

Witness Name: Susanne Mayoufi

Statement No.: WITN3592001

Exhibits: WITN3592002

Dated: 11/03/2020

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF SUSANNE MAYOUFI

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 24 February 2020.

I, Susanne Mayoufi, will say as follows: -

Section 1. Introduction

1. My name is Susanne Mayoufi. My date of birth GRO-C 1947 and my address is known to the Inquiry. I am a retired Personal Assistant, and I live alone. My only child, Simon, lives with his wife and my grandson in Australia. Mayoufi is my name from my second marriage. I was born Susanne Ireland and became Mason upon my first marriage to David Mason.
2. I intend to speak about my infection with Hepatitis C Virus ('HCV') and Human Immunodeficiency Virus ('HIV'). In particular, the nature of my illness, how the illness has affected me, the treatment received and the impact it had on me, my family and our lives together.

Section 2. How Infected

3. I was born in Birmingham, in the West Midlands, on GRO-C 1947. I grew up with two sisters, who are both sadly no longer with us.
4. When I was aged 15 years old, around 1963, I was involved in a serious road traffic accident. I was treated in The Birmingham Accident Hospital, which has since been demolished. I had a fractured femur, and I have a metal implant from my right hip down to my right knee to this day. During this operation, I received a blood transfusion.
5. After this operation, I lived a normal life. My sister and I both had Monday to Friday jobs, and we were huge fans of The Rolling Stones. We regularly travelled down to London at the weekends to see them perform, and I have some great memories of these times. I have kept an extensive photography collection of these concerts, and I cherish these memories with my late sister.
6. I met my first husband, David, in 1970. We had our only son Simon, in GRO-C 1974. When I first went into labour with Simon, David took me into Good Hope Hospital in Sutton Coldfield. The hospital sent me home, and I returned to the hospital on Friday.
7. From the Friday onwards, I was in a 72-hour labour. This was followed by a forceps delivery. This was an extremely prolonged childbirth, and I stayed in hospital for 10-12 days afterwards. I lost a lot of blood, and I was given a blood transfusion as a result. I was unable to care for Simon during this time because of the after-effects of this ordeal.
8. Soon after, my husband was offered a good job and as a result, we moved as a family to Cheshire in 1975 when Simon was 8 months old. During this period, I recall getting the flu very easily. Whenever a cold or a virus was going around, I would always get it. I also remember being extremely fatigued. At the time, I attributed this to the stresses and

strains of raising a young child and being a mother at home and then a working mother when Simon started school.

9. By the end of the 1970s, I was visiting my GP more and more often. Eventually, my GP decided that there was something not quite right and that this had to be resolved. I knew something was not right. I would regularly be forced to leave work due to my constant tiredness and general sense of fatigue.
10. I held numerous jobs at that time, including working as a Personal Assistant for an American company in Manchester, and I managed an Estate Agents in the local area. I always wanted to work, and considered myself a proud working mother. Yet, by the early 1980s, this had become increasingly difficult.
11. Because of this, my GP took a number of blood tests to establish the cause of my persistent low energy levels. When the results of these came back, my GP said that there was a problem with my liver. I affirmed that I rarely drank alcohol. The GP said that he would refer me to a specialist who would explain the situation and deal with it from thereon.
12. I was duly referred to Dr Crampton, the Consultant Hepatologist at Wythenshawe Hospital. Dr Crampton saw me for a one-to-one meeting in his office, where he informed that he had some bad news and that I had chronic hepatitis C genotype 4. He explained to me that it was a virus that caused my liver to not function properly, and that this could ultimately lead to cirrhosis and possibly cancer of the liver. I recall that Dr Crampton had apparently worked in Egypt for a number of years to study hepatitis where it is a serious problem and so I knew that I was in good hands.
13. From then on, I would visit Dr Crampton for regular check-ups. He checked my blood test results on each visit, to monitor my liver function scores and the development of my HCV infection.

14. In the early to mid 1980s, Dr Crampton offered me a treatment for my HCV. I cannot recall the name of this treatment, though I remember that it was a new drug. I was worried that this was maybe a trial and I did not want to be a guinea pig for a drug when I was not aware of the side-effects. I told Dr Crampton that I did not want the treatment yet and expressed my reservations to him.
15. Having resisted treatment for my HCV infection, I suffered from depressive episodes as well as continuing severe fatigue. Dr Crampton diagnosed me as suffering from Chronic Fatigue Syndrome and Fibromyalgia. I also continued to pick up colds and flu on a regular basis. I managed to work on and off during this period, though this was certainly inhibited by the effects of my HCV infection.
16. I continued to endure these side-effects until I was referred to Professor Warnes at the Manchester Royal Infirmary in the early 2000s. Professor Warnes encouraged me to start treatment for my infection. When I voiced my concerns about the treatment and what it would involve, he replied abruptly, saying "Do you want this treatment or not because it is expensive".
17. In 2002, I had a liver biopsy at Wythenshawe Hospital. The results showed a moderate degree of chronic hepatitis with fibrosis (Ishak necro-inflammatory score 6 and fibrosis stage 3/4). At this point I will exhibit a hospital letter dated 2nd September 2019 (but referring to my clinic appointment of 8th August 2019), from Deborah Kennedy, a nurse at the Infectious Diseases Unit at Wythenshawe Hospital to my GP JE Shipston, which lists my treatment and diagnoses as **WITN3592002**.
18. I started Interferon and Ribavirin combination treatment in 2003. The course of treatment was meant to last for 12 months. The treatment involved an injection of Interferon once a week, which was administered by a nurse from my local health centre, who used to attend my home. I also took a Ribavirin tablet once daily.

19. The treatment made me feel absolutely dreadful. I suffered from extreme tiredness, low mood and depression, rendering me bedbound and unmotivated to do anything. I was alone by this time, having divorced my first husband when Simon was about three years old. He has since died. I forced myself to stay strong as I knew I had to clear the HCV. I would feel awful for 24 hours after the infection, and the treatment felt like a surge of depression upon me. I also had a dramatic weight loss, such that my friends didn't recognise me.
20. One day during the treatment, I wanted to take my son to the airport to wish him goodbye before he went on holiday. After dropping him at the airport, I completely forgot where I was and where I lived. I remember going to the helpdesk at the airport and asking for assistance, though I could not remember my address. I was in a complete daze and utterly lost. This brain fog I encountered during the treatment continues to this day.
21. After 9 months of suffering from the Interferon and Ribavirin treatment, the course of medication was cut short because I developed sepsis. I experienced hallucinations as a consequence. I remember being in the hospital and seeing doctors get out of lifts with shotguns, people were on fire, and patients in the hospital bleeding to death.
22. I was terrified to visit the hospital as I attended at the same time as countless drug addicts who were there for treatment. A lovely nurse at the hospital arranged for me to come at a different time as she saw how upsetting this was for me.
23. Whilst being treated in Wythenshawe Hospital for sepsis, I discharged myself whilst still hallucinating. I signed the paperwork, much to the frustration of the nurses looking after me. I was adamant that I had to leave, and I walked out with the cannula still in my arm. I realise that I put myself in danger by doing so. Someone had to come out to remove it. I have always had a mind of my own when it comes to my medical treatment.

24. I should say that my nurse Debbie at Wythenshawe Hospital, who works on my consultant's team, told me that the Sepsis had been caused by the treatment I had had. She said that she knew others who had contracted Sepsis from the Interferon/Ribavirin.
25. After the Interferon and Ribavirin treatment, and the subsequent sepsis, I was still HCV positive. I had the same symptoms, feeling tired and depression. Quite ironically, I also began to have difficulty sleeping at night, which again continues to this day. I am lucky if I have 2 hours sleep. I remained very poorly during this time.
26. In 2013/2014, I was at a regular check-up for my HCV when the Consultant Pippa Newton decided that I should have a full blood test check-up. This was to establish if there were any underlying problems that could be affecting my health and to rule out any other infections. I was gobsmacked when the results came back showing that I am HIV positive. I had no inkling that I could be infected with HIV as well as with HCV.
27. I was told that I had a good CD4 count and a low HIV viral load (Exhibit **WITN3592002**). The doctor described me as the 'miracle woman'. My viral load was incredibly low having been infected with HIV for such a long time following the blood transfusion in 1974, there being no other way that I could have contracted it.
28. In October 2016, I underwent heart surgery to replace my aortic valve and to perform a heart bypass. The surgery was a success, though it was draining for me. After the operation, I was visited by a consultant Pippa Newton from the Hepatology Department. The doctor said that they were always there for me and that she would get me HCV treatment once I had recovered from surgery.

29. With reference to **Exhibit WITN3592002**, I had a Fibroscan in October 2018. The scan revealed hepatic steatosis (S3) and a Metavir score of F2.
30. I then began a course of Zepatier treatment for my HCV on 29th August 2019. This was a 12-week course involving one tablet of Zepatier taken daily. The medication was much better than before. I felt more tired than normal, though I still struggled with insomnia. I also lost a lot of hair, which became noticeably thinner, and my skin was itchy. Despite these side-effects, I was able to tolerate it. Compared with the previous Interferon and Ribavirin treatment in 2003, it was like a walk in the park and I could not believe that I had waited this long to be treated.
31. After 4 weeks of the Zepatier treatment, I showed no evidence of having HCV infection, and this continued all the way through to the end of the course in November 2019. I could not believe after all these years that I was clear of HCV. My most recent test, on 19 February 2020, showed that I am all clear of the virus. I have a follow-up appointment on 20 May 2020, and the doctors will continue to test for 12 months after the completion of the course of treatment, around November this year.
32. I should say at this point that immediately after I completed the Zepatier treatment, I became quite ill with flu and I had a high temperature. I then developed a chest infection and this took me through Christmas last year into January this year. I had to get friends and neighbours to take the dogs out and get medication and shopping. I had two GP visits during this time as I was unable to leave the house. I believe that the Zepatier though successful in getting rid of the HCV, must reduced my immunity.
33. The nurse at Wythenshawe Hospital said that I was a hero for completing the treatment after all I had suffered during the 2003 Interferon and Ribavirin treatment. The nurse told me that she had met lots of other people who were too scared to start the new treatment after the brutality of the earlier HCV treatments. Indeed, I remember Dr Crampton telling me that he had witnessed patients throw the Interferon and Ribavirin

treatment back at him within weeks of the start of the course of treatment.

34. My next appointment with regards my HIV infection, is on 15th April 2020.

I am under the care of Dr Noel Connolly, Consultant in Genitourinary Medicine at the East Cheshire Centre for Sexual Health at Macclesfield District Hospital. Dr Connolly is a very nice doctor, who encouraged me to get my HCV treated. I believe that I will begin treatment for my HIV infection at some stage this year.

Section 3. Other Infections

35. Aside from my infections with HCV and HIV, I do not believe that I have had any other infections as a result of receiving an infected blood transfusion after childbirth. In fact, I cannot be sure that the HIV came from that transfusion but I don't know where else it would have come from. Certainly not my lifestyle.

Section 4. Consent

36. I consented to all courses of treatment I have received in relation to my infections with HCV. I have not yet had any treatment for HIV.

37. I consented to being tested for HCV. When I was tested for HIV, I was told that I was being tested for a number of infections. I therefore believe that I consented to being tested for HIV amongst other viruses.

38. I believe that I would have been the subject of research had I consented to starting treatment for HCV in the mid-1980s under Professor Warnes and Dr Crampton. I am glad that my concerns surrounding this new trial drug meant that I refused to undergo treatment at that time.

Section 5. Impact

39. My life has suffered massively as a result of my infections with HCV and HIV, and the subsequent treatments I received. I have always endured extreme tiredness, categorised by my diagnosis with chronic fatigue syndrome. I believe this was unquestionably caused by my infection with HCV over such a long period.
40. My relationship with my son has been detrimentally affected by my illnesses. My son now lives with his wife and my grandson in Australia. I have tried to visit him, though I feel physically and mentally unable to do so. I sincerely regret that I am unable to see my grandson grow up. My son does not know that I am HIV positive as I do not want to worry him. My son has blamed me for not being there more often, but I am simply overwhelmed by the physical demands of visiting. This has put a strain on our relationship, which upsets me deeply. We are effectively estranged. There is currently no contact.
41. I suffer with severe depression, and have done so for a number of years. My GP asked me if I was suicidal. I am not, I could never do that to my family. I am interested in lots of different things, I read a lot and am quite bright but I am unable to do things that I want to do because I am overcome by a powerful wave of depression. On one occasion recently, I bought tickets for a concert that I wished to see, but as I got to the front door I was overcome by depression and low energy levels and just could not manage to go.
42. I believe that the first treatment I received for my HCV in 2003 was the cause of a lot of these problems. The Interferon and Ribavirin medication was debilitating and caused me brain fog that persists to this day. I also lost a lot of hair, which was very distressing, and I struggle with insomnia on a daily basis.
43. My relationship with my first husband was affected by my constant fatigue, and this ultimately led to divorce. My second husband and I have since divorced, though we remain friends and he calls me regularly to

check-up on my health. I have a good network of friends around me who support me, offer me lifts and help with some tasks around the house. I have told a small group of friends about my infections with HCV. Only my doctors know about the HIV.

44. I was forced to retire aged 50 in 1997 as a consequence of my infections.

This has inevitably impacted my finances and coupled with two divorces, means that I struggle financially. I am in receipt of a state pension and Disability Living Allowance. Although I can survive, I have very little means of improving my home and treating myself, which I would very much like to do.

45. I live a simple life with my two dogs, that I am content with. I do regret

that I am inhibited by my infections with HCV and HIV. I am lonely and feel isolated by my inability to get out and do things for myself. I would love to live abroad during the winter but am frightened by the thought of not having my doctors and GP nearby.

46. My dentist is aware of my HCV and HIV infections, and was grateful to me for informing him. I do not feel that I have been treated any differently by my dentist as a result of these infections.

Section 6. Treatment/Care/Support

47. I have not faced any difficulties in accessing treatment for my HCV and

HIV infections. I was offered treatment by Dr Crampton in the mid 1980s for my HCV, which I refused on the grounds that I was worried about the side-effects of the trial drug in question.

48. Though I have not yet received any treatment for my HIV, I believe this

is because my HCV infection and heart surgery were a priority. I also have a good CD4 count and a low viral load, which meant that to date, treatment has not been imperative. I have an appointment with Dr

Connolly at Macclesfield District Hospital soon, and I expect I will receive treatment for my HIV from then on.

49. On the whole, I feel that I have been lucky to have received the treatment and support I have from the medical profession and the NHS. Aside from Professor Warnes, who was grumpy and rude when offering me the first HCV treatment in 2003, I have been treated wonderfully by my many doctors and nurses.

50. I have not been offered any form of counselling or psychological support as a consequence of my infections with HCV and HIV. I have spoken regularly with my GP regarding my mental health difficulties, and Dr Connolly has suggested I attend a group session for HIV-infected persons, though I do not currently feel ready to attend this.

Section 7. Financial Assistance

51. I received the application form for the Skipton Fund some time ago, though because of my brain fog and fatigue I forgot about it and neglected to complete the application.

52. I recently received the application form from the English Infected Blood Support Scheme ('EIBSS'). I believe that I am entitled to receive some financial support because of all that I have endured as a consequence of my infections. This would be a massive help for me as I do not want to rely on my friends for help. Any form of support from the EIBSS would help me to feel less of a burden on them, and would hopefully help me to get out and do more of the things that I want to.

Section 8. Other Issues

53. I just wish my life could have been different. It could have been so much easier. My life has changed as a direct result of my infections with HCV and HIV, and the treatment involved. I used to love to travel, I was

interested in music and I loved being out and about doing things. I aspired to do things which have been deprived of me through no fault of my own.

54. I would like a good outcome from the Inquiry. I would like it to be recognised that this was somebody else's fault, and it was not our fault that we were infected.

Statement of Truth

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

Signed GRO-C

Dated 11 / 3 / 2020