Witness Name: Louisa Martinez
Statement No.: WITN0860001
Exhibits: **WITN0860002 -**
WITN0860004
Dated: 26th June 2019

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF LOUISA MARTINEZ

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 29 March 2019.

I, Louisa Martinez will say as follows: -

Section 1. Introduction

1. My name is Louisa Martinez. My date of birth is GRO-C 1979 and my address is known to the Inquiry. I live with my husband and am a mother to two young daughters. I intend to speak about my life after contracting Hepatitis C ("HCV") from blood transfusions. In particular, the nature of my illness, how the illness affected my family and I, the treatment I received and the impact it has had.

2. I can confirm that I have chosen not to be legally represented and that I am happy for the Inquiry team to assist me in writing my statement.

The Inquiry team has explained anonymity and I do not require any information to be kept private.

Section 2. How Infected

3. I was born with a genetic condition called Beta thalassemia major, a blood disorder where you do not produce enough red blood cells. Because of this condition my whole life is, and has been, based around obtaining blood transfusions. I received my first blood transfusion at six weeks old. Ever since then I have received blood transfusions approximately every four weeks. These transfusions were all carried out at the North Middlesex University Hospital ("NMUH").

4. The doctor who treated me during my early childhood retired around 1990. I then started seeing a new doctor, Dr Yardumian. She took a more modern approach in comparison to my previous treatment that I would describe as quite 'old school'. When I started seeing Dr Yardumian she took many tests that had not previously been undertaken. One of these tests showed that I had low thyroxine. Following this Dr Yardumian then started doing further investigations. In my opinion these were not sinister investigations but she was just doing what should have been done in the first place. From these investigations it transpired that I was given contaminated blood from a transfusion in 1988, when I was only 9 years old.

5. I was then diagnosed with 'non-A, non-B hepatitis'.

6. In October 1990 I was officially diagnosed with HCV. Following this diagnosis, I was sent to Dr Wonke for treatment at the Whittington Hospital ("Whittington"). At the time doctors were worried about my iron levels and cardiovascular problems so I did not receive treatment straight away.

7. In February 1992 I underwent a liver biopsy. In March 1992, when I was just 12 years old, I started Interferon treatment.

8. I did not get on well with Interferon. It was a horrible drug. My first course of treatment was meant to be a six-month course, but as my platelets were dropping too much I only managed two months. Although I have limited memories of this time, I do remember having many nosebleeds. I think that the doctors had intended to start me on Interferon again but it wasn't having any impact on fighting the virus.

9. In 1993 my liver became very enlarged to about twelve centimetres. There were no other symptoms that I can remember other than my liver becoming larger and more damaged. As I was so young I cannot recall if I felt any symptoms. I annex a letter dated 5 October 1993 by Dr Yardumian, which outlines the state of my health at the time, as Exhibit WITN0860002.

10. In October 1993 Dr Yardumian received a letter from Dr Wonke regarding my prognosis. This letter states that my prognosis was poor and that they did not think I would reach the age of twenty. A copy of this letter from Dr Wonke, dated 13 October 1993 is attached as Exhibit WITN0860003.

11. During this time I also felt that my Mum and I were essentially being bullied by medical staff at the Whittington and North Middlesex, and we were seen by them as being difficult and awkward. I was encouraged to have a port-a-cath device fitted, however we always refused as I wanted to go to school and have a normal life. I didn't want to take a pump to school. I understand that it was implied to my Mum that by refusing this treatment she would kill her child.

12. I also recall that doctors didn't seem to think that I was taking my medication correctly. I was, in fact, adhering to my treatment plan, but because of the way that HCV and thalassemia intertwined, and with the

lack of knowledge and understanding from medical professionals in this area, I think my results weren't indicating this.

13. I was then left without treatment for about three years until Interferon Ribavirin became available in 1995. In 1995 I had another liver biopsy. I started taking Interferon and Ribavirin from October 1995 until April 1996. Following this treatment my results showed as negative, so I was considered clear of HCV in April 1996.

14. In October 1998 my ALT measurements had started increasing again despite previously being normal, however, following this I have had no further increases.

15. The current state of my liver is not bad; when I have ultrasounds it shows a rough surface, but I do not currently experience any negative symptoms. I undergo fibro-scans and ultra-sounds about once a year to monitor my liver.

Section 3. Other Infections

16. I have not contracted any other infections, beside HCV, from having blood transfusions.

17. I, along with my parents and husband have been tested multiple times for other infections, such as HIV. GRO-C, GRO-C.

18. Now when I am having blood transfusions for the treatment of thalassemia, the bags of blood state that there is a risk of vCJD. This is stated in an obvious place on the bags, but at the time that I received contaminated blood there was nothing on the bags regarding non-A non-B hepatitis, or HCV. There was no awareness or information regarding the risk of receiving contaminated blood. I can appreciate

that I was young at the time, but my Mum also did not know that there was a risk that I was receiving contaminated blood.

Section 4. Consent

19. I was tested without my knowledge or consent.

Section 5. Impact

Stigma

20. As a child I was not really aware of any stigma surrounding non-A non-B hepatitis (or HCV), as not many people knew what it was at the time. Because of this I think the gravity of my diagnosis did not get to me until I was much older. I do however remember an incident that happened when I was at school playing rugby. During the game I suffered a nose-bleed and the P.E. teacher would not let me leave the pitch. I remember saying, "Stay away", "No one touch my blood". I recall my mother then visited the school, and from then on I was permitted to leave a class if I needed to.

Physical impact

21. The worst thing about being infected with HCV was taking the drugs, Interferon and Ribavirin. I believe they are the worst combination of drug that anyone could have to take.

22. Physical effects that I suffered from during this time included the swelling of joints, itchy skin, a dry scalp, skin lesions and hair falling out.

Mental impact

23. During the time I was taking Interferon and Ribavirin I also suffered with depression. I had suicidal thoughts and I believe that this was related to the medication I was taking. I would cry most days and my Mum would stay home with me and not go to work. My GP referred me to a psychologist to help with my depression. Once I stopped taking Interferon and Ribavirin my depression subsided. At that age, 15-16 years old, to be so deep in depression was very odd but in my opinion, it was all down to the medication. I didn't really confide in anyone at the time, not even my best friend. I attach a letter from Dr Wonke dated 29 November 1996 as Exhibit WITN0860004. The letter states, "We saw Louisa on the 13th of November. She was cheerful and the depression which was quite severe has disappeared after we stopped alpha interferon treatment".

Education, work and social impact

24. I was undergoing the Interferon and Ribavirin treatment around the time that I was in Year 11 at school and was about to sit the GCSEs.

25. Because of the physical and mental side effects I wouldn't go to school and missed quite a lot of lessons. Because it was a big school, no one really noticed if you were there or not, but some teachers were quite mean and would comment in school reports that I needed to improve my attendance.

26. I missed approximately thirty per cent of schooling in the year before I sat my GCSE's, which is quite a vital year. Although I was quite good at school, and managed to achieve good GCSE results, with the amount of schooling that I missed I do think that I probably should have and could have achieved higher. I think that due to the resilience of being young I was still able to obtain the results that I did. I got my A

levels and studied psychology at University, however I think I could have achieved more and gone for high paying jobs.

27. Even when I was younger I always had HCV in mind. I have always been cautious to take care of my liver, for instance when I got my driving licence I would always volunteer be the sober driver for my friends as I wouldn't drink. Even now I don't drink very much; I would only ever have a few glasses of Pimms every couple of months, if that.

Impact on Family

28. My Mum went with me to every appointment and missed work to take me. This also impacted my brother as many evenings we were at late appointments etc. All the family were worried about me and my grandmother would pray for me, bless me, and even took a wax model of my liver to be blessed by a priest.

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29. I first took Interferon when I was twelve. From the moment I started taking it my development halted and I never went through puberty. I didn't develop breasts or have a menstrual cycle. Although I have never been told that this is a result of taking Interferon I feel as though this is related and that Interferon is what has had a great detrimental impact on my life.

30. From the age of 17 I was given hormone replacement therapy (HRT), and have been taking them ever since.

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Ongoing effects

38. An ongoing issue I have is that I now have an increased blood consumption compared with others with thalassemia of my age and proportions. I believe this is in response to having had Interferon treatment; my haemoglobin levels dropped rapidly, and I needed a lot of blood, which in turn impacted my iron levels and doubled my blood consumption whilst on Interferon/Ribavirin. I now have two to three units of blood every four weeks which is quite a lot for my size.

Section 6. Treatment/Care/Support

39. As I was quite young when I was diagnosed with non-A non-B hepatitis (HCV), it was just something else that I had, without really knowing what it was. I think that the doctors probably didn't have much knowledge about it, because it didn't even have a name.

40. I was fortunate to be treated by Dr Yardumian. She has recently retired, so she treated me for most of my life. Dr Yardumian has been supportive and I feel lucky that I have had such a good doctor who has been caring throughout.

Section 7. Financial Assistance

41. In January 2004 Dr Yardumian recommended that I apply to the Skipton Fund for ex gratia payments. Dr Yardumian was very supportive and provided a lot of information including printouts in respect of the process. I was required to submit a form and evidence, such as medical records to support my application. In 2005 I received the Stage 1 funding of £20,000. In 2006 I qualified for Stage 2 funding, which was a payment of £25,000. In 2013 I received a call from a representative of the Skipton Fund who informed me that I would be receiving further funding, which was an additional payment of £25,000 and back payments for the past two years. I currently receive a monthly payment of £1,500 from the Skipton Fund with a recent uplift coming into place from July 2019 backdated to April 2019.

42. I am aware that there are some schemes in place to provide payments for dependants of those with HIV however as far as I am aware there are no similar schemes or trusts for HCV. I don't qualify to obtain any payments for my dependants, due to current means testing and I am also unable to obtain life insurance, and this puts pressure on my husband to bring in enough to sustain our family. There are also so many hoops to jump through in order to obtain payments despite the fact people need support and the authorities need to accept that we require compensation.

Section 8. Other Issues

43. One main issue that will continue to affect my family and I is the fact that because of HCV I am unable to obtain life or travel insurance. This means that even though I may have cleared the virus I am still unable to lead a normal life.

44. I feel that because I had treatment while I was so young I still do not really know what the full effects of having HCV and treatment have had on me. I have grown up with it, so I'm not sure how different my life would have been if I hadn't been infected. I am fortunate that I have been able to achieve my dream of having children; however, if this had not happened then I'm not sure that I would have been able to move on as I have.

45. I have been following the campaigning done by groups, including the Contaminated Blood Campaign. It has been assuring to know that there is support available from people who can share and understand my experience. As I am a mother to two young daughters it makes it difficult to attend meetings and events, but I hope by providing this statement I am showing my support to those also infected and affected.

Statement of Truth

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

Signed GRO-C

Dated 26th June 2019