Witness Name: Helen-Marie Wilcox
Statement No: WITN1606001
Exhibits: WITN1606002 - 3
Dated: January 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF HELEN-MARIE WILCOX

I, Helen-Marie Wilcox will say as follows:-

Section 1. Introduction

1. My name is Helen-Marie Wilcox, I was born on GRO-C 1959. I live at GRO-C GRO-C with my husband. I no longer work and I am registered disabled.

2. This witness statement has been prepared without the benefit of access to my full medical records. If and in so far as I have been provided with limited records the relevant entries are set out in the medical chronology at the end of this statement.

Section 2. How Infected

3. In or about 1975, I was diagnosed with mild Von Willebrand's disease. My mother, grandmother and daughter also suffer from Von Willebrand's disease.

4. I was initially treated with Cryoprecipitate and later I was given Factor VIII (FVIII), which was only administered at the hospital. My condition was very mild and therefore I was treated as and when I had a bleed, a prolonged nose bleed or a planned procedure/operation.

5. I believe I was first given FVIII in or about 1978 and I continued to receive it until my last operation in 1995. I also received a blood transfusion when I was 17 years old, in or about 1976.

6. I was initially treated at the Park Hospital, Manchester which has now closed. My care then moved to the Withington Community Hospital, Manchester. I was under the care of Dr David Tebener, who was the main Haematologist.

7. When I retired in the mid 00s, my husband and I moved to France. I became very unwell and was suffering from diabetes and rheumatoid arthritis. As a result of my health, we came back to England and moved to GRO-C. I was required to register with a new GP when I moved back and therefore had routine blood tests. I was not told what tests were done, just that I needed to have routine blood tests.

8. I believe I contracted Hepatitis C (Hep C) through FVIII. I do not know when I was first diagnosed with Hep C or when the first blood test was done for Hep C. I believe that the hospital knew for years as there is a blood test record exhibited at **WITN1606002**, that shows I was tested for Hep C as well as Hepatitis Hep B and A in 2003. I was informed on 23/06/2006 by my GP that I had Hep C. I was not aware that I was being tested for Hep C in 2003.

9. On the 23/06/2006, I was told by my GP that the routine tests above showed that I had Hep C. I was initially asked about the use of drugs and my previous sexual partners. I informed the GP that I have never taken drugs and I only had one partner. I was then told that there was a possibility that I contracted Hep C from FVIII blood products.

10. The GP did not know much about Hep C at the time, but she researched it and at my next appointment she provided leaflets and told me everything she knew about it. She told me about the risks involved in relation to infecting others. GRO-C GRO-C I was grateful that the GP had brought it to my attention, had I not had the above routine tests I would not have known that I had Hep C.

11. I wrote to the Manchester Royal Hospital and asked them why I was not told about my results and they said they were unaware of my Hep C. However, as previously stated at paragraph 8, the hospital had knowledge of the Hep C prior to the blood test requested by the GP. I believe that I should have been told about the above tests in 2003 if not before. I am not sure if blood tests were done before 2003 in relation to Hep C.

Section 3. Other Infections

12. In or about 2009, I received a letter that stated that I may have been exposed to a contaminated batch of blood products contaminated with vCJD. I have not received any follow-up letters or information about it. I did mention it to my liver specialist and he did not say anything or provide me with any further information.

Section 4. Consent

13. I believe the hospital was aware of my infection prior to my diagnosis. I therefore believe that I was treated and tested without my knowledge and consent.

14. When I was reading through my limited medical records on the 09/01/2019 in preparation of my meeting with my Solicitors, I found a blood test record showing that I was tested for HIV. This test was done in 1988. A copy of the blood test is exhibited at **WITN1606003**. I was never told that I was being tested for HIV until I found the blood test record. Luckily the test was negative.

15. From 1979, I used to go to the hospital to be injected with FVIII. I then had a blood test every two weeks. I was told this was routine because of my Von Willebrand's disease, but I do not know what the true reason was. I was never shown the test results.

Section 5. Impact of the Infection

16. When I was first told that I had Hep C in 2006, I had a complete mental breakdown. I did not want to speak to anyone about it because I was completely heartbroken. After my diagnosis I went into a decline and did not want to do anything. I stopped living. I completely isolated myself and did not go out, not even to the supermarket. I only attended hospital appointments. I had five sessions of counselling, but I believe it was not good enough.

17. I had already been suffering with mental health issues since 1989 and the doctors never got to the bottom of it. I was prescribed medication for it, which I have been taking ever since. I had no reason to be depressed, because I lived a happy life with my husband and children. I believe that my depression was caused by the Hep C. I felt miserable and really unwell all the time. I went to the doctors hundreds of times and they just kept prescribing me more medication and telling me to have more counselling, but they never diagnosed me with Hep C. When I moved back to the UK from France I was prescribed Prozac, and I have been taking three tablets a day ever since. I am scared to know what will happen to me if I stop taking it. Last year, I had another mental breakdown due to the Hep C and I am currently having more counselling for this.

18. I also suffered from chronic fatigue, and when I travelled on holiday with my family I stayed in the hotel room because I did not have the energy to do anything. My children and husband would go out and then come back to tell me about their day.

19. In or about the late 2007, I started a 48 week course of treatment with Interferon and Ribavirin. I had the injection on a Wednesday and then I was in bed until Sunday afternoon as I was unable to get out of bed. I was basically bedbound. I cannot remember what happened from Wednesday to Sunday. I have been told that I used to watch things on the television whilst I was in bed, but I do not remember doing it. As a result of the treatment, I suffered from the shakes and I was always cold and sweating at the same time. I lost nearly all of my hair and around 11 kilos in weight. I lost

approximately 7 to 8 teeth as a result of the treatment, and had to attend a private dentist. At week 40 of the treatment, I was advised to stop the treatment because it had cleared the Hep C.

20. I faced difficulties and obstacles accessing the treatment. I could not get this treatment in GRO-C so I had to travel GRO-C to Leeds to get the treatment. I could not drive myself so my husband or children had to take time off from work to take me.

21. Other medical complications I have suffered which I believe are as a result of the Hep C and/or my treatment for Hep C, are; diabetes, rheumatoid arthritis, osteoporosis, cryoglobulinemia, fibromyalgia, high blood pressure, depression, osteoarthritis, hernia, peripheral neuropathy, gallbladder contracted, enlarged liver and spleen, heart problems, itchy skin, bowel bleeds, hearing loss and retinal myopathy. I was told in October 2016 that I have cirrhosis, so I am unable to take any pain medication. Since my treatment, I have had four strokes which I believe are attributable to the Hep C infection and/or the treatment I had for it.

22. I lost loved ones because of the stigma associated with Hep C. When I told my immediate family that I was infected with Hep C, my GRO-D stopped contact with me because she was worried that I would infect her. Even though my GRO-D now knows that I have cleared Hep C, she still does not talk to me. Prior to my diagnosis we were very close and used to see each other all the time. However, since 2008 she has not been able to cope with my diagnosis. I have also lost friends because of my diagnosis. I wanted to talk about the Hep C, but not everyone could accept that.

23. When people found out that I was ill they thought I had cancer because I looked so poorly and my hair had fallen out. When I told them that I had Hep C people were worried about me, but I felt that they did not really want to know me as they were worried that I might infect them. I do have some friends that I see occasionally, but I have not informed the people that left my life that I have now cleared the infection.

24. In addition to the social effects, my infection has had an impact on my finances. I wanted to retire in France. However, as previously stated because I was not well, I returned back to the UK. If I had been told that I had Hep C before I moved to France, I would not have moved. I sold my family home in the UK and we lost a lot of money when we sold the property. When I came back to UK, I tried to go into work. However, I was unable to work because I was so ill. Had I not been unwell, I would have worked until retirement age.

25. My family was traumatised when they found out that I had Hep C and it impacted our family life. We used to go horse riding, skiing, swimming as a family, but after my diagnosis I found even simple tasks like putting on my shoes difficult, so it really impacted what we did together.

26. My husband was absolutely heartbroken GRO-C about what has happened to me. It was hard for him because he did not want me to tell anybody. But over the past two or three years he has become more open about it and his attitude towards it has changed.

27. My husband, daughter and son took shifts to look after me and were my carers during this time. My children were only 18 and 21 years old at the time, but they took it in turns to sit with me and take me to the doctors appointments.

28. I had another mental breakdown in January 2018. I wanted to end my life as I was not living, just existing. I have no life at all.

Section 6. Treatment/care/support

29. When I was informed of my infection I was not offered any counselling or psychological support.

Section 7. Financial Assistance

30. Approximately a year after I was diagnosed I received £20,000 from the Skipton Fund. In approximately October 2016, I was diagnosed with cirrhosis. I provided blood tests and Fibroscan to the Skipton Fund and then received a

Stage 2 payment in the sum of £50,000 in July 2017. The hospital was very helpful in assisting me.

31. I now receive a monthly payment in the sum of £1,500 from the EIBSS.

32. I have not faced any difficulties in applying for the above financial assistance. My doctors told me to apply to Skipton and when I received the application form I gave it to the doctor and they filled it in and sent it off for me.

33. I also applied for a grant from the Skipton Fund after I had a stroke to assist me financially for a downstairs washroom because I was unable to go up and down the stairs on my own. The Skipton Fund asked for proof that the local council would not pay for it, which I provided. I also had to provide two estimates and it was approved and paid directly to the builders. I do not consider that I had difficulties with The Skipton Fund.

Section 8. Other Issues

34. I have applied for life insurance a few times, but my application were all rejected. I struggled to get travel insurance because it was very expensive; the last time I applied for it cost nearly as much as the holiday. I am not really capable of travelling now, but the Hep C has previously stopped me from travelling.

Anonymity, disclosure and redaction

35. 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.

36. I do not wish to give oral evidence to the Inquiry.

Statement of Truth

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

Signed... GRO-C

Dated 29.01.2019.