



HEPATITIS C
SUPPORT PROJECT

www.hcvadvocate.org

living with HEPATITIS C

a series of stories written
about people living with
hepatitis C

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I was first diagnosed with hepatitis C in the winter of 1993. It was just six months after the HCV+ antibody test became widely used to screen the nation's blood supply. I was working with a local television station and I had arranged for a local bank to sponsor the annual blood drive. As with many of my colleagues I went into the studio and gave my pint of blood to our regional blood bank.

Several weeks later I received a letter in the mail saying that I had hepatitis C and I was going to die. Actually, the letter said I had tested positive for the HCV antibody and that there were serious implications and that it was estimated that 50-60% of those HCV+ would develop chronic liver disease. In my shock I had simply translated "chronic" to "terminal." A brochure was enclosed that provided scant details on HCV because there was not a great body of evidence at that time. The scientific community had just quit calling it Non-A, Non B.

Although the brochure was emphatic about not drinking alcohol, I am an alcoholic and continued to drink alcholoically for almost two more years. I have been happily sober since October 25, 1995.

A few months later I received another letter and a call from BloodSource asking if I would consider being a research blood donor for some HCV research they were conducting. I leapt at the chance. I am happy to say that over an eight year period my blood and the blood of many other HCV+ folks in my community and around the world went into the development of the tests for genotype, viral load etc.

Some of this research was published. The research coordinator at BloodSource sent each of us a copy of the study with our individual results highlighted. I was patient 17. This was one of the first studies that demonstrated there was no correlation between ALT levels and viral load. While my viral load soared to 38 million, my ALTs stayed within normal range.

By now I had learned a little more about HCV. I was lulled into a false sense of security, thinking that, as long as my liver panels remained within range, I would never get sick. I remember at my first Hepatitis C training as we introduced ourselves with every fourth person stating they were HCV+, when it came to me I said, "I am HCV+ and asymptomatic." That changed and changed quickly.

In 2001 I started having health problems. I could not think as clearly as before, I had trouble concentrating. I was a person who did not need to make lists and now I could not even find the list. I was growing more easily fatigued. Some days I had to go home from work to take a nap. I started having joint and muscle pain. A few months later I developed carpal tunnel syndrome, and started having difficulty swallowing. Although I had become a non-smoker that spring and expected to gain a little weight, I was unable to stop the weight gain. My nails, cuticles and hair became brittle. The most bizarre manifestation was my yellow hands. I asked my primary care, my GYN and even my pharmacist what could be causing my yellow hands. Each would look into my eyes and say, "Well, you're not hepatic," and just shrug.

As my collection of symptoms increased, my visits to my doctor increased as well. This particular doctor claimed he was doing research in HCV. I asked him if any of this could be related to the HCV. He was dismissive. As my symptoms increased, especially the pain and lack of ability to concentrate, I started failing at my job. For thirty years I had excelled in my career and now I was barely competent. One day it was no longer safe to drive so my sponsor drove me to my doctor for one last

visit. In tears, I begged him to do something, I was losing my job, and soon I would have no insurance.

I remember it clearly. He said, "You have some serious problems, you need to get some mental health counseling."

Thank goodness I had a Participating Provider Organization (PPO) that allowed me to seek out a physician of my choice. Someone recommended a particular practice associated with UC Davis Medical Center and I got an appointment with one of the 2nd year residents. I brought my eight years of research lab tests. She listened to my symptoms and immediately ordered a thyroid test. Next she said, "Let's get you vaccinated for HAV and HBV." She confirmed that I did not drink alcohol. Then she asked if anyone had ever talked to me about being treated for HCV. She told me that not only did I have the easiest genotype to treat (2b) but I also had the best form of health insurance.

As it turned out I was extremely hypothyroid. My TSH was almost 72. A normal range for TSH at my lab is 0.2 to 5.5. Just a few days before meeting with this doctor I had finally discovered on-line what could be the reason for my yellow hands. In extreme cases of hypothyroidism, the hands and feet can turn yellow. Within two weeks of being put on thyroid replacement hormones I started feeling better. I still could not function well, but I could safely drive and my pain level dropped from a 9.5 to a 6 or 7.

I was referred for a liver biopsy, but before I could get in, I lost my job due to my inability to perform. At that time the new pegylated

interferon was only recently introduced and there was a waiting list. I was on unemployment and tried to find work that I could perform. I was not yet considered disabled although daily life was difficult.

Three months later I started treatment. Yee gads that first night! Whoever thought that taking the interferon injection before bedtime can help you sleep right through it? Flu-like symptoms, BAH! More like torture on the rack. But it was never that bad again. My sweetheart asked me if I was going to be able to tolerate the treatment. From that first week I accepted that it was the hardest thing I had ever done, but it was doable. I had remembered all the pain I ever had in my life and recognized that this pain was also going to become just a memory. I am hard-wired for optimism so I expected to be rid of the virus.

I had expected to lose a little of the extra weight I had gained, but I indulged in the “white food” diet: bread, bananas, brie cheese, *ice cream*, pasta. All the comfort foods.

Every morning and throughout the day I would say my prayers and thank all those who had developed the drugs I was taking. I was extremely fatigued but had trouble sleeping. They had told me I would be limited to four extra strength acetaminophen a day, so I decided to mentally raise my threshold of pain by ten percent. Arbitrarily I just decided to ignore 10% of my side effects. I spent a lot of time in bed so I bought one of those memory foam mattress toppers at the local warehouse store and that eliminated another 10 to 15% of the body aches while I was in bed. I did get up and walk and get some exercise every day. However, my dreams of catching up on all the

gardening and all the books I wanted to read were just dreams.

Did I have trouble with my providers? Yes! If I called my GI with problems, it would be 5 to 10 days before he would call me back. I sent him the last blood test results from the research study from a blood draw taken two days before I started treatment. He called and said the treatment wasn't working and I had to come off. I had been on treatment for less than a month and had not had my second viral load test. I couldn't figure out what he was talking about. I finally figured out he was reading the lab report from BloodSource. Another time, as I was scanning my medical records at my PCP while waiting for the doctor, I noticed that none of my lab tests were in my file but that another woman's advanced directive with a DNR order was in my file!

My G.I. had told me I would be on treatment 48 weeks. At 26 weeks with no detectable virus he said I was done and I didn't believe him. I called a friend at UCD to get a second opinion.

I have questions. For eight years while I was bounced from doc to doc whenever my employer's health plan changed, not one provider suggested I get vaccinated for HAV and HBV. Why isn't everyone provided these vaccines? There was no information on support groups or even the need for one.

Not one provider addressed my HCV status unless I brought it up. To this day when I tell doctors that I have been cured of hepatitis C, they continue to tell me there is no cure. I have been fully restored to health. I have had not a trace of virus in my system since the fall

of 2002. To me and to leading hepatologists, this constitutes a cure.

When I got off treatment a local hepatitis C task force was just forming. I got involved and joined the Education Sub Committee. With the help of HCSP, we developed a ninety minute HCV 101 class that we started taking to folks at risk for HCV. Our local task force is one of the most dynamic and effective organizations I have ever seen. We are blessed with a collection of individuals who seem to have sublimated their egos and stay focused on the goal: eradication of the HCV epidemic in our community. As a group we have sought out every entity in our community that has or should have a hand in combating HCV. The task force joined the HCV Improvement Collaborative formed by Martha Saly through the Center for Health Improvement. We reached out and learned from others and shared our growing expertise freely.

Because we are in the state capitol we also recognize our obligation to influence our elected officials and policy makers on behalf of all Californians. All of our outreach and awareness efforts have one eye on the people at risk and the other on the people who have the power and influence to make the needed changes.

In October 2004 I formed a small non-profit and applied to the IRS for 501c3 status. Our non-profit is thriving out of a 10 x 12 foot world headquarters. Last year we conducted 120 HCV 101 classes reaching over 1500 at-risk individuals. We developed materials where there was a gap. This year will be our third annual HCV Awareness Day. We have partnered again with eight of our local Rite Aid stores to distribute information on hepatitis A, B and C. At

a recent Health and Fitness Expo with the television station that let me go when I could not work, we tested 119 people for HCV antibodies and returned a 12.7% positivity rate.

Our non-profit has initiated three new projects in our region: *Say Yes to Life*, a pilot program to provide an appropriate level of care for clients of a local methadone maintenance treatment provider; *The Patient Provider Partnership*, which endeavors to educate those who are HCV+ so that they can have a more effective alliance with their healthcare provider as well as reach out to physicians and their practices to do a better job of screening, managing and treating their HCV+ patients; and *Moving Mountains*, a monthly series of half-day CME workshops by the leading experts in hepatology from around the country. The Moving Mountains group is made up of providers from medical doctors to medical assistants at both county health departments and community based clinics in our area.

For more information about hepatitis C, hepatitis B and HCV coinfections, please visit www.hcvadvocate.org.

• Living with Hepatitis C •

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The information in this fact sheet is designed to help you understand and manage HCV and is not intended as medical advice. All persons with HCV should consult a medical practitioner for diagnosis and treatment of HCV.

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