you will never understand it. I would like to say that with the passage of time it gets easier, but it doesn't. It gets harder. This whole contaminated blood tragedy is a mess.

30. In February 2011, I was placed on the liver transplant list at St James' Hospital in Leeds. That was the first time I could see a light at the end of the tunnel. In a weird way, I had a glimmer of hope. I was extremely ill on my liver assessment, I remember I was being drained most of the time. What should have been a three day assessment, turned into 11 days, as I got an infection in the ascites fluid. I was on the list until November 2011. Me and my family were together celebrating bonfire night when I got a call from Leeds: we thought this was it and they had a liver. As I took the call, the phone was on speaker so we could all hear. I was informed they were suspending me from the liver transplant list. Naturally, I asked why. I was told that if a liver became available this weekend, I would not survive the procedure. I was shocked at the reply, though in a way secretly relieved: no more dreading the phone calls, and I could now travel more than two hours away from Leeds. No more taking my hospital bag with me wherever I went. My family were devastated: they were angry and confused. The whole family had been living the nightmare for the nine months while I was on the transplant list.

31. I went for an appointment in Leeds in January 2012 where things became a little clearer. They told me that if I went back on the transplant list, I could be transplanted with a less cirrhotic liver and then treat the new liver. I was also told they were going to try and treat my HCV in Manchester, but that they could not treat me if I was on the liver transplant list.

32. The MRI placed me on a waiting list for the treatment around Christmas 2012. In 2013 I went to a pre-treatment meeting with a view to going on treatment. By that time I had faced that many demons I was quite battle hardened. So much had happened to me and my family, and I was aware I had been given contaminated blood.

I was quite obnoxious and aggressive with the staff. The next week I started the triple treatment with interferon, Ribavirin and Telaprevir. I had to inject myself in the stomach every a week. I started on 20 March 2013, but it was stopped after eight weeks due to poor response. I was traumatised when they stopped treating me. At that stage, I really did think that the nightmare would never end. All my hopes had been pinned on this wonder drug and I can remember how I felt like it was yesterday.

33. My viral count was checked every four weeks, and after the second check I knew it was not good. So I pleaded with a hepatology nurse to call me on the phone and tell me if they were going to stop my treatment rather than at an appointment. She was reluctant to do it at first but, after I explained why, she agreed. You see my whole family thought I would get cured and everything would be fine. They were all depending on it. I did not want my wife to go into a hospital room and be told the treatment had failed, then have her have to walk through a crowded waiting room crying and upset. I had seen this happen to other patients and families. I was in my car when the call came about the treatment. It was a different nurse who called me. She expressed her concerns about telling me over the phone but I told her it was at my request. It was short and sweet: I had failed the treatment. It took me two or three days to work out how to tell my wife. I eventually did and naturally she was extremely upset. There were tears, anger and all kinds of emotions. Then we talked and, after a while, calmed down. It was in the comfort of our own home and we both had each other. We then both informed the people closest to us. The nightmare just seemed to be never ending. I will always be thankful to the MRI for the treatment and also the understanding and patience the staff at the liver clinic showed me and my family.

34. I then had to wait until 7 August 2014 to start my second treatment. I was prescribed Sofosbuvir, Daclatasvir and Ribavirin, which was a success. The treatment was given to me on compassionate grounds in May 2014. Dr Kolchar really helped me with this. The symptoms were not as bad as the ones I suffered in the first treatment but it was still a bit rocky. I am thankfully now SVR and hepatitis clear, though I have no immunity towards a repeat infection.

35. As I mentioned earlier, my consultant helped me to access the second treatment on compassionate grounds. It was exceptionally difficult to obtain treatment due to funding.

36. I must say that the triple therapy treatment was by far the worst treatment. I would like to add to anyone reading this statement that if they are waiting for, or have been offered treatment that the treatment today is very different from what it was like in 2013. The new treatment has hardly any side effects and the treatment time is much shorter. It also has a 97% success rate. So please, if it is offered to you, take it. And if you start it, finish it as it's very good.

37. The mental and physical effects of the treatments were terrible. The drugs I took during the first treatment would send a lunatic mad. I suffered from vomiting, restless nights, suicidal thoughts and my cramps intensified. It really played tricks on my mind. It completely changed the way I was: I became so agitated and aggressive it was like going back in time. It made me feel like crap: my body was under attack (again). Sleep was a luxury and pains the norm. I seemed to develop chronic breathing problems that are still with me today, plus many more side effects. I would not complain such was my desire to get rid of this filthy, horrible virus that had affected every part of mine and my families life.

38. The mental impact from the treatments was and still is enormous. I over-analyse things to such an extent that I have to play a game with myself. I tell myself that if I have imagined a problem or think I have a problem, I have to wait four days then I will know if it is real. If in four days it is not a problem, I have to tell myself it is my encephalopathy or the anxiety. It is my coping mechanism: I cannot stop worrying. Had I been aware of the hepatitis C, people out there could have helped me. I really have been left to paddle my own canoe.

39. I will discuss how my infected status has impacted on my dental care in paragraph 46.

40. In terms of the impact on my family life, it has been huge. We do not go away anymore because of the risk of infection to me. My wife goes away with her sister. When I take her to the airport, I have the feeling that I should be there. In July 2018, we went on a flight simulator. It was the first time we have done anything as a family for eight years. My youngest grandchild is six years old, and one of the things that bothers me is that I may have never met her, she may have never met me. My family would have said he was a great guy, and she would have thought I drank myself to death.

41. Friendships are difficult. When I meet someone and they find out I do not work, they automatically ask what is wrong with me: obstacle

number one. Then they tell me I look alright and I do not want to tell them that I have hepatitis C. I told someone once that I was given contaminated blood and he asked, "Contaminated with what?". I did not answer. I avoid people I grew up with. I have lost a lot of associates. At work, I had a great relationship with the guy I used to work with. At that point I was on £60K a year. He thought again nothing was wrong with me. When cirrhosis popped up, he thought it was self-inflicted. That was the end of my career (in 2009).

42. I have not really suffered from any stigma. The thing is because stigma is so prolific, you avoid it at all costs. The main times I have felt it is when I used to have my bloods done at Leeds Hospital. On my sample bag there was a big, yellow sticker and it said hazardous material. Like a fool I sat in the waiting room hiding my bag with this hazardous warning on it, together with my wife. I should have complained in such a way that the whole hospital could of heard, and let everyone know just what the Department of Health had done to me and tens of thousands of other victims, many of them now dead. I also remember being an inpatient at the MRI. At the main nurses station, where all visitors would go to enquire about relatives and where patients would also go for any sort of problem or advice there was my name, with my bed number on and next to that in big, red letters "hepatitis C" for all and sundry to see.

43. I have a very large family, with about 150 family members, and I have not told them. Some are aware but not all. I am still very conscious of stigma. I do not care about the cross I have to bear, but I think more about how it might have to be carried by others in my family. I have to explain why I do not drink. My wife said she would stop drinking with me, and I told her that she should not. I do it alone.

44. As for financial and work-related effects, I had to give up my job in 2009. I thought I was having a stroke, or a breakdown. I had to go on sick. I was quite good at what I did. I was taking care of back office procedures, paying wages. I had a very rosy future. I went from £800 a week to £80 plus housing benefit. I have been the provider for my family since I was 15 years old: not only have they taken away a father figure and a grandfather, they have taken away a provider who could have offered his family a degree of stability. I had private healthcare but I did not use it because I did not think my illness was serious enough. If I had known that I had hepatitis C and needed a liver transplant, I could have used my private health insurance. Though at that stage I thought I was much safer with the NHS, after all our NHS is the envy of the world?

45. The impact on my family and those close to me has been huge. One example was my son came to see me in hospital and he said that I just looked right through him, like he wasn't there and when he spoke to me I just couldn't work out who he was. Put yourself in that position, and just imagine how you would feel if you were him. Then couple that with the DNR and everything else he had witnessed, and at that stage none of us were aware of the reason why I was in this sorry state. We were all the victims of this contaminated blood nightmare. I am sure of one thing, the impact on my family was much worse than the impact on me. They must have felt so helpless, there was nothing they could do to help me, they just had to stand by and watch me deteriorate and they were kept completely in the dark as to why all this was taking place. I'm not an angry person, I don't have the energy to be angry but if it was me who had done something like this contaminated blood cover up, been responsible for tens of thousands of deaths and my actions had impacted on the victims families, I would expect to be punished. Yet the perpetrators of this cover up seem to think they are above the law, and maybe they think they can just pay us some money and the problem will go away. That cannot be allowed to happen.

Section 6. Treatment/Care/Support

46. In 2013, I had to go to the dentist because all my teeth started to go wobbly and I needed extractions. The dentist told me that he could not do it. When I asked why, he said that if they injected me the drugs might go to straight to my liver. I just got the feeling I was being fobbed off. They referred me to the hospital, where they could anesthetize me as my roots were that bad. When I arrived at the hospital, they told me that they could not anesthetize me because the anaesthetic would go to my liver. They did an x-ray and told me that my roots were not actually that bad so the dentist there told me that they would just rip them out. I was given some numbing injections and they pulled my teeth out. I was ok straight afterwards but then was on my back for three weeks. Now I do not get teeth removed, I just get temporary fillings.

47. I did not have any counselling or psychological support when I was told about my HCV. My daughter applied to the Department for Work and Pensions (DWP) for a disability living allowance: I got a lifetime award. I have recently been migrated to the Personal Independence Payment, where I had to run the DWP gauntlet and my family had to try and explain to someone who had three weeks training to become

a disability assessor, who also had little or no knowledge of the seriousness of my condition and how it affects me. I got an award: I was one of the lucky ones and I have a good support network from my family. I was offered counselling at Leeds Hospital for my drinking, but I had already stopped drinking. I have not drank from almost nine years. I stopped without any help or prescribed medication or counselling. I tried to get counselling from my GP recently. I received a call from some guy who basically said he couldn't help me. I enquired about counselling from EIBSS and they told me I had to find a counsellor, get a price per session, get an estimation of how many sessions I will need, get a copy of the counsellor's registration certificate and get a copy of the counsellors insurance. Then I would have to get them confirmation that all other sources of support available, such as local authority grants have been exhausted, then give them two quotes, then get them medical supporting letters and recommendations. Then they may release funding (up to £900) and get them a receipt. You would think this scheme would understand more than anyone else that the infected and affected may need help with counselling. This is just one of the problems we have identified.

Section 7. Financial Assistance

48. I applied to the Skipton Fund in June/July 2011. I became aware of it through a flyer in a lift in Leeds Hospital.

49. I received the Stage 1 payment in August 2011, and a Stage 2 payment in about July 2011 because I automatically qualified for it being on the transplant list. I also receive annual payments, which have gone up now.

50. I applied for my own medical records, as I was aware that medical records were being altered and going missing.

51. I personally did not face any difficulties or obstacles in applying for financial assistance but I know a number of people who did. I got quite good at dealing with the Skipton form and helped to obtain 7-8 payments for other people. Two sisters had applied and Skipton refused to pay them because they had no medical evidence to link their status to infected blood. One was a blue baby. I met them and we went through their story: they had been infected at birth. Their mother was rhesus negative, and they had to have transfusions at birth. I asked them to sign an authority for me to act for them and to obtain copies of their parents' medical records and their birth certificates. I took the evidence to Skipton: one of the sisters was

accepted and one not. The one that was refused financial assistance swears they changed her medical records. The Skipton Fund said she was covered in tattoos and rejected her application. That was not true.

52. EIBSS are the new support scheme ran by the NHS, or under the NHS umbrella, financed by the Department of Health (as I understand it), and these are the very people who put me in this predicament. This new scheme is probably the worst one to date, and has echoes of the DWP throughout, and it definitely needs addressing. They run what they call focus group meetings, where they meet victims and discuss the scheme. They have adopted the exact same principle as the DWP working group meetings, with the same results: none. This will be used by them in the future as a PR exercise, where they can say, "We have engaged with victims in an open forum, for the first time in the history of any schemes". We may be victims but we can read the writing on the wall. We have had to battle with these schemes for many years, and we will continue to do so until they begin to treat us with the respect we deserve. If you ask a question to EIBSS or apply for help they treat you with total disrespect with answers like, "The information is available on our website". They do not have a dedicated website, it's more like an information page. There is no interaction facilities for victims. In this age of technology, it's a pretty shoddy job, just like their approach to our community. I have had to resort to emailing EIBSS and I still can't get a definitive answer, or when I do it's after asking the same question many times. They seem really reluctant to want to help you gain any kind of independence. I think people impacted by this contaminated blood tragedy are seen as an imposition and a burden by this new scheme. They always seem to want to distance themselves from giving you any help by referring you to other departments like Citizens Advice Bureau signposting, doctors, mobility schemes for grants, the DWP. I fear the next referral will be food banks, which some of the victims are already registered with. All we want to do is live what time we have left with a degree of dignity.

53. I do believe there should be some kind of representation from within the contaminated blood community working alongside this new scheme, who actually deal with queries or questions from victims. This would make this scheme totally transparent and their intentions clear. Even if they only engage with the representative to get a victim's point of view on what matters to our community and how this contaminated blood tragedy affects our everyday lives. They will say at this stage, "That's why we have focus groups", but at these groups

they simply don't listen, they don't give answers. We can offer knowledge that can't be learnt from a book or in a classroom. We know they have sent out questionnaires but they mean nothing if there is no willingness to listen and learn. We are not ungrateful and we know they do a difficult job under difficult circumstances. We would welcome the chance to engage with this new scheme even on a temporary basis and even if it's just to put them on the right track. This is easily achievable and would be seen as a positive indicator by everyone from within the contaminated blood community.

54. I do not fully understand why the funds and schemes do not put something in place to allow people to paddle their own canoe. You only need a safety net if you are vulnerable. The annual payment should be doing what it is designed to do: make you less financially insecure. If these schemes were working, there would be no reason for beneficiaries to have to suffer the indignity of applying for discretionary grants. The fact that we have to apply for grants is a clear indication that this scheme is not fit for purpose. I don't think they want you to be independent of them. It's as if they want you to be dependant on them, then they have control of you. Everything seems to be money orientated. There is no easy access to psychological help and they intentionally pay different rates to different victims. This creates division throughout our community and turns victim against victim. You only have to look at the difference between the payments in Scotland and the rest of the UK. England, Ireland, and Wales should, in the short term, be brought up to the same level of the payments as in Scotland, with a view to getting all victims (affected and infected) to a level where they are financially able to support themselves. That way the Department of Health (or the Treasury) can begin to be seen to be trying to put right the terrible wrongs they have inflicted on our community.

Section 8. Other Issues

55. I am the Chairman of the Board for a Liver Support Group at the MRI. It first came about when I was raising funds for a FibroScan machine at the MRI in 2013/4. I used to give pre-treatment talks at the MRI but there is not much need for that now because the treatment is gentler. There is a need to tell people the impact of not taking treatment though. That is my role now. I am also a member of the transplant support group at St James' Hospital in Leeds and I am involved with Contaminated Blood Products. I have known GRO-C for a while: he has been campaigning for years.

56. I am a new kid on the block, but I am passionate about helping to find people who have not yet been identified as being infected. I think there should be a "get tested" awareness campaign for hepatitis C and hepatitis B. For hepatitis B, the symptoms are identical and it is underrepresented. We should be reaching out to people with liver problems to check for hepatitis. And if people find they have HCV or any other condition, then they should have a good think and try and remember if they have had any transfusions or any blood products prior to 1992 as they too could be victims. I believe there are tens of thousands more victims of this contaminated blood tragedy still undiagnosed out there.

57. Despite everything I have written in my statement, I consider myself to be one of the lucky ones. I could have got a much more serious virus, infected all of my family, as has been the case with other victims infecting their loved ones, or my family could have thought they were burying an alcoholic and never truly known the truth about what had taken place. Those accused really do need to take a long hard look at themselves. I hope they like what they see. Every government's job is to protect their citizens, and make sure they are safe. Previous governments have let us down, as has this one. There is a slight difference, however as this government may say they have given more to our community and acknowledged there have been mistakes (why else would they have apologised?). But this government is standing by and watching victims die on a monthly basis, while at the same time trying to distance themselves from any responsibility, both financial and humanitarian. That in itself makes this government as bad, if not worse, than previous governments because this government has been confronted with all the undeniable facts and they know that we know that it's adding insult to injury, yet they are still standing by and watching this tragedy develop and letting victims die without them knowing justice has been served. They could and should at the very least, let every victim know now that if anything happens to them, that there family's future is financially secure, and that would be a massive weight of the victim's mind. Infected and affected victims have a right to be treated with empathy and respect. This is easily doable. They need to start tidying up this mess.

Statement of Truth

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

Signed GRO-C

Dated 22/01/2018.