Witness Name: Brenda Hamilton
Statement No.: WITN0567/001
Exhibits: WITN0567/002
Dated: 28th March 2019

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF BRENDA HAMILTON

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 2nd February 2018.

I, Brenda Hamilton, will say as follows: -

Section 1. Introduction

1. My name is Brenda Hamilton. My date of birth is GRO-C 1946 and my address is known to the Inquiry. I was widowed on GRO-C 2009 and am a retired librarian.

2. I intend to speak about the forty years that I have suffered with the Hepatitis C Virus ("HCV"). In particular, I intend to discuss the nature of my illness, how the illness affected me, the treatment received and the impact it has had on my life and the life of my family.

3. I confirm that I have chosen not to be legally represented and that I am happy for the Inquiry team to assist me with my statement.

Section 2. How Infected

Factor VIII

4. I was born in GRO-C, London, where as a child I suffered from prolonged bleeding after several operations and dental extractions. At the time this was unexplained. As a result of this, in my twenties, I was subject to various tests. The first of these tests was carried out at Kings College Hospital, London and later in the 1970's at the Royal Victoria Infirmary, Newcastle.

5. It was at the Royal Infirmary in Newcastle that I was told that I suffered from von Willebrand's disease. Each time I underwent surgery or dental extractions, I was given clotting agents to prevent my bleeds; I was treated with Factor VIII.

6. I became seriously ill during a dental operation in late 1977. I was treated at Charles Clifford Dental Hospital in Sheffield and received Factor VIII.

Hepatitis C

7. After several months, I became severely jaundiced and covered in an unexplained rash, which left me with a skin problem for over forty years. My GP at the time diagnosed me with some form of hepatitis, and visited me daily in my home to administer me with Vitamin K injections.

8. I was not hospitalised because I had two children under five; my mother assisted me with looking after them. After my recovery, there were still many unexplained health problems.

9. When I moved from GRO-C, I was referred to the Sheffield Haemophilia and Thrombosis Centre at the Royal

Hallamshire Hospital. Here, I was under the care of Professor Makris for many years. My hospital number was AY 2262. Whilst under Proffessor Makris's care, I received a letter in 1991 asking me to attend his clinic. Whilst attending his clinic, I was told that I was among a number of people who had their blood routinely tested after receiving Factor VIII products.

10. As a result of the routine testing of my blood, one particular result had shown that I had contracted Hepatitis C ("HCV"). Further tests revealed that I was Genotype 1a, which I was told was extremely difficult to treat.

11. Professor Makris explained to me what the implications of HCV were and I was given a booklet containing advice. Then followed months of visiting hospitals for various blood tests.

12. When I was first alerted to the fact that I was HCV positive, it was a very anxious time. I tried to research how my husband and family would be affected. This initially put a great strain on my relationships at first.

13. Knowing I was infected with HCV put me under great shock and worry when I was first told, as I knew so little about the condition. I received various leaflets and was given a telephone number of the Haemophilia Centre in Sheffield, to receive various blood tests and check-ups. However, there was a geographical problem; the hospital was located in Sheffield but I lived in Lincolnshire. Journeys to Sheffield from Lincolnshire were tiring and expensive.

14. Thankfully, after receiving treatment of Harvoni and Ribavarin at Kings College Hospital in November 2018, I am now clear of HCV.

Section 3. Other Infections

15. I do not believe that as a result of being given infected blood products that I have contracted any infection other than HCV. I was tested for variant Creutzfeldt-Jakob disease ("vCJD') on 20 September 2004 but fortunately this was negative.

16. However, I do believe that as a result of my infection and subsequent treatment, I have suffered with various mental and physical effects.

17. The HCV and treatment completely ruined my immune system and in turn, in 2015 I suffered with complete organ failure as a result of sepsis. I cannot say for sure that these problems are directly linked to HCV, but I feel my infection has definitely had some influence on my health problems. This has been confirmed by my GP who in the past stated that my infection had exacerbated my health problems. He stated the virus likely had some bearing on the other physical symptoms that I was experiencing.

18. Other effects include suffering from joint problems and liver cirrhosis. The pain this causes me is profound and has severely impacted my life and the life of the people closest to me. I am sure that my HCV has led to these problems.

Section 4. Consent

19. I have been asked if I believe that I have ever been treated or tested without my knowledge or consent and the answer is no, I have always consented to the treatments I have received.

20. However, I would like to state that I was never made aware that I was being tested for HCV. The doctors used my previous blood tests to test for HCV. This is something that I had not consented to nor was made aware of. It came as a shock to me once I was told.

Section 5. Impact

21. The impact that HCV has had on my life has been harrowing, worrying and has caused me various health problems over the years. This includes continuous skin eruption, which has led to depression. I have also had to deal with extreme embarrassment and have suffered from chronic exhaustion. This exhaustion has made me feel that I need to lie down wherever I am.

22. As previously stated, I suffer from immune system problems causing many infections, the worst of which resulted in contracting sepsis that caused complete organ failure in 2015. My GP has previously told me that he felt the HCV had worsened my joint problems.

23. As a result of HCV I now have cirrhosis of the liver, which needs continual monitoring.

24. I have spoken to my sons about their memories and how they believe these events impacted me. They stated that they remember visits to our local GP in the eighties. Here, I could never get an answer as to what was wrong with me and what was causing my symptoms. They further stated that this had led me to depression.

25. My sons also remember the depression I had whilst on the first course of treatment in 2001, which did not work. They told me that normally I have a very up-beat sort of personality, which made my depression particularly noticeable.

26. In 2001 my local NHS: The Lincolnshire NHS Trust, refused funding for my course of treatment. Professor Makris represented me at an appeal to the Complaints Manager. This resulted in joint funding for my first course of treatment: a combination therapy of Interferon and Ribavarin for 6 months. Unfortunately, this treatment was unsuccessful.

27. The self-administered injections were very painful and I suffered with horrendous side effects of flu-like symptoms, all to no avail.

28. I was fortunate to receive a course of treatment of Harvoni and Ribavarin at Kings College Hospital in November 2018. Although the side effects were less severe than previously, the tiredness and depression were still quite intense. Thankfully on this occasion the treatment was successful. I am now clear of Hepatitis C.

29. I am unsure why I was not offered any further treatment after my initial treatment in 2001. Having had one course of treatment fail and having been told that Genotype 1 was the hardest to treat, I just assumed that there was no other treatment available. It was not until I moved to my present address and asked my GP about a HCV check-up, that I was put in touch with a local HCV Specialist Nurse. The nurse informed me that there was a new treatment that could work for Genotype 1a.

30. As a result of HCV I have also encountered prejudice and discrimination. This includes being refused treatment by a dentist who claimed to be unable to treat me in a surgery where there was a risk of it being "passed on". I was not sure if he meant to himself or other patients.

31. The stigma of being associated with HCV has been and still is profound. The stigma has affected my social life, in that I have felt at times people do not want to go out with me in case they catch the infection. Previously, I have felt that I might as well have been wearing a label around my neck that stated, "Unclean." I was always kept in isolation in hospitals, which further added to my thoughts of feeling unclean.

32. As a family we were unable to afford holidays abroad because of the high premiums involved in travel insurance. Other forms of insurance have also been affected.

33. My infection with HCV has also affected my working life. The accumulation of symptoms further caused me to take health retirement from my job that I loved. This was seven years earlier than originally planned. This in turn caused me various financial struggles, which has taken its toll. When I did work I constantly felt exhausted which impacted my ability to carry out my work. However, I always did the best I could. Furthermore, my joint problems restricted my mobility making it hard to move around. All of these effects impaired my work life, as I struggled with certain aspects associated with working in a library.

34. Part of my financial struggles came from the expense travelling to and from hospital. Currently five different departments see me. The travel, along with the car parks can be very expensive.

35. As previously stated, my infection with HCV has put a strain on my family relationships and in particular, my husband and children. I was constantly worried about the risk of transmitting the infection. I had to research the risks associated with HCV. This was not easy and put a lot of unnecessary stress on my shoulders.

36. I cannot describe how much of my life has been affected over forty years of suffering with liver damage. All because of the mistake made by this country not testing blood for impurities until 1991.

Section 6. Treatment/Care/Support

37. As stated in Section 5, I had great difficulty in obtaining the first course of treatment offered due to my local health authority. I was initially refused treatment, which led to an appeal from my GP. This

appeal was successful but the process was arduous and caused me great stress, not least because of the worries of dealing with my infection. I should not have had to further worry about my treatment.

38. I have also faced many difficulties in obtaining dental treatment. As previously stated, a dentist told me that I could not be treated because of the risk of infection; this made me incredibly upset. It always seemed like a hassle in hospital. I was always isolated and constantly being asked about my infection with HCV. This made me feel as though they did not want me there.

39. I can confirm that I have never been offered psychological support for my infection with HCV.

40. I can also confirm that I have been informed about access to the support mechanism that the British Red Cross is providing in conjunction with the Inquiry.

Section 7. Financial Assistance

41. I was made aware through my consultant at Hallamshire Hospital of the Skipton Fund. I applied and received a basic payment of £20,000. This was paid to me on 15 October 2004. This payment seemed to be a very small amount in view of the life changing implications of contracting HCV.

42. An application was later made to the Caxton Foundation for a regular payment under stage 1 of the allowance. I am now in regular receipt of Stage 1 payments under the England Infected Blood Support Scheme ("EIBSS"). This commenced in 2018.

43. I am in the process of applying for Stage 2 under the EIBSS grant. However, the form that I have left with the liver clinic at Kings College Hospital has not been returned to me. I suspect that it has been lost

before reaching my consultant. I have attempted to contact the hospital multiple times, but keep being told that I will be contacted later with further information. I am yet to receive any of this information. I have also sent an email to the hospital, which to this day has not been responded to. This money would be extremely useful to me, as I am currently travelling to five hospitals and the cost of this is very expensive.

Section 8. Other Issues

44. Last year I received a letter from East Kent Hospitals. The letter informed me that my recent tests for von Willebrand's screening and intrinsic factor testing had come back normal. The letter also informed me that this could be possible as the levels of Factor VIII or von Willebrand's factor had naturally risen over time, or that my underlying cirrhosis may be pushing the said factor levels up **[WITN0567/002]**.

45. I would like the Inquiry to know that it has been very traumatic recalling all the ways in which HCV has affected my life over forty years. However, I feel as though for me it is something that I must do for people who have lost loved ones and still suffer in countless ways.

46. I feel the government should stand up and must put right the terrible mistakes made and admit to the "cover up" of infected transfusions and blood products.

Statement of Truth

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

Signed **GRO-C**

Dated 28th March 2019