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FDA Panel Backs Adefovir for Hepatitis B

By **Liz Highleyman**
Contributing Editor

On August 6 the Antiviral Drugs Advisory Panel to the Food and Drug Administration (FDA) unanimously recommended approval of adefovir dipivoxil (Preveon) for the treatment of hepatitis B.

Adefovir – produced by Gilead Sciences of Foster City, California – is a nucleotide analog drug. Similar to nucleoside analogs such as lamivudine (3TC, Epivir), nucleotide analogs require one less processing step in the body.

Several studies have shown that adefovir significantly decreases hepatitis B virus (HBV) DNA viral load, reduces ALT levels, and may improve liver damage. The drug is active against both “wild-type” HBV and virus that is resistant to lamivudine. The drugs currently approved to treat hepatitis B are interferon and lamivudine.

A successor to adefovir called tenofovir (Viread) has also shown promising results in ongoing studies. As with HCV and HIV, combination therapy appears to be the most promising approach to HBV treatment. Adefovir was initially developed as a treatment for HIV disease, but proved too toxic to the kidneys and was denied FDA approval in 1999.

However, the drug was well tolerated in HBV trials, in which it was administered at much lower doses and for a shorter periods than in the earlier HIV studies. Nevertheless, some panel members expressed concern about kidney damage in people taking the drug longer than the 48 week duration examined in trials. Studies of longer-term use of adefovir are ongoing.

FDA advisory panels consider drugs for approval, looking at scientific data and sometimes hearing testimony from community advocates and people

affected by the disease in question. At the August hearing AIDS activist and playwright Larry Kramer – who is recovering from a liver transplant due to damage related to HBV – said he considered adefovir “a wonder drug” that “helped to save my life.” Although the FDA is not required to accept advisory panel recommendations, it does so in most cases. The FDA is expected to issue its final decision on adefovir approval by the end of September. Gilead representatives said the company is prepared to begin marketing the drug very soon after approval.

Is Adherence to HCV Therapy Important?

By **Alan Franciscus**
Editor-in-Chief

It is widely known and accepted that a person’s adherence to highly active antiretroviral therapy (HAART) is one of the most critical factors in attaining sufficient suppression of the HIV virus to avoid the development of HIV resistance. Regardless of how critical adherence to therapy is, factors associated with adherence remain poorly understood and methods of assessing adherence, including physician assessment and patient self-report, are infamous for being extremely unreliable.

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Chronic Hepatitis C and Skin Disorders

By Lucinda K. Porter, RN, CCRC

Chronic hepatitis C virus (HCV) infection mainly affects the liver. Hepatology, a branch of gastroenterology, is the medical subspecialty devoted to diseases of the liver.

Typically, patients with chronic HCV infection may be under the care of a gastroenterologist or hepatologist. HCV-related complications can affect an organ or body system other than the liver. This is referred to as an extrahepatic manifestation. There are a number of known HCV-related extrahepatic manifestations.

In general, these are uncommon and the vast majority of HCV-positive individuals may not develop these additional features.

Since a wide spectrum of skin disorders can be noted in patients with chronic HCV, it may be of interest to discuss this topic. The medical specialty that focuses on skin disorders is dermatology. This article will describe some of the known dermatological diseases that have been associated with HCV.

Pruritus – This is the medical term for itching. Pruritus may be caused by many factors. Two causes in the presence of HCV are dry skin and a build-up of bilirubin. The first cause is common, whereas bilirubin build-up is generally uncommon. High bilirubin levels can be associated with advanced liver disease and should be evaluated.

Cutaneous lichen planus – This skin disorder usually begins with pinhead-sized, shiny eruptions. Later these eruptions can become rough and scaly lesions. The rash is accompanied by itching and responds quite favorably to treatment.

Porphyria cutanea tarda (PCT) – The best description I have read for PCT comes from the web page commonly referred to as [Peppermint Patti's FAQs](#) (HepCBC - HEPV-L HEPATITIS C FAQ v5.6 May 24, 2002). "Porphyria cutanea tarda is a rare deficiency of a liver enzyme essential for cellular metabolism. The enzyme deficiency may cause sun-exposed skin to blister, ulcerate, turn dark, or bruise. Hair may increase on the forehead, cheeks, or forearms, and the urine may turn pink or brown. It now appears that

hepatitis C is the most common trigger of porphyria in people who are predisposed."

Necrotizing cutaneous vasculitis – In short, this is a skin disorder as a consequence of circulation problems, originating in the blood vessels. There are many factors that may cause this condition.

In addition to the dermatological diseases already mentioned, there are other extrahepatic manifestations that do not fit into the specialty of dermatology, but have dermatological symptoms. Examples of this are **lupus erythematosus** and **cryoglobulinemia**.

Lupus is an uncommon chronic autoimmune disease. Rash can be noted in patients with lupus, although this occurrence is less common in patients with coexisting lupus and chronic HCV.

Cryoglobulinemia is the abnormal accumulation of a protein in the blood. Cryoglobulinemia is symptomatic in 1% to 2% of patients with chronic HCV and rash is one of the clinical features. Please keep in mind that in general, rash occurs commonly and the presence of a rash is not cause for alarm.

However, if you do consult a dermatologist, it is worth mentioning that you have chronic HCV. The presence of itching and rash during treatment with interferon and ribavirin is fairly common.

Standard therapy for chronic HCV infection tends to dry out the skin and any mucus-lined organ or part of the body. Dry skin can be very itchy and sensitive. Scratching can lead to skin breakdown and increases the risk of infection.

Additionally, psoriasis, eczema, and other forms of rash can occur or worsen while undergoing HCV-related treatment. Some patients are sensitive to the sun, especially during treatment, resulting in additional dermatological problems.

Finally, injection site problems can arise that will affect the skin.

The following are tips can help prevent and minimize itching and rash:

Drink sufficient water. Dry, scaly, and itchy skin is a common complaint during treatment. From the outset, keep skin well hydrated.

HealthWise

Hepatitis C Maintenance Therapy

By Liz Highleyman
Contributing Editor

In most trials of new treatments for hepatitis C, researchers have looked at the “gold standard” endpoint of undetectable HCV RNA viral load six months after the end of therapy—sustained viral response, or SVR. Most studies have looked at results after 24 or 48 weeks of combination therapy with interferon plus ribavirin.

However, several studies have suggested that even people who do not achieve a sustained undetectable viral load—so called “non-responders,” partial responders, and relapsers—may still benefit from treatment, and that long-term, low-dose interferon maintenance therapy may be effective in delaying disease progression and liver damage.

For example, Dr. Mitch Shiffman and colleagues reported in the November 1999 issue of *Gastroenterology* that in a small study “maintenance interferon may prevent histological progression of chronic HCV in patients who remain viremic.” In this study, those receiving ongoing interferon therapy had lower HCV viral loads, decreased ALT levels, and reduced liver inflammation and fibrosis as determined by biopsy; when interferon was discontinued, fibrosis scores increased in one-third of the patients.

It makes good sense that even less-than-perfect antiviral treatment should help reduce liver disease progression. Because HCV multiplies in and destroys liver cells, any substantial reduction in virus replication should have a protective effect. In HIV disease—which in many ways has proved to be a model for HCV treatment—it has been shown that therapy that decreases viral load is beneficial, even if HIV RNA is not reduced to an undetectable level.

Although HCV maintenance therapy appears promising, it is not known whether the benefits of long-term interferon will outweigh the often-daunting side effects of treatment. Two large, currently enroll-

ing studies—HALT-C and COPILOT—are designed to shed light on this question. Both studies will attempt to determine whether long-term treatment with low-dose pegylated interferon can help delay the development of fibrosis and cirrhosis, slow the progression from compensated to decompensated cirrhosis, and reduce the chances of developing liver cancer (hepatocellular carcinoma). Ultimately, re-

searchers want to know whether maintenance therapy can reduce the need for liver transplants and keep people with chronic HCV alive longer—hopefully until more effective HCV treatments are developed.

The HALT-C study will test Roche’s Pegasys brand of pegylated interferon-alpha (currently undergoing priority approval review), while the COPILOT study will use Shering-Plough’s Peg-Intron brand of pegylated interferon-alpha (currently on the market). Both studies are for participants with existing fibrosis or cirrhosis who have not achieved a sustained, undetectable viral load using current interferon or interferon plus ribavirin regimens. Both trials will continue for four years.

HALT-C (the Hepatitis C Antiviral Long-Term Treatment Against Cirrhosis study), conducted by the National Institutes of Health, will include over 1,000 participants who have not achieved an SVR after at least twelve weeks of treatment with any type of interferon or interferon plus ribavirin. Participants will begin receiving full-dose Pegasys plus ribavirin once weekly for six months. Those who still have detectable HCV viral load at the end of six months will be randomized to received either half-dose Pegasys for an additional 3.5 years, or no treatment at all (the current standard of care for non-responders). People coinfecting with HIV or HBV are not eligible for this study.

COPILOT (the Colchicine versus Peg-Intron

“...several studies have suggested that even people who do not achieve a sustained undetectable viral load—so called “non-responders,” partial responders, and relapsers—may still benefit from treatment...”

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Maintenance

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Long-Term study), which is already well underway, will include about 1,000 participants who have not achieved an SVR after more than one treatment attempt using current regimens. Participants will be randomized to receive either low-dose maintenance Peg-Intron once weekly or an oral drug called colchicine twice daily; colchicine is an antifibrotic drug that has been shown to benefit people with liver damage related to heavy alcohol use. People with decompensated cirrhosis, liver failure, and HIV coinfection are not eligible. At the Digestive Disease Week meeting in May 2002 researchers presented preliminary COPILOT results for 250 participants who had received maintenance therapy for one year. Early data show that those receiving maintenance Peg-Intron had a reduction in HCV RNA, while the viral loads of those taking colchicine remained the same. In both HALT-C and COPILOT, HCV viral load and biochemical markers such as ALT will be measured throughout the study. Blood tests and ultrasound scans will be used to detect liver cancer. Biopsies will be performed at baseline (unless a recent biopsy result is available) and later during the course of the study to assess the degree of liver disease progression.

HALT-C is being conducted at eleven research sites across the United States: Worcester, MA; Boston; Farmington, CT; Dallas; St. Louis; Los Angeles; Long Beach, CA; Ann Arbor; Denver; Richmond, VA; and Bethesda, MD. There is no study site in the San Francisco Bay Area. For contact information, see

the web site at www.haltctrial.org.

COPILOT has some 100 study sites throughout the country, including San Francisco, Oakland, Boston, New York City, Chicago, Detroit, Dallas, Denver, Seattle, Pittsburgh, and Baltimore. For the site nearest you, contact study coordinator Jocelyn Leone at 617-632-1071.

A third new, currently recruiting maintenance trial called AEGIS aims to look at the safety and effectiveness of interferon-gamma (InterMune) in reducing fibrosis in people with chronic HCV who are at risk of developing complications of advanced liver disease. Participants will be randomized to receive one of two doses of InterMune or a placebo. There are over fifty AEGIS study sites in the U.S. and Canada including San Francisco, Los Angeles, Seattle, Houston, Minneapolis, Cincinnati, New York City, New Orleans, Atlanta, Miami, and Ontario, Canada. For the site near you call 866-618-4634 (toll free).

Clinical trials are the best way to advance the state of the art of HCV treatment. As these trials proceed, it should become clear whether interferon maintenance therapy can help reduce the long-term negative effects of HCV infection and improve patients' quality of life.

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Hepatitis C Support Project - A Tides Center Project

Healthwise

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Hypoallergenic lotions applied immediately following bathing can reduce dry skin. Add a couple of drops of lightweight oil to the lotion for extra protection. (Neutrogena sells an excellent body oil. Baby oil is another choice.)

Use sun protection. Use a product that has at least a SPF of 15. Hats, long sleeves, and avoiding sun exposure are important measures to consider.

Scratching leads to more itching and skin breakdown. Try to avoid scratching, especially with fingernails. Cold packs or pressure can be applied to areas that are itchy. If a rash develops, talk to your doctor about nonprescription and prescription hydrocortisone products. In some cases, anti-histamine may be recommended.

Try to avoid chapped lips by lubricating frequently, especially with a product that contains sunscreen. For cracked or very chapped lips, Clinique makes a product called "All About Lips." It is expensive, but effective and will last a long time. Another product is "Lansinoh" which was formulated for nursing mothers with cracked nipples. This or similar products can be purchased at a drugstore. (Editor's note: I have found Burt's Bees Lip Balm to be very effective treatment for chapped lips.)

Injection site redness is extremely common. Rotate injection sites. Report any signs of infection,

such as red lines running along your skin or an area that is swollen or hot to the touch.

Consult a dermatologist. An out-of-control skin problem can create a lot of misery. Do not dismiss a skin problem. The liver may be the largest internal organ, but the skin is the largest organ. It is also the first line of defense in the immune system.

Taking care of your skin is taking care of your whole body. I would be interested in hearing from those of you who have had a dermatological diagnosis, especially one that has not been mentioned in this article. In particular, please let me know if any of you have been diagnosed with granuloma annulare.

Please email me c/o HCSP: sfhepcat@pacbell.net. Please put attention L. Porter in the subject line of your email. If you do not have access to email, feel free to send a note via U.S. mail. The address is on this newsletter. Thank you Aijaz Ahmed, MD for editorial feedback for this article.

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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.

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Adherence

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Given the similarities of HIV and hepatitis C viral dynamics, one should not be surprised to learn that taking the medication is important in the management of HCV infection. In HIV adherence to antiretroviral therapy correlates with HIV treatment efficacy. Virologic treatment failure has been reported in 87% of patients with less than 80% medication adherence, 47% of those with 80% to 90% adherence, and 10% of those with greater than 90% adherence.

It is not clear however if the 80% level with HCV treatment adherence is as important as with HIV, hypertension and other diseases that have tested this threshold, but until those studies are done, patients with hepatitis C will hear a lot about 80/80/80 which is based upon the 80% threshold studied in HIV disease. 80/80/80 as a goal for adherence to hepatitis C therapy means 80% of the interferon dose, 80% of the ribavirin dose, for 80% of the recommended duration. Hopefully, future studies will focus on different adherence strategies such as 70/70/70 or say 60/60/60 to effectively answer HCV related adherence questions.

Currently, interferon and ribavirin do not become HCV resistant so the question of adherence is only important right now in treatment outcomes. However, the question of adherence will become even more important in the future with the development of anti-viral therapies such as HCV protease and helicase inhibitors that will have the potential to mutate and become HCV resistant.

Adherence to therapy, as defined above has demonstrated to have an important impact on treatment outcomes in hepatitis C, resulting in enhanced sustained virological response rates to both interferon alpha/ribavirin and pegylated interferon alpha/ribavirin. A number of predictors of adherence to HIV therapy have been recognized, and it is likely that many of these are also predictive to adherence in hepatitis C therapy also.

Reasons for increased adherence include the patient's belief in the treatment, provider's experience in using the therapy and managing the side effects, social support and adherence to follow-up

visits. Reasons that show a relationship with diminished adherence include active injection drug or alcohol use, current psychiatric disease and side effects to treatment. Reasons that have no effect on adherence include gender, race, history of injection drug use and stage of disease.

There have been some retrospective analyses looking at the impact of adherence on treatment outcomes and it is very clear that adherence to both interferon and ribavirin appears to make a difference in hepatitis C treatment outcomes. So what strategies can be implemented to help promote adherence? The first ones that come to mind are the importance of building a strong and open minded relationship between the medical provider and the patient which is nonjudgmental and non-threatening, providing appropriate education, encouraging use of support systems, regularly evaluating psychosocial status as well as proactive management of side effects to treatment.

Additionally it is important to customize the treatment regimen to meet the patient's lifestyle so as to make treatment part of, not all of, their lives. When feasible, patients should be encouraged to continue working while they are on therapy as work can help distract from the side effects and may increase their chances of staying on therapy.

One specific strategy now that pegylated interferon is available to help patients comply with their therapy is timing the pegylated interferon dose according to the patient's work schedule. For example, the pegylated interferon would be administered on a Thursday or Friday for those who work a Monday through Friday job. Other helpful strategies may include pill organizers for the ribavirin and anti-depressants etc., reminder phone calls from the doctor's office or directly observed therapy of the pegylated interferon injections.

Lastly, the person with hepatitis C has the most valuable tool available, themselves, to help make treatment outcomes successful by being proactive in the management and treatment of HCV by using all the resources available to them including family, peers, nurses, physicians assistants, nurse practitioners, case managers, pharmacists, psychologists and patient support programs.

Hepatitis C and Depression: Part 1

By Alan Franciscus
Editor-in-Chief

Clinical depression is a complex, debilitating disorder that affects more than 17 million adults in the United States each year. Unfortunately nearly two thirds fail to recognize their illness and get treatment.

Depression can strike anyone. People with serious illnesses such as hepatitis C may be at greater risk. Most patients with serious, progressive illness like hepatitis C confront a range of psychological challenges, including the prospect of real and anticipated losses, worsening quality of life, the fear of physical decline, and coping with uncertainty.

As with other serious illnesses such as cancer, heart disease, stroke or HIV, hepatitis C often can be accompanied by depression, an illness that can affect mind, mood, body and behavior. If left untreated, depression can increase the risk for suicide.

Persons with depression and hepatitis C must overcome the stigma associated with both illnesses. Despite the enormous advances in brain research in the past 20 years, the stigma of mental illness remains. Even people who have access to good health care often fail or refuse to recognize their depression and seek treatment.

Depression is a disease that affects how a person relates to people around them, and if left untreated, can cause relationships to deteriorate. Some people respond to depression by becoming angry and abusive to people who care about them, or children who depend on them. Others choose to treat their depression themselves with alcohol or street drugs, which can escalate the progression of hepatitis C while others turn to herbal remedies. Still others may isolate themselves from family and friends. We do not yet know all the causes of depression, but there seems to be biological and emotional factors that may increase the likelihood that an individual will develop a depressive disorder.

Depression can strike anyone. People with serious illnesses such as hepatitis C may be at greater risk.

Research over the past decade strongly suggest a genetic link to depressive disorders; depression can run in families. Bad life experiences and certain personality patterns such as difficulty handling stress, low self-esteem, or extreme pessimism about the future can increase the chances of becoming depressed. Additionally imbalances in certain body or brain chemicals or abnormal sleep behaviors may give rise to depression.

Prescription antidepressant medications are generally well tolerated and safe for people with hepatitis C. So, if you or someone you know with hepatitis C is exhibiting the pattern of depressive symptoms, seek out the services of a health care provider.

Some of the symptoms of depression could be related to hepatitis C, specific hepatitis related disorders, or medication side effects. They could just be a normal part of living. Everyone has bad days. Clinical depression is different though from normal ups and downs. Clinical depression is a serious health problem that affects the person.

In addition to feelings, it can change behavior, physical health and appearance, academic performance, social activity and the ability to handle everyday decisions and pressures.

Clinical depression is described as:

The symptoms last all day every day for at least two weeks.

The symptoms occur together during the same time period.

The symptoms cause daily events such as work, self-care and child care or social activities to be extremely difficult or impossible.

Taking the above characteristics into account, examine the symptoms listed below and see if they characterize you or someone you know living with hepatitis C:

Feelings of sadness, hopelessness

Loss of interest in formerly enjoyable activities, including sex

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Depression

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A sense that life is not worth living or that there is nothing to look forward to

Feelings of excessive guilt, or a feeling that one is a worthless person

Slowed or agitated movements (not in response to discomfort)

Recurrent thoughts of dying or of ending one's own life, with or without a specific plan

Significant, unintentional weight loss and decrease in appetite; or, less commonly, weight gain and increase in appetite

Insomnia or excessive sleeping

Fatigue and loss of energy

A diminished ability to think, concentrate, or make decisions

Physical symptoms of anxiety, including dry mouth, cramps, diarrhea, and sweating

Many therapies are available, but they must be carefully chosen by a trained professional, based on the particular circumstances of the patient and family. Recovery from depression takes time. Medications for depression can take several weeks to begin to work and should be combined with on-going psychotherapy. Not everyone responds to the medications in the same way. Dosing may need to be adjusted. Medications may need to be changed.

Combined treatment of psychotherapy and medication is the usual and preferred treatment of choice for depression. This is likely the most commonly used treatment for depression today and has proven very effective. Other mood disorders besides depression, such as various forms of manic-depression, also called bipolar disorder, may occur with hepatitis C. Bipolar disorder is characterized by mood swings, from depression to mania.

Mania is characterized by abnormally and persistently elevated (high) mood or irritability accompanied by at least three of the following symptoms:

Overly-inflated self-esteem

Decreased need for sleep

Increased talkativeness

Racing thoughts

Distractibility

Increase in goal-directed activity such as shopping

Physical agitation

Excessive involvement in risky behaviors or activities

It takes more than access to good medical care for persons living with hepatitis C to stay healthy. A positive outlook, determination and discipline are also required to deal with the extra stress: avoiding high-risk behaviors, keeping up with the latest scientific advances, adhering to challenging toxic treatment options, reshuffling schedules for doctor visits, and grieving over the diagnosis of being infectious. The causes of depression are still not clear. It may result from an underlying genetic predisposition triggered by stress, or by the side effects of medications, or by viruses like hepatitis C that can affect the brain.

Whatever its origins, depression can sap the energy needed to keep focused on the necessary task of staying healthy. Remember, depression is a treatable disorder of the brain. Depression can be treated in addition to whatever other illnesses a person might have, including hepatitis C.

If you or someone you know with hepatitis C is depressed, seek help from a health care professional who is experienced in treating persons with both diseases. Don't lose hope. Part II will focus on the association between depression and the disease, hepatitis C.

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Book Review: My Mom Has Hepatitis C

By Alan Franciscus
Editor-in-Chief

My Mom Has Hepatitis C, by Hedy Weinberg, Gregory T. Everson, Joy Chen and Shira Shump.

In the United States there are over four million people infected with the hepatitis C virus and each and every one of them in one way or another is involved with a child that feels the impact of their chronic illness.

Children throughout the country have parents, grandparents, aunts, uncles and family friends that are infected with hepatitis C and this book should be proudly and prominently displayed on their bookshelf.

My Mom Has Hepatitis C, an easy to understand story filled with 25 beautiful watercolor drawings, eloquently explains what a virus is, what the liver does in the body, how hepatitis C is transmitted, and why the person that they love that has hepatitis C is sometimes so tired that they are unable to join in family activities.

Chronic illness affects the entire family and so often as adults we dismiss the true impact that the uncertainties of a chronic illness have on the children in our busy and consumed lives.

This book sensitively addresses the child's grief, anger, fears, and questions in such an effective way that it not only gives them a wealth of easily understandable information about hepatitis C but also provides a wonderful platform for which they can ask an adult their unanswered questions. The story follows a family over about a year. Jake describes his family's experiences when Mom is diagnosed with hepatitis C.

At the beginning of the story, Jake visits Mom's doctor, where he learns factual information about the disease, hepatitis C. Mom has to have a liver biopsy; the procedure and recovery are covered well. During the story Mom experiences the fluctuations in the symptoms of hepatitis C, sometimes she feels just fine and can do all the family activities, other times she is too tired to do anything, or the drugs make her feel ill.

Throughout the book a series of family conversations provide emotional reassurance to both Jake and his sister. The children are sometimes hurt and upset

that Mom cannot do fun family things or on some days even make their lunches. At a support group Christmas party, the family meets Mr. Gomez, who is not doing well on his medications.

By the end of the book, "Mom" has cleared the virus and Mr. Gomez has had a liver transplant and is doing much better demonstrating how the authors cover the entire range of treatment options and hepatitis C outcomes in this book.

The book also includes a straightforward and simple glossary of terms along with a list of recommended readings.

Hedy Weinberg is an award-winning writer and essayist. Diagnosed with hepatitis C in 1993, she brings personal understanding of how patients feel and what they want and need to know.

Shira Shump, a specialist in early childhood education, works in the psychiatric day treatment program at the Square One Preschool.

Gregory T. Everson, MD, a nationally recognized expert on the treatment of hepatitis C, is Professor of Medicine and Director of Hepatology at the University of Colorado School of Medicine and author of the national best seller *Living With Hepatitis C: A Survivor's Guide*. Joy Chen was born in Taiwan. She is now a freelance artist in New York City.

Part II of this book review will be written by a ten year old child who like so many children has felt the impact of someone close to them having chronic hepatitis C. The review will include the perceptions that they had of hepatitis C prior to reading the book *My Mom Has Hepatitis C* as well as those they had after reading the book.

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