Witness Name: Terry White

Witness Number: WITN1724001

Exhibits: WITN1724002 - 05

Dated: July 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF TERRY WHITE

I, Terry White, will say as follows:-

Section 1. Introduction

1. My name is Terry White. My date of birth is GRO-C 1966. I live with my partner at GRO-C. I have one son.

2. I have mild Haemophilia A and I was infected with Hepatitis C genotype 2B following treatment with contaminated Factor VIII concentrate (FVIII).

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

4. I applied to Bradford Royal Infirmary (BRI) for my medical records. By letter dated 27 November 2018 the hospital replied stating it is the Trust's policy to destroy records 8 years after the last attendance by the patient.

Section 2. How Infected

Family history

5. In 1970 aged 4, I had a severe tooth bleed. My parents took me to BRI and at this visit the doctors diagnosed me with mild Haemophilia A. I had not suffered from any other bleeds.

Bradford Royal Infirmary (BRI) – 1970 – 2014

6. From 1970, my parents started taking me to BRI for treatment.

7. There is now shown to me marked **WITN1724002** a copy of my treatment records from the UKHCDO National Haemophilia Database. This shows that I was initially treated with Cryoprecipitate and that I was first treated with Kryobulin FVIII in 1979. I was then treated with BLP FVIII in 1982, 1983 and 1984.

8. In 1984, doctors asked me whether I wanted to treat myself at home. I declined because I did not consider my condition to be serious enough to warrant it. However, I note that my UKHCDO records suggest that I did have regular home treatment in this period. I believe this record is incorrect but have no way to prove this as BRI have destroyed my records.

9. I do not know the name of the professor who treated me in the early years. I do know however that Doctor GRO-D was a consultant at BRI who may have been responsible for making decisions about my health in and about the time that I was infected. However, I cannot remember any particular consultations that I may have had with him.

10. I was 16 years old when I was first treated consistently with FVIII concentrate. I was old enough for the doctors to discuss all health issues that affected me. However, they never gave me or my parents any or any proper advice. It did not occur to us to question the doctors on how best they felt I should be treated. We took it for granted that the FVIII products had been properly

screened and were safe to use. Like any other reasonable family, we placed utmost faith in the doctors.

11. From 2003 to 2014, I did not have any bleeds that required treatment. I did however still attend BRI once or twice a year for clinic appointments until 2006 for yearly check ups and blood tests. Following 2006 I did not attend any clinic until registering at St James' Hospital in Leeds.

Leeds Teaching Hospital (LTH) – 2014 to date

12. In 2014, my regular dentist referred me to Leeds Dental Teaching Hospital for a tooth extraction. My dentist recommended that I register with the Leeds Haemophiliac Clinic, which I did. My tooth was treated by a dentist at LTH and because I did not require an extraction, I was not given any FVIII products.

13. From 2014 Dr Horn has been my current consultant at LTH. In early 2015, she invited me to be tested for virology because my treatment history was unclear and it was possible that I had been treated with blood products prior to the time of them being screened for infection. She informed me that some haemophiliacs who were treated with FVIII products were infected with viruses caused by contaminated blood. I was totally unaware of this because no doctors at BRI had ever mentioned to me that I may have been infected.

14. There is now shown to me marked **WITN1724003** a copy of Dr Horn's letter to my GP dated 8 January 2015.

15. In 2015 I underwent tests and, after about 6 weeks, Dr Horn informed me that the results confirmed that I was infected with Hepatitis C. She also informed me that the tests revealed that Hepatitis B anti-bodies were detected. It is not clear whether the Hepatitis B anti-bodies were present because of a past infection or a previous vaccination.

16. There is now shown to me a copy of Dr Horn's letter to my GP dated 7 April 2015 marked **WITN1724004.**

17. This came as a complete shock to me because I could have unknowingly passed on my Hepatitis C infection to other people. GRO-C to be tested for Hepatitis C but fortunately the test was negative.

18. Dr Horn then informed me that I could apply to The Skipton Fund for a payment and agreed to help me complete the relevant paperwork. She was aware that I was treated with FVIII in the 1980s and informed that, in her opinion; I was likely to have been infected when I visited BRI for treatment in 1979, 1982, 1983 and/or 1984.

19. I have attended the same GP practice my whole life therefore a short letter from my GP would have informed me of the possibility of the infections. It was only by chance that I found out that I was infected with Hepatitis C. No doctor at BRI has ever informed me that I was infected and what I should be doing to prevent the infection from spreading.

Section 3. Other Infections

20. BRI have told me nothing. It seems doctors tested me for Hepatitis A and B. It seems that they also tested for HIV without my consent and without informing me of the results. So far as I am aware, Hepatitis C is the only infection that I have.

21. I have also been told that I am at risk of vCJD.

Section 4. Consent

22. I remember Factor VIII being referred to as the *"new wonder drug"* that the doctors were going to use to treat haemophiliacs. I remember the doctors referring to FVIII products as *"good stuff"*. They never told me or my parents where this blood came from or whether it carried with any risks.

23. I was tested for HIV without my consent. I refer to an extract from the BRI under **Exhibit WITN1724005** which is a list of redacted data dated 1974 and 1975 which shows testing for present inhibitors and jaundice.

24. I do not know whether the doctors tested me for the purposes of research. If they have, it has been without my knowledge or consent.

Section 5. Impact

Education

25. I consider my education was affected. In junior school I was in an elite group of students. However, that changed when I was at secondary school. This was around the same time that I was being treated with FVIII products and I believe that the treatment had an adverse effect on my ability to absorb information. Throughout high school I assumed I was not intelligent but my career later in life says otherwise. I have tried Open University as a mature student and passed my first year but during my second year I struggled with retaining information and it did not matter how much effort or how many hours I put towards studying I had to drop out as I was too far behind with material.

Employment

26. Although I suffered from tiredness I have managed to live as normally as possible with a successful career. I was employed as a Production Manager in a manufacturing company in Yorkshire for 12 years until 2015. Upon being

informed of the Hepatitis C and undergoing the treatment, my life changed for the worse.

27. Dr Horn informed me in 2015 that there was a slight scarring on my liver. She gave me as many leaflets to read as she could. She informed me that it could affect the functioning of my liver and advised me to undergo treatment. Dr Horn was not directly involved in my treatment but oversaw my care as I was a haemophiliac.

Treatment for hepatitis C

28. On 5 November 2015, I started combination treatment of Ribavirin and Interferon and this finished in April 2016 under the care of the nurses at the liver clinic at St James' Hospital. During this period, I was unable to function and spent most of my time in bed and in December 2015, my immune system failed to function. The nurses informed me that I had no antibodies to fight infections because of the medication I was taking and recommended that I should not invite anyone for Christmas because of my illness. I had to take additional injections for my low immune system for several weeks as a result.

29. I was told to expect flu like symptoms for the first 2 weeks of treatment which proved correct in my case. My health did not improve throughout treatment and I attended the liver clinic as I was experiencing brain fog, joint pains, muscle pain and forgetfulness. I repeatedly asked the nurses about the symptoms and when they would subside. They said there was nothing they could do and I just had to see the GP. When I started the treatment the nurses said that the symptoms would last a few days, then a few weeks and then I was told that they could last up to 3 months. I was still employed at this time and I was beginning to feel anxious and concerned about returning to work. My GP has advised that the side effects could take anything from 2 years and 5 years to clear from my body.

30. At my 3 month post-treatment I attended my final Hepatitis C clinic appointment and I was told that I cleared the infection following treatment.

31. My GP has carried out many tests on me with a view to treating the side effects but to no avail. These symptoms have continued to this day.

32. I finished the treatment on my 50th birthday in GRO-C 2016. I was amazed that the doctors failed to advise me of the infection and the how much of a danger I was to others. I was very concerned that I could have been infecting others unknowingly. My mind was partly put to rest when subsequent tests confirmed that my liver was not as bad as anticipated but that did not change underlying emotions of feeling upset, angry and scared. Although I have suffered from tiredness most of my life I was capable of holding down a full time managerial position at a well respected firm. During and since the treatment I struggled to make it through the day even when I am involved in activities which require little to no effort. I was diagnosed with chronic fatigue syndrome and fibromyalgia.

<u>Redundancy</u>

33. My employer supported me throughout my treatments meaning that I could go to work and leave depending on my health. However after 9 months of full pay and no improvement in my health my employer had no alternative but to offer me a redundancy package. They gave me two options. Firstly, to accept redundancy due to medical grounds or a work capability assessment which we both knew I would fail. I accepted the redundancy package that included a payment of £20,000 and outstanding holiday pay which was far above my entitlement. In September 2016, I was made medically redundant. Following my redundancy I was unable to claim benefits for approximately 6 to 12 months due to the redundancy payment and the savings I already had. Since my redundancy has depleted I have been claiming ESA payments.

Present medical condition

34. I stopped cycling in my early 20s due to knee pain which has gone undiagnosed since. The side effects of Interferon have been horrendous and have had such a profound effect on my life both professionally and socially. I feel that it has cost me my career and self worth. I do not know whether other treatments were available that could have treated my condition without it being so intrusive to my life. My family are also affected because our trips have always depended on my health and whether I was able to get involved due to my ill-health.

35. I have been diagnosed with chronic fatigue syndrome and fibromyalgia. Since I have cleared Hepatitis C, only my family and close friends know of the infection.

36. I do not socialise now as I am usually too tired to do so and I am often in bed by 9pm latest. My mood is often low due to the effects of the treatment and I am unable to drink alcohol.

Section 6. Treatment/Care/Support

37. I have not faced any difficulties obtaining treatment. The only time I was offered counselling was when I was diagnosed with PTSD because of the infection. The doctors thought it was PTSD but it was really fatigue as a result of the treatment.

Section 7. Financial Assistance

38. Dr Horn advised me of The Skipton Fund and helped me with the application.

The Skipton Fund Payments

39. In June 2015, I received £20,000 from The Skipton Fund. I encountered no difficulties receiving this payment. It also helped me with a payment of £500 towards my fuel bills during the winter months.

The Caxton Fund

40. The Skipton Fund advised me to approach the Caxton Fund for financial support. This was when the redundancy monies that had almost been spent. I received a single payment of £500.

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41. This support group pays me £1500 per month and because my wife and I are a low-income household, we get a further £362 per month.

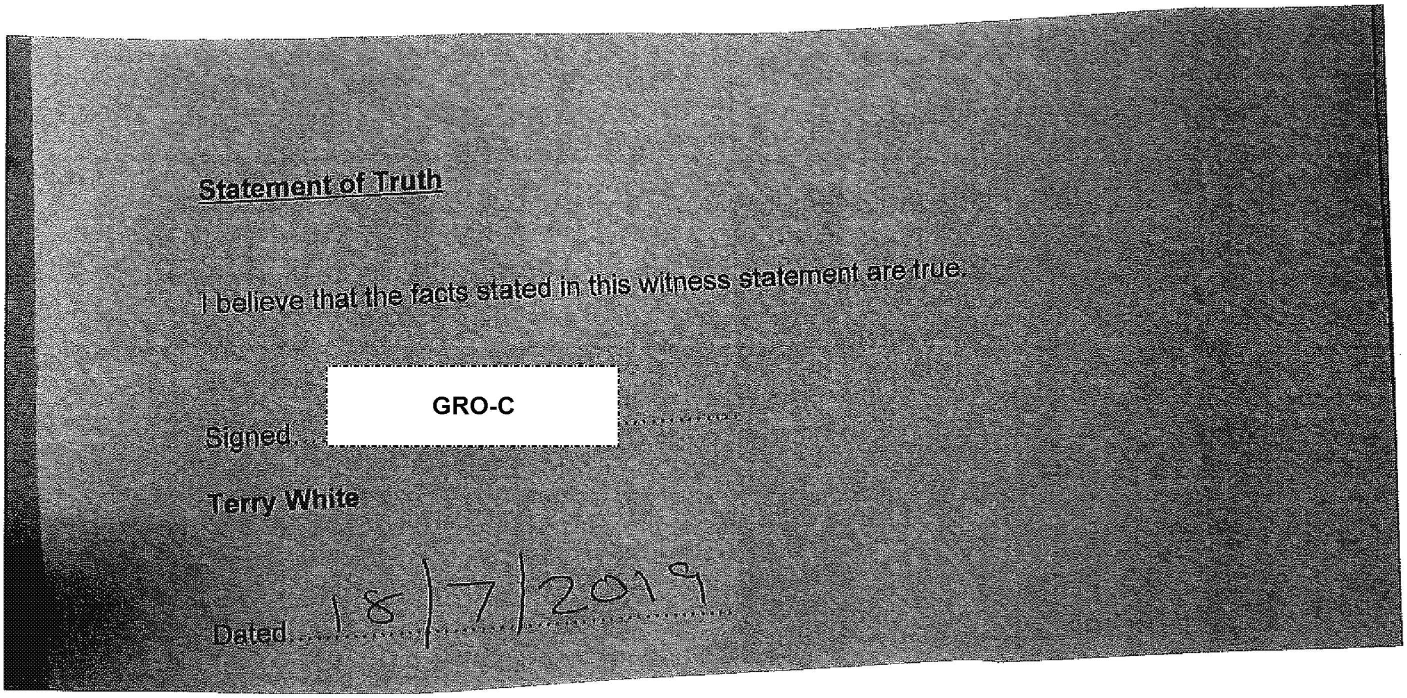
Section 8. Other Issues

42. The hospital has known for such a long time and the doctors were not bothered about telling about my Hepatitis C infection.

Anonymity, disclosure and redaction

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

44. I wish to be called to give oral evidence.



Statement of Truth

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

Signed GRO-C

Terry White

Dated 18/7/2019