Witness Name: Mark Helliar
Statement No.: WITN1065001
Exhibits: **WITN1065002-5**

Dated: 24th Sept 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF MARK CHRISTOPHER HELLIAR

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 22 August 2019.

I, Mark Helliar, will say as follows: -

Introduction

1. My name is Mark Helliar and I was born on the GRO-C 1958. I am living and working in GRO-C Florida USA at the moment.

How Infected

2. In the very late 1950s when I was approximately 2 years old I fell from my high chair and hit my head on the floor. I had internal bleeding in my head. I was diagnosed with mild Haemophilia A with a clotting factor of 5%

3. In those days we were given Cryoprecipitate which was frozen and had to be heated up which took a long time.

3. I really had a normal childhood. I had a few knocks, for which I was treated with Cryoprecipitate. I did not treat myself at home, as I was not really in hospital that often. In my teens I was probably in hospital a lot more as I used to play football and lots of other sports, of which I got lots of knocks.

4. By the time I was 24 I was living with my parents in GRO-C and was attending the Royal Free Hospital Hampstead. I had a good job in London, and life was good. I travelled back and forth every day to GRO-C

5. From my medical records I can see that I had a bleed and that I was treated with concentrate Immuno G in April 1982 (**WITN1065002**). This is from what I gather, how I was infected with Non A Non B Hepatitis on 20 April 1982 and developed symptoms of hepatitis on 29 April 1982.

6. From what I can remember this bleed was no more severe than any other bleed that I had previously. In hindsight I think the decision to change my treatment to factor concentrates was strange. Treating doctors must have known the risks involved with treatment with factor concentrates at this time because they were aware people were contracting HIV through them. Looking back on this now I do believe I was being used to test these concentrates for infections. My blood was regularly taken for storage and research without my knowledge. I was never told what it was taken for. Why would I question it, these were doctors who I had put my trust in to help me

6. During the 6 months prior to the onset of my hepatitis, my medical records (**WITN1065002**) show that I received:-

- Cryoprecipitate on 8 November 1981, 20, November 1981, 23 November 1981, 14 January 1982, 18 January 1982 and 23 January 1982.

- I received a total of 120 Units.

- Immuno Factor VIII (Kryobulin) on 20 April 1982 (batch number 1/81) in the total amount of 1494 units.

It says in my notes that it took only a matter of days for the onset of Hepatitis (**WITN1065003**); I was quite ill, I was jaundiced, vomiting, and could not eat. I lost a lot of weight, I could not work.

7. My medical records note:

"26-5-82. Now has acute Hepatitis AB NON flu like off food, vomited.
4-6-82 Clinically jaundiced. Advised not to work.
15-7-82 N/B NHS VIII Concentrate to be used in future."

8. After a while I went back to work. I noticed that on my records from then on, at the top of the page it says "NANB" or "Acute Hepatitis." (**WITN1065004**) On the records it says that my consultants were Dr. Tuddermans, Dr. Kernoff.

9. I have only seen my medical records in the past year, before that I had never seen them.

10. I don't remember being told to take any precautions, when I was infected with Hepatitis, or about any risks of others being infected as a result of the infection. I do remember being told not to drink alcohol. I was not told how the infection might affect my liver in the future or anything like that.

11. I attended every year for check-ups on my liver, everything was good and healthy. I was never told that I had Hepatitis C until in or around 1991, when I was asked to partake in a proposed trial of interferon for patients with chronic ongoing liver disease. This was my first time I thought I had something really wrong with me. It was never put to me that you might get cirrhosis of the liver if you don't get the treatment. At the time HIV was in the news all the time, not Hepatitis C, so I thought that by not being infected with HIV I was lucky.

12. I am sure that neither my parents nor I were never informed about or given information about the risks of infection from blood products and particularly, factor concentrates.

13. On 3rd December 1994 a letter was sent to me informing me about CJD and the concerns that the agent causing this may be transmitted by transfusion and blood products. The letter said that, according to records, I had never been treated with an implicated batch of factor concentrate or cryoprecipitate.

14. In my medical records, on 24th September 2004, there is a confidential patient VJCD exposure assessment form, saying a copy should be sent in confidence to the national Haemophilia Database Coordinator, University Dept of Hematology, Manchester Royal Infirmary. The form asked whether I had receive any UK sourced pooled factor concentrates or antithrombin between 1980-2001. In brackets it said "yes" and then next to it, says "patient is at risk of vCJD for public health purposes". It gives a list of batch numbers, dates of exposures. My list just has 0 against all doses. The name of the assessor is Dr. Carclyn Millar. I had never seen this until I accessed my medical records and I have not received any other information on this topic since.

14. From my medical records in 1982 and 1983, just after I was exposed to NANB Hepatitis, I can see that blood was taken from me for storage and research (**WITN1065005**). I was never given any information on

this, and this was without my knowledge or consent. My records say that the consultants responsible were Dr. Tudderman and Dr Kernoff.

15. Up until I had my first treatment for Hepatitis C in 1997, I had no physical effects from being infected. I lived a normal life, I went for check-ups every year. I think my mother knew I had Hepatitis C, but we never talked about it. However I am unsure how she could have known because my parents were never informed of my diagnosis by myself or a medical professional.

16. In June 1991, when I was asked to partake in the trial of interferon, I declined because I was not keen on treating myself intravenously three times a week.

17. I think as the years went on, I began to understand that having Hepatitis C was very serious, and that I could get chronic liver disease if I did not try to clear it.

18. On 21st April 1997 I started a combination therapy with Interferon and Ribavirin under the supervision of Dr. Bhagani. I finished the treatment in May 1998. It did not clear my Hepatitis C. On 13th September 2000 I signed a consent form to participate in a research study for Pegylated Interferon 2b in combination with Ribavirin for the treatment of Hepatitis C. I cleared the Hepatitis C on the 12th September 2001. I went back 6 months later and I was still clear.

19. I never faced any obstacles in obtaining hepatitis treatment. I was approved by Kensington, Chelsea, and Westminster for funding.

20. The doctors didn't prepare you for the effects and the impact Interferon had on your body, and the mental effects it had on you. I had chronic fatigue, I lost a lot of weight, my hair thinned and I was very depressed. I had trouble sleeping at night as I was itching and scratching all over. I had incredible mood swings. After the first trial did not work, I was in

no hurry to try again, but I knew I had to. The side effects were truly horrendous both times. Both physically and mentally.

21. Going to the dentist was a major problem. No normal dentist would touch someone with Hepatitis C so I had to go to the Royal Free Hospital for treatment. The dentists there were not the best.

22. Having Hepatitis C did not bother me up until I started having treatment with Interferon. I lead a normal life with my friends and girlfriends. I never told my parents or any of my friends I had Hepatitis C. We never really disclosed me having Haemophilia, so I didn't see the point in telling them I had Hepatitis C. When I started taking Interferon everything changed. I stopped drinking alcohol, so I had to tell my friends why. I told them I had to inject myself every day because I caught Hepatitis C through a blood transfusion due to my Haemophilia. I stopped having relationships with women. I didn't think anyone would want to see me inject a needle in my stomach every day. I just worked and went to bed as soon as I got home, because of the fatigue. I became withdrawn and I looked awful.

23. As I told no one up until I started the Interferon that I had Hepatitis C, no one knew. In contrast to those infected with HIV, there was no stigma associated with Hepatitis as far as I was concerned. But still, I did not tell my parents. I did not want to worry them as they were getting much older by this point.

24. As I was self-employed in the antique business, I could work when I wanted to. During the course of Interferon treatment, if I was fatigued I went home to bed. I was single at the time, I rented a flat, other than that I had little expenditure. So I could afford not to work sometimes.

25. To the best of my knowledge I was never offered any counselling or psychological support during or after I was treated with Interferon nor was I ever offered any counselling in relation to my diagnosis with

Hepatitis C. When I look back on it now, I think it would have helped a great deal. The effects of Interferon physically and mentally are very damaging. I still to this day am affected by itching and scratching at night time. I believe the Interferon is still in my system.

26. I was told by my cousin, who also has Haemophilia that I could apply for financial assistance, this was in June 2004. This was with the Skipton Fund. I filled out a form from the Skipton Fund and I got it signed by Dr. Christine Lee from the Royal Free Hospital. It stated that I had been infected with Hepatitis C through factor VIII concentrates. I received a one off payment of £20,000. I had to sign a form which included as a precondition, that I would take no further legal action.

27. It was interesting that I was not told by the Royal Free Hospital, when I was infected with Hepatitis C that I could apply for financial assistance. I had to find out for myself.

28. I did not have any difficulties with the process of applying for financial aid. For me it all went very smoothly.

29. In 2009 I moved to the USA and got married; I have two stepdaughters. It wasn't until last year (2018) when talking with my cousin that she told me about the EIBSS. I knew nothing about this as I had been out of the country for a while. I went on to the EIBSS website and provided them with all of the details and documents they requested. They were very helpful. I then started to receive monthly payments of $333.33. In April this year, the government announced changes to the scheme. As from July this year I am receiving $1,534.17 monthly.

30. I think I have most of my medical records. If there are any that might be relevant to the inquiry I am happy to disclose them to the inquiry.

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

32. I would not like to give oral evidence at the inquiry.

Statement of Truth

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

Signed . GRO-C

Mark Christopher Helliar

Dated 24 September 2019