

# HCV ADVOCATE

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## HealthWise: Feeling Infectious

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There is a common concern shared by many who have chronic hepatitis C viral (HCV) infection. This complaint is seldom reported to physicians and is not reported with great frequency in medical literature. However, for many patients it is an overriding problem, quite possibly greater than fatigue, muscle aches, and the challenges that accompany living with a chronic illness. The concern is the sense of "feeling infectious". Invisible, pervasive, and hideous, this feeling of the potential to infect another human being can be an incredible burden. Isolation can result as a preoccupation with potential infectiousness.

Society can reinforce this isolation. Many people are ignorant of how to prevent transmission of HCV in particular, as well as viruses in general. Patients have reported stories of friends and family who will not let them in to their homes out of fear

*continued on page 2 -*

## INSIDE THIS ISSUE

- 1 HealthWise / INFO UPDATES
- 3 Treatment Advocate
- 5 Living With Hep-C (Post Transplant)

### HCV ADVOCATE

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## INFO UPDATES:

### Osteoporosis and Liver Disease

Lynn Shawn

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Metabolic bone disease has been correlated with chronic liver disease. One of these bone diseases is osteoporosis, a condition in which bones become less dense, more brittle, and fracture easily. This degenerative process of bone thinning causes fractures and pain often found in many patients with chronic liver disease. Many patients affected by osteoporosis include those with biliary cirrhosis, but those patients with alcoholic liver disease and cirrhosis from chronic hepatitis may also be involved.

Risk factors for osteoporosis in chronic liver disease are low body mass index and use of corticosteroids. Other risk factors for osteoporosis include female sex and the age of the patient. (Ormarsdottir) One study by Suzuki et al noted that osteoporosis in liver disease patients was possibly caused from nutritional deficiencies with calcium and/or vitamin D. (Suzuki) Another study on post-liver transplantation showed that osteoporosis became a significant problem with transplant patients as patient life expectancy increased. This study showed that preventive treatment with calcium and vitamin D supplementation might help eliminate deficiencies due to poor nutritional intake. (Ng)

Patients with osteoporosis show a decrease in bone mineral density (BMD). The study by Tsuneoka et al determined that bone mineral density was significantly lowest with patients with liver cirrhosis, followed by patients with chronic hepatitis. (Tsuneoka) Patients with chronic liver disease should recognize the implications of metabolic bone disease and discuss their concerns with their medical doctors. Those patients who exhibit signs of osteoporosis can be monitored through BMD clinical tests.

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*continued on page 5*

*HealthWise - continued from page 1 -*

that their children will become infected. Hugs and kisses can cease. Sexual relationships stop or are never initiated. In the extreme, even marriages have been challenged.

It is tragic to witness this unnecessary and avoidable ostracism. Those struggling to live with a chronic disease need more support, not less. To some, the isolation is worse than the virus. Just like other aspects of chronic hepatitis C, learning to manage these complexities is a key to learning how to live with HCV infection.

Having a potentially infectious disease carries with it the weight of responsibility. Simply stated, when at all possible, we need to take reasonable steps to prevent the further transmission of HCV. In my experience, HCV patients take this responsibility quite seriously. People want to know how to protect their loved ones. They ask questions about sexual transmission. On a deeper level, they express fears that they will infect someone else. It can be very moving to hear the stories of those who donated blood before they knew they were infected. The most heart-breaking stories are those rare occurrences told by HCV infected parents whose children carry the virus.

In addition to wanting to protect others, there can be a feeling of living fettered to the virus, as if one can never really be free in the world. Some patients describe themselves as “feeling contaminated”. This can drive some to endure many years of interferon therapy even when they are nonresponders. One patient I know is on her fourth round of treatment. She feels that it is her responsibility to “try whatever it takes to get rid of the virus”.

What are the responsibilities of those who carry hepatitis C? The following are a few suggestions. First, be as informed as possible about transmission issues.<sup>1</sup> Second, translate that information into action. Start with the most common routes of transmission. Do not share razor blades, toothbrushes, or cuticle scissors. Practice adequate dental hygiene, including flossing.<sup>1</sup> Needles and syringes should be disposed of in biohazardous containers. Clean up spilled blood with a diluted bleach solution. Wear adhesive strips on open wounds. Women need to properly dispose of sanitary products. Nursing mothers are advised to practice nipple care so as to avoid cracks in the skin. Those with multiple sex partners are advised to practice barrier contraception. Those in monogamous relationships need to discuss these issues with one another.<sup>1</sup>

A third responsibility is to one’s self. This means striving to live the healthiest lifestyle possible. In order to accomplish this, it means letting go of what we cannot control. Barely a week passes without my having to reassure someone that his or her inadvertent actions probably did not infect another human being. Most of us have had some experience with this. As I write this, I think of the instances in which I wish I had acted differently.

There was that time I was bleeding and did not have a band aid with me or when I neglected to inform the phlebotomist to don gloves. For a while I actually believed I infected the entire city of Istanbul (trust me, it is a long story). We carry these moments on our backs, bending from guilt and sorrow. However, guilt has never done much to enhance health. Our responsibility is to do the best we can, not to be perfect. Presumably, all adults have a responsibility to protect themselves from contracting a transmittable organism. If we all make the effort to protect ourselves, it makes it easier to protect others. Let go of the guilt and move on.

Those of you who speak with great despair while discussing the blood you donated without knowing you had HCV, please let go of this. It is not your job to monitor the purity of donated blood. Your responsibility is to provide honest answers to the blood donation screening questions, prior to donation. I have a more personal response to this issue. As someone who contracted HCV via a transfusion, I am grateful for the blood I received. It saved my life. Sure, I would have preferred to have safer blood, but my gratitude for being alive overshadows the long-term ramifications.

The fourth recommendation is to educate others. This involves some risk, possibly further ostracism. However, the goal is to stop further spread of the disease, not to win a popularity contest. Initially relationships can be strained, but education, time, and patience can heal the most difficult situations. Obviously, use your judgement. Everyone does not need to know. Consider telling members of your health care team, such as your dental hygienist, dentist, physician, nurse, and phlebotomist. Tell your facialist and manicurist if you use these services. Precautions can be taken to minimize the risk of transmission. If your hair regimen involves shaving, tell your stylist. Use similar precautions regarding body piercing and tattooing.

As for the patient who feels the need to try every available treatment in an attempt to eliminate the virus, this decision is a personal one. Treatment decisions are complicated and cannot be based solely on potential transmission issues. HCV does not emerge in casual relationships. If one follows some standard precautions, transmission is unlikely to occur. Presumably, treatment decisions will be based on medical necessity.

Finally, it is worth promoting something that can be infectious – laughter. HCV issues can be painful and burdensome – if we let it. Laughter is not a cure, but it can lighten the load. It is the one contagious condition that feels good and for which you do not need a doctor’s order. Prescribe it for yourself today.

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## TREATMENT ADVOCATE

Joe Shaw

As I write this, my head is throbbing with my "first dose of the week" headache. That's the bad news. The good news is that there's only 15 shots to go! By the time you read next month's column, I will be finished with my year of dancing with interferon. And boy do I look forward to that. But for now, I'll get down to business. Here are the various studies, news articles research updates, etc. that were culled from various sources on the internet. If you have any questions, you can always e-mail me at [joesha@yahoo.com](mailto:joesha@yahoo.com).

### **News from the Sixth International Symposium on HCV & Related Viruses, 6-9 June in Bethesda, MD-**

Some Statistics on the Progression of HCV Evidence accumulated over the past few years indicates that the immune system of 15-25% of people infected with HCV will overcome the virus during the initial infection and clear it from the bloodstream. The remaining 75-85% will develop a chronic infection. Cirrhosis occurs in perhaps 10-20% of chronically infected people. Another 1-5% of the chronically infected also develop a liver cancer called hepatocellular carcinoma. Yet, as several studies presented at the international meeting show, the majority of patients have none of these symptoms even 20 years after infection. NIH's Alter and Jay Hoofnagle from the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) reported results from a 7 year study of more than 400 would be blood donors who tested HCV positive and whose infection could be traced to a transfusion or injection. Even though they had been infected for an average of nearly 20 years, only 13% had severe fibrosis and a mere 2% had cirrhosis. These results closely match those from an Irish study published in 22 April New England Journal of Medicine that charted disease progression over 17 years in 376 women who had received contaminated blood products in the 1970s. And a study by NIDDK's Leonard Self looked at 8568 blood samples stored by the U.S. Air Force between 1948 and 1954 and found that 17 tested positive for HCV antibodies; current records revealed that only one of those infected individuals had died of liver disease (5.8%).

**High Hepatitis C Virus Levels: Patients Clear Virus More Slowly, More Likely to Relapse** -Sustained responders to anti-HCV treatment clear virus more slowly if they start out with higher virus levels. Patients with chronic hepatitis C have a wide range in the concentration of the virus in their blood. Researchers reported at the Digestive Disease Week conference that this so-called baseline viral concentration closely correlates with the rate at which sustained responders clear the virus from the bodies. And it appears that a

higher baseline viral load increases the likelihood that a patient who initially responds may relapse in the post-treatment period. More patients with lower baseline viral concentration responded early compared to patients with the highest starting viral concentrations. By weeks 2-4 of consensus interferon treatment, most sustained responders in the lowest three quartiles had undetectable HCV RNA values. Sustained responders in the highest quartile required treatment for 12 weeks before achieving undetectable HCV RNA levels. These findings may help predict early in treatment who will benefit from therapy, according to the study's lead researcher, F. Blaine Hollinger, M.D., professor of medicine, virology, and epidemiology at Baylor College of Medicine, Houston, Texas and director of the Eugene B. Casey Hepatitis and HIV Research Center and Diagnostic Laboratory. He believes that the next step is to take all data from the study and combine it with genotype and other factors to come up with an algorithm to better predict treatment response. "So that if you came up to me as a patient and I did your baseline [viral concentration], I did your genotype, I looked at your liver to see how bad your liver disease was, I might be able to say to you, 'If you wanted to be treated, here's what I think your probabilities of success are.'" *FROM: Patients NewsWire*

**8-Year Hepatitis C Study Launched** - The government is launching an eight-year study to test anti-viral drug treatments for the 4 million Americans infected with chronic hepatitis C. The \$28 million clinical trial will be funded by the National Institute of Diabetes and Digestive and Kidney Diseases, a division of the National Institutes of Health.

Researchers will try to determine if long-term treatment with drugs can slow or prevent the progression of liver disease in non-responding hepatitis C patients.

The trials will begin next year at nine centers around the country, the Institute said. Researchers will decide this summer which drugs will be used and the number of volunteers to be recruited. "As the largest and longest study of hepatitis C, this trial should provide answers to difficult questions concerning management of hepatitis C," Dr. Jay H. Hoofnagle, director of the division of digestive diseases and nutrition, said in a statement.

The nine trial centers are the University of California, Irvine; University of Southern California, Los Angeles; University of Colorado Health Sciences Center, Denver; Massachusetts General Hospital, Boston; University of Massachusetts Medical School, Worcester; St. Louis University, St. Louis, Mo.; University of Michigan, Ann Arbor; University of Texas Southwestern Medical Center, Dallas and Medical College of Virginia, Richmond.

*FROM: Wire Reports*

[continued on page 4 -](#)

**Pharmacy Discounts Hepatitis C Drugs** - Three Pittsburgh pharmacists tired of turning away hepatitis C patients who couldn't pay \$1,400 a month for the only treatment available are bottling and selling the drugs themselves at half the price. Fisher's Specialized Pharmacy Services, a drug store in Pittsburgh, began selling its version of the drugs this month. Until now, they had to be purchased from Madison, N.J.-based Schering-Plough Corp. "How would you like to have a disease and have insurance and still not be able to afford the drug?" said Don Kerrish, one of the three druggists who own the pharmacy. Schering-Plough's treatment, known as Rebetrone, consists of Ribavirin and interferon. The company uses a type of interferon called Intron A, the only type approved for use with Ribavirin for treating hepatitis C. Fisher's is selling Ribavirin for \$225 a month and, separately, an interferon not made by Schering-Plough for \$420 a month. The pharmacists said they have received about 10 calls a day from potential patients since they started the sales July 9. For now, the Food and Drug Administration is letting both sell their drugs. Brian Klein, an activist with the Hepatitis C Action and Advocacy Council, said Schering-Plough packages the drugs together just to make more money. "Doctors and patients need to have the access and flexibility to make the choices they deem appropriate, not the drug company," he said. Schering-Plough has asked the FDA to look into whether Fisher's is violating federal guidelines. By promoting the drugs, the pharmacy is moving toward manufacturing, which is not allowed, Schering-Plough claims. Kerrish said the pharmacy is meeting federal regulations and selling safe drugs. Schering-Plough says its treatment -- which earned \$248 million in the 12 months ending May 1999 - is the only one proven to work. However, the company says it is effective in only about 40 percent of the people who take it. That's one reason some people are clamoring for an alternative. Fisher's isn't claiming its version is as good as Schering-Plough's, only that it's a choice. *FROM: Wire Reports*

**Scottish Firm Says Hepatitis C Drug Tests Approved**

- A Scottish bio-technology company said Thursday it had been given the green light to begin testing a new drug to fight Hepatitis C. The Scottish arm of Florida-based U.S. biotech firm Viragen said it had perfected the production of naturally derived alpha interferon, a natural protein in the body's immune system that fights infections. The company said synthetic interferon is often used as the standard treatment for the virus along with other drugs, but that it is often ineffective or has side-effects. The drug, named Omniferon, could be available within three years after trials to volunteers and

patients, the firm said. *FROM: Wire Reports*

**Caremark Announces Agreement with Schering-Plough** - Caremark Inc., the pharmaceutical services subsidiary of MedPartners, Inc., today announced that it has reached a collaborative agreement with Schering-Plough Corporation. According to the agreement's terms, Caremark will act as a preferred specialty pharmacy provider for Schering-Plough's REBETRON(TM) Combination Therapy used to treat the hepatitis C virus. Caremark said that it anticipates significant market demand for the therapy, among both existing and future customers. Moreover, REBETRON Combination Therapy is considered to be the standard of care for hepatitis C sufferers, and can be administered in patient homes. As a leading provider of comprehensive pharmaceutical services, Caremark plans to add significant value for its patients by offering the specialized delivery of REBETRON Combination Therapy together with enrollment in Caremark's patient-medication management program for hepatitis, HepCare. The disease management program offers hepatitis patients a single point of contact for a comprehensive range of support services including monitoring of treatment efficacy, compliance, and side effects. HepCare also assists with third-party billing and reimbursement, and, for clinicians, the program provides decision support by providing access to centralized therapy utilization information. A toll free number, 800-237-2767, is available to patients who wish to enroll or need additional information. Further information regarding hepatitis C and Caremark's HepCare program can also be accessed on Caremark's website, at <http://www.caremark.com>. *FROM: Wire Reports*

**HCV Mystery Solved** - A new finding that explains how hepatitis C virus (HCV) evades the destructive effects of interferon could lead to more effective therapies against the potentially fatal infection. In the July 2 Science, Michael Lai, MD, PhD, of the University of Southern California School of Medicine, and his research team report that a protein component on HCV's envelope uses a kind of bait-and-switch tactic that allows the virus to survive. As interferon binds to receptors on HCV-infected liver cells, production of protein kinase (PRK) causes phosphorylation of key proteins, which results in cell death and the demise of HCV. But the protein component on HCV's envelope, known as E2, mimics PRK's protein targets. When PRK binds to E2 instead of its normal targets, phosphorylation is inhibited and the virus lives on. Even though HCV has a highly varied genome, Lai believes that his team's findings will allow pharmaceutical companies to develop strategies that will overcome HCV's ability to neutralize interferon. *FROM: Journal of the American Medical Association*

## LIVING WITH HEP-C (POST LIVER TRANSPLANT)

*John Devlin*

My name is John. I am 53 years old. Apparently, it was during the 1960's, when I experimented with intravenous drugs, that I contracted the Hep-C virus. The reason we suspect it was during this time, is because the severity of the liver disease, i.e., end-stage and cirrhotic. According to my doctors, the amount of damage had to take many years. I have not used intravenous drugs since 1965. It really doesn't matter how and when I contracted the disease and it really shouldn't matter to anyone living with HEP-C how they got it. The important thing is; where do we go from here?

During the summer of 1996, I told my primary physician that I had been feeling sluggish and fatigued. She ordered some laboratory tests and was the first one to diagnose the hepatitis. She immediately referred me to a gastroenterologist/liver disease specialist, who monitored my condition over a 6-month period and suggested interferon therapy. However, just 2 days before I was to begin the interferon injections, the results of a sonogram came back, showing a small (2 centimeter) growth on my liver. Upon seeing this, the specialist cancelled the interferon therapy and informed me that I will need a liver transplant. The first step was chemo-embolization, to neutralize the 2-centimeter hepatoma. A camera-guided tube was inserted in a portal vein and directed to the site, in order to kill the tumor. Then the long and apprehensive wait began for an organ donor. It took approximately 2 years on the waiting list before I received the most important telephone call of my life.

At midnight, on August 9, 1998 I was instructed to be a New York University Medical Center within 2 hours, as they identified a compatible liver donor. I arrived within one hour and was immediately prepped for surgery. The organ was coming by ambulance from a hospital 75 miles away. Unfortunately, the surgery had to be aborted, as the organ was not healthy enough. It had too many fatty deposits, according to the surgeon. I went home and continued the nerve-racking wait. However, this time, I would "jump out of my skin" every time the phone rang. Exactly one month later, on September 10, 1998, I received the call to come in again. At 8:00 a.m. on September 11<sup>th</sup>, I was on the operating table. Twelve hours later, I was in the recovery room. We were told that the donor was a 28-year-old male who died in an automobile accident. I will be forever grateful to his family, who I'll probably never meet. They ultimately made the decision to donate the organ.

I was discharged in 9 days, and back to work (part-time) within 60 days. After 90 days, I was working full time and feeling great. During this time, I reported to the out-patient transplant clinic, bi-weekly, for laboratory tests and follow up. I also received chemotherapy once a month, from January 1999 to June 1999, which I'm told was standard procedure due to the cancer threat from the previous hepatoma.

In March 1999 lab results indicated elevated liver enzymes, resulting in a hospital readmission for a biopsy. The test revealed that the hep-C was recurrent, necessitating the inevitable course of treatment with interferon/ribavirin. To aggravate matters, I developed diabetes from the transplant medications, probably the prednisone. I also had to inject neupogen 3 times a week, due to low white blood cell count. This drug was discontinued in May 1999.

Meanwhile, in spite of what appears to be a nightmare, I have never felt better. I am no longer fatigued, lost a desired 60 pounds, going from 240 lbs. before the surgery to 180 lbs. today. And most interesting is the fact that I have not experienced any discomfort whatsoever with the interferon therapy. However, we had to reduce the ribavirin dosage from 800 milligrams per day to 400, due to signs of anemia.

I took my first vacation in July 1999 and went white water rafting, deep sea fishing and drove 1500 miles. I'm feeling terrific.

### *INFO UPDATES - continued from page 1 -*

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