

## **August 2000's Advocate:**

### [Hep C Activism 101: Tell Congress You've Got Some Issues](#)

Speaking out on Hepatitis C will not only help you but many others as well.

### [Treatment Advocate: Depression: I Know How Real It Can Be](#)

Journal entries reveal the seriousness of clinical depression and underlie the importance of treatment.

### [Healthwise: What's to Eat? Basic Nutrition for Hep C Patients](#)

Inquiring minds want to know: what kind of diet is right for the HCV patient?

### [New Studies May Give Clue to the Natural Disease Progression of Hepatitis C](#)

These studies may change the way we look at the natural disease progression of HCV.

### [Schering's Peg-Intron\(tm\) Receives Approval in Europe](#)

Once weekly treatment will soon be available to the estimated 4 to 5 million Europeans with HCV.

## August 2000's Advocate:

### Hep C Activism 101: Tell Congress You've Got Some Issues

By Ralph Napolitano  
HepatitisActivist.org

"Few will have the greatness to bend history itself, but each one of us can work to change a small portion of events, and in the total of all those acts will be written the history of this generation." - Robert F. Kennedy

Yes, you can make a difference!

By taking part in a nationwide hepatitis advocacy initiative, you can help more than just yourself or a loved one. Your effort may also help millions of other people in our nation with liver disease concerns.

As you may already know, liver disease research, education and other related issues are significantly underfunded in the United States.

Did you know that long-term damage from hepatitis C infections alone may cost the U.S. economy more than \$81 billion by 2019? This is according to a study presented at the 1999 American Association for the Study of Liver Diseases meeting.

The U.S. Centers for Disease Control estimates that approximately 4 million people in this country are infected with hepatitis C. This is four times the number estimated for HIV/AIDS infection (and that 4 million number doesn't even include other liver diseases and conditions such as chronic Hepatitis B and cirrhosis).

Unfortunately, liver disease research and education gets only a pittance in terms of government funding. Given the serious individual and societal ramifications of these diseases, the fight against HCV deserves much more financial support.

Truly, the need for Hepatitis C education and research is an important topic for our government to address. Yet the odds are that it won't be taken seriously, or addressed appropriately, unless your voice and the voice of many others is heard.

#### Why You Should Write To Congress

In the dictionary, advocacy is defined as "the act or process of advocating or supporting a cause or proposal." Grass-roots advocacy is when concerned individuals, like you, attempt to influence policy through personal effort, usually by lobbying (or e-mailing) their representatives. This is a way you can truly make a positive difference in our world.

When enough people contact their congressional representatives about an important issue, congress listens. They have to-their jobs depend on it.

If just 10% of the people with liver disease wrote to congress (and had ten of their friends do the same) our representatives would be getting over 4 million messages telling them they need to do something about the issues involved!

Incidentally, this method works much better when you write to your own specific representatives. They are too understaffed to be concerned about non-constituent desires. The more they hear from actual constituents (the people who might vote for them) the more likely it is they will respond with appropriate action. This is why targeting your own representatives is so important. And you may send letters on as many issues as you want, as often as you want.

## Important Hepatitis-Related Issues To Write Congress About

The following is just a sample of issues you may want congress to address:

1. Increasing Government Research Funding for HCV and Other Liver Diseases
2. Increasing Government Funding for Public Education on HCV and Other Liver Diseases
3. National Transplant Program Improvement Initiatives
4. FDA Fast-track Approval for Promising HCV and Other Liver Disease Treatments
5. Increasing Government Liver Disease Funding for NIH, Complementary & Alternative Medicine
6. Social Security Reform for HCV and Other Liver Diseases
7. Medical Insurance Issues for HCV and Other Liver Disease Sufferers
8. U.S. Military Veteran Liver Disease Research and Compensation Issues
9. Disability Insurance Reform for HCV and Other Liver Disease Sufferers

You can probably think of even more issues to add to this list. Once you determine the one or ones that are most meaningful to you, it is time to let Congress know.

### Here Is a Quick and Easy Way To Do It

A simple yet powerful way to accomplish this task of writing to congress is through the Automated Congressional E-Mailer (ACE) system at [HepatitisActivist.org](http://HepatitisActivist.org).

This is a chance for you to make a real positive difference, as part of a nationwide electronic grass-roots lobbying effort, to get more attention (and funding) for hepatitis C and other liver disease issues.

At this advocacy site you can quickly and easily e-mail your own representatives in Congress about issues relevant to hepatitis C and other liver diseases. By participating in this congressional e-mail letter writing campaign you will help get more attention for liver disease where it counts most-on Capitol Hill.

This is an opportunity for you, your friends and your loved ones to take action, to be heard and to make a significant difference. All with very little effort on your part. The more people who write to congress, the more attention hepatitis and other liver diseases will receive. More funding and more assistance will follow.

The ACE system makes it easy for people who have never before written to their representative to do so quickly and automatically. The system actually finds your specific representatives for you, through a simple zip code search so your efforts are properly targeted.

Even people who don't feel confident writing a letter can choose a sample letter to customize from a variety of topics and then just copy, paste, customize and send it by e-mail.

There are nine letter samples you can choose from and modify (matching the topics listed above), or you can compose your own. At the click of your mouse (through a zip code search) you will find your own representatives and send your e-mail directly to their attention.

And the ACE system makes it so easy, you may be more inclined to write congress on a regular basis (perhaps even monthly), making it an even more effective endeavor. In fact, one user called the process "fun."

### This is Important, Act Now

Everyone says they want help make a positive difference during their lives. Now you can meaningfully contribute to a cause that is clearly important to you. Go to [HepatitisActivist.org](http://HepatitisActivist.org) and e-mail your congressional representatives today.

Silence works against us. So, let your voice be heard! And make a commitment to pass this link on to at least ten people you know who may want to help. Together we can make a real difference. So, let's do it!

If not us, who? If not now, when!

Ralph Napolitano has chronic Hepatitis C. He is the president of Natural Wellness and director of the Institute for Integrative Healthcare Studies. He is a co-founder of the HepatitisActivist.org website, and developer of the Automated Congressional E-mailer (ACE) system. Mr. Napolitano is also the founder of LiverSupport.com, a website offering Maximum Milk Thistle, the world's most cost-effective natural liver protector.

## August 2000's Advocate:

### Treatment Advocate Depression: I Know How Real It Can Be

By Joe Shaw

**Journal entry: I feel scared and lonely. No one will help me and I'm too proud to ask anyone anymore and no one calls me and I just can't do it anymore.**

A brief look into my journal from seven years ago reveals that I was depressed. It was a dark summer for me in sunny L.A. I rarely left the apartment except to work and I ate incessantly as if the food would make me feel better. I wasn't in contact with my family or my friends. Looking back it was just one of many episodes of depression I've gone through in my life.

The American Psychiatric Association (APA) estimates that 18 million people in the U.S. are clinically depressed. Sad thing is, nearly half fail to get treated. For people with hepatitis C, depression screening is especially important. One of the side effects of interferon therapy is depression and even suicide. Visiting a psychiatrist before beginning treatment is essential.

A new study gives another reason why: People who are depressed are three times more likely to discontinue medical treatments or practices prescribed or recommended by their doctors, according to a report published in the July 24th issue of the Archives of Internal Medicine.

**Journal entry: Just been feeling like there's a big black hole and I'm falling into it and I'm paralyzed by f\*\*\*\*\*g fear.**

What are the symptoms of depression?

According to the APA, a person suffering from a major depressive episode experiences a depressed mood or a loss of interest or pleasure in daily activities consistently for at least a two week period. This mood must represent a change from the person's normal mood; social, occupational, educational or other important functioning must also be negatively impaired by the change in mood. A major depressive episode is also characterized by the presence of a majority of these symptoms:

- ◆ depressed mood most of the day, nearly every day, as indicated by either the patient or observation made by others
- ◆ markedly diminished interest or pleasure in all, or almost all, activities most of the day, nearly every day
- ◆ significant weight loss when not dieting or weight gain (e.g., a change of more than 5% of body weight in a month), or decrease or increase in appetite nearly every day.
- ◆ insomnia or excess sleep nearly every day
- ◆ fatigue or loss of energy nearly every day
- ◆ feelings of worthlessness or excessive or inappropriate guilt nearly every day
- ◆ inability to think or concentrate, or indecisiveness, nearly every day
- ◆ recurrent thoughts of death (not just fear of dying), recurrent suicidal ideation without a specific plan, or a suicide attempt or a specific plan for committing suicide

**Journal entry: I just don't want to be here feeling totally hopeless and afraid and lonely and tired, so f\*\*\*\*\*g tired. I don't know what to do and I want to run and hide.**

I can't say it enough, don't wait. If you think you need help, don't hesitate. Get it at once. Call your doctor. And if you're going to begin interferon therapy, it's essential to be screened for depression. I

waited until two months into interferon-ribavirin treatment to see a doctor about my depression. It took two more months to see a psychiatrist and begin medication.

Why did I seek treatment? Because I stopped exercising, which I had done regularly for years, and I shunned social events and mostly just stayed at home. I felt exhausted and tired all the time and when at home, I found it hard to do anything but lie on the couch.

My partner was supportive, but didn't understand what I was feeling. Finally a friend told me, "You're depressed, you are describing depression. Get some help."

I, like many others, have always tried to "go it alone." I thought I could persevere through virtually anything. Only in retrospect can I see that throughout my life, I had at least three or four episodes of major depression.

More than eighty percent of the people with depression can be successfully treated. I am now taking Zoloft, and while I'd rather not have to take any medication, it has improved my quality of life. I get out of the house now and basically lead a more "normal" life. Everything's not perfect all the time, but that's the way life is. I no longer feel overwhelmed or tired all the time.

**Journal entry: It was a pretty okay day! I was slow getting started but it was okay because I found that if I took it a little bit at a time, it's okay. I get overwhelmed when I try to think of everything I have to do. Just a little bit at a time is working fine.**

Joe Shaw was diagnosed with HCV in January 1998 and lives with his partner and his two pugs, Willie and Sammie in Long Beach, CA.

### Healthwise: What's to Eat? Basic Nutrition for Hep C Patients

By Lucinda K. Porter, RN

Patients with chronic Hepatitis C (HCV) infections frequently ask questions regarding what to eat and what to avoid in their diet. The subject of diet and nutrition can be controversial, and there are those who have very strong opinions on this issue. I take a moderate position, based on my experience that strict rules and extremes generally fall by the wayside.

Unless your doctor has advised you otherwise, the basic healthy heart diet works for individuals with chronic HCV infection. There is a common misconception that protein is bad for the liver; on the contrary, a diet with a normal and adequate amount of protein is recommended for hepatitis C patients. Exceptions to this general rule are those with very advanced liver disease or a compounding medical condition. In these situations, it is advisable to work with your doctor and a nutritionist for a diet tailored to your needs.

A basic healthy diet includes the following components:

- ◆ 60 to 70% carbohydrates - These should be primarily complex carbohydrates that are high in fiber, such as fruit, vegetables, and whole grains. Keep refined white flour and sugar to a minimum.
- ◆ 20 to 30% protein - If you consume protein from animal sources, choose lean forms of protein, such as fish and chicken. Beans, nuts, and other some other vegetables are acceptable sources of proteins.
- ◆ 10 to 20% fat - The American Heart Association guidelines state that up to 30% of one's diet can include fat. If excess weight or other issues related to high dietary fat content are not issues, then this recommendation should be fine. Avoid saturated fat. Olive oil is one example of a fat that has been shown to be beneficial.
- ◆ Reach for high-fiber foods.
- ◆ Strive for 9 servings of fruits and vegetables daily.
- ◆ Keep processed foods to a minimum.
- ◆ Avoid raw or undercooked shellfish.
- ◆ Do not eat wild mushrooms unless you are positive of what you are ingesting.

Of all of the above recommendations, the last two are my personal unbendable rules. Raw or undercooked oysters or clams can carry *Vibrio vulnificus*, a bacterium that cause a number of serious clinical conditions, or other infections such as hepatitis A. High-risk individuals include those who are immuno-compromised or have liver disease. Certain wild mushrooms contain toxins that can destroy even the healthiest livers.

In addition to maintaining a nutritional diet, strive to practice safe food habits. Food poisoning is a serious problem in our country. Hepatitis A can be a food or water borne virus. It is recommended that those with hepatitis B and C be immunized against hepatitis A. (It is also recommended that those with HCV infection receive the hepatitis B vaccine.) For specific guidelines about food hygiene, try the consumer advice icon at [www.foodsafety.gov](http://www.foodsafety.gov) (apologies to those without Internet access).

This article is very basic. My intention is to provide a framework for a more personalized approach. One should strive for good eating habits, but the truth be told, for most of us, barely a day passes without room for improvement.

Notice I did not say avoid chocolate. There have been recent reports of the potentially positive effects of small amounts of dark chocolate in the diet. An ounce of dark chocolate a day may keep the doctor away. Until it is proven otherwise, I would be hard pressed to give it up. That would be one research study I would be interested in joining...unless I was randomized to the non-chocolate group!

Lucinda K. Porter, RN is a research nurse and patient educator at Stanford in the area of hepatology. She co-facilitates a support group and is active in many aspects of hepatitis C education. In addition to being HCV positive, she has a life which include her husband and teenaged daughter.

## **New Studies May Give Clue to the Natural Disease Progression of Hepatitis C**

By Alan Franciscus  
Editor

Disease progression of hepatitis C (HCV) has been difficult to predict because of inadequate research data. Currently, it is believed that between 20-25% of HCV-positive individuals progress on to serious liver disease.

Two recent studies examined HCV populations over 45-50 years. These studies may give a clue to the true nature of HCV liver disease progression, and could change way we look at the natural disease progression of hepatitis C.

Earlier this year, a study by Leonard B. Seeff et al. looked at 8,568 frozen blood samples of service men from 1948-1954. Seventeen of these samples tested positive for HCV. This group was examined 45 years later and only 1 person died of liver disease. Although, this was an important finding it has been criticized because of the small number of HCV-positive persons studied. However, a recent study reported in the July issue of Hepatology by Wiese et al. lends support to Seeff's findings.

Between August 1978 and March 1979, 2,867 East German women were inoculated with 14 batches of HCV tainted anti-D immune globulin. Immediately after inoculation several patients were diagnosed with non-A, non-B hepatitis. Subsequently, all the women were tested for elevated alanine aminotransferase (ALT)- a liver enzyme. All patients that showed elevated ALT's were given financial compensation and follow up medical care. Fifteen years later, the frozen samples of 14 tainted anti-D immune globulin batches were tested and found to be contaminated by a single dose of hepatitis C - genotype 1b.

Wiese et al. studied 1,018 of the women infected from the tainted batches. Only 10% of this group were treated with interferon and the remainder received only follow-up medical care and given information on positive lifestyle changes.

Twenty years after the original inoculations, only 3% of the women developed bridging fibrosis and 1 patient advanced to decompensated liver disease. However, none of the patients progressed on to cirrhosis.

Both studies found a slower rate of natural disease progression than is currently believed. The importance of the Wiese, et al. study is that following inoculation with the contaminated batch, acute infection was detected and these young women received immediate follow up medical care.

This study may confirm the opinion of many physicians that follow-up medical care and lifestyle changes may prevent severe disease progression in HCV-positive individuals.

## **Schering's Peg-Intron(tm) Receives Approval in Europe**

By Alan Franciscus  
Editor

The European Union (EU) Commission of the European Communities has granted authorization to market Schering's Peg-Intron(tm) (peginterferon alfa-2b) as a once-weekly treatment for chronic hepatitis C (HCV) in adults. Peg-Intron(tm) will be available to the general public in Europe as soon as individual EU members obtain pricing approval. Between 4 and 5 million Europeans are believed to be infected with HCV.

Schering's Peg-Intron(tm) is a time-released form of pegylated interferon, a new treatment for hepatitis C, eagerly awaited by both physicians and HCV patients. Pegylated interferon is created by attaching hair-like threads of synthetic polymer called polyethylene glycol, or "Peg" to interferon. This process prevents the body from breaking down the interferon immediately, allowing the drug to attain higher levels and remain active for longer periods of time. It is believed that this enables interferon slow down or stop virus replication. Another benefit is once a week injection instead of injecting 3 times weekly.

Recently, clinical trial data released by Schering at the European Association of the Study of the Liver (EASL) showed an overall sustained response rate of 25% of patients receiving Peg-Intron(tm) 1.0 mcg/kg and 18% of patients receiving Peg-Intron(tm) 0.5 mcg/kg. This compares to 12% of patients receiving standard therapy of Intron A (3 mu times a week) in this 48-week trial. The majority of the study participants (70%) were genotype 1, the most difficult genotype to treat, and 74% of participants had low-moderate viral loads greater than 2 million. Side effects experienced by the clinical trial group were similar to those treated with Schering's Intron A.

Application for two brands of pegylated interferon - Schering's Peg-Intron(tm) and Roche's Pegasys(tm) was submitted to the United States Federal Food and Drug Administration earlier this year. Approval is expected early to mid 2001.