Witness Name: Patience Moore
Statement No: WITN3498001
Exhibit No: WITN3498002-3
Dated: 13th OCTOBER 2019

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF PATIENCE NAH NYELEY MOORE

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 12 August 2019.

I, PATIENCE NAH NYELEY MOORE, will say as follows: -

Section 1. Introduction

1.1 My name is Patience Nah Nyeley Moore. My date of birth is GRO-C 1948. I reside in Yorkshire, my full address is known to the Inquiry.

1.2 I am a retired Secretary. I have three sons, two of whom are biological, born 1974 and 1977 and one adopted born in 1960.

1.3 I intend to speak about my experience being infected with the Hepatitis C Virus ("HCV") following a blood transfusion. In particular the nature of how I found out about the infection in April 2018, my illness, how the illness has affected me, the treatment I have received, and the impact it has had on my life and the lives of my family.

1.4 I confirm that I have chosen not to be legally represented in regards to providing evidence to the Inquiry.

1.5 The Inquiry investigator has explained the anonymity process to me. I have not elected to be anonymous. I wish for my story to be heard in full because I don't wish to hide behind my diagnosis and my friends and family are aware of my diagnosis.

Section 2. How Infected

Blood Transfusion

2.1 On GRO-C 1974, I gave birth to my first son at Lister Maternity Hospital in Hitchen, Hertfordshire.

2.2 I gave birth to him at around 3pm. That evening, while still in hospital, I realised that I was bleeding internally. I had studied nursing the six months prior, so I was aware of the signs. I called the nurse and told her I was bleeding internally and wanted to see a doctor. The nurse would not call the doctor at first. I had to insist on seeing one.

2.3 The next morning the doctor visited and confirmed I was bleeding internally. I was then taken to the operating theatre where I was operated upon to repair my urthea/bladder. It was after the operation that I was given the three pints of blood by IV due to blood loss.

2.4 I know I was given three pints of blood because I saw the blood being given to me. Also after I was discharged I was given my maternity card. This card states I received three pints of blood by IV due to bleeding.

The medical document advising of my transfusion is attached and marked Exhibit **WITN3498002**.

2.5 There was no discussion prior to the transfusion about the risk that came with blood transfusions.

2.6 I believe it was during the transfusion I was infected with HCV. This is the only occasion I have been given blood products. I do not have tattoos, I have not been a drug user. I do not believe I have been exposed to HCV on any other occasion.

Hepatitis C

2.7 In August 2017, one night I went to bed around 9pm everything seemed 'normal' however when I woke up at 7am my tongue was severely swollen. My son took me to the General Practitioner (GP) clinic. When we arrived the receptionist would not allow me to see the GP.

2.8 We returned home and my son called 999. The ambulance came and the paramedic said we should have called earlier given the severity of the swelling. I was taken to A&E and rushed to intensive care.

2.9 Following investigations, I was diagnosed with Tongue Angioedema, swelling of the tongue resulting from an allergic reaction.

2.10 Once discharged from hospital, I was referred to the Allergy Clinic at St James's University Hospital ("St Jimmys") in Leeds, to investigate the cause of my anaphylaxis. Dr Gururaj Arumugakani at the Department of Clinical Immunology told me he wanted to carry out blood tests including testing for HIV and Hepatitis to find out if I had an underlying disease because my anaphylaxis was not a "*normal case*". I did not have the usual signs of anaphylaxis which include rashes and itching.

2.11 When I heard he was testing for HIV, I panicked. I felt like my life was turned upside down. The possibility worried me a lot while I waited for the results.

2.12 It took what felt like a long time for the test results to come back. When they did come back I remember being told at St Jimmy's Hospital that I did not have HIV. However, I had Hepatitis C ("HCV"). I did not know what HCV was, at first I thought I was going to die. The nurse gave me some information about HCV to read.

2.13 Further tests had to be carried out to determine what genotype my HCV was. I was allocated a Hepatitis nurse. I remember the doctors and nurse saying my HCV wasn't a "*by the book case*" and the nurse saying something along the lines of it being a "*mutation*". I don't remember a lot more than that other than my records showing I was diagnosed with HCV genotype 5 in April 2018 and that is what I was treated for.

2.14 If it was not for Dr Arumugakani carrying out the blood tests following my Tongue Angioedema, I do not believe that I would have found out that I have HCV.

2.15 I remember during the 1980's, it was announced that Arthur Ashe (the African American tennis player) had contracted HIV through a blood transfusion. I remember thinking that I had had a blood transfusion too. I am not sure if I mentioned this to my GP at that time, but I was so sure that I had had so many blood tests that if I had any dangerous disease it would have been found. It turns out I was wrong to assume that.

2.16 Since being diagnosed with HCV, I have been informed by the doctor that I have cirrhosis of the liver and that the damage is irreversible. I have been told that the treatment plan for my cirrhosis of the liver will be to monitor it every six months to make sure everything is normal. As soon as something changes, the doctors will re-evaluate.

2.17 I should have been tested for HCV at an earlier stage in my life. Had I been tested for HCV earlier when it came to the notice of the government about the gross mistake made, instead of covering it up, I could have been treated years ago and may not have had this scarring on my liver.

Information

2.18 Once I had been diagnosed with HCV, I was given both verbal and written information about HCV from my doctor and Hepatitis nurse. The written information has been in the form of pamphlets and letters. I have found it useful.

2.19 The Hepatitis nurses have given me a lot of support. If there is anything I don't understand, I ask them and they explain it to me. The nurses have been very helpful. I feel like I have adequate information to manage my health.

Section 3. Other Infections

3.1 I do not believe that I have received any other infections other than HCV as a result of being given a blood transfusion in 1974.

3.2 I have suffered with ongoing medication issues that I will speak about in further detail in this statement.

Section 4. Consent

4.1 I do not believe that I have been tested or treated without my knowledge or consent.

4.2 I do not believe that I have been treated or tested without full information.

4.3 I do not believe I have been tested or treated for the purpose of research.

Section 5. Impact

Physical and Mental of HCV

5.1 Prior to having the blood transfusion in 1974, I was a healthy person who had a normal pregnancy.

5.2 While I did not know it at the time, now knowing that I had HCV infection inside me I believe it offers an explanation for many of the illnesses and issues that I have suffered in the years since the transfusion.

5.3 After giving birth to my first son, I suffered from depression. My doctor prescribed me with anti-depressants which I took short time.

5.4 After giving birth to my second son, I went back to work as a secretary in 1980. As far as I knew, I was reasonably healthy and was kept busy raising my sons. However, I suffered from a lot of 'odd illnesses' over the years which presented in unusual ways.

5.5 In the early 1990s I had my gallbladder removed at York District Hospital. Following this operation, I once again suffered from depression and was admitted to the psychiatric hospital six times and later received treatment as an outpatient. I was often suicidal and had Agoraphobia, meaning I was scared to go outside. Due to this I was put back on anti-depression medication but this did not help me and due to the side effects, I was eventually taken off the medication.

5.6 I have also suffered from a number of physical issues. I often experience symptoms which are not 'normal' for the illnesses I have. I believe this is a result of the HCV playing havoc with my body.

5.7 For example, I have suffered from fainting and blackouts. The doctors carried out tests but could not find anything wrong. Although they did not know what the issue was, it was decided that I needed a heart monitor. In 2007 I had the monitor inserted.

5.8 In addition, I have had lumps form in my body that move around. I describe it as feeling like there is an alien inside me. In February 2019, I had a lump in my throat. It was getting worse and I was having difficulty breathing when lying down. I went to my GP who felt the lump but couldn't see inside my throat so referred me to a head and neck consultant at York District Hospital. The consultant felt my neck and agreed that he could feel the lump and said I would need an ultrasound and biopsy.

5.9 When I went to have the ultrasound, the lump had disappeared. This is not normal. I worry that the lump has moved somewhere else in my body. I worry that it could lodge in my heart and kill me.

5.10 Earlier this year I had severe pain behind my eyes. I was rushed to hospital by ambulance and spent eight days in hospital. I was diagnosed with Scleritis which is nerve damage at the back of my eyes. The nerves are swollen and inflamed. This is being treated with steroids.

Medical Conditions

5.11 I suffer from hypertension, recurrent angiodema, osteoporosis, diabetes and high blood pressure. I also have cirrhosis of the liver. On reflection, I believe these illnesses may have been caused by, or made worse as a result of my immune system being weakened by the HCV. I believe the HCV is putting additional strain on my body, making it harder for my body to deal with these ongoing health issues.

5.12 I am aware that Dr Gururaj Arumungakani, Consultant Immunologist at St James's University Teaching Hospital, Leeds has written a letter dated 9 October 2018 stating that "*...it is possible that the ongoing episodes of angioedema are triggered by immune activation cause by the hepatitis virus...*". I have attached and marked this letter as Exhibit WITN3498003.

5.13 I worry about the impact of the medications I take to treat the above illnesses on my liver. I have to choose what medications are most important to try to keep the load on my liver down so that the cirrhosis doesn't get worse. Where possible, I try to manage some of my illnesses through diet rather than medication.

Treatment

5.14 When diagnosed with HCV, I was anxious to start treatment as soon as possible. I had to wait for it to be determined which genotype of HCV so treatment could be the most effective.

5.15 I started treatment for HCV with anti-viral therapy Maviret on 11 October 2018. I had to take three Maviret tablets a day for 12 weeks.

5.16 The medication made me feel terrible. I felt like I was going through Chemotherapy. I was nauseous all the time, I could not eat, I was constantly tired and spent most of my time in bed. If I did manage to get out and walk for a bit, I would be exhausted and have to return home.

5.17 My moods would go from high to low, it was like being on a rollercoaster. I felt depressed but didn't want to tell the doctors how I was feeling because I didn't want to be put back on anti-depression medication.

5.18 I finished the 12-week Maverit treatment and on 3 January 2019 I had blood tests taken to check for the presence of the HCV virus. I received a letter dated 8 January 2019 informing me that I have cleared the HCV infection.

5.19 The treatment I have received has been very good.

5.20 I do not believe I have faced obstacles obtaining treatment once diagnosed. I believe I was able to make an informed decision about what treatment to undergo.

Stigma

5.21 I do not believe that I, or my family, have suffered from stigma related to HCV. The only time I recall feeling like I was treated badly was when the original blood tests were being carried out to determine if I had HIV or Hepatitis. The nurse taking the blood test saw what I was being tested for and was extremely rude. This is the only time I felt there was any prejudice towards me.

5.22 I advised my dentist of my infected status and treatment. He was fine about it. I do not think my HCV has impacted the treatment I have received from him.

My Life

5.23 Managing my chronic illnesses has caused me to have a significant lifestyle change. I have had to simplify my diet as a result of my allergies. This impacts my ability to socialise because I cannot eat certain things. Cooking and socialising around food was a big part of my life before my allergies. Now my friends and family worry about cooking for me in case I get ill. If I go to a friend or family members' place for dinner, I need to bring my own food with me.

5.24 My family and close friends have been a big support to me. Initially I wasn't going to tell them about my HCV diagnosis because I didn't want them to worry. My GP encouraged me to tell my family and friends so they could understand why I was sick.

5.25 My son blamed himself since I had the transfusion after I gave birth to him. I have to reassure him that it is not his fault.

5.26 Since finding out I have HCV and completing the treatment, I have tried to put it out of my mind but it is hard. I worry that once my other illnesses are under control, all I will be left to think about is the HCV and the impact it has had on my liver. I worry I will get depressed again

Section 6. Treatment/Care/Support

6.1 I was not offered any counselling or psychological support at the time of receiving the blood transfusion, nor at the time of being diagnosed with HCV and/or throughout the treatment of the virus.

6.2 I have discussed with the Inquiry investigator the existence of the counselling and psychological support service the British Red Cross is running in collaboration with the Inquiry. I have been provided their contact information and will consider using it.

Section 7. Financial Assistance

7.1 I was informed about the existence of the England Infected Blood Support Scheme ("EIBSS") by Dr Emma Page, my Virologist at Leeds Teaching Hospital.

7.2 In early April 2019 I submitted an application for the HCV Stage 1 payment with the help of Dr Page. On 24 May 2019 I received a letter from EIBSS stating that my application for the Stage 1 payment was unsuccessful because "*there was no evidence included that shows you were chronically infected after the acute phase of the illness had passed.*"

7.3 I am furious that my application was rejected because I had not long finished the Maverit treatment and was so sick.

7.4 When I called EIBSS and they told me my application was rejected because my doctor had not included a lot of the information that EIBSS needed.

7.5 After receiving the information from EIBSS that had been submitted, I saw that some of the documentation required had not been sent by Dr Page. I have appealed the decision, sending in the information required, including a supporting letter from Dr Page.

7.6 Dr Page has told me to apply for a Stage 2 payment as well as I have cirrhosis of the liver.

7.7 I am waiting to receive a response from EIBSS about my appeal. I am hopeful that I will receive both a Stage 1 and Stage 2 HCV payment but I believe the Government will do everything in its power to avoid making the payments. I do not trust them based on their treatment of me so far.

7.8 Every time a letter arrives I don't want to touch it because I am so worried that it will say my application has been rejected.

7.9 I believe that I should receive the EIBSS payments. I think all people who were infected by contaminated blood should receive financial support.

7.10 I have not been able to use my life potential because from the 1990's, I have been plagued with one illness after the other. I have not been able to work. If I hadn't suffered from all these illnesses I would have been able to work and save money. I would not be sitting at home in winter wrapping myself in a blanket because I cannot afford heating.

7.11 In future I will need help as my health worsens and at the moment I will not be in a position to pay for it because I don't have the money. I cannot rely on my children all the time. I worry about how I will afford care when I am older.

Section 8. Other Issues

8.1 I am upset that the Government knew about the blood contamination and did nothing about it. Maybe they didn't know about it in the 1970's but once they became aware of it, why did they not test everyone who was given blood transfusions? If I had been tested for HCV when the issue came to light, I would not have cirrhosis of the liver and other people would not be sick or have died.

8.2 I do not want this to happen again. Not just with blood transfusions, but with other areas too. The people that made this decision shouldn't be afraid of being transparent. People make mistakes. Hiding it and destroying information and records is not the way to go about fixing the mistake.

8.3 I want an apology. The people involved may have been trying their best but a mistake was made and they should acknowledge it.

Statement of Truth

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

Signed GRO-C

Dated 13th October 2019