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HCV Persistence and Long-Term Response to Therapy



Liz Highleyman

When evaluating medical treatments for hepatitis C, many patients and health-care providers speak of sustained virological response (SVR) – continued undetectable HCV viral load 24 weeks after completing therapy – as a “cure.” But with the availability of new testing technology, a growing body of evidence suggests that a true cure may remain elusive.

The good news is that most individuals who achieve SVR do, in fact, have a durable response – at least according to traditional measures. At the annual meeting of the American Association for the Study of Liver Diseases this past October, Mark Swain and colleagues reported on 845 participants in Phase II/III trials of pegylated interferon (Pegasys). After follow-up periods as long as five years, more than 99% of sustained responders still had undetectable serum HCV, with just seven subjects showing renewed evidence of HCV relapse or reinfection.

In another study, after up to 7.5 years of follow-up, 96% of sustained responders maintained undetectable serum HCV RNA; only 4% relapsed over the next six years if they did not do so within the six-

month period immediately following completion of therapy. Similarly, John McHutchison and colleagues found that about 4% of sustained responders had detectable HCV RNA in their livers 24 weeks after the end of therapy, and only about 1.2% had a return of detectable serum HCV RNA after up to 3.5 years of follow-up.

The most long-term data comes from Natsuko Tsuda and colleagues in Osaka, who reported in the November 2004 *Journal of Medical Virology* that HCV clearance was sustained for up to 12 years after completion of therapy in all 38 sustained responders studied. Nor was HCV RNA detectable in the livers of any of the 15 SVR patients who had biopsies. “Collectively, these findings suggest that HCV seroclearance at six months after [interferon] therapy withdrawal would usually imply virological cure.”

SVR appears durable even in HCV/HIV coinfecting individuals, who tend to respond less well to therapy and are more prone to relapse. In a study by Vincent Soriano and colleagues published in the December 2004 issue of *Antiviral Therapy*, both HCV replication and

IN THIS ISSUE

HealthWise: Knowledge, Thinking and Power.....3

Are You at Risk for Hepatitis C.....5

Starting a Support Group: Part 6.....6

liver damage appeared “permanently halted” in coinfecting subjects who achieved SVR. After an average follow-up of about four years, none of the 77 sustained responders showed HCV relapse, elevated liver enzymes, hepatocellular carcinoma, or decompensated cirrhosis.

But closer examination reveals a more complex picture.

Most studies to date, including those described above, have used standard, commercially available reverse transcription-polymerase chain reaction (RT-PCR) tests to measure HCV genetic material (RNA) in patients’ blood serum. Other testing methods may detect smaller amounts of HCV lurking in white blood cells or elsewhere in the body.

In a study by T. Watkins-Riedel and colleagues published in the December 2004 *Clinical Infectious Diseases*, researchers used four different types of RT-PCR assays (including the commonly used Cobas Amplicor) to measure HCV in whole blood, serum, and plasma from 56 previous nonresponders retreated with interferon/ribavirin. (Serum is the liquid portion of blood after coagulation; plasma is blood with

continued on page 2

PERSISTENCE

continued from page 1

the cells removed). At the end of treatment, serum and plasma specimens indicated that 18 subjects had undetectable HCV viral load. But analysis of their whole-blood samples showed that 12 of these (about 66%) did in fact have evidence of low-level HCV RNA. Testing of only serum or plasma “underestimates the true circulating HCV load and leads to an overestimation of antiviral response rates,” the researchers concluded.

In addition to looking for HCV beyond the blood serum, more sensitive assays can also reveal heretofore hidden virus. In a study reported in the January 1, 2004 *Journal of Infectious Diseases*, Immaculada Castillo and colleagues used an extra-sensitive RT-PCR assay and *in situ* hybridization to test peripheral blood mononuclear cells (PBMCs, a type of immune system white blood cell) and liver biopsy specimens. They detected “occult” (hidden) HCV in the liver cells of more than one-half of subjects (57 out of 100) with persistently elevated liver enzymes but no evidence of HCV infection using commercially available serum tests; in addition, 40 subjects had HCV RNA in their PBMCs.

Similarly, in the June 2004 *Journal of Virology*, Tram Pham and colleagues reported that low-level virus remains present up to five years after apparent spontaneous or treatment-induced HCV “clearance.” Using an extra-sensitive RT-PCR-nucleic acid hybridization assay, the researchers detected residual HCV RNA in serum or PBMC samples from all 16 subjects examined; six of seven tested also showed evidence of HCV RNA in their monocyte-derived dendritic cells (another type of white blood cell). Furthermore, in

about 75% of subjects the researchers found traces of negative-strand HCV RNA, an intermediate form of genetic material that suggests ongoing viral replication.

A study in the January 2005 *Hepatology* confirmed Pham’s findings. Marek Radkowski and colleagues looked for HCV RNA in serum and PBMC samples from patients who achieved SVR after interferon/ribavirin treatment; they also examined liver biopsy specimens from 11 subjects. After an average follow-up of five years (range 40-90 months), also using an extra-sensitive RT-PCR test, they detected HCV RNA in 15 out of the 17 subjects studied (11 with HCV in macrophages, 7 in lymphocytes, 4 in serum, and 2 in liver tissue). Negative-strand HCV RNA was detected in the white blood cells of six subjects, but in none of the liver samples. “[O]ur results suggest that in patients with SVR after therapy, small quantities of HCV RNA may persist in the liver or macrophages and lymphocytes for up to nine years,” the authors concluded.

In an editorial accompanying Radkowski’s article, Jordan Feld and T. Jake Liang from the National Institute of Diabetes and Digestive and Kidney Diseases reviewed what the latest studies tell us about HCV persistence and long-term response to therapy, concluding that HCV may persist at low levels after apparently successful therapy, but that the clinical significance of this occult virus remains unclear.

Some studies suggest that residual HCV may have a deleterious effect, although data are inconsistent. In Castillo’s study, patients with evidence of occult HCV were more likely to have fibrosis and necroinflammatory activity compared to subjects with no evidence of residual virus, though most had

only mild liver damage or steatosis (fatty liver). In Radkowski’s study, subjects with residual HCV RNA in their livers showed no histological improvement, while those with no evidence of occult virus had reduced fibrosis and lower inflammatory scores. In addition, the presence of occult HCV may explain why some patients experience hepatitis C recurrence after a liver transplant even if they were apparently successfully treated prior to the procedure, and sheds light on why people retain HCV-specific CD4 and CD8 T-cell immune activity long after apparent spontaneous or treatment-induced viral “clearance.”

Little is known about the treatment of occult HCV, or even whether it would be beneficial. Since HCV destroys liver cells as it replicates, any substantial reduction in viral load should have a protective effect against cirrhosis, liver cancer, and liver failure. Studies are now underway looking at new therapies for retreatment of nonresponders – including consensus interferon (Infergen) and interferon gamma (Actimmune) – and evaluating whether long-term interferon maintenance therapy can help prevent liver disease progression in people who continue to have detectable HCV RNA (the HALT-C and COPILOT trials). Treatments that prove beneficial for individuals classed as nonresponders using traditional measures will likely also help those with occult HCV.

Many questions remains to be answered about HCV persistence and long-term response (for example, whether people with residual, low-level HCV can transmit the virus to others). While research continues, Feld and Liang remind us, “the word ‘cure’ must not be used prematurely.”

continued on page 8

HealthWise: Knowledge, Thinking and Power



Lucinda K. Porter, RN, CCRC

Most of us have heard the expression, “Knowledge is power.” What is knowledge? The Oxford Dictionary defines knowledge as “information and skills acquired through experience or education.” It is important to note that the definition includes both information and skills. Information alone has little value unless you are on Jeopardy. Information requires the ability to use it correctly in order for there to be knowledge.

We live in the information age. Facts and figures are available to us at the touch of a finger. Unfortunately, all information is not fact, and facts without knowing what they mean are not helpful either. Skill is the necessary companion to information in order to sift out fact from fiction. Critical thinking is the process of using one’s brain and experience in order to utilize information well.

Let’s examine some information and see what happens when critical thinking skills are applied. LiverCare® (also known as Liv.52®) is sold by Himalaya Herbal Healthcare. Its website states that 258 research papers have been written and directs the reader to review its research page. It also claims the following:

“LiverCare was introduced in 1955 as a specially formulated liver support product. Since then, LiverCare has been sold worldwide & is widely recognized by thousands of health professionals as one of the most effective liver formulas, with beneficial effects reported in over 300 studies. LiverCare ensures optimum liver function through the protection of the hepatic parenchyma, and by way of its potent antioxidant properties, it acts as a powerful detoxification agent. LiverCare neutralizes all kinds of toxins from food, water, air and medications. By protecting one of the body’s most

important organs, LiverCare has enormous health benefits for everyone.”

This sounds good to me. I don’t want toxins to hurt my liver. I would really like my liver to be at its optimum function. I wonder if LiverCare can do all of these things. I am vulnerable to health-improvement claims because, like most humans, I want to protect my health. As a person living with chronic hepatitis C virus infection (HCV), I am particularly interested in safeguarding my liver. If LiverCare can deliver on these claims, then I will try it. To find this out, I analyze the information.

I start with the research. I look at the most recent research first. The website lists 258 research papers. The vast majority of the research was conducted in India. This does not mean the research wasn’t valid. It does mean that none of the research was

subjected to common research standards found in the United States or was evaluated by the Food and Drug Administration (FDA). Some of the listed research had absolutely nothing to do with supporting the use of LiverCare. The studies used small sample sizes, which means that they did not test the product on very many

people. There were flaws in the way some of the studies were designed.

I did not read every paper about LiverCare, but the ones I did read did not support any claim of the product’s ability to ensure optimum liver function. It wasn’t even clear what optimum liver function is. One of the published papers using a larger sample size, compared four other compound formulations to a placebo group (patients who were given a pill that did not have any active ingredients in it). Two

“This is in response to the Federal Trade commission’s \$60,000 fine and order to stop making unproven medical claims.”

continued on page 4

KNOWLEDGE

continued from page 3

of the formulations were found to be more effective than LiverCare. There was a noticeable absence of solid research methodology, such as liver biopsies as a measurement of scientific support. The common practice of repeating the research to see if the results are the same was also not done on most of the studies I reviewed.

Another question I would want answered before I took this supplement – was the product tested on someone like me, that is to say a Caucasian woman in her early 50's with HCV? I could not find any research that came even close to fitting these criteria.

The statement that “LiverCare has been sold worldwide & is widely recognized by thousands of health professionals” doesn't really tell me much about the efficacy of the product. It also does not state that these health professionals who recognize it also endorse or use LiverCare. It only needs to be sold in one other country outside of the manufacturing country in order to be telling the truth and if two thousand chiropractors or ayurvedic practitioners were sent free samples of LiverCare, then the claim could be true.

At first glance the Himalaya Herbal Healthcare website is outstanding. It is packed with information, including herbal monographs which review each ingredient in all of their products. Unfortunately, I had no way of knowing what the source was for this information, leaving me with just that – information, but not knowledge.

Now, before I irritate some of my readers and Himalaya Herbal Healthcare, please allow me to say

a few things. LiverCare could be wonderful. There is value in many healing arts, including ayurveda and chiropractics. LiverCare was randomly chosen as an example for the purposes of this column. I could have chosen Liveraid which is sold by Liverite®. It claims to “cleanse the liver from impurities in the diet and environment, increase energy level, and support liver function.” The folks at Liverite Products were very careful to add a disclaimer stating that “these statements have not been evaluated by the FDA” and that the “product is not intended to diagnose, treat, cure, or prevent any disease.” Instead, their claims are vague, using terms like “support, increase, and cleanse.” This is in response to the Federal Trade Commission's \$60,000 fine and order to stop making unproven medical claims.

A word about the notion of cleansing or detoxifying the liver: the liver helps to rid the blood of impurities, but that doesn't mean it needs to be cleansed. It's not like a clogged filter which needs to be cleared. Toxins are excreted from the body. Sometimes minerals and chemicals will accumulate in the liver, but that is usually because of some other problem that needs to be fixed, such as having too much iron. Supplements are not the best way to treat this. The best way for HCV patients to decrease the accumulation of undesirable substances in the liver is to 1) not put these substances in the body in the first place, and 2) keep the liver healthy by avoiding alcohol and toxic drugs, eating a low-fat diet, and being vaccinated against hepatitis A and B.

Here are some terms that can be misleading:

- “Clinical proof,” “solid, scientifically backed,” “in one study,” and “clinically proven in animal studies” – These statements do not support any product claims, especially if the product was tested in animals and not in humans.

- “An independent study” and “randomly selected” – These are solid scientific concepts that are essential to good research. Unfortunately these concepts can be applied in a sloppy manner and ultimately serve the manufacturer rather than science.

- “Four out of five doctors recommend,” “48% more relief from pain,” and “a survey said” – Statistics can be manipulated and misused to support almost anything. These claims can be completely misleading.

How can the average patient with little or no medical training separate fact from fiction? Start by looking for genuine experts whom you trust. Ask your doctor or nurse for reliable resources. Support groups can be a great place for finding trustworthy information. Ask what websites and literature other people depend upon. Be objective and patient. Learning to think critically is a skill. Practice as much as possible and in time you will be forming opinions based on evidence and reason. This is knowledge.

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ARE YOU AT RISK FOR HEPATITIS C?



Alan Franciscus, Editor-in-Chief
and Paula Fener

This article is designed to help you stay healthy by letting you know about those things that can put you at risk for getting hepatitis C (HCV). Avoiding the situations listed below can greatly reduce your risk of getting hepatitis C as well as other diseases that are transmitted by blood-to-blood-contact.

DIRECT BLOOD-TO-BLOOD CONTACT

Hepatitis C is spread by direct blood-to-blood contact. Anything that places another person's blood in direct contact with your blood, or vice versa, should be handled with care. Being careful and using common sense in any situation where blood is present (yours or someone else's) will help protect you from hepatitis C as well as other blood-borne diseases.

SHARING DRUG USING EQUIPMENT

Sharing equipment for injection and non-injection drugs such as needles, cottons, cookers, ties, straws, pipes and even water are some of the easiest ways to get hepatitis C. Even the smallest amounts of blood that you may not be able to see can transmit the virus. Making sure your equipment stays personal and isn't shared with anyone will help you stay healthy. If you have ever injected street drugs or shared a needle with another person – *even just*

once – you should be tested for hepatitis C.

BLOOD TRANSFUSIONS & MEDICAL PROCEDURES BEFORE 1992

Before 1992, many people contracted hepatitis C through blood or blood product transfusions.

“If you have ever injected street drugs or shared a needle with another person even just once you should be tested for hepatitis C.”

If you had a medical procedure where blood or blood products were used you could have been at risk. Now the blood supply is considered safe. The likelihood of contracting hepatitis C through infected blood is less than 0.01%. The risk of getting hepatitis C from a medical procedure is rare, but safety procedures have to be followed carefully.

MEDICAL AND DENTAL PROCEDURES PERFORMED IN SOME FOREIGN COUNTRIES

Immigrants from foreign countries are at risk for hepatitis C if the country that they immigrated from does not follow standard safety precautions to prevent

transmission of hepatitis C in any situation where blood is involved. Talk to your medical provider if you believe you are at risk.

BLOOD CLOTTING FACTORS BEFORE 1987

People who received blood clotting factors before 1987 should be tested for hepatitis C.

HEMODIALYSIS

People who receive hemodialysis should be tested for hepatitis C.

CHILDREN BORN TO HEPATITIS C POSITIVE WOMEN

The likelihood of transmitting hepatitis C from a hepatitis C positive mother to her child is very low. Current studies have found that about 5% of babies born to HCV positive mothers get hepatitis C. If your mother is HCV positive you should be tested.

SEXUAL TRANSMISSION

Sexual transmission of hepatitis C is uncommon. People who are in a stable long term monogamous relationship are at a low risk of getting hepatitis C from their sexual partner. However, in some so-called high risk groups, including people who have unprotected sex with multiple partners or have sex with someone with a sexually transmitted disease, the risk of getting hepatitis C is higher.

continued on page 8

How to Start a Support Group: *Part 6*



Alan Franciscus, Editor-in-Chief

GROUND RULES

In order for a community to survive it must enact certain laws or rules to govern everyone in the community. If all the people in the community ignore the law, the community would falter and it would be thrown into a state of chaos. In many ways, a support group can be compared to a community, and, like a community, a support group must have certain rules or the group meetings will be chaotic – the members would not feel safe enough to talk about personal issues or offer advice to others. Setting the ground rules is one of the most important steps to take before the first meeting. Start by drafting a list of ground rules to be discussed at the first meeting. Discuss the reasons for the ground rules, and ask for comments from all the group members. The members may also have additional rules or changes to the ones that you suggested. After a discussion about the rules, they should be adopted by the entire group membership. It is much easier for people to obey rules if they feel that they have taken part in the approval process. In the future, the ground rules can be changed as long as a majority of the members agree to the changes.

Example of ground rules:

- I will always arrive on time – this is a courtesy to other group members.
- I will attend every meeting if possible – the group is not the same if I am not there.

- I will not inflict physical or verbal violence – it is ok to get angry and to disagree, but it is also important to respect one another’s individual differences and points of view.

- I respect the confidentiality of all group members – what is said in the support group stays in the support group.

- I respect that only one person speaks at a time.

- I will not interrupt others – it is disrespectful to the person speaking and to the other group members.

- I will not have side conversations – these are disruptive to the group and disrespectful to the person who is talking.

- I will not monopolize the conversation.

- I am willing to talk, but it is also ok if I decide not to talk if I do not feel like it.

- I will accept other group members without judgment.

- I will accept other members’ feelings, whether positive or negative.

- I will keep any discussion in the first person – always use “I.”

- I will give advice with care.

- I will listen carefully.

- I will not attend a meeting if under the influence of any non-prescribed drugs or alcohol.

As they say, rules are made to be broken, but some of the rules described above should be followed to the letter. As a facilitator you will develop strategies to help you remind the members about the ground rules that you and they have approved and implemented.

FUNDING

In general, a support group leader does not need very much money to run a meeting, especially if other agencies are able provide free meeting space or donate materials and other services. However, if a support group decides to expand its mission to provide more support groups or services to the community, a fundraising strategy should be well thought out and in place before the first group meeting takes place. Regardless of whether you decide to go large or small, a budget of possible expenses is recommended at the beginning of the planning stage.

NON-PROFIT STATUS

In order to receive grants an organization must apply for commercial or non-profit status with both the federal and the local state government. A support group or any advocacy organization will usually apply for non-profit status since they do not intend to make money from running a support group or advocacy organization. Applying for non-profit status is not too difficult, but the application process can be time-consuming and the day-to-day business operation has to be carefully managed. In addition, all of the revenue and expenses have to be carefully recorded and tax returns have to be filed with both the state and the federal government. If you decide to apply for non-profit status, check with your local, state or federal government to learn more about the application process.

Another option would be to find a non-profit agency that would be willing to act as your fiscal agent. Some agencies will act as your fiscal agent for free, but usually the agency will charge you a small percentage of the money you generate to provide this service. This is a very

continued on page 7

SUPPORT GROUP

continued from page 6

good option for many smaller advocacy groups because they will not have to devote precious time to the “business” of running a non-profit, and can therefore spend more time running and maintaining the support group.

BUDGET

The first step to managing money is to develop a budget. Try to estimate all the possible expenses, such as postage, copying, snacks, beverages, telephone or any other charges you might incur for the first year of operation – well before the first meeting. Once the expenses are estimated, you will have a better idea of the amount of fundraising you will need to keep the group running for one year. Many times, the expenses you budgeted for can be covered by volunteers and/or in-kind donations; but it is important to have a realistic picture of the support group expenses.

CASH

Raising cash for the support group operations is one of the easiest ways to run a support group if your expenses are minimal. There are many ways to generate cash to help with any of the support group costs.

CASH DONATIONS

At the beginning or end of the support group pass around a jar or can for donations. Don't be afraid to tell the members that certain items cost money and that there is an expectation that all the members help offset the expenses. Also, try asking the members to bring in food and beverages on a rotating basis or to be responsible for copying educational materials for the support group meetings.

GARAGE OR SIDEWALK SALES

One of the easiest ways to raise cash is to have a garage or sidewalk sale. Enlist the help of the support group members, their family and friends to help organize and staff the sale, and ask them to donate items for the sale. You would be surprised how much money a sidewalk sale can bring in to help offset support group expenses. Ask the support group members if they live in an area that is highly trafficked and see if they could host the sale.

DONATIONS FROM AGENCIES

As the saying goes – it never hurts to ask! Approach agencies or companies and ask them to donate services or food for the meeting. This may include bakery shops, coffee houses, local physicians' offices or any other group you think might be willing to support your group meetings.

DONATIONS FROM PHARMACEUTICALS

Pharmaceutical companies that sell hepatitis C drugs may be willing to help defray some of the expenses of a support group. Contact your local pharmaceutical representatives and ask if they would be willing to donate food, beverages or even speakers for your group. If you do not know the local representative, contact the national office for a referral to the local representative. They may also be able to provide speakers and materials for the meetings.

A word of caution: it is very important to make sure that information presented or given at the meeting is free of bias. Pharmaceutical representatives should always disclose their affiliations.

Resources:

- Guidestart – National Database of



**Executive Director
Editor-in-Chief,
HCSP Publications**
Alan Franciscus
alanfranciscus@hcvadvocate.org

Managing Editor, Webmaster
C.D. Mazoff, PhD
cdmazoff@hcvadvocate.org

Contributing Authors
Liz Highleyman
Lucinda K. Porter, RN, CCRC

Design and Production
Paula Fener
Blue Kangaroo Design
blueroodesign@aol.com

Contact information:
Hepatitis C Support Project
PO Box 427037
San Francisco, CA 94142-7037

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continued on page 9

RISK

continued from page 5

Most government agencies do not recommend routine testing for someone who falls into a high risk sexual category or someone having unprotected sex with an HCV infected steady partner. However, if you are worried about sexual transmission and would like to get tested, talk with your medical provider.

OCCUPATIONAL EXPOSURE

Health-care workers who come in contact with blood are at risk for getting hepatitis C and should be tested. However, the general rate of transmission is very low with about a 2% prevalence of hepatitis C in the healthcare industry. The most common cases of transmission occur in needle-sticks with hollow-bore needles. If you were exposed to any hepatitis C infected blood you should be tested.

GETTING TATTOOS AND PIERCINGS

If you ever received a tattoo or piercing in an unsafe setting you should be tested for hepatitis C. Most commercial tattoo parlors follow standard safety precautions and make sure that only new needles and a separate ink pot is used for each consumer. In other settings, such as in a prison or on the street, the chance of getting hepatitis C is higher.

ACUPUNCTURE

If you get acupuncture, the same safety precautions apply. Only new acupuncture needles should be used for each client, and your acupuncture provider should take safety precautions against spreading hepatitis C.

SHARING PERSONAL ITEMS

The transmission of hepatitis C from personal hygiene items is uncommon. But there is a possibility of getting hepatitis C from sharing toothbrushes, razors, clippers, and nail files. If you come in contact with a hepatitis C infected personal hygiene item get tested to be safe.

If you want more details about these risk factors, or need more information about hepatitis C, visit www.hcvadvocate.org



CHECK OUT THE LATEST FACTSHEETS

www.hcvadvocate.org

- *Alcohol and HCV*
- *HCV Disease Progression*
Cirrhosis
Fibrosis
Steatosis
- *HCV and Mental Health*
Overview of Depression
Depression: Self-Help Tips
HCV and Depression
Managing Depression
Mental Health Resources
- *Side Effect Management:*
Hemolytic Anemia
Mouth Sores
Nausea
Neutropenia
Rashes
Water
- *Advocates and Activists Needed!*
- *Dispelling Myths about HCV*
- *How to Tell Children They Have Hepatitis*
- *Interferon*

PERSISTENCE

continued from page 2

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SUPPORT GROUP

continued from page 7

- Non-profit Organizations –
<http://www.guidestar.org/>
 • Internet Non-Profit Center
<http://www.nonprofits.org/>

NEXT STEPS

Now that you have the information you need to start a support group or maintain an existing group, the next steps are up to you. HCV support groups can have a tremendous positive influence in people's lives. Almost every support group leader I have ever talked with has commented that leading a support group has been one of the most rewarding experiences of their lives. As well, the vast majority of people with hepatitis C who attend support group meetings have commented that the experience of attending a

support group and being supported by their peers is the one event in their lives that transformed them from ignorance, fear and anger to acceptance. This process also helps people develop strategies to move forward in their lives and to become better self-advocates.

I hope this series of articles has helped you to become a more effective support group leader. I look forward to working with many of you to improve the guide and bring more support and care to people affected by hepatitis C. Any suggestions to improve this guide or our services would be greatly appreciated. Please send comments to alanfranciscus@hcvadvocate.org



The Hepatitis C Support Project has launched a new campaign to help bring about more awareness of hepatitis C with a red awareness bracelet. Embossed on the bracelet is "for living positively. being well." To receive a bracelet just make a donation of \$10.00 or more. Proceeds from the bracelet will be used to develop a new web-based patient learning center. You can make a donation to the Hepatitis C Support Project by going to our web site www.hcvadvocate.org or you can use the form below.

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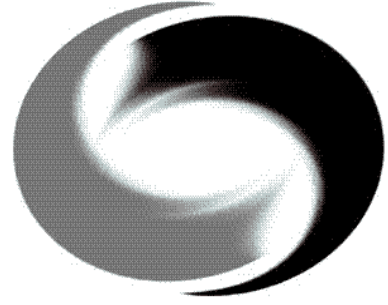
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P.O. Box 427037
San Francisco, CA
94142-7037