

Witness Name: Mrs Maria Fletcher

Statement No.: WITN1876001

Exhibits: WITN1876002

Dated: 14 February 2019

**WITNESS STATEMENT OF MRS MARIA FLETCHER
INFECTED BLOOD INQUIRY**

Section 1: Introduction

1. My name is Mrs Maria Fletcher. My date of birth and address are known to the Inquiry.
2. I live at home with my husband and step daughter.
3. I used to work with a large cosmetic company; I was no longer able to continue with my work once the treatment started in 1999.

Section 2: How Infected

4. I was born with a blood disorder called beta thalassaemia major which has required me to have regular blood transfusions throughout my life. The condition means that I do not produce enough haemoglobin for my body. This resulted in a severe lack of energy, it was so bad sometimes that I did not have the energy to make a cup of tea, to dress, to do every day standard things. I

was diagnosed with the condition when I was one. The amount of blood I had at any one time changed as I grew up. When I was one I received approximately one unit of blood once every three weeks, this changed to two units when I was around four and then three units when I was 12. I could never have any more than three units at a time because of the risk to my heart; an over supply of iron to the body can damage organs, it is also life threatening and can kill me. I can now only have two units because I have developed problems with my heart. The quantity of blood that I receive at any one time, determines the period of time to my next transfusion; generally, the more blood I have at a time the longer I can wait until the next, but it also depends on how active I am in the interim. If I am overactive then I use up the energy that the blood gives me and so I need a transfusion sooner.

5. Due to the iron overload from the blood transfusions I had to have daily injections to regulate the iron supply and to help me get rid of the excess that had been stored in body. As a result of this I had to have liver biopsies on an annual basis from around 1986 (I was 17 at the time). I was told that I needed the biopsies so that the iron levels in my liver could be checked and for any damage that the iron overload many have caused. My understanding is that not all thalassemia patients had biopsies and that the requirement to have them was isolated to older patients. I do not understand why this is the case. I know this to be so because I have a friend who has the condition. She is five years younger than me she has only ever had one liver biopsy in her life. Regarding the biopsies, when I was provided with some of my medical records I noticed a letter dated 29 January 1986 which was written by a Mark Worwood, based at the Department of Haematology, University of Wales College of Medicine to my haematology doctor at UCLH. The letter stated that a biopsy for me had been received by the college in good condition. Importantly, the letter also states that I do not have infective hepatitis and that I am not positive for HTLV3; the letter further asks my haematology doctor to make that this is the case in the future. I did not know that this had happened; I never heard of or even visited a hospital in Wales. I believe this letter shows a level of knowledge about

hepatitis at this time. I have provided this letter to the Inquiry. [WITN1876002].

6. As I have said my treatment for the beta thalassaemia major began when I was one and was provided by University College London Hospital (UCLH); the treatment continued at that hospital until approximately five years ago when I moved to the Leicester area.
7. I was infected with hepatitis C as a result of receiving infected blood that was given to me to treat my condition. I do not have the dates of or reference numbers for the blood units which carried the infection but I know that the hospital has them. My records have not arrived yet but when they do I feel sure I could provide this information to the Inquiry. I will make a supplementary statement with further relevant information should that be helpful. I know that the infected blood that was given to me was from Brentwood Blood Transfusion Centre; from the medical records I have been able to find, there is a record from my haematologist at UCLH to my GP which states "*I have also contacted Brentwood Blood Transfusion Centre, so we can screen all potential donors for hepatitis c.*". I was also told by one of the doctors who treated me at UCLH, that the blood came from Brentwood. I believe that all of the blood that I received from UCLH up to my 20s came from Brentwood; this is because when I was receiving treatment if there was a delay at all with the supply, the medical teams would tell me that it was caused by delays from Brentwood. The hospitals used to tell me, and patient friends, that we were assigned to a specific donor, so in my mind I have always thought that a specific person gave me the blood I received. The Blood Transfusion Service was able to trace back the contaminated blood to the donor who was contaminated.
8. I was not infected as a result of my relationship with another person.
9. I was never given any information or advice about the possibility or risk of being exposed to infection before receiving any blood; not in the time that I was treated at UCLH, or since. Even when I was told that I had hepatitis C, I was

never told what it meant or where it came from.

10. The medical notes that I have tell me that I have been infected with hepatitis C; I assume that this is the only virus I carry.

11. Before I was diagnosed with hepatitis C, I had been feeling unwell for about a year; I was really tired, had flu symptoms all of the time and aching bones. I felt really run down, and the strange thing was that I did not feel the flu get worse; it was just really bad all of the time. I knew something was not right, I felt differently. I recall that I was having real difficulty commuting and did not have the energy to get to work; my whole body ached with the flu. It was very stressful. I needed to be off work to rest but did not feel that I could afford the time because I needed to impress at work. I kept going back to the doctor as I could not understand why I was so sick. This was unlike me as usually I would not go to the doctor. I put the way I was feeling down to the beta thalassaemia and thought that I needed blood but actually I did not. My consultant haematologist at UCLH began conducting various tests over a period of approximately one year and eventually; when I was about to turn 21 in early 1990, he told me that I had hepatitis C. My medical records show that in January 1990, he attributed my symptoms to a flu-like illness and possibly a post-transfusion hepatitis because my AST was raised. At that time he did not tell me that he was making a possible diagnosis; he told me I had hepatitis C. I believed it was a firm diagnosis. I was also diagnosed with non-insulin dependent diabetes at the same time; however, within one year the diabetes had progressed to insulin dependent diabetes. I do not understand the reason for the delay in the diagnosis of the hepatitis C, particularly because I was so sick for so long and attending the haematology clinic at UCL and because my haematology doctor had already received the letter from the haematology department at the University of Wales; [WITN1876002], which questioned the presence of hepatitis and advised my doctor to make sure that this was the case in the future. Again this letter was dated January 1986 and I was visiting my haematology doctor as I was very sick at this stage.

12. I was told I had hepatitis C by my consultant haematologist, I was not provided with any further information about the infection. The fact that I had the infection was brushed under the carpet. I did not think it was serious because of the way the consultant dealt with it with me. He did say that if it came to it I could just have a liver transplant. This shocked me but still I did not appreciate the seriousness of the condition. It was like I just had to accept it and get on with it.
13. I was given no information to help me understand and manage the infection.
14. Information should definitely have been provided to me earlier; I think I was not diagnosed early enough. I believe that I (or my parents) should have been informed about the risks associated with having a blood transfusion before I was treated. My parents and I could have been alert to any possible side effects and sought help sooner. I also think that I should have been informed that there was the possibility of contamination from the blood when it was known that the blood supply had become contaminated.
15. I am angry about how I was told. The medical profession; my doctors should have told me more. I needed to tell me more about it; I needed to understand. I was only young. It was important to me to be prepared for what I was going to face in relationships that were to come into my life; to manage those, and especially how people would see me as a person.
16. I was given no information about the risk to others of becoming infected. Everything I know about the infection now I have taught myself, through research and attending conferences and speaking to others who carry the infection. Some of my best friends have died from it. My very best friend passed away nine years ago.

Section 3: Other infections

17. I believe I have been infected with hepatitis C only; however, I have no confidence that I do not carry another virus. So much was kept from me and for so long, that there is always fear that something else will be revealed. I do not allow myself to sit around and think about this. I have to hope and pray that I do not carry any other virus.

Section 4: Consent

18. Yes I believe that I have been treated and tested without my knowledge, without my consent, and without being given adequate or full information.
19. I think that I was treated and tested without my knowledge and consent because of the tests that were run and the biopsy that was sent in 1986 to the University of Wales that I had no knowledge of at the time. I have enclosed this letter for the Inquiry to reference, [WITN1876002]. I believe I was treated and tested for the purposes of research when I was given the treatment for the hepatitis C. I was treated over a period of 24 years, and I had five different treatment during this time.
20. I think that I was treated and tested without being given adequate or full information because I was never informed of the risk to me of infection through a blood transfusion despite having them every two to three weeks throughout my life.
21. I believe that research must have been done on the biopsy that was taken. I was told it was for iron overload but the 1986 letter shows that it was for much more than that.

Section 5: Impact

22. The impact of the infection on my life has been immense.
23. The physical and mental effects have been very difficult to bear.
24. I was almost 21 years old when I found that I was infected with hepatitis C. At the time I did not know what it meant. I started to become aware of the seriousness of it when I saw my friends die and when I noticed myself becoming more and more ill. I have tried to be strong and to block out the meaning of the hepatitis C to my life. It is all I can do. I know now that it can and does kill. It is very difficult because I want to block it out so I try to make out that everything is ok. I have struggled with it in relationships; especially with my step-daughter, I am on constant watch to make sure she does not touch any razor blades or toothbrushes that I use and because of my diabetes, I have to make sure my blood strips are not left around. The thought of telling someone that you have found yourself in a relationship with that you have hepatitis C and how they might react towards you does your head in. Especially, when I test my sugar levels ten times a day. These are small things that are constantly going around in my mind and challenge me mentally every single day. I have cried many times over this. I have cried over how this virus has affected my life. The anger that I have towards the hepatology clinic at the Leicester Royal Infirmary is very strong as I feel that they treat me in a discriminatory way. The department is signposted as the "Infectious Diseases Clinic" which I find deeply upsetting and extremely insensitive. It feels like I have a label on me, wherever I go I carry it. On the blood tests it says on a bright yellow label "Risk of Infectious Disease" to alert anyone coming into contact with me. Why do they need to do this? Why do they need to shine a light on me like this; particularly now when I am supposed to have cleared the virus? In this day and age, it is disgusting. I have raised this matter with my local MP but I was not made to feel understood or that I mattered and I believe that it was not taken seriously.

25. Physically I am tired, I am tired of it. It has totally and utterly drained me. My symptoms initially were akin to the flu, I have felt drained for years. I don't have the strength for anything. I don't have the strength to go to the gym or to have a normal life. It is tiring. It is like I have had my life sucked out of me. My memory is affected too; I don't remember things, everything seems fuzzy. It feels like I am in constant daze. I describe this as brain fog. I have to force myself to think about things all the time; like what I need to remember, what I have to do.
26. My legs have become really irritable; they are restless and ache most of the time but especially at night, in the heat or in cold weather. I usually have to stick them outside of the bed sheets at night. The restlessness in my legs keeps me awake at night. I have insomnia as a result. I now take pregabalin medication for this which does help to deal with the irritation that my legs cause. My legs are usually much hotter than the rest of my body. Before the medication I could not sleep at all, I was so tired.
27. I believe that the pains in my hands are as a result of the hepatitis C too. I get shooting, stabbing pains in my hands.
28. I was diagnosed with diabetes at the same time as the hepatitis C; this became insulin dependent within a year of diagnosis. I was diagnosed with rheumatoid arthritis and neuropathy last summer. I find my legs and my hands the hardest things to deal with physically. I am in constant pain and unable to sleep as a result. The infection has presented difficulties in a very broad way. Back in 2013 I sought help to try to get pregnant. I was informed that my liver function was not an absolute contraindication to becoming pregnant but would require very careful care and follow up throughout. Although the thalassemia major condition would have contributed to the difficulties that I faced in attempting to become pregnant, the hepatitis C has also played a significant role. It is not easy for me to have a baby with the hepatitis C nor as a result of the treatments

I have had since. I have not been able to have a baby despite my attempts to do so, amongst other things the process made me too ill.

29. I have been given five different treatments for hepatitis C. The first was interferon in around 1992, which I was on for about six months. I could not tolerate it, it made me extremely ill with infections; my neutrophils dropped significantly. Essentially it did not work. Next I was given interferon with ribavirin. The viral load was undetected during the immediate term of the treatment but after some weeks my viral load rose sharply. In the end I had to come off the treatment early. The third lot of treatment consisted of pegylated interferon and ribavirin for a period of one year. Again, I failed treatment. In October 2007 it was decided that I would not have this treatment again; the chance of success with re-treatment was considered very small, I did not wish to have the treatment again and so it was decided that I should wait until new treatment became available. In 2013 I was given telaprevir, peginterferon and ribavirin. I had the same problems and at week 33 the treatment had to stop. It was until the end of 2016 that I was given harvoni. I was on this treatment for 12 weeks and my virus is now undetected.
30. After an almost four year wait, my haematologist consultant at the Leicester Royal Infirmary Hospital insisted that I be treated with the harvoni. I was so relieved because actually the treatment for the hepatitis C began in 1992, 24 years previously. At this stage my condition had deteriorated to cirrhosis. The hepatologist at the Leicester Royal Infirmary did not want to treat me with it and delayed for a number of years in doing so. He wanted my hepatitis C to have reached a certain level of seriousness on the fibroscan results first; but, the problem with using a fibroscan as a yardstick is that they are not accurate. He repeatedly said that I did not need the harvoni treatment, that my fibroscan grade should reach over 12 and because it was only six, I could not have it. This was despite me being diagnosed with chronic hepatitis C, genotype 1 and cirrhosis and having failed to clear the virus on four previous non-harvoni treatment attempts. He tried to argue that I did not have the conditions I had

been diagnosed with. He tried to say that the cirrhosis I had was due to an iron overload and the four periods of treatment I had meant I no longer had iron overload and so did not warrant the harvoni treatment. He was adamant that I did not need it. To me these were just excuses he made to avoid giving me the treatment I needed. His approach caused me a great deal of unnecessary stress. Eventually, my haematologist wrote to the hepatologist and insisted I started on the harvoni treatment. Once I had the treatment, I cleared the virus and after six months the hepatologist tried to discharge me from the clinic. I insisted that he did not do this because I still had cirrhosis of the liver and needed care, follow-up. I feel like he has repeatedly tried to get rid of me. I know that he does this to his patients at that clinic. I know that it is not guaranteed that the hepatitis C will not come back and so I have fought to stay on his list. I know a lady who received harvoni treatment and who cleared the virus but who passed away from cirrhosis last month. An undetected virus does not mean you do not have to worry. We need to stop being made to believe that this is the case. The doctors need to make sure we are having regular blood tests and ultrasounds to ensure that no cancerous cells occur and if they do, that they are acted on promptly.

31. I was being treated for the virus from 1992 through to 2016 when I was given the harvoni treatment. The harvoni treatment was not given because of the funding which I think is totally wrong. This should have been given quickly. We do not have time to play with this infection, we do not have time to play with our lives. I believe that the harvoni could have been and should have given to me sooner. I should not have had to go through what the hepatologist put me through. The treatment I now get in Leicester compared to the treatment I used get in London is terrible. It is not the same; I am not treated the same. I believe I would have got the harvoni much sooner in London whereas in Leicester I had to fight for it. The knowledge and approach that they have in London is so much different to Leicester. The treatment and the service is different. In Leicester they do not have time for you as a patient, it is a completely different service.

32. The treatments are extremely harsh. I got paranoid. I got ill, I got depressed. I had fevers, I developed shakes and shivers. I was not able to function properly. I could not work. I needed to be at home and tucked up in my bed. The pain both mentally and physically was extreme. I was prone to infection. My neutrophils dropped right down.
33. When I was trying for a baby and had artificial insemination. I was presented with the problem of possible infection of hepatitis C to the baby. The way in which it was dealt with was very clinical; the objective was to ensure that infection did not pass over to the foetus. With dental treatment, extra care is taken to ensure that I do not spread infection.
34. I have been scared to tell people about my hepatitis C, all throughout my life. This includes potential partners, employers and friends. I have been scared of being labelled that I am contaminated. I have never told people straight away for fear that they will run a mile away and not give me a chance. Telling someone about thalassaemia major in and of itself is difficult for people to digest. I told my husband in the second week of our relationship, it played a big part in our relationship because he was more aware of it. I wish that this did not have to be the case, but sadly it is. I remember dropping some blood once when I was testing my sugar levels. He became overly cautious about it and extremely protective of his daughter. When I told my close family they were understanding and accepted it; together we would not tell anyone that I had hepatitis C.
35. When I attend the Leicester Royal Infirmary Hepatology Clinic I am constantly reminded of the stigma attaching to this virus because of how they very publicly describe it. I have indicated this above. I was born in London but my father and mother are Greek Cypriot. That community does not deal with either thalassaemia or hepatitis C very well. I believe that I would have been heavily discriminated against by member of the community had I told them. Even at

work; when I worked for a beauty company, I could not tell them that I had hepatitis C in case I contaminated a customer. You had to be very careful who you told. My work was very supportive. They knew about thalassemia. I only told them about the hepatitis C treatment when I was off with the hepatitis C treatment so they medically retried me.

36. In the summer of 1999 I started a different combination treatment; the side effects were so severe that I had to retire from work on medical grounds in 2000. I was lucky as I had a private pension, I was able to access some financial support but it was lower than my income, it was half the amount. When I found out that I had the hepatitis C I already had a mortgage. I became severely in debt because I was unable to work and unable to get any financial support and as a result there were many times when I could not afford pay my mortgage. I had to get money from my parents who helped me. I ended up being about £50,000 in debt. Eventually Skipton stepped in to help.
37. My partner, parents, friends and other family members do not talk about it. Everyone is too ashamed to talk about it.

Section 6: Treatment/Care/Support

38. I have not been able to access travel insurance because of my hepatitis C. It was too expensive. Once, I wanted to go to Australia for five weeks; the cost of the insurance was £2,500. In the end I went without.
39. Counselling and psychological support was not ever made available to me as a consequence of being infected. It was available to me as a result of my thalassemia major.

Section 7: Financial Assistance

40. I received financial assistance from Skipton, Caxton and the England Infected

Blood Support Scheme over the years.

41. In around 2006 and through the UK Thalassaemia Society I became aware that there may be funding available to help me from the Skipton Fund.
42. The payments were made not long after I found out they were available. I received £20,000 in 2006 and £25,000 approximately one month later. I used this money to pay off my debts. In 2012, I received another £25,000 and monthly payments of approximately £1,200. The payments have increased slowly over the years from 2018 and through EIBSS to £1,500 per month. I also received a Winter Fuel Allowance through the Caxton Foundation; a one off payment of approximately £500 per year, which has now been added to the EIBSS payments.
43. With Skipton I had to apply first and prove that I had hepatitis C and what stage it was at. I had to get the consultant at UCLH to write a letter and fill out the application form confirm that I had hepatitis C, the stage of the hepatitis C and that it was as a result of receiving infected blood. The application was successful first time around.
44. Applied for support for fertility treatment from Skipton and was refused. Now that I am in Leicester I have had to apply for a mattress and for dental care. When I was in London my dental care was provided free by Eastman's Dental Hospital. I needed the treatment because of ulcers I got from the hepatitis C treatment. Every month I used to go to the hygienist for infection control. In Leicester I have to pay for my dental care which is £56 per go. I do not understand the difference in approach and particularly, why I have to pay here. I have applied for dental care from EIBSS but I have to prove that it is required because of the hepatitis C. The doctors in Leicester will not say that it is despite the fact that the doctors in London said it was. The ulcers came from the treatment I received. I am trying to get my previous London doctors to do this for me now but they are extremely busy; I have been waiting since

September last year. I made an application for funding for an orthopaedic mattress from EIBSS, they will not give the funding unless it is hepatitis C related. How do I do this? How do you convince a fund that the mattress you need for your arthritis is because of the hepatitis C? I am presented with the same problem time and again, and I feel a real reluctance to place even more pressure on my doctors to provide the schemes with the evidence they need from them. It is unfair and feel that it is all about delay.

45. The conditions imposed are that whatever I claim for has to be hepatitis C related; this was only made clear to me by telephone conversation and after the original application was made.
46. I do not know what assistance the funds actually offer; what I mean is the extent of the help that they offer. This has never been made clear to me. I find the process of applying extremely difficult, especially because I am sick. I always feel as though I should not ask. I think it is made purposely difficult so that people give up. When do you ask and when do you not ask for assistance, I am confused about this. There is no clear guidance. I always feel like I am made to beg for it.

Section 8: Other Issues

47. The 1986 letter that I have referred to above should be considered by the Inquiry so that they can consider it in relation to the Terms of Reference. I believe this document shows a level of knowledge by the medical profession about hepatitis C at that time; that testing was being conducted without the patient's knowledge or consent and that there may have been a cover up. I was totally unaware of the fact that my biopsy was being tested.
48. All areas should be investigated as to why this has happened. I want justice so we can be at peace to understand what happened and why. I would like to know what they were trying to achieve. Was research involved? I want some

answers. I want closure. This has dragged on far too long. I would like some proper financial support for the pain that I have been through to move on with my life. I want security for care and treatment that I think I deserve. Sometimes I ask myself, am I being greedy but when I think about what I have been through: the pain; the treatment; the hiding; not being able to tell people; those who I have lost, my very best friend, I know that I am not.

Signed: GRO-C _____

Full Name: Mrs MARIA FLETCHER

Date: 13.02.19