



JOAN: MY STORY

I was diagnosed with hepatitis C back in 1991. I was tired of having stomach and intestinal problems all the time, and decided to get them fixed, if possible, once and for all, so I went to the doctor.

She had a series of tests done, all of which turned out normal, except for my liver function tests, which were slightly high. She called to tell me so. She decided to repeat the test. The second test came back with my enzymes high again. After convincing her that I really don't drink alcohol, she decided to test me for hepatitis A, B and C. I came back positive for hepatitis C, so she sent me to a gastroenterologist, who assured me that I had nothing to worry about. He asked me if I had symptoms. I said that I didn't. I mean, after all, sure, I was tired. I work long hours. And yes, I got achy, but arthritis runs in the family.

And OK, I was itchy all the time, but it must be allergies, right? He assured me that my enzyme levels were nothing to worry about, and of course, he added, I didn't want to have a biopsy, did I? He told me that at least there was a cure for hepatitis C. Not so for hep A or B, he said. Interferon would be available for me if I got sick enough.

So it wasn't until a couple of years later that I found our local support group, the Hepatitis C Society of Canada. I was able to borrow a copy of Allan Powell's big yellow book of articles he had compiled about hepatitis C. I literally got sick reading the truth about this disease. Little by little, I was able to assimilate the information, and decided it was time to do some serious investigation. I went out and got a computer and hooked up to the Net, and found the HEPV-L list.

Thanks to the information I got on the internet, I got a couple of second opinions from other specialists outside the country. They both insisted that I needed a biopsy and treatment with interferon. One of those doctors is a family friend that I trust completely. I was extremely reluctant to take any sort of medication, especially one

with so many possible side-effects. But after reading many medical articles about the possible outcome of the disease, and after the second opinions, I decided that I didn't want to look back in five years and say to myself, "I wish I had started treatment back then." You see, I think I have had my hepatitis for 27 years.

I started interferon in September of 1995. After a week, my gastroenterologist in town took me off the treatment because my neutrophil counts dropped drastically. Luckily I had read about that possible effect, and called Schering to talk to them about it. As a result, I asked my specialist to send me to Vancouver to Dr. Anderson for a second opinion about IFN treatment.

Dr. Anderson insisted on a biopsy. It came back that I had fibrosis grade II, stage II. I had my appointment in December, and walked out of the office with a prescription for IFN under my arm. After 8 months, I was declared a non-responder. My viral load had gone from 210,000 to 260,000. I was put on the IFN/Ribavirin trial. Six months later, my enzymes were well within normal range, and my viral load was non-detectable.

Unfortunately, after a year on the combo trial, I relapsed immediately after ceasing to take the medication. I felt better, though, and the wonderful news was that my biopsy, done in December of 1997, showed that my liver damage was reduced to a grade I, stage I. In the meantime, I am grateful for the rest the treatment seems to have given my liver.

I have found great joy, as well as great sadness, in this adventure with hepatitis C. I had never been involved with any sort of volunteer work until now. I find it interesting, challenging, and fun. At the present time, I am treasurer of our local support group, and I help edit the monthly newsletter. I have met many very special people, and feel I am surrounded by genuine friends and loved ones who know just what I'm going through.

I am hoping to start a new trial sometime this year. What is being offered is a low-dose maintenance program of IFN, or a combo IFN/Amantadine trial. I will have to pay for either, so I have not yet decided.

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