

Witness Name: William Trevor Marsden
Statement No: WITN1372001
Exhibits: WITN1372002 – WITN13720013
Dated: April 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF WILLIAM TREVOR MARSDEN

I, William Trevor Marsden will say as follows:-

Section 1. Introduction

1. My name is William Trevor Marsden. I live at GRO-C
GRO-C My date of birth is GRO-C
GRO-C 1959.

2. I live with my wife, Louise Marsden. We have four children; three daughters Nicola Christie, Lucy Larkham and Rachael Garrett and a son Samuel Marsden.

3. This witness statement has been prepared without the benefit of access to my full medical records. I have been provided with limited records and the relevant entries are set out as exhibits to this statement.

Section 2. How infected

4. I have Haemophilia B.

5. I was treated with Factor IX blood products. As a result of receiving contaminated blood products I was infected with Hepatitis C. I do not know which product infected me when. I exhibit at WITN1372002 notes from my medical records of the Factor IX products I received.
6. I believe I was infected with Hepatitis C prior to 1991. There is an entry in my medical records dated 18th January 1991 which states that I needed testing for Hepatitis B and C at my next appointment, but there are no corresponding test results. I exhibit this extract at WITN1372003.
7. I find it hard to believe that if there was a note in my records that I should be tested for infections in 1991 that this wasn't done. If this was done the results seem to be missing from my medical records. I began experiencing severe fatigue, a symptom of Hepatitis C, in the 1980s.
8. I believe I was infected with Hepatitis C as a result of receiving Factor IX at the Royal Victoria Hospital in Northern Ireland whilst under the care of Dr Elizabeth Mayne. I sustained an ankle injury in 1970s and consequently received blood products to treat this.
9. I cannot say for certain which product infected me, but over the years, I have wondered whether my treatment for this ankle injury was when I was infected, due to the timing of my symptoms. I exhibit at WITN1372004 the extract from my medical records relating to my attendance at the Royal Victoria Hospital for this injury.
10. I exhibit at WITN1372005 my Hepatitis C test results.
11. Up until around 20 years ago, I worked as a farmer. Over the years I have sustained several injuries requiring treatment with blood products. Each time I hurt myself, I would be in severe pain and was treated with Factor IX, however I had no idea that the blood products came from America and that it was not heat treated. I was not given a choice of treatment and I assumed that the doctors were doing what was best for me.

12. I was never advised by any medical professional about the risk of infection from blood products.
13. I also exhibit at WITN1372006 extracts from my medical records which refer to blood tests of mine which indicate past infection with Hepatitis A and B. I do not recall being vaccinated against Hepatitis A and B and there is not any record of me having any vaccinations in the medical records I have received, so I can only conclude that I received these infections from contaminated blood products. I have never been told that I was infected with Hepatitis A or B.
14. I was not informed prior to my diagnosis that I had been tested for Hepatitis C. I was also not informed that I had been tested for Hepatitis A and B or HIV. I exhibit my HIV test results at WITN1372007.
15. I was informed of my Hepatitis C infection when I attended hospital for a routine blood test in 1996.
16. I was therefore not told about my infection for five years. I would not be surprised if the infection had been identified years before 1991, as I had regularly attended hospital for bleeds and when I did, blood samples were taken from me.
17. When I was eventually told, Dr Mayne simply said, 'By the way, you have Hepatitis C,' without giving any further explanation. This was a shock to me. I did not know what Hepatitis C was or what the implications of it were. She didn't tell me how I had got it. I exhibit at WITN1372008 extracts from my medical records which record Dr Mayne telling me about my infection with Hepatitis C on 20th May 1996.
18. My grandparents were still alive at the time and after my appointment, I went to their house and phoned my wife who was at work.
19. When Dr Mayne told me that I had Hepatitis C, she did not give me any information or advice on how to understand or manage the infection.

20. It was only at a later date, when I was called back in to discuss Interferon treatment, that I was given some information about Hepatitis C. I was told that Hepatitis C had affected my liver and that I had no choice but to have the treatment. Dr Mayne also told me that she believed I was infected after being given infected blood products following a sprained ankle in approximately 1976.
21. I was then advised that there were certain foods I could not eat with Hepatitis C, which prior to being told about my infection I had been eating for a while. These included cream, chocolate and alcohol, which are all hard on the liver.
22. It would have been helpful if my wife and I had been provided with information about my Hepatitis C sooner. We would have acted quicker and been more careful with my health if we had been better informed.
23. When Dr Mayne told me about my infection in 1996, she did so in a very cold manner. I felt there was no compassion or empathy from her whatsoever and I was left to deal with a virus which I thought they could do nothing about. It was a frightening day.
24. When I was diagnosed with Hepatitis C in 1991, my wife and I had three children and we had been trying for a fourth. We were not told that Hepatitis C could be transmitted through sexual intercourse or that if my wife became pregnant, as she later did, that our fourth child could be at risk of contracting Hepatitis C or that I could end up infecting Louise.
25. When Louise asked whether she was at risk of being infected through intercourse with me, Dr Mayne told her that she would be absolutely fine, but it was in fact a very serious risk. Fortunately, our son Samuel was born without Hepatitis C. It was a miracle.
26. I was never given any advice about the risk of transmitting my Hepatitis C to others. The risk of transmission was something we discovered over the years through articles and the media.

Section 3. Other Infections

27. At one point, I received a letter asking that if I had received blood products from a donor who had died from vCJD did I want to know. I was later invited to a vCJD conference in Birmingham. My wife accompanied me to the conference.
28. Two nurses sat either side of me on my table, which was pretty terrifying. They told us that all the people in the room had received blood products from blood donors who had died from vCJD. We were told that if the disease presented itself, we would have a maximum of twelve months to live. There was an incubation period of 14 years for the illness to appear and we were advised to put our affairs in order just in case.
29. We were told that there was no test or cure for the disease, so there was nothing that could be done about it. I live in fear that vCJD may surface one day and being told about it certainly did not help me. The conference was extremely frightening. On top of everything else I had been through, it was shocking to hear. I would have preferred to remain ignorant on the matter.
30. I exhibit at WITN1372009 some of the documents I have received in relation to vCJD.
31. I was diagnosed with Alzheimer's disease in 2011. My medical records refer to the fact that I received blood products which left me at risk of vCJD, as a risk factor associated with Alzheimer's. I exhibit at WITN1372010 extracts from my medical records regarding my Alzheimer's diagnosis.
32. My medical records show that in 1996 I was tested for Parvovirus and CMV and I tested positive for both of these infections. I exhibit these test results at WITN13720011.

Section 4. Consent

33. I believe that I have been tested without my knowledge, consent and without being given adequate or full information. In hospital, my blood was regularly taken without any explanation of why it was being taken. I was always suspicious that the hospital was conducting experiments on me. I believe that Haemophiliacs were treated like guinea pigs.

Section 5. Impact of the Infection

34. For years I struggled to cope with my infection. I suffered terrible mood swings and was always angry or frustrated. I went into a depression which was extremely traumatic, not just for me, but also for my family.

35. Before I was told about my Hepatitis C infection in 1996, I suffered from lethargy and lack of energy and I had been struggling to keep up with the heavy manual work on the farm. At the time, I did not know that this was due to my Hepatitis C infection, which in hindsight I think it was. My parents thought I was being lazy. Previously I had been able to work from the early hours of the morning until late at night without a break. I started getting tired more easily and I would go into the house for long breaks, often going to bed early and being unable to get up in the mornings.

36. The further medical complications I have experienced due to Hepatitis C are cirrhosis of the liver and severe fatigue. I do not know the current extent of the damage to my liver and I am currently awaiting the results of a scan I had in late March 2019. I have been told I have half a liver remaining, which is a serious concern.

37. In 1998 or 1999, I underwent Interferon treatment for six months which was supposed to last for a year. The side effects were severe. Other than being told I may experience flu like symptoms, I was not warned how severe the side effects of the treatment could be. 'Flu like symptoms' was so far from the reality.

38. The treatment was extremely difficult for me. It made me severely depressed and I had suicidal thoughts whilst I was on the treatment. We live close to a railway line and on one occasion I stood on it waiting to die. Before anything happened, Louise found me and pulled me away. That was a very difficult episode for me and is still hard to admit out loud. I feel ashamed about it, but I felt so low and could not take any more.
39. The first round of Interferon treatment was unsuccessful.
40. In around 2006, Pegylated Interferon was introduced. Although I knew how tough the side effects of Interferon could be, I risked everything to go on it. At first, I was told I could not be given Pegylated Interferon, since the original treatment had failed. However, after several attempts at persuading the doctor, it was agreed I could be put on the second course. I was warned that if I stopped taking that medication I would not be prescribed it again.
41. The side effects of the second course of Interferon were worse than the first course, and it was a struggle for my family to keep me on the treatment for twelve months.
42. We were offered no support during either courses of treatment. My wife and I felt we were left to cope on our own.
43. During my first round of treatment, in the late 1990s I was completely bed ridden. I would have the Interferon injection every other day and by the time the side effects wore off I would have to repeat the injection. Louise and I tried our best to shelter our children from how unwell I was, so for the majority of the first year of my treatment, I locked myself in my room to prevent my children from entering, but there were times when that wasn't possible.
44. At times, I did not realise what was happening to me. I suffered from uncontrollable violent shivers, rigors. All the blankets in the world were not enough to warm me up. I could not lift my head off the pillow, which made going to the bathroom a massive issue. I also lost a considerable amount of weight.

45. During the treatment, I only had the company of my wife as I could not bear to have anyone else see me in that state. One of my childhood friends found out that I was unwell and visited me. He never got over seeing me in that state.
46. I had a second course of Interferon treatment in 2006. However, the second round of treatment was successful and I cleared the virus. It was again extremely difficult to endure that year of treatment for myself and my family.
47. Although I may have cleared the virus on paper, in reality I do not feel much different. The doctors tell me that I no longer have Hepatitis C, but I do not feel reassured by this. I have no faith in the NHS or the doctors. I have only had one consultation with a liver specialist. I have never managed to feel like myself again and I still live with fatigue.
48. I exhibit at WITN13720012 extracts from my medical records relating to my treatment.
49. I do not know if there were other treatments that ought to have been made available to me as I do not know if there was any other treatment available.
50. My dental care was carried out at the hospital and they used to destroy all the equipment they used after my treatment. I faced some stigma during my medical care from doctors and nurses as well.
51. Throughout my life, I have enjoyed physical activities such as hunting and motorcycling. I believe I would have been able to enjoy these more had I not been so unwell. I had hoped to race motorbikes. I also used to enjoy accompanying my brother to shooting events and thought about taking this up myself at one stage. My brother managed to achieve his dream, but I wasn't physical able to participate in such sports.
52. Over the years, my energy levels and health have restricted me in social activities, which in turn have impacted my family. I have spent much of my adult life feeling anxious about the future, which has made me feel withdrawn.

53. Before I was diagnosed, fellow haemophiliacs I grew up with and knew from the hospital died from infections they contracted as a result of receiving contaminated blood, which was frightening.
54. I grew up with horses. When I was younger, I would go hunting on my horse alongside my children, which was great fun for all of us. Now we only have one horse left and cannot afford to buy more.
55. I now have to watch what I eat and am wary about doing things that may be physically exhausting for me.
56. Since birth I have lived in a small community. There is a stigma and fear associated with Hepatitis C. It took me a while to tell my parents and brothers about my infection. The locals are nosy and after I told my parents about infection it got out when they told someone in the wrong way that I had Hepatitis C. Many locals treated me differently. In my local shop people would stare at me as though I was on stand in court having committed a heinous crime. It's remained that way and is just the way people are towards such things where I live. I tried not to let it affect me and I don't row with people about it. Once I went into a shop and the girl serving me asked, "Why don't you do to your local shop?". This is how I've got used to being treated.
57. I hope that my children have not been impacted by the stigma associated with my infection. However, I don't think they would tell me if they had, as they wouldn't want to upset me. My family generally don't tell people about my Hepatitis C infection and I don't advertise it. As a family, we never openly discuss my condition.
58. The farm I live on has been in my family for 6 generations. I have lived there my whole life. Due to my Hepatitis C infection, I had to give up full time farming 20 years ago, which devastated me. I have let out the farm over the years and my son in law has now taken it over. I do bits to help out here and there which I enjoy, but nothing like I once did.

59. When I was at secondary school, I would wake up at five in the morning and would milk 135 cows before going to school. When I returned home, I would work on the farm until late at night. When I became unwell, my wife and children had to take over the running of the farm, as it was our livelihood. They had to take time off work and school to work on the farm.
60. I used to own 112 acres of land which I inherited from my parents. The land had been passed down many generations of my family and is in the area where I live. The land meant a great deal to me, but I had to sell parts of it when money became very tight when I was unwell and unable to work for long periods. Selling the land was not something I had ever envisaged doing and it was very much a last resort for me.
61. With the land that was left, I had to cut down what we were doing on the farm so that we could cope with it, which further reduced our income. I had to get rid of cattle and try to change the system to make the farm work in a way that reduced the pressure on my family and I. I diversified and took on contracts fixing machinery, which was more physically manageable for me.
62. After a while, I let the farm to a local farmer who brought his own cattle in. It was difficult for me to give the farm away and my Dad was very unhappy when I did, but I was faced with a difficult situation and had to make difficult choices. I was trying to give the children their education and take the burden away from Louise.
63. In terms of daily living, Louise and I had to scale everything down. We had to do what was necessary to survive. We let out sheds to businesses. I had to be fair to myself and accept that my health had to be prioritised over the farm. I would not have allowed Louise to milk cows her whole life.
64. I have let out my adjoining property as a bed and breakfast which is run by my daughter Rachael. Other farmers in the local area think I'm mad for doing what I've done, but they don't know what I've been through. The value of my estate has reduced considerably and the little that is left is in a poor condition. There is mould on the ceilings and cracks in the walls of my house, but I

cannot afford repairs. However, somehow, we have survived through the hardships and Louise deserves a lot of the credit for this.

65. When I couldn't work, Louise had to earn money for the family and she got a job in financial services. She is very well educated.

66. Louise brought up and helped to educate the children. She read to them every night when they were growing up, which opened up their minds to opportunities outside of farming. She helped them with their studies and supported them when they were moving on to further education. I was not well enough to help with this.

67. My family have been extremely supportive of me. Louise took on an awful lot; looking after the farm; the children; and caring for me when I was unwell. I do not know if I would have coped if the situation were reversed. Local farmers could not believe what she was able to achieve and my girls have been inspired by her.

68. Despite the dark times, all four of my children obtained degrees at university and achieved successful careers, a massive shock for our community.

69. During my first round of treatment, my mood swings almost cost me my marriage. I do not know how we managed to overcome it. The way I was also made my children walk on eggshells around me. Having seen me suffer with Hepatitis C, my children are constantly worrying about me. Nicola and Lucy call me twice a day to check how I am. Both of them live close by. Rachael visits me often as she also lives nearby and Sam, although he lives in England, is always calling home.

Section 6. Treatment/care/support

70. As a family, I feel we received no support in dealing with the effects of my Hepatitis C when we most needed it.

71. After the first treatment for Hepatitis C, I was offered a social worker I could go and talk to, but it was too late for them to offer me help. The damage had been done and I refused the offer of help.

Section 7. Financial Assistance

72. My wife deals with our finances and has applied for the financial assistance we have received. I refer to her statement, number WITN1371001 regarding this.

73. I believe I now receive approximately £300 a month by way of financial assistance plus a winter fuel allowance. Given what I have been through, and accounting for what I have lost, the financial assistance is nothing in comparison.

74. I exhibit at WITN13720013 an application form for financial assistance from my medical records.

Anonymity

75. I do not wish to be anonymous and I would be willing to give oral evidence to the Inquiry.

Statement of Truth

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

Signed. GRO-C

Dated..... 11/04/17