Witness Name: Joseph Louis Pisharello
Statement No: WTN1469001
Exhibits: WITN1469002-007
Dated: March 2020

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF JOSEPH LOUIS PISHARELLO

I, Joseph Louis Pisharello, will say as follows:-

Section 1. Introduction

1. My name is Joseph Louis Pisharello. I live at GRO-C GRO-C with my wife, Marilyn. I was born on GRO-C 1947 in GRO-C, where I have always lived.

2. I was infected with the Hepatitis C Virus (HCV) through contaminated blood products.

3. This witness statement has been prepared without the benefit of access to my full medical records.

Section 2. How infected

4. I have severe Haemophilia A. At the age of four months my parents noticed some bruising under my arms. Our GP advised that it could be haemophilia, however back in 1947 there was no way to confirm/diagnose this. Throughout

my childhood and teenage years I continued to suffer from bleeds which were treated with with lots of rest, ice and elevation.

5. In 1966, at the age of 19, I continued to suffer bleeds in my legs and so I was admitted to hospital. During this time knowledge of haemophilia was minimal and they did not have the facilities or the expertise to properly diagnose patients with haemophilia. Sending patients to the UK for further investigation was also not an option back then. The doctors decided it would be best to immobilise the joint in my left knee to avoid further bleeding and so it was put into a plaster cast. I spent three months in hospital. The plaster was changed every four weeks initially and, at the end of two months, the last plaster was kept on for a period of 8 months. When the plaster was eventually removed the left knee joint had fused, due to the fusion in the muscles surrounding the knee cap and I have never again been able to bend the left knee.

6. In 1970 (at the age of 23), I went to the UK on holiday and my private GP arranged for me to go to the John Radcliffe Hospital (JRH) in Oxford. There I spoke to other haemophiliacs and was informed that they took cryoprecipitate during bleeding episodes. I was not aware that this treatment even existed. After the visit to the JRH I went to London and, during my stay, I suffered a knee bleed and attended the Royal Free Hospital (RFH). It was there that my Haemophilia A diagnosis was confirmed and I was treated with cryoprecipitate.

7. In April 1972 I suffered a serious car accident in GRO-C and was taken to RFH in London where I spent six months. During this time I was treated with a lot of Factor VIII (FVIII) concentrate and cryoprecipitate. I refer to **Exhibit WITN1469002**,a copy of the hospital record of that treatment.

8. During the late 1970s (and into the 1980s and 1990s), whenever I flew over and stayed with my wife's family on holiday (my wife is from GRO-C Middlesex) or when I went over for my yearly check-ups, I visited the RFH as well as Addenbrookes Hospital. During these visits I was administered and

provided with FVIII concentrate to cover my stay in UK and I contracted HCV. I refer to **Exhibit WITN1469003**,a copy of my UKHCDO annual patient b2 lookup record listing the names of the blood products I received.

9. Professor Christine Lee had responsibility for my care at the RFH. She was always pleasant and supportive and she took over from Dr Kernoff (whom I believe has since died) as the Haemophilia Centre Director when he retired.

10. I refer to **Exhibit WITN1469004,** a letter I received from the RFH in 1990 informing me that I had tested positive to anti-HCV (HCV) from a blood sample provided by me on 8th January 1990. At my next appointment I asked Professor Lee about the content of the letter. I was told that I should not have received the letter as there was nothing that could be done.

11. No information was given to me to help me to manage the infection. There was simply no treatment for it. No information was provided to me in the letter about when I would have been infected. However, I remember having a conversation (with a different doctor I think) at the Centre and was told that I had had the infection for a while and had most likely contracted it in the 1970s/80s.

12. I now also refer to **Exhibit WITN1469005,**copy correspondence from Professor Lee sent in November/December 2003 stating that I was likely to have had HCV for 25 years, the date of infection being then placed at around 1978 (and informing me that some of my liver cells are being regularly destroyed). However and referring to **Exhibit WITN1469006** being Professor Lee's clinical note recorded on 10th February 1997, she appears then to have placed the date of infection at 1972.

13. Nobody pre-warned me that the FVIII concentrate might be tainted. Marilyn and I had a daughter in June 1984. I should have been informed personally (rather than by letter) at a clinic and much sooner. I would have been deeply concerned about my wife getting pregnant and about passing on the infection

to our child, had I known. GRO-C

GRO-C

14. Prior to the early 2000s when the possibility of treatment was first raised, there was no information at all about what could be done to help me. There wasn't social media at the time either so I could not get the information from there. The media at the time were saying that haemophiliacs in Spain were getting HIV/AIDS and I was more scared about that. I had to rely on the media for the information about the disease.

15. When I went back to Professor Lee in 2003 she said that I should try the treatment in an attempt to clear the virus. However I was still more worried about contracting HIV and dying from AIDS at that point.

Section 3. Other Infections

16. It would appear (from a review of the limited number of medical records I have in my possession), that I have been exposed to the Hepatitis A Virus (HBV) and the Hepatitis B Virus (HBV).

17. On 20th September 2004 I was informed by Addenbrookes Hospital and RFH that a patient with inherited bleeding disorders who had been treated with UK sourced plasma derived clotting factors between 1980 and 2001 was found to have the agent that causes vCJD. I was treated with clotting factor during that period.

18. On 26th September 2004 I received a letter from both hospitals stating that I did not receive an implicated batch. Subsequently, on 18th and 26th February 2009, I received another letter from both hospitals informing me again that all patients who were treated with UK derived plasma products between 1980 and 2001 may have been exposed to vCJD. It related to a person with haemophilia who was treated with plasma derived clotting factors between 1980 and 2001 and had died of causes unrelated to haemophilia. At post-

mortem, they had discovered evidence of vCJD in his spleen. I am still very deeply concerned of the future consequences for me.

Section 4. Consent

19. I was treated and tested without my knowledge and without my consent. I was treated and tested without adequate or full information. I also believe that I was treated and tested for the purposes of research. I refer to **Exhibit WITN1469007** being copy correspondence sent to GRO-C Hospital, GRO-C 5th September 1989 and 22nd December 1992. I had no idea that I was being tested for HBV and HIV at six monthly intervals or at all. I had no idea that I was being tested for HCV until I received the letter informing me of the HCV positive diagnosis.

Section 5. Impact of the Infection

20. When I was informed that I had HCV back in 1990 my daughter was five years old. I was extremely worried that she as well as my wife could get infected too, or more worryingly, that they were already infected. As a father and husband this was on my mind every day and it affected me significantly, as I could not bear the thought of them contracting an illness because of me.

21. They, in turn, were deeply affected. I held back in being affectionate with them. I was cautious enough not to even kiss and cuddle my own daughter. I had a full time job with the MoD. I was also a musician. In the evenings I played at dances in a band. After diagnosis, I was on edge and vigilant to ensure that my drink wasn't mixed up with any of the drinks belonging to my fellow band members. I gave up and stopped playing music from around 1993.

22. I had fears in relation to future consequences. I was worried that I would be unable to work and provide for my family. Not knowing much about the illness, I could not shake the thought that I would die from this illness, leaving behind my wife and my young daughter.

23. GRO-C is a bit behind the UK and in the 1990s the fear and stigma in relation to HIV/AIDS was rife. People were dying. I was (knowingly) tested for HIV on one occasion and the wait was very worrying for me. I was very careful not to discuss anything about having the HCV infection with anybody outside the immediate family. If for example anyone asked me if I had read a report about haemophiliacs being infected, I was sure to play it down or move the conversation on to something else. I was sure not to acknowledge or engage in any form of conversation about people being infected (and dying) with HIV/AIDS or anything else.

24. I have endured horrible clearing side effects to the extent that I have, on occasion, felt suicidal. I have developed liver cirrhosis from having HCV over such a long period of time. I have also developed type 2 diabetes which I believe to be linked to the detrimental impact of HCV and the treatment on my health.

Section 6. Treatment/care/support

25. I received Ribavirin and Peg-Interferon treatment from the end of 2005 until 2006 for a total of 11 months to try to clear HCV. For the duration of the treatment I suffered side effects to include bad flu, diarrhoea, a bad temper, feeling always on edge, extreme fatigue, suicidal thoughts, loss of appetite and subsequent weight loss of about 2 stone. These side effects meant I was absent from work a lot and had to explain my situation and circumstances. Thankfully my boss and colleagues were understanding and supportive. After the 11 months of treatment and suffering from all these side effects the blood tests confirmed the worst; that the treatment in fact had not worked.

26. In January 2017 I was persuaded to try another treatment, being a combination of Ribavirin and Harvoni for a total of three months. This time the treatment was not as bad as the first and at the end I received the good news that the treatment had worked and I was cleared from HCV. Since then I have started to put on weight and I appreciate food more, which I had never been able to do in all the years I was infected with the virus (something in the region of forty years or more). I also realised that I am not as ill-tempered, something fully noticed/recognised by my wife and daughter. I also feel much happier and appreciate life more.

27. Counselling or psychological support was never offered to me.

Section 7. Financial Assistance

28. I have received financial assistance from The Skipton Fund and through EIBSS.

Section 8. Other Issues

29. There are no other issues.

Anonymity

30. No anonymity is required.

Statement of Truth

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

Signed...... GRO-C ....

Dated 6 April 2020.