Witness Name: Fiona Cunningham
Statement No.: WITN0062001
Exhibits: **NIL**
Dated: 13th MAY 2019

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF FIONA CUNNINGHAM

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 03 March 2019.

I, Fiona Cunningham, will say as follows: -

Section 1. Introduction

1. My name is Fiona Cunningham. My date of birth is GRO-C 1963 and my address is known to the Inquiry. Before I became too ill to work, I was employed as a support worker. I have 3 grown-up sons; my youngest son, Scott, currently lives with me.

2. I intend to speak about my infection with Hepatitis C ("HCV") which I contracted after a blood transfusion in 1989. In particular, I will go into detail about how I discovered I was infected, how the illness affected me, how the illness caused liver cancer, and the treatment I received for both HCV and liver cancer. I will also cover the impact my illness has had on me and my family.

3. I can confirm that I have chosen not to be legally represented and that I am happy for the Inquiry team to assist me in writing my statement. The Inquiry team has explained anonymity to me and I do not require any information to be kept private.

Section 2. How Infected

4. On GRO-C 1989, I gave birth to my second son via C-section at the Royal Infirmary of Edinburgh ("the Royal Infirmary"). The C-section caused me to haemorrhage, and as a result I was given two units of red blood cells through a transfusion. At the time I didn't know that these units of blood were given to me. I didn't find out that I'd had a blood transfusion until 2015.

5. It wasn't until September 2015 that I began to feel unwell. Before 2015 I had led a normal life. I went travelling and enjoyed going on holiday. There was no sign that there was anything wrong with my health. I didn't realise there was something wrong until one day, I suddenly felt very ill. I was out in the community visiting clients, when I started to feel very ill. I felt so sick I had to get off the bus to get some water. I called the office to tell them I had to go home. My symptoms at this point were fatigue, severe bloating, sickness and diarrhoea.

6. I knew something was not right so I went to see my GP, Dr GRO-D on 29 September 2015. The appointment was very quick. Dr GRO-D told me he thought I had Norovirus and gave me a prescription for some sachets to treat my symptoms. I was unhappy with this appointment as Dr GRO-D didn't do any tests or even check my blood pressure.

7. I know my own body and I knew I wasn't well, so as soon as I finished my appointment with Dr GRO-D I went straight to the reception desk at the GP surgery and scheduled an appointment with a nurse to have blood tests. This appointment was within a week of my appointment with Dr GRO-D

8. Three or four days after the nurse took my blood I got a call to say that they had found an abnormality in my blood, but they didn't know what it was, so they needed to run some further tests. I was told that they were going to test for HCV, Hepatitis B ("HBV") and HIV.

9. The following week on 6 August 2015, I received a call from a doctor at the Royal Victoria Hospital and was told the results had come back as positive for HCV, which completely threw me. I felt the blood draining from my face. I didn't know much about HCV. I was aware that there was a stigma around it because it was linked to drug users. I just couldn't understand how I'd been infected, I was shocked. I have never taken drugs and I'd been with the same partner for 30 years.

10. I attended an appointment with Dr Stewart, another GP, because I couldn't understand my diagnosis, it just didn't seem right. Dr Stewart asked me questions, such as whether I'd had any tattoos. I said I hadn't, I didn't know how I could have got HCV. All I could think of was that I'd had a C-section in 1989 and that at that time I was very unwell. It was Dr Stewart who figured out that I had been given two units of blood after giving birth. Dr Stewart was brilliant, she had all my medical records in the surgery. It was at this point that I learned that the blood given to me in 1989 was contaminated with HCV.

11. I was quickly referred to Dr Rebecca Sutherland, a HCV consultant at the Western General Hospital ("the Western General"). She told me I had lived with HCV for the last 26 years without knowing I had it. Dr Sutherland provided me with adequate information about the disease, including some pamphlets. I found Dr Sutherland's conduct to be very good, she was very thorough. Dr Sutherland also advised that my third son should be tested for HCV.

Section 3. Other Infections

12. I have not received any other infection, other than HCV, as a result of being given infected blood. At the time when the doctor found an abnormality in my

blood, the blood was sent to be tested for HBV and HIV as well as HCV. It came back negative for HBV and HIV.

13. Although I did not receive any other infection at the time from the blood transfusion, I later developed liver cancer as a result of having HCV. I will discuss this in more detail under Section 5 of this statement.

Section 4. Consent

14. I do not believe that I have been tested or treated without my knowledge or consent. I was aware of the tests that were carried out on my blood and I consented to the treatment offered.

15. Although I did not consent to any blood transfusions, I accept that the doctors were acting in my best interest at the time in order to save my life. I didn't know about HCV at that time, and I understand blood wasn't screened before it was given to patients. However, I never would have consented if I knew that the blood was infected.

Section 5. Impact

Treatment and physical health

16. Following my initial diagnosis, I was referred to the Western General Hospital to have some further tests and to start treatment for HCV. It was at this point that I had some scans done and they discovered I had liver cancer.

17. The HCV consultant, Dr Sutherland, called and asked me to come into the hospital. I sat in the waiting room expecting my special nurse to come and take me into the appointment like usual. But it was Dr Sutherland who came for me instead. I realised instantly that there must be something wrong. She said to me, "Fiona, I've got some bad news. You've got cancer." I was devastated. I

sat and cried. My eldest son had to come and get me. It was the HCV that had caused the cancer in my liver.

18. As a result of my cancer diagnosis I could not start the treatment for HCV as it was thought that I would need a liver transplant. The doctors couldn't offer me a transplant at this point because I wasn't well enough.

19. When I was first diagnosed with cancer, the doctors thought I had 3 tumors in my liver. These tumors were too big which was also a reason why I couldn't have a transplant at this time. They later found out that I actually had 11 tumors. At the time, they couldn't see them because they were buried so deep in my liver.

20. As I wasn't well enough for a transplant, I started chemotherapy instead. The consultant said we should give it one year and if the chemotherapy went well then they could potentially offer me a transplant. I had 6 or 8 chemotherapy treatments over that period of approximately a year.

21. I made an effort to be healthy to try and give myself the best chance of getting better. I had already stopped drinking the odd glass of wine once I received my initial HCV diagnosis.

22. The form of chemotherapy treatment I received was chemoembolization, so it was injected into the groin to target the liver. The treatment lasted 3 days, and I had this every 3 months for over a year.

23. During this period, I was very unwell. I felt sick and spent 3 or 4 days in bed following every treatment. The chemotherapy caused me to have a very low platelet count of between 34 and 36, when it should have been 184.

24. The chemotherapy went well so the doctors determined that I qualified for a liver transplant. I only had to wait 3 weeks for the operation. I was lucky they had an exact match for me so quickly. On 10 October 2017 I got a call at 2

o'clock in the morning to say that they had a liver for me, and I went into the hospital and had the liver transplant that day.

25. I was lucky to have the transplant when I did. If I hadn't have had the transplant then, I could have died, given that I had 11 tumors when the doctors thought there were only 3.

26. It was an 8 hour operation and it went well. My children got a call at 4 o'clock in the afternoon to say that I was ok and that all was going well after the transplant. I was in hospital for just less than 10 days before I went home.

27. The recovery after the operation was tough. I couldn't do anything for 3 months. I couldn't drive or even put the kettle on.

28. After the liver transplant I began treatment for HCV. This began on 26 October 2015. I underwent a 3 month course of Mavyret. The treatment caused me to feel unwell with nausea and headaches. But it seems to have worked well; I feel much better. I have gone from having follow up appointments every week to every fortnight. Now I go every 2 months, and this will hopefully become just once a year. I will have tests done soon to see if the virus has completely gone. If the HCV hasn't cleared the doctors have informed me they will start me on another course of treatment.

29. Following the transplant, I now have to take anti-rejection medication for the rest of my life. I have come off most of the medication I was initially prescribed, but I still currently take Tacrolimus (Prograf) and Azathioprine.

30. Since the transplant in 2017 my health has improved. I can live a normal life again and I have started swimming again. When I was undergoing treatment, I was so ill, I couldn't do anything, my life was on hold.

31. I have been warned of the risks of the cancer coming back, though as the cancer was completely contained to the liver, the risk is small. I continue to look after myself and eat well.

Mental health

32. I am now a year down the line from my HCV treatment and have realised that this whole experience has had a massive impact on my mental health. I thought I could cope and get through my treatment and re-establish my life after a transplant on my own, but I have now decided to get some psychological support. A coordinator at the Royal Infirmary Hospital has referred me for psychological support, which I will start soon.

Impact on family and social life

33. My illness has also had a massive impact on my family, particularly my sons. I know they worry a lot. My eldest son, David, took care of things for me when I was undergoing treatment. He was allowed to come with me while I was being prepared for the liver transplant. I was worried that I wouldn't come out of the surgery and he told me not to worry if I didn't make it because I'll never know. It is very hard for a mother to hear her son speak like that.

34. To my knowledge, none of my sons have been tested for HCV.

35. I separated from my son's father prior to my HCV diagnosis, and I don't currently have a partner in my life. I am very conscious of the scar I have from the transplant. I am not embarrassed by it, but at this stage I do not want to have to deal with explaining what I've been through. My focus has been on getting well.

36. I have 3 grandchildren. Before I was ill, I used to look after my grandchildren every second weekend. For a long time I was too unwell to look after them, and now I worry too much about getting infections and colds. My immune system is not the same as it used to be, so I worry about catching public transport and

touching handles in public. Before Christmas 2018 I was unwell with a cold which worried me more than it should have.

37. Although my health has improved and I can do certain activities again, there are still things that I am missing out on. For example, I am not allowed to go into the sun. I used to enjoy spending time in the sun when I go on holiday, now I have to cover up.

Stigma

38. I am aware of the stigma surrounding HCV, but I have not experienced any stigma myself. I have told my closest circle about what has happened to me. They know me well and my life, so I am not worried about stigma.

Work-related and financial effects

39. Before I became unwell, I worked as a support worker. Once I had received the diagnosis I decided that I didn't want to go back to work because I knew what I was going to be going through. My boss was understanding and told me I was more than welcome to come back if I wanted to. I now do some volunteer work, cooking in a community centre.

40. Although I had given up work, during treatment I was able to cope financially because I had help from Macmillan Cancer Support who helped me manage my finances and bills.

Section 6. Treatment/Care/Support

41. I lived with HCV without knowing for 26 years. I was never contacted by the NHS or a hospital during the period of time between the transfusion and my diagnosis. I am concerned that a look-back exercise was not conducted.

42. Once I was diagnosed with HCV and liver cancer, I had no difficulties obtaining treatment, aside from the fact that the HCV treatment had to be put on hold until after my liver transplant. The doctors and the transplant team were brilliant and dealt with what I needed quickly. I appreciate that in the past treatment was not available like it is now.

43. I was not offered any counselling or psychological support during my treatment, but as mentioned in section 5, when I later realised that I wasn't coping I went to the consultant at the Royal Infirmary Hospital who has found me support.

44. The general support I have had from the doctors and consultants that have treated me has been brilliant. Particularly Dr Stewart, my GP who found out that I had had the transfusion in 1989, my HCV consultant, Dr Sutherland and the transplant team. The only negative experience with any medical professionals was with the initial GP I visited, Dr GRO-D as he didn't conduct any tests.

Section 7. Financial Assistance

45. I was told about the Skipton fund by the Royal Infirmary before my liver transplant. I applied for the Skipton fund in 2017 and did not have any difficulty. I had to supply my medical records. I was initially given a lump sum of £75,000, and now receive £2225 every month for the rest of my life. They contact me every 3 to 6 months to see if my circumstances have changed, but I can't foresee that they will. I received the initial payment a week before Christmas. I have not applied to any other funds.

46. I am happy with the funds I have received, but no sum of money is going to be adequate to compensate for what has happened. My life has completely changed, my physical and mental health has been significantly impacted. Money does not make up for this.

47. After diagnosis I qualified for a Personal Independence Payment ("PIP") disability allowance after the diagnosis. A nurse from the Western General

contacted me to help sort this out. I have had no trouble in continuing to receive this allowance since receiving the Skipton fund.

Section 8. Other Issues

48. Last year I attended a meeting held by the Inquiry in London because I want to keep up to date with what's going on in the Inquiry. It is terrible what has happened to so many people and I understand why there is so much anger, especially surrounding the destruction of records. I was lucky that my GP had all of my records.

49. I am planning to attend the hearing in Edinburgh so I can see what's happening and how the Inquiry is progressing.

50. I hope that one of the outcomes of the Inquiry will be that it will lead to those infected and affected receiving compensation.

Statement of Truth

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

Signed GRO-C

Dated 13 MAY 2019.