

Witness Name: Irene Louise Ellis

Statement No.: WITN4899001

Exhibits: Nil

Dated: 2-4-21

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF IRENE LOUISE ELLIS

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 18 February 2021.

I, Irene Louise Ellis, will say as follows: -

Section 1. Introduction

1. My name is Irene Louise Ellis. My date of birth is GRO-C 1956 and my address is known to the Inquiry. I am currently unemployed, but I am approaching state pension age soon. I am also my adult daughter's primary carer.
2. I intend to speak about myself in this statement and my late husband Andrew Ellis, Hepatitis C (HCV) separate infection in a second statement (**WITN4899002**) they should be read in conjunction. Andy was infected with a different HCV genotype to me, so I am providing a separate account of his infection as an affected person.

3. I intend to speak in particular, about the nature of our illnesses and how HCV affected each of us, the treatments we received separately, and the impact it had on us as individuals, and our lives together as a family.

Section 2. How Infected

4. I gave birth to my second child on GRO-C 1976 by way of a forceps delivery at the Royal Gwent Hospital, Newport. The day after the birth of my son, I was haemorrhaging and was given 6 pints of blood to replace all the blood I had lost. I remained in the hospital for ten days before I was sent home.
5. Four days after I returned home, I had to be rushed back to the hospital. This time, I received two pints of blood. I was kept in the hospital and two days later, was rushed into the theatre again. I received a further 3 units of blood after the surgery. I received 11 pints of blood in total.
6. I was anaemic when I finally came out of the hospital, and it took months before I started to feel like myself again. Even then, I felt very unwell and I used to get dizzy spells. I did not realise that there was an issue, and I did not know about non-A or non-B Hepatitis back then. I used to feel very tired and I would get a bit of brain fog.
7. I always put my tiredness down to having five children and being so busy as a result.
8. I first found out about non-A and non-B hepatitis in 1980 or 1981 when my husband Andy was diagnosed as having non-A, non-B hepatitis but there was never any link to me. I was not told to get tested and the doctors didn't give us any information about non-A, non-B hepatitis anyway.

9. In 1996, when Andrew was ill again, he was finally tested and diagnosed as HCV positive. At this point, the doctors told me to get tested too, and I was diagnosed with HCV. It was also confirmed that Andrew and I had different HCV genotypes which meant that neither of us had given it to the other.
10. My memory is terrible now due to having HCV and Interferon treatment, but I remember that they told me that my genotype was the hardest type to treat.
11. I had three other children after my son was born, and I have had four children by caesarean section. I don't remember if I had any other blood transfusions during those deliveries. I was also in a car accident when I was 16 but I don't think I required a blood transfusion.
12. I have my ears pierced but they were pierced by reputable jewellers when I was about 6 or 7 years old. I have a tattoo now but this was done in recent years and at a professional establishment.
13. I used intravenous drugs for a couple of months when I was younger. I took morphine and heroin about half a dozen times and always used fresh needles. I was never an addict and did not have any issues coming off them.

Section 3. Other Infections

14. I was tested for HIV and AIDS and I do not have it. I do not believe that I have received any infection other than HCV as a result of being given infected blood.

Section 4. Consent

15. As far as I am aware, I have never been treated or tested without my knowledge or consent.

Section 5. Impact

16. I only began to feel unwell after I had my son in 1976. Before that I was fine. My first son was born through a caesarean section but I had not experienced any of the symptoms I did after the birth of my son. I felt really ill for several months then I was fine.
17. Although I was diagnosed with HCV in 1996, it took a long time for the government to offer people the treatment and I had to wait for about 12 years for treatment. This was again at the Royal Gwent Hospital. The first time I was offered treatment was around 2008 or 2009, but my son was GRO-C at the time and I was looking after him, so I delayed receiving the treatment for about two years. I was informed that there were side effects and I could not afford to be ill at the same time as my son and my husband.
18. I think that they were only giving treatment to people with liver cirrhosis at first. Apparently, the infection is worse in men than women so I knew I had to wait. I know that the reason I was not given the treatment earlier was because it was expensive and the government was not funding it.
19. My HCV nurse was very good. When I was first offered treatment in 2008 or 2009, I explained my circumstances and told her I would rather wait because I knew the treatment would make me very ill and would interfere with caring for my son.
20. I had my first round of Interferon treatment in late 2009 or 2010, and at first, it wasn't too bad. The treatment was supposed to last for a year and the side effects seemed cumulative, building up slowly so the longer I was on it the worse I felt.

21. It was only after I came off it that I realised how awful I had really felt. I walk a lot generally, but when I was on Interferon I couldn't walk a mile without needing to stop for rest halfway. I was shaky, I developed eczema, thrush and I had thyroid issues. One day, I got a call from my HCV nurse informing me that I had no thyroid function. I could not understand what was wrong with me but the thyroid issue later resolved itself.
22. I was having terrible anxiety and palpitations so the doctors had to put me on antidepressants. One time I went shopping and could not find my car afterwards and I started having anxiety and severe palpitations. This was only a few months after I had begun HCV treatment. After that incident, the doctors put me on Citalopram, which is an antidepressant.
23. I had always been a housewife but when my husband's illness meant that he could no longer work, I had to start working, doing childminding and other odd jobs as the kids grew older. My son had fallen ill with cancer and Andy wasn't well so there was a lot of pressure on me.
24. It affected us financially because my income was small in comparison to what Andy used to earn, and had to be stretched to take care of the entire family.
25. I was on the Interferon treatment for a whole year but it did not work. As soon as I stopped it the HCV came back.
26. A few years later the HCV nurse offered me a new course of treatment. They said it was much cheaper and I would only need to take the tablets for 12 weeks.

27. The side effects of the second course of treatment were a walk in the park in comparison to the interferon treatment, I don't recall the name of it. I had terrible stomach problems but I managed to carry on working while I was on it. Towards the last week, I felt very ill but it was still more manageable than the treatment I had a few years earlier.
28. All I kept thinking of during my second round of treatment was that if Andy was still alive, he could have had the tablets.
29. The second course of treatment worked and I don't think I have suffered from any lasting effects from it. I think any problems I have are from the Interferon and the HCV. I still have brain fog and memory problems. Some days I have total memory block. I also have slight liver damage but they are not dealing with it and I don't even see anyone now for regular check-ups.
30. I had my children tested for HCV but thankfully all of their tests came back negative. We also faced some stigma back then because people sort of looked at HCV like it was AIDS. I didn't tell too many people because you could see it from their faces. I don't know if the attitude towards HCV has changed but my daughter believes that there is still a stigma.
31. I did not face any obstacles getting care from other medical professionals due to my HCV. When I had to have a carpal tunnel on my right hand I had to be the last person seen on that day, but I understood that. When I had to have the other hand done, they had not read my notes so they took me into the procedure room first. I told them I had HCV so I had to go back out into the waiting room to wait until last.
32. When I have blood taken I always remind them that I have HCV in case they have not read the notes because they don't always read the notes.

Section 6. Treatment/Care/Support

33. I think that by the time I was diagnosed with HCV, the doctors were much more aware of the damage the disease could do compared to when Andy was first diagnosed in 1988. I think they did a good job.
34. I did have to wait 12 years for my first round of treatment because the treatment was expensive and my liver was not as damaged as the people they prioritised. I know that the nurse pointed out that my second round of treatment was cheaper.
35. I was not offered any psychological support, in fact, the only time my HCV nurse offered me counselling was after Andy passed away in 2011.

Section 7. Financial Assistance

36. I found out about the Skipton Fund from an HCV nurse. I used to accompany my husband Andy to all of his appointments, and it was on one of these occasions that the nurse informed us about the Skipton Fund.
37. In May 2007, I put in separate applications for myself and Andy but both of our applications got turned down. My application was refused because I had used intravenous drugs, and they rejected Andy's application on the basis that there was no proof that he had ever received a blood transfusion.
38. Our appeal to the Skipton panel was also rejected in October 2007.

Section 8. Other Issues

39. When I was 16 I overdosed on Mandrax tablets and my stomach had to be pumped.

Statement of Truth

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

Signed GRO-C

Dated 2-4-21