



The Future Burden of HCV



Alan Franciscus, Editor-in-Chief

There have been three major papers published about the future disease burden posed by hepatitis C: “Estimating Future Hepatitis C Morbidity, Mortality, and Costs in the United States,” by J.B. Wong and colleagues (2000); “Projecting Future Complications of Chronic Hepatitis C in the United States,” by G.L. Davis and colleagues (2003); and the recently published “Trends in Health Care Resource Use for Hepatitis C Virus Infection in the United States,” by W.C. Grant and colleagues (2005). The implications of the future disease burden of HCV is important because all three papers document and warn of the urgent need for identification, management and treatment of the HCV population to prevent an impending medical and societal catastrophe that will hit the United States in the near future. This series of articles will review the three publications listed above. Part 1 of the series will review the projections by J.B. Wong and colleagues.

J.B. Wong and colleagues¹ derived their projection from a computer simulated model by following the disease progression of a selected patient group over time. Liver histology (health), presence or absence of HCV viral load, decompensated cirrhosis, hepatocellular carcinoma (HCC),

or liver transplantation were recorded as health states. The progression of these states over time from mild hepatitis to moderate hepatitis to a cirrhotic stage was recorded and used for the computer model.

In this model, the likelihood of progression to more severe states was based on probabilities derived from a review of literature available at the time. Expert opinion was used when data wasn’t available from published literature. The model was also adjusted to include the states of health for those groups with known and unknown hepatitis C infection. The authors assumed that the patients who did not know that they were infected with hepatitis C would not incur any medical costs until they developed hepatocellular carcinoma (HCC) or decompensated cirrhosis.

The number of people infected with hepatitis C used in this computer simulation was based on the prevalence of HCV obtained from the NHANES III survey. It is important to remember that the NHANES III survey did not include certain high risk populations (incarcerated, homeless, patients in hospitals, nursing home residents and active-duty military personnel). The exclusion of these populations could

IN THIS ISSUE



Healthwise:

Living with the Label of HCV.....3

Liver Transplantation:

Part 2.....5

Treatment Success.....7

lead to an underestimation of the true burden of care.

It was found that in 1991 there were 25,429 deaths as the result of chronic liver disease and cirrhosis. From 1979 to 1988, 36% to 41% of the deaths related to chronic liver disease were the result of hepatitis C, so the authors estimated 9154 to 10,426 deaths were related to HCV. In order to provide a conservative estimate, the authors used 8,000 HCV-related deaths for their model.

Cirrhosis, hepatocellular carcinoma (HCC), liver transplantation, alcohol, persistently normal liver enzymes, and death as the result of other causes were also factored into their analyses.

Of interest, the authors examined the use of alcohol on the disease progression of hepatitis C. It is well known that heavy alcohol consumption increases the rate of disease progression in

continued on page 2

BURDEN

continued from page 1

people with hepatitis C. Based on several factors the authors estimated that if alcohol intake of ≥ 50 g/day could be eliminated then the annual likelihood of disease progression would be reduced by 15%.

The medical cost prediction was based on medications, laboratory tests, office visits, and hospitalizations in 1995 dollars and adjusted to 1999 dollars based on the medical care component of the Consumer Price index. A separate analysis was included of the indirect costs associated with disability and death.

PREDICTIONS

The authors predicted 181,300 HCV-related deaths from 2010 to 2019, with another 27,200 deaths from HCV-related HCC. Direct medical care costs for the period from 2010 to 2019 would be \$10.7 billion.

A separate analysis to estimate the upper level of the future disease burden was performed. It was modeled on the assumptions that patients with normal transaminase levels progressed at a higher rate than currently believed at that time, and that half the population with HCV ingested more than 50 g/day of alcohol. Based on these assumptions the authors estimated that there would be 225,800 HCV-related deaths with another 34,990 deaths from HCV-related HCC, and that direct medical care costs would reach \$14.1 billion during the ten year period.

Another analysis was used to estimate the lower level of dis-

ease burden. Excluding other causes of death unrelated to HCV that may arise from complications resulting from the mode of transmission (injection drug use and transfusions), it was estimated that there would be at least 105,700 HCV-related deaths and another 17,700 deaths from HCV-related HCC. The direct medication care costs in this analysis would exceed \$6.7 billion dollars in the period from 2010 to 2019.

The predictions for indirect costs associated with HCV are projected to reach \$54.2 billion in societal costs resulting from the premature deaths of those younger than 65, while the costs of disability related to decompensated cirrhosis would be \$21.3 billion.

The authors concluded that the deaths related to HCV will continue to increase over the next 10 to 20 years, and that their results “confirmed that hepatitis C may be an awakening giant.” They believe that “there is some urgency for action because hepatitis C is frequently asymptomatic until cirrhosis develops, at which time treatment is less effective.”

THE BOTTOM LINE:

The burden of care for HCV from 2010 to 2019 (medium):

- HCV related deaths = 208,500 HCV related deaths
- Direct medical cost = \$54.2 billion.
- Indirect costs = \$10.7 billion
- Disability costs = \$21.3 billion

Factors that could increase the disease burden:

- The 800,000 to 1.2 million more people not counted in

the NHANES III survey and the above study.

- The increased costs for HCV medicines, lab work, liver transplantation (transplant and post transplant costs).
- Shortage of donated livers which would require more medical costs to manage the person who develops decompensated cirrhosis.

Factors that could decrease the future disease burden:

- Identification and disease management of those (greater than 70%) who do not know that they are infected with HCV.
- Medical management of all persons with HCV to educate about lifestyle changes (reducing alcohol consumption, nutrition and exercise) and treatment if needed.
- Higher treatment response rates of pegylated interferon plus ribavirin therapy.

Part 2 of this series will review the data from the G.L. Davis and colleagues publication “Project Future Complications of Chronic Hepatitis C in the United States.”

Reference:

¹John B. Wong, MD, Geraldine M. McQuillan, PhD, John G. McHutchison, MD, and Thierry Poynard, MD. “Estimating Future Hepatitis C Morbidity, Mortality, and Costs in the United States.” *American Journal of Public Health.* 2000; 90, No. 10, 1562-1569.



HealthWise:

Living with the Label of HCV



Lucinda K. Porter, RN, CCRC

We live in a label-conscious society. Clothes, sports apparel, handbags, even our eyewear sports some sort of label. But what happens if *you* wear a label? What would you say if you were asked, “Who are you?” Take a moment and answer that question. Make a list of everything you are. You might answer, “I am a mother or a father; a son or a daughter; a sister or brother; a spouse, a partner, or a friend; a Buddhist, a Hindu, a Methodist, a Jew; a computer programmer; a carpenter; a dentist; a hepatitis C patient. If you labeled yourself as a hepatitis C patient, this article was written for you.

Labels define us. They tell others who we are. They tell us about our values and beliefs. Some labels describe our relationships and identify the people in our lives. Some labels describe what we do, such as an occupation or hobby. Declaring our religious preferences gives insight into our spiritual beliefs. However, being a hepatitis C patient is quite different from being a parent or a nurse. Saying, “I am a hepatitis C patient” defines us. It says, “I am sick.” It ties us to a state of disease rather than to a state of health.

It is easy to identify with an illness. Hepatitis C (HCV) can be all encompassing at times. Sometimes it is in the foreground; other times in the background. Nevertheless, it is always there. However, living with HCV is not the same as being an HCV patient.

To some of you, this may seem like hair splitting; but before you dismiss this idea, try an experiment. If you imagine or describe yourself as an HCV patient, try substituting words and images that are more powerful. Imagine yourself as strong and calm. Say to yourself, “I am living with hepatitis C, but I am much more than this.” How does this feel as compared to “I am a hepatitis C patient.”

There is a healthy side of identifying with an illness. We can’t let go of something without first accepting it. An important part of moving through HCV is to acknowledge it, assess it and recognize the meaning of it. In *Man’s Search for Meaning*, Viktor Frankl notes, “seriously ill people are often not given the opportuni-

ty to suffer bravely, and thereby retain some dignity.” He goes on to say that when we tell people to cheer up and be optimistic, the ill are made to feel ashamed of their pain and unhappiness.

Frankl is imminently qualified to speak about the human search for meaning. His contributions to modern psychotherapy were forged by his experiences as a Holocaust survivor. Frankl spent three years in Nazi death camps, including Auschwitz. The Nazis slaughtered his family. Frankl endured more than most of us. He did not let pain, torture, or grief interfere with living a life filled with compassion and integrity.

The problem occurs when a line is crossed between finding the meaning in the illness versus letting the illness define you. What does having HCV mean to you? Does it mean a lifetime of fatigue? Loss of opportunity? Perhaps HCV is a wake-up call, motivating you to make lifestyle choices that bring renewed vigor. Maybe you appreciate life more because of HCV.

A Buddhist principle is that our energy follows our attention. If we focus on illness, that is where our energy will go. Illness can takeover, robbing meaning and joy from our lives. The entire self becomes defined by illness.

If any of this rings true for you, consider an attitude adjustment. Try to live in the positive rather than the negative side of life. Optimism is not wishful thinking. If an earthquake is rocking the world around, it is foolhardy to act as if you are on steady ground. The wise thing is to protect yourself and others, and to try to minimize the damage. Once the shaking stops, assess the damage and make a plan for recovering. The optimist looks at what is left and plans around this. The pessimist looks at what is gone and in doing so, lives in the loss and pain.

Here are some tips on how to cultivate a healthy attitude:

- Be honest and realistic. Do not build your attitude on thinking things are worse than they are or

continued on page 4

LABELS

continued from page 3

better than they are.

- Make sure you know the truth. Get accurate information about HCV. Some people think that HCV is an automatic death sentence. This is not true. The majority will die *with* HCV, not *of* HCV.

- Stay in the present. Don't make things worse by imagining a future with pain, disability or loss.

- Accept your situation, but don't overly identify with it. HCV may be a part of your life, but that doesn't mean it should control your life.

- Maintain your perspective. Focus your attention on something that brings peace, joy, laughter and meaning.

- Watch your words. If you hear

yourself talking negatively, substitute positive phrases. Say, "I will find a way to live with HCV" rather than "HCV is ruining my life."

- Try to relax. Tell yourself that difficult moments will pass.

- Visualize health, not illness. Visualization is a powerful tool for self-transformation.

- Practice gratitude. Make it a habit to find things for which you are grateful.

- Learn what you can control and what you cannot. There are things you cannot control, such as the fact that you have HCV. However, there are things you can control, such as your attitude and what you say to yourself about having HCV.

- Learn from HCV. Ask yourself what HCV can teach you about living.

- Get support. Being with others

who are dealing with the same issues can bring encouragement and hope. See if there is an HCV support group in your area.

- Help others. When it comes to stepping outside of ourselves, probably nothing works as well as reaching out to others who are also struggling.

In Minding the Body, Mending the Mind, Joan Borysenko writes: "Adversity is the crucible in which the spirit is forged." A similar expression is "that which does not kill us, makes us stronger." Hepatitis C is an invitation to cherish each day, to live fearlessly and fully. It is the opportunity to wear a new label.

Next month: "Stigma - Living with the Labels of Others"



Help Us Reach More People with Hepatitis C!
SUPPORT US THROUGH EITHER A PAID SUBSCRIPTION OR DONATION

YES! I'd like to subscribe

\$20 one year—12 issues

\$10 one year—12 issues
 (for those with fixed incomes)

Renewal

NAME _____

ADDRESS _____

CITY _____

STATE _____ ZIP _____

YES! I'd like to make a tax deductible donation

\$10 \$25

\$100 other

Please make checks payable to: HCSP/The Tides Center

Please mail form to:

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



The Hepatitis C Support Project does not share its mailing list with any individual or organization. All subscribers' names and addresses are strictly confidential

Liver Transplantation: *Part 2*



Liz Highleyman

The last issue of HCV Advocate discussed the lack of available livers for transplantation and new techniques – including split liver and living donor transplants – that could help relieve the shortage. This article looks at HCV recurrence after liver transplantation in people with hepatitis C.

A large body of research has shown that in untreated liver transplant recipients with chronic hepatitis C, HCV almost always infects the new liver within weeks, and sometimes in as little as 24 hours. Some – but not all – studies suggest that patients with hepatitis C fare less well after liver transplantation than HCV negative individuals. As reported in the June 27, 2004 issue of *Transplantation*, for example, Ergun Velidedeoglu, MD, and colleagues analyzed more than 13,000 patients in the United Network for Organ Sharing (UNOS) database, 57% of whom had hepatitis C. They found that the five-year survival rate was 74.6% for HCV positive patients, compared with 83.5% for HCV negative individuals. Indeed, liver failure due to recurrent hepatitis C is a leading cause of death among liver transplant recipients.

Some experts have gone so far as to describe post-transplant HCV recurrence as “universal,” but here again, data are mixed. It is evident that many patients who achieve sustained virological response (SVR) with interferon-based therapy prior to transplantation still experience viral recurrence. This

indicates that a low level of HCV genetic material remains in the body waiting to “seed” the new liver, even if it is undetectable using standard tests. As reported in the January 2006 *Journal of Hepatology*, for example, Martina Gerotto and colleagues found that 26 of 208 hepatitis C patients (12.5%) who had repeatedly undetectable HCV viral load at the end of treatment using common polymerase chain reaction (PCR) technology still had residual detectable HCV RNA using a more sensitive transcription-mediated amplification (TMA) assay.

Based on research to date, the natural history and prognosis for post-transplant HCV recurrence remain uncertain, as studies have yielded conflicting data. In a forum on liver transplantation and hepatitis C in the April 2005 *Journal of Hepatology*, Greg Everson, MD, described three patterns of recurrence. While a small proportion of patients experience severe cholestatic hepatitis, recurrent HCV infection most often becomes chronic and evolves in a manner similar to that seen in nontransplant patients – but typically more rapidly and with a higher viral load set point. Everson estimated that approximately 25% of transplant recipients develop cirrhosis in the grafted liver within 5-10 years (compared with 10-40 years in nontransplant patients). Various studies have revealed a number of factors associated with rapid fibrosis progression, including genotype 1 (especially 1b) or 4 HCV, non-Caucasian race/ethnicity, donor and recipient age,

and ischemia time (period without oxygen between removal from the donor and insertion into the recipient); surprisingly, female sex has also been linked to worse progression, since among nontransplant patients, women usually fare better than men.

Accelerated HCV-related disease progression is thought to be the result of impaired immunity due to immunosuppressive drugs used to prevent organ rejection. Some studies have shown that administration of a large dose (bolus) of corticosteroids to treat acute rejection can worsen HCV disease severity. Conversely, other research suggests that avoiding corticosteroids altogether may be beneficial. On the other hand, there is also evidence that rapid reduction of corticosteroid dosages may exacerbate HCV disease progression. Data on the risks and benefits of other types of immunosuppressive therapy, including mycophenolate mofetil and azathioprine, has also been inconsistent. Thus, for now, the best approach remains open to debate. According to Everson, it is likely that “the interplay between the immune system and the virus,” along with recipient genetic factors and the quality of the liver graft, influences post-transplant outcomes. Recent experience has shown that HIV positive transplant recipients have survival rates similar to those seen among HIV negative recipients, as long as they have well-controlled (ideally undetectable)

continued on page 6

TRANSPLANTATION

continued from page 5

HIV and relatively intact immune systems (e.g., CD4 cell counts of at least 200 cells/mm³); however, HIV/HCV coinfecting patients fare more poorly than HIV positive people receiving liver transplants for other reasons.

The good news is that some patients experience minimal liver disease progression several years after transplantation. Certain individuals show no evidence of HCV recurrence or damage to the new liver even after 10 years. Because hepatitis C normally progresses so slowly, even if fibrosis advances at a similar or moderately accelerated rate in original and newly transplanted livers, this can buy recipients 10-20 or more years of good liver function and the associated improvement in quality of life.

While data on the ubiquity of post-transplant HCV recurrence may appear grim, there is ample evidence that the lower one's HCV viral load at the time of transplantation, the less chance of recurrence – and the less chance of severe disease and rapid progression if the virus does come back. In some studies, more than half of patients achieving SVR with pre-transplant interferon-based therapy did not experience HCV recurrence. Yet individuals awaiting transplants typically are quite ill and often have difficulty tolerating the side effects of interferon and/or ribavirin. Looking at the debate over whether to treat hepatitis C patients on the liver waiting list, Everson noted that while tolerability of therapy remains a serious concern, it is often worth pursuing since pretransplant treatment currently prevents post-transplant recurrence in as many as 25% of cases. And

even therapy that does not eradicate the virus may still help prevent fibrosis progression.

If pretransplant treatment is the first line of defense, commencing hepatitis C therapy immediately after transplantation – a sort of post-exposure prophylaxis – may also help prevent recurrence by inhibiting the rapid viral replication that typically occurs in the hours and days following the operation. Though post-transplant SVR rates are lower than those seen in non-transplant patients – largely due to the inability to tolerate therapy – roughly 25% achieve long-term undetectable HCV RNA. Here, too, interferon may help stave off liver damage even if viral load remains detectable. But, as Isabelle Morard and Francesco Negro, MD, explained in the *Journal of Hepatology* forum, post-transplant disease progression varies widely among patients, and it is not clear whether immediate preemptive therapy – which would subject some patients unnecessarily to adverse side effects – is preferable to waiting until evidence of damage to the new liver becomes apparent. (For more on post-transplant hepatitis C treatment, see the September 2004 *HCV Advocate*.)

In addition to hepatitis C therapy, liver selection and transplant procedures can also make a difference. Since HCV patients are at greater risk for poor post-transplant outcomes, they may derive more benefit from receiving livers from younger donors. As Yasuhiko Sugawara, MD, and Masatoshi Makuuchi, MD, discussed in the *Journal of Hepatology* forum, some research indicates that HCV patients experience faster viral recurrence and more severe and rapid liver disease progression after living donor, compared with cadaver donor, transplants. The reasons for this

phenomenon are not yet known, but may be related to heightened HCV replication as the liver section from a living donor regenerates in the recipient. On the other hand, success rates for living donor transplants have increased in recent years, and the apparent detriment seen in earlier studies may have been attributable to lack of experience with the procedure.

As treatment for hepatitis C improves – ideally becoming both easier to tolerate and more effective at suppressing the virus – more HCV positive individuals may truly eradicate the virus before or immediately after transplantation, thus minimizing the risk that HCV will invade their new livers.

References:

- Berenguer, M. What determines the natural history of recurrent hepatitis C after liver transplantation? *Journal of Hepatology* 42(4): 448-456. April 2005.
- Everson, G. Should we treat patients with chronic hepatitis C on the waiting list? *Journal of Hepatology* 42(4): 456-462. April 2005.
- Gerotto, M. et al. Hepatitis C minimal residual viremia (MRV) detected by TMA at the end of Peg-IFN plus ribavirin therapy predicts post-treatment relapse. *Journal of Hepatology* 44(1): 83-87. January 2006.
- Morard, I. and Negro F. How should we treat recurrent hepatitis C after liver transplantation? *Journal of Hepatology* 42(4): 462-468. April 2005.
- Sugawara, Y. and Makuuchi M. Should living donor liver transplantation be offered to patients with hepatitis C virus cirrhosis? *Journal of Hepatology* 42(4): 472-475. April 2005.
- Velidedeoglu, E. et al. Factors differentially correlated with the outcome of liver transplantation in HCV + and HCV- recipients. *Transplantation* 77(12): 1834-1842. June 2004.



Treatment Success



Alan Franciscus, Editor-in-Chief

In this article, I will briefly describe my treatment experiences and my general feelings about what it means (to me) to be hepatitis C virus free. First of all, I am not recommending treatment for anyone. Not everyone should be treated and treatment is not for everyone. Treatment decisions should be made after gathering as much information as possible and weighing the pros and cons as they apply to each person. No one should rush into it because I or someone else you know has had a successful treatment outcome. The ultimate decision is between you and your medical provider. Below are my thoughts, experiences and feelings, but as the saying goes “It don’t make it so.”

In 1994 I was feeling the symptoms of hepatitis C – moderate to severe fatigue and other mild flu-like symptoms, but I didn’t know the cause. I went through many tests over a two-year period and no one could medically explain my fatigue or the other symptoms. That was really frustrating because I thought I had this bizarre disease that no one knew about. I’ll never forget the day that I had a doctor’s appointment with my new primary care physician. After I explained my symptoms, he ordered blood work, including a hepatitis C antibody test. I had never heard of hepatitis C, but luckily, he had. A week or so later I received my test results – I had hepatitis C. Of course, I was devastated by the news, but in some ways, it was a relief to finally find out what was

causing the severe fatigue.

About 3 months after I was diagnosed I decided to try treatment with non-pegylated interferon monotherapy (3 injections a week). I was on treatment for a year, but I did not achieve an SVR. In fact, during treatment my viral load never reached a point where it was undetectable. I also had many side effects. The first evening I had severe chills and a fever. After a while, the physical side effects such as the flu-like symptoms seemed to diminish somewhat – at least to the point where I could handle them. However, the psychological side effects (anger and depression) slowly became worse. After about three months, it was decided that I should start on anti-depressant therapy. I also started to meditate regularly and between the meditation and the antidepressants, I felt better and was able to finish treatment.

Looking back, I wished that I had been more educated about the chances for a successful treatment with monotherapy because I am not sure I would have tried it. The data about the treatment at that time showed that I only had a 9% chance of achieving an SVR. However, even though it didn’t eradicate the virus, treatment did help with the fatigue, for a while at least.

But eventually the fatigue returned so in 1999 I decided to try high daily dosing of non-pegylated interferon monotherapy. At first, there was a dramatic reduction in

HCSP GUIDES

The Hepatitis C Support Project has published various publications in our “Guide” series. The Guides are available on our Web site www.hcvadvocate.org

A Guide to Understanding and Managing Fatigue – this Guide provides a comprehensive overview of the causes of fatigue as well as simple tips to help manage this often debilitating symptom of HCV.

Management of Hepatitis C by the Primary Care Provider: Monitoring Guidelines. This Guide gives the medical provider with the necessary information to help identify and manage hepatitis C positive individuals. (Available in English and Spanish.)

A Guide to Hepatitis and Disability is one of the most comprehensive documents available on how to prepare and file for social security disability. There is additional information on commercial disability insurance, and health insurance.

First Steps for the Newly Diagnosed is an HCSP guide designed to help the person who is newly diagnosed with the medical aspects of HCV including a lab tracker, questions to ask your medical provider and more.

Women and Hepatitis C: An HCSP Guide, by Lucinda Porter, RN, discusses the issues around hepatitis C and how they differ in women.

The Guides are downloadable in copy-ready format. Permission to reprint is granted and encouraged with credit to the hepatitis C Support Project.

continued on page 8

SUCCESS

continued from page 7

HCV RNA (viral load) levels, but after 10 months, the virus came back so I stopped therapy. Again, my energy level dramatically improved, but over the next couple of years the extreme fatigue as well as some of the other symptoms like brain fog, lack of concentration, difficulty with mental retention and other annoying symptoms came back. Surprisingly, the side effects of high daily dosing didn't seem that much worse than when I took interferon three times a week. I think this might be because of what I learned the first time about managing side effects. I also started on anti-depressants a couple of months before I started therapy.

In 2002, I decided that I wanted to try pegylated interferon plus ribavirin therapy. I began towards the end of 2002 and my viral load began to drop, but not as quickly as I had hoped. After about 3 months, I had a 2-log drop in HCV RNA, so I was well on my way. At about the 9-month mark, I began to do some

research on treatment duration for people who had characteristics similar to me – older, genotype 1, high viral load, had HCV for a long period of time. Most data suggested that I should be treated for a longer period of time. After consulting with my doctor, it was decided to extend the treatment from 48 weeks to 72 weeks.

The side effects of pegylated interferon plus ribavirin were much less than the side effects I experienced while on the first two courses of therapy. In fact the morning after the first shot I felt so good that I wondered if I really did take the drug at all! That slowly changed and by the third month, the side effects became worse, but I was able to manage them fairly effectively. My blood chemistries looked pretty good throughout therapy, except that eventually I developed anemia. I am VERY fortunate to have insurance to cover all of my medications including erythropoietin (EPO). Epo worked wonders for the anemia and the related fatigue, allowing me to finish treatment.

One of the strategies I put into place was to have a good support system well before I started therapy. I relied a lot on my friends and family for support. The side effects were managed aggressively with early intervention to prevent them from becoming worse. I am very fortunate that I love the work that I do for the Hepatitis C Support Project. This really helped to distract me from the side effects. Don't get me wrong – it wasn't a walk in the park, especially since I was trying to run a non-profit agency. I traveled extensively during this period and logged about 100,000 air miles. However, I made it through, and it was well worth it.

It has been well over a year since I finished treatment, and I am still negative for the hepatitis C virus. This was not totally unexpected, but, as most people who are treated know, it wasn't totally expected either. Ever since the news, I have been thinking about what successful treatment and getting rid of the virus means for me.

continued on page 9

ILLINOIS DONOR REGISTRY:

It is easy to be a potential organ donor in the state of Illinois. Like many other states, Illinois maintains an organ and tissue donation registry. Beginning in 2006, potential donors can give their own consent. Pre-death authorization on the Organ Donor Registry will be legally binding and cannot be overridden by family wishes. You can always remove your name if you change your mind.

Anyone of any age can be an organ donor. About 15% of Illinois organ donors are over age 60. About half of corneal donors are over age 50. A young father is alive because of a new liver. His donor was 79.

Interested Illinois residents should do the following:

1. Join the Organ Donor Registry. You may do this by toll free phone at (800) 210-2106, online at www.cyberdriveillinois.com (Click on "Life Goes On: Organ and Tissue Donor Program"), or by mail at:
Secretary of State Jesse White
Organ/Tissue Donor Program
2701 S. Dirksen Pkwy
Springfield, IL 62723

2. Illinois residents who previously indicated their wish to be organ donors will need to re-register for the new registry.

For more information about the Illinois Organ Donor Registry: www.lifegoeson.com/home.html

SUCCESS

continued from page 8

First, it was fantastic news that the virus was out of my body. I only wish that everyone with hepatitis C could experience the feeling of beating HCV. It took awhile but the side effects gradually went away and I began to feel better. The hepatitis C symptoms that I had been experiencing for so long also started to get better. Slowly, my energy returned. In fact, my energy level is better than it has been in 10 years, and most of those hepatitis C flu-like symptoms have gone away. Best of all I now feel clear-headed and I feel a general calmness that I haven't experienced in years. This is a big difference from the way I felt before treatment.

Many issues come up after successful treatment. One of the most frequent questions people ask is if they can drink alcohol again. For me, this was a no brainer. I'm in recovery so drinking again is not an option. Unfortunately, there is no data on whether someone who achieves an SVR can drink alcohol. Until there is significant data on this issue, the general recommendation is to abstain from alcohol.

Another big issue is blood. Should I cover my wounds or take precautions if blood is present? Definitely. Always be cautious where there is any blood present whether it's yours or someone else's.

Feeling infectious is probably one of the strongest emotions that almost everyone with hepatitis C feels especially after being newly diagnosed. I used to be so concerned when my blood was present that I would needlessly become almost hysterical about it. I still believe and practice safety precautions in the presence of blood. But there is a big difference between com-

mon safety precautions as opposed to knowing that you have infected blood that could potentially infect another person.


Do I feel like I will live longer without hepatitis C? I do feel that I will live a longer life, but more importantly, I feel that I will not have to suffer with the severe fatigue or the other symptoms of hepatitis C. For me, the decreased quality of life and suffering was worse than the idea that I might die from hepatitis C.

My advice to someone who is thinking about treatment is to research hepatitis C treatment medications. If you decide to start treatment, set up personal and medical support well in advance of starting treatment. Another strategy that helped was finding something that I enjoyed, which distracted me from the side effects. Probably the best advice I can give is to take treatment one day at a time.

"But let us remember, we cannot wait for others to tell our stories. We must remain visible, vocal, and unified."

– Yvette Sangster and Ed Kramer





Treatment of Chronic Hepatitis C: Impact on Natural History

Emmet B. Keeffe, MD, MACP

Professor of Medicine,
Chief of Hepatology,
Co-Director, Liver Transplant Program,
Stanford University Medical Center,
Stanford, California

Now available at www.hcvadvocate.org



**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

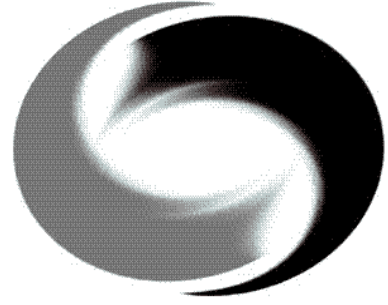
Contact information:
Hepatitis C Support Project
PO Box 427037
San Francisco, CA 94142-7037

The HCV Advocate offers information about various forms of intervention in order to serve our community. By providing information about any form of medication, treatment, therapy or diet we are neither promoting nor recommending use, but simply offering information in the belief that the best decision is an educated one.

Reprint permission is granted and encouraged with credit to the Hepatitis C Support Project.

© 2006
Hepatitis C Support Project

For Living Positively. Being Well.



www.hcvadvocate.org

HCSP

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