Witness Name: Francis Noel O'Hora
Statement No: WITN1439001
Exhibits:0
Dated: December 2018

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF MR FRANCIS NOEL O'HORA

I, Francis Noel O'Hora, will say as follows:-

Section 1. Introduction

1. My name is Francis Noel O'Hora. I live at GRO-C GRO-C with my wife. My date of birth is GRO-C 1951. I have 2 children and 6 grandchildren.

2. I worked for the London Underground for 38 years as a train driver. I am retired.

3. I was diagnosed with mild Haemophilia B (Christmas disease) at the Royal Victoria Hospital, Belfast (RVHB) when I was 12 years old after I had my tooth extracted and injured my leg.

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

Section 2. How infected

5. I was first treated with Factor IX (FIX) blood products at the RVHB when I had a tooth extracted and when I injured my leg after playing football. When I moved to England in or about the mid/late 1970s, I was given more FIX when I attended The Royal London Hospital (Whitechapel) (RLH).

6. I married in 1976. I did not consider I had a medical condition as I had mild Haemophilia and I did not require treatment on a regular basis. However, in the early 1980s I was advised by my brothers to register with the haemophilia centre at the RLH, which I did. I was under the care of Dr Colvin.

7. After I registered with the RLH I would have two routine appointments every year. The doctors would do blood tests at each appointment and I was told that the tests were to monitor the haemophilia.

8. From the 1980s I attended the RLH on multiple occasions to have my teeth extracted. At each visit I was given FIX to keep the bleeding under control. I believe I attended the hospital approximately 10 or 12 times over a period of 20 years for the extractions. I also recall I attended the hospital when I had a bike accident and injured my leg. I was given FIX for the injury and I had the treatment for approximately 2 to 3 weeks.

9. In or about the early 1990s, I was diagnosed with polyps. I had a colonoscopy and I recall I had a lot of FIX before the procedure. I had a procedure every two or three years and each time I had FIX.

10. I only had FIX at the hospitals. My condition never required me to have FIX on a regular basis, or at home.

11. In or about the mid-1990s, I attended RLH for a regular routine appointment in relation to my haemophilia. It was at this appointment that I recall being told that I had Hepatitis C (Hep C). I was told by the doctor that it was possible that I was infected from the FIX products that I received at either BRVH or

RLH. I was given some leaflets about Hep C, which were very brief. I do not recall receiving any other information about Hep C at the appointment.

12. As time went on, I was given a bit more information about Hep C. However, I do not believe that the information I was given was adequate. There were a lot of unanswered questions. I was told a few years after I was diagnosed that treatment was available. However, a family member told me that the treatment was not always successful, so I declined it.

13. I believe information about Hep C should have been provided to me earlier.

14. When the doctors told me that I had Hep C, I never really thought about it much. I was naive and wanted to get on with my life. However, the more I read about Hep C the more I was angry about it.

15. A few years after I was diagnosed with Hep C I was told that I could infect my partner. I must have also read about it. I was shocked when I was told and angry that I was not told earlier. I was also told not to drink alcohol as it could affect the liver.

<u>Section 3. Other Infections</u>

16. Between 2002 and 2006 I attended the hospital to have a colonoscopy. I recall I was sitting around for a few hours waiting for my procedure. I thought something was not right and asked a haemophilia sister on the ward why my procedure was delayed. I was told that there was a discussion between the surgeons about possible contamination of the equipment with the vCJD virus. Although I was told it was a very small chance, the equipment had to be destroyed after it was used on me. I was very offended by what she told me, it still lingers on my mind. Apart from this, I am not aware of any other infections.

Section 4. Consent

17. I believe I was treated and tested, without my knowledge, without my consent and without being given adequate or full information.

18. I also believe I was treated and tested for the purposes of research.

Section 5. Impact of the Infection

19. I suffered from a foggy head and I believe the symptoms were in relation to Hep C.

20. When I was told that I had Hep C I was not sure what it was initially as very little information was provided. It took me a few years to understand the infection and understand where the infected blood products came from. I became very angry about the whole situation.

21. I was very cautious and nervous about infecting my children. I was very aware that the infection could be transmitted by body fluids and I was always cautious about this. I had to change the way I lived at home, because I was worried about infecting my children.

22. I was given Interferon and Ribavirin in or about 2006/2008 and I was told it was a 12 month course. The treatment was horrible and it affected me mentally and physically. I had depression. I was also trembling and had hot and cold shivers. My sleep and my appetite were also affected. I had to force myself to eat as I could not afford to lose weight. However, I did lose some weight during the treatment. The experience that I had with the treatment was unpleasant and horrible. After 9 weeks I was unable to continue with the treatment. I told the doctors that I was finding it difficult, but they pushed me to complete at least 12 weeks of the treatment in order to get some readings, which I did.

23. I faced no obstacles or difficulties in accessing the treatment, I was told to start the treatment when it was available which I initially rejected, but later accepted. I was not given any information about alternative treatment or if any alternative available.

24. I do not consider the stigma affected me. I was very private about the infection and only my immediate family were aware of my condition.

25. I was not studying when I was diagnosed with Hep C, so my education was not affected.

26. My employment was affected when I was having treatment for Hep C. As previously stated, I was employed as a train driver for the London Underground and I was required to do various different hours. However, because my concentration levels were extremely low due to lack of sleep, I was not able to drive the train. I told my employers that I was on medication for Hep C and I was finding it difficult to drive the train. My employers then changed my shift to a 9 to 5 to work on the station grounds. The treatment became unbearable at about 9 weeks and I had to take sick leave. Once I finished the treatment I returned to my original job as a train driver.

27. I started a second course of treatment, Zepatier, which was a two-drug combination administered with Ribavirin as a single daily pill containing Elbasvir and Grazoprevir, last year, which cleared the Hep C.

Section 6. Treatment/care/support

28. When I was diagnosed with Hep C I had to pay for all my prescriptions. I found out a few months before my 60th birthday that I was entitled to free prescriptions. I cannot recall where I got the information from. I was quite annoyed when I found out. It would have been nice if somebody told me that I was entitled to it.

29. I do not recall being offered any counselling. However, I found that the doctors were very forthcoming about Hep C, so it was possible that counselling was available. I may have considered it had it been offered to me.

Section 7. Financial Assistance

30. In or about the late 1990s or early 2000s I was informed that I was entitled to some funds through The Skipton Fund. I cannot recall if I was told by the doctors or if I received a letter. I applied for the stage 1 payment and received a lump sum payment of £20,000 in September 2004. The application form was straight forward.

31. In 2017 I received a letter in the post stating that I was entitled to a monthly payment because I had Hep C. I completed the form and posted it back. I now receive a monthly payment from EIBSS in the sum of £333. I think the payment is reviewed annually.

32. To the best of my recollection, there were no preconditions when I applied for the above payments.

Anonymity, disclosure and redaction

33. I confirm that I do not wish to apply for anonymity and that I understand this statement will be published and disclosed as part of the Inquiry.

Statement of Truth

I believe that the facts stated in this witness statement are true.
I also confirm, that i do not wish to give oral evidence at the Inquiry.

Signed. GRO-C ....

Dated 18/12/18.