Issue Number Two

Fall 2003

Hepatitis C Review

NATAP ❖ 580 Broadway Suite 1010 ❖ New York NY 10012 ❖ 212 -219- 0106 ❖1- 888- 26 NATAP ❖ email: info@natap.org ❖ www.natap.org

Diagnostic Evaluation of Patients with Hepatitis C

Ira M. Jacobson, M.D.

Ira M. Jacobson, M.D., Vincent Astor Professor of Clinical Medicine Chief, Division of Gastroenterology and Hepatology Medical Director, Center for the Study of Hepatitis C Weill Medical College of Cornell University

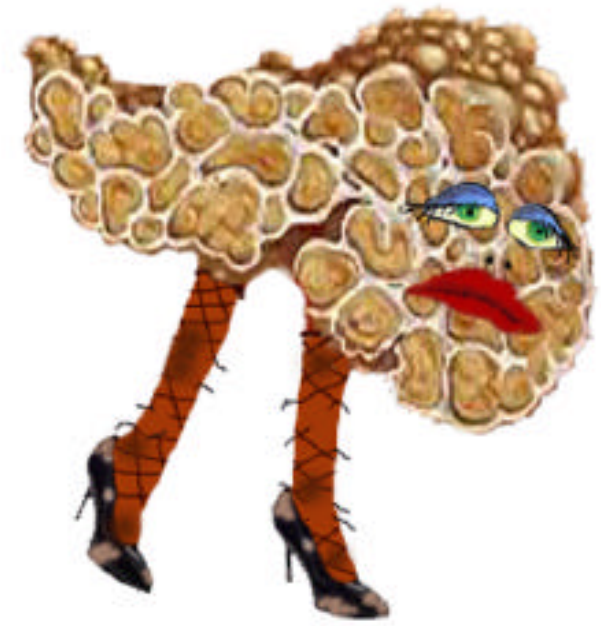
The approach to patients who have been diagnosed with hepatitis C consists of a combination of history-taking, physical examination, laboratory work, and, in most patients, biopsy of the liver. The culmination of this evaluation is careful consideration of the role of antiviral therapy in the patient's care. It is helpful for the patient to understand that, as in all chronic liver diseases, the ultimate concern in chronic hepatitis C is that over the years progressively greater amounts of scar tissue can be deposited in the liver, with cirrhosis representing the state of advanced scarring in which complications impairing health, or even endangering life, can eventually ensue.

Underlying the extensive interaction between physician and patient is the uniqueness of each patient in terms of his or her duration of infection, symptoms, concurrent risk factors for other liver disease (e.g. alcohol consumption), concomitant liver disease (e.g. fatty liver disease), laboratory results, viral load and genotype, liver biopsy results, occupation, family circumstances, and, not least, the patient's "mindset". Some patients are eager to do anything possible to eliminate their infections even if their liver damage is mild and of longstanding duration, while others can live comfortably with the slight uncertainty about their potential progression in the next several years and await future therapeutic developments.

A cornerstone of the patient's history is the determination of the likely duration of infection. Frequently, this entails discussion about "high-risk behaviors" (intravenous drug use, intranasal cocaine use) in which the patient may have engaged in the past. Patients should be reassured that such questions are nonjudgemental and intended simply to place the infection in a temporary context. With such information,

Still engaging in Risky Behavior?

You could be as sorry as Sarah-rossis.



IN THIS ISSUE:

Published and Edited by: Jules Levin, Executive Director, NATAP
Managing Editor: Dawn Schuk, MHA
Layout and Production: Jessie Gibson

NATAP NATIONAL AIDS TREATMENT ADVOCACY PROJECT
EDUCATING COMMUNITIES ABOUT HIV AND HEPATITIS

combined with the findings of laboratory tests and liver biopsy, the physician can ultimately come to meaningful conclusions about the rate with which the patient's liver disease is progressing. For example, thirty years of infection resulting in minimal liver scarring suggests a slow rate of progressive scarring while ten years of infection in a patient with substantial scarring is of greater concern and more urgently warrants antiviral therapy.

Alcohol consumption is another matter that requires sensitive inquiry on the physician's part. Many patients consulting a liver specialist for hepatitis C already have the misconception that it is exclusively alcohol that is associated with chronic liver disease. They must be reassured that questions about alcohol center around its potential role as a cofactor in promoting liver injury and scarring, and do not imply a lack of trust on the physician's part about representations by the patient of minimal or no alcohol consumption. At present, the medical literature clearly indicates a relationship between over 50 grams of alcohol daily (about 4 drinks) and promotion of more rapid liver scarring in patients with chronic hepatitis C. This creates a dilemma about what to tell patients who consume lesser amounts of alcohol. Few if any liver specialists permit patients with chronic hepatitis C to consume alcohol on a daily basis, but there is some division of opinion about whether to prohibit alcohol completely in all patients or whether patients with mild liver disease may continue to consume small amounts of alcohol, such as a drink on "special occasions". The author subscribes to the latter school of thought, permitting occasional alcohol consumption in patients with mild findings on liver biopsy and no suspicion that alcohol consumption is heavier than is represented by the patient. However, in patients with advanced liver scarring or a history of problems with excessive alcohol use, it is considered better to advise complete abstention. Similarly, for patients with a history of drug/substance abuse, complete abstinance from alcohol use is recommended. This is also the advice most experts give patients who are embarking on antiviral therapy, because even moderate amounts of alcohol have been shown to promote hepatitis C viral replication.

Physical examination of patients with hepatitis C centers on findings that suggest advanced liver disease. Such findings may include enlargement of the liver or spleen, reddish discoloration of the palms, small vascular (related to blood vessels) markings called "spider angiomas" on the torso or arms, distention of the abdomen suggesting fluid, or ascites, and swelling of the ankles or calves. However, the absence of these findings does not guarantee that only mild liver disease is present, and their presence does not conclusively prove the presence of advanced liver damage.

Laboratory data include the liver enzymes ALT (SGPT) and AST (SGOT), which are liver proteins that leak out of liver cells in excess quantities when the cells are damaged. Some patients place too much emphasis on the magnitude of their enzyme elevations, believing that the degree of elevation in ALT predicts the severity of liver disease, or that if the enzymes are higher than previously on a followup evaluation that the liver disease must be accelerating. Although it is true that five-fold elevations or more do have some association with more progressive scarring, and patients with persistently normal enzymes tend to have milder liver disease, the correlation in general between liver damage and enzymes is highly imperfect and no definitive conclusions can be drawn from this information alone. Other routine laboratory data of greater utility in predicting the degree of liver scarring include the ratio of ALT to AST, which shifts from greater than one to less than one as liver disease progresses; the albumin level, which reflects the liver's ability to manufacture proteins; and the platelet count, which if reduced below normal can suggest impaired filtration of blood by the liver by extensive scarring, with consequent backup of blood into the adjacent spleen where platelets can be sequestered. Other laboratory tests are important to exclude concomitant liver diseases. These include hepatitis B, immunologic liver diseases such as "autoimmune hepatitis", and genetic liver disease such as hemochromatosis related to iron overload.

Indispensable virologic tests early in the evaluation process include the viral load and the viral genotype. The viral load measures the amount of viral genetic material (RNA) in the blood, and thereby the number of viral particles. This is usually determined by a specialized test called polymerase chain reaction (PCR) or branched DNA (bDNA). The assay for viral load serves several purposes: (1) it confirms the actual presence of the virus in the body; (2) it helps to predict response to antiviral therapy; (3) it gives a baseline viral level against which to compare future levels if antiviral therapy is initiated, since the degree of drop in viral load at certain critical time points during therapy, e.g. 12 weeks, can be used to predict the likelihood of a successful treatment outcome and, therefore, the utility of continued therapy. Equally important is the determinant of viral genotype because genotype is the most powerful predictor of response to therapy with interferon and ribavirin. There are several major genetic strains of hepatitis C virus around the world, numbered 1 through 6, with genotype 1 being present in about 70% of U.S. patients and genotype 2 and 3 in most of the remainder. Unfortunately, genotype 1 is associated with the lowest likelihood of sustained virological response and requires 12 months of therapy to achieve optimal results compared with genotypes 2 and 3, which are eradicated much more frequently and appear to require only 6 months of therapy. Genotype 4 is the most common strain in the Middle East, particularly Egypt where HCV is extremely common, and appears to have a response rate intermediate between genotype 1 and genotypes 2,3. Genotypes 5 and 6 are seen in Africa and Asia.

Because of the inability of blood tests to predict the status of a patient's liver disease with precision, liver biopsy remains a cornerstone of evaluation in most patients with hepatitis C. This is an outpatient procedure in which a quick puncture on the right side under local anesthesia is performed to obtain a small specimen of liver tissue for microscopic evaluation. Observation for several hours after biopsy is required because the major risk of the procedure is internal bleeding, which occurs in about 1 in 1000 cases. Despite concern about the possibility of "sampling error", the specimen of liver obtained by biopsy is generally a reliable reflection of the liver as a whole, because most chronic liver diseases affect the liver in a uniform manner throughout the organ.

The specimen of liver is evaluated by a pathologist for two parameters: the grade of inflammation and the degree of fibrosis, or scarring. There are several scoring systems, but the simplest and most widely used system assigns a score for each of these on a scale of 0 through 4. Stage 0 reflects the absence of any scar tissue, while stage 4 denotes cirrhosis, which consists of completely round nodules of scar tissue encircling "islands" of liver tissue. Stage 1 fibrosis represents a mild state of scarring, stage 2 is intermediate, and stage 3 represents the presence of dense, long strands of scarring that are a precursor of cirrhosis. There is uniformity of opinion that

patients with stage 3 and 4 fibrosis require antiviral therapy with little or no delay, and that therapy should also be strongly considered in patients with stage 2 fibrosis. In patients with stage 0 and 1 fibrosis, particularly when infection is of long-standing duration, therapy may be viewed as more "optional", but there may be compelling factors favoring treatment in these patients as well. Such factors include young age, genotype 2 or 3, contemplation of future pregnancy, employment in the health care profession, and the presence of symptoms such as fatigue. Even patients who do not meet these criteria should be informed of the option of therapy, the success rates and side effects, and the fact that treatment results are somewhat better in the presence of mild scarring than more advanced scarring.

In addition to its obvious importance in assessing the need for antiviral therapy, liver biopsy has other important uses. It is the final step in ensuring that other liver diseases are not present. The most common of these is nonalcoholic fatty liver disease (NAFLD), for which there is no reliable blood test. Information from the biopsy is often incorporated into decisions during treatment about the aggressiveness with which to continue therapy or maintain initial doses of interferon or ribavirin in the face of side effects. For the many physicians who believe, based on published literature or their own experience, that antiviral therapy has beneficial effects on inflammation and fibrosis independent of its virologic effects, the degree of liver scarring is critical in deciding whether to continue treatment even if it becomes clear that the patient is not destined to be cured. The concept of "maintenance therapy", now the subject of several major international studies, is applicable only to patients whose biopsies show very substantial scarring. Finally, a liver biopsy is important as a baseline for future comparison should the patient and physician decide not to initiate antiviral therapy after the initial evaluation. In such patients, liver biopsy is often repeated at 3-5 year intervals to reassess the need for antiviral therapy or to assess the need for repeat treatment with newer therapy if older treatment has failed.

Despite its great utility, there are some circumstances under which liver biopsy may be deferred. In young patients with HCV genotype 2 or 3 and no evidence of cirrhosis on noninvasive evaluation, the high rates of cure associated with current regimens of pegylated interferon and ribavirin create a rationale for treatment regardless of biopsy findings. Some patients may decline a biopsy and request therapy regardless of what their biopsy might reveal; it is reasonable to accede to such requests. It must also be acknowledged that experienced physicians vary somewhat with regard to the importance they place on the initial biopsy. Finally, there is intense interest in blood tests that have been developed to assess for markers of fibrosis. More data are expected soon, but at present these tests are not yet considered a proven substitute for liver biopsy in most patients.

Patients sometimes ask why an ultrasound, CT scan or MRI cannot be used in place of a liver biopsy. These noninvasive imaging tests do not offer nearly the same level of information about the microscopic state of the liver as does a biopsy. Although frequently abnormal in the presence of advanced cirrhosis, they may be unrevealing even in patients with considerable scarring. The main utility of imaging tests is in screening patients with cirrhosis for liver cancer (hepatocellular carcinoma, or HCC), which unfortunately arises in HCV patients with cirrhosis at a rate of 1-4% per year. Many physicians have increased the frequency of imaging in cirrhotic patients to twice a year instead of the traditional once yearly. The adjunctive blood test for HCC, called the alpha fetoprotein (AFP), continues to be used for screening but is less reliable than serial imaging.

In summary, the evaluation of patients with chronic hepatitis C is a complex constellation of history, physical examination, laboratory tests, and liver biopsy. The ultimate goals include the identification and treatment of any other concomitant liver diseases or risk factors for liver disease are present, the determination of the state of the patient's liver, the pace at which the liver disease is progressing, and the role and expected outcome of antiviral therapy. The evaluation of HCV infection is a "labor intensive" process requiring extensive communication between physician and patient. The presence of highly trained personnel on the physician's staff, including nurses, nurse practitioners and physician assistants may be extremely helpful in ensuring that patients have the level of communication and depth of understanding they deserve so that they may be full participants in their care.

Quality of Life & Hepatitis C

David Bernstein, M.D.
North Shore University Hospital,
Manhassett, NY

The perception of chronic hepatitis C infection is that it is an asymptomatic disease with less than 20% of patients experiencing the non-specific symptoms associated with the disease(1), including fatigue, musculoskeletal pain, pruritus (severe itching), jaundice and headache. Despite this widely held perception, several studies have documented impaired health-related quality of life (HRQL) associated with chronic hepatitis C infection.(2-4) Achieving sustained undectable HCV viral load can improve vitality and social and job functioning.

Perhaps the greater question is "Why all this sudden interest in hepatitis C related quality of life? The simple answer is that quality of life has moved to the forefront of patient concern. Aside from efficacy, patients care most about their quality of life. Nobody wants to feel miserable and unhappy. Examples of quality of life considerations include the ability to maintain a job, the ability to maintain personal relationships with friends, spouses and children, the ability to continue to feel productive and effectivual, and the ability to enjoy situations or events that previously gave pleasure. Since current therapies are not yet good enough to eradicate the hepatitis C virus in all treated patients, factors regarding the impact of therapy on quality of life must be entertained and discussed with the patient, prior to embarking on a course of treatment.

The assessment of quality of life in the doctor's office is difficult. Because of this challenge, self-administered tools have been developed to aid the health care professional estimate the effect of hepatitis C on a patient's quality of life. Examples of tools used to measure quality of life include the following: SF-12, SF-36, hepatitis quality of life questionnaire, sickness impact profile, gastrointestinal quality of life index, chronic liver disease questionnaire, the liver disease quality of life instrument and the fatigue severity scale.(5-10) The most common tool used to date in patients with chronic hepatitis C is the Short Form 36 or SF-36. The SF-36 is a tool comprised of 36

questions which is used to measure general health status. The 36 questions measure 8 domain scales; physical function, role limitations-physical, vitality, general health perceptions, pain, social function, role limitations-emotional, and mental health.(6) Domain scale scores are linearly transformed onto a scale from 0 (worst health) to 100 (best health). Subscores assessing mental and physical health summary (MCS and PCS respectively) scores are also generated. The SF-36 has demonstrated good reliability and validity in primary care and chronic disease populations including chronic hepatitis C infection.(6)

The effects of hepatitis C virus infection on quality of life are emerging factors in the evaluation of patients. Physicians perceive that patients with hepatitis C are largely asymptomatic and that the disease seldom impacts patients' lives. However, studies with large numbers of patients show that hepatitis C has a negative impact on quality of life, which may help justify therapy in patients with less advanced histological disease.(3,4,11,12) Quality of life has also been shown to decrease in patients recently made aware of their hepatitis C status. The reason for this decline in quality of life seen after diagnosis, in the absence of treatment, may be in part secondary to a labeling phenomena (stigmatized).(13)

A study of 642 patients confirmed that patients with hepatitis C report lower quality of life scores than healthy control patients.(4) Furthermore, this study demonstrated that patients who achieved a sustained viral response with interferon monotherapy experienced significant improvements in perceived wellness and functional status, translating to significant improvements in quality of life. The hepatitis quality of life questionnaire was used to evaluate patients who relapsed following interferon monotherapy and subsequently underwent treatment with interferon in combination with ribavirin. *Sustained virological response was associated with improvements in vitality, social functioning, and health distress*.

Hepatitis C infection has also been associated with increased fatigue and a decreased ability to function at work, at home, and in school. People with hepatitis C report less confidence in their current health and more concern about their health for the future.(14)

Implications of side effects on response and quality of life
Perhaps the greatest challenge facing clinicians who treat patients with chronic hepatitis C virus is maintaining full-dose therapy for the appropriate duration of time. Pegylated interferon and ribavirin have significant side effect profiles that reduce quality of life and make patient adherence to long-term therapy difficult to achieve. Poor adherence to therapy results in inferior sustained virological response rates. Examples of common side effects which negatively impact quality of life include fatigue, flu-like illness, anxiety, depression, irritability, insomnia, mood swings, loss of libido, loss of concentration, anemia, rash, pruritus, joint pains, muscle aches and fever. All studies which have measured the impact of interferon alone or interferon plus ribavirin therapy on quality of life show a decline in quality of life on therapy. Recently, studies have shown that both therapy with pegylated interferon alfa-2a alone and combination pegylated interferon alfa 2a in combination with ribavirin have less of a deleterious effect on quality of life while on therapy than standard Rebetron™ therapy.(11,15) In patients who develop anemia on anti-viral therapy, the addition of the growth factor, erythropoetin, (Procrit) has been shown to improve patients quality of life on therapy, especially fatigue.(16)

Anti-viral therapies are associated with a decline in quality of life, which returns to baseline when therapy is terminated. Therefore, the effect of therapy on quality of life is best assessed not during therapy but once therapy is completed. At this point, treatment may have a positive effect on quality of life. It has been previously shown that patients who have a sustained viral response to interferon alfa-2b in combination with ribavirin report an improved quality of life and have significant improvements in work functioning and productivity.(14) Perillo et al showed that pegylated interferon a-2a was associated with superior health related quality of life and superior work productivity during the first four weeks of therapy when compared to standard interferon a-2b plus ribavirin.(17) For employers, this can be translated into cost savings. When patients are treated with pegylated interferon alfa-2a versus standard interferon alfa-2a, quality of life parameters such as fatigue severity scales and SF-36 scores, are statistically better.(18) Sustained viral response rates correlate positively with improvements in quality of life.(4) These improvements are seen whether the patient, on liver biopsy, has minimal disease or cirrhosis. Unfortunately, non-responders to combination interferon and ribavirin therapy are not as lucky. This group does not see any significant improvements in quality of life at the end of therapy, regardless of the therapy received.(4,11,14)

Poor virologic response rates, high side-effect profiles, and poor quality of life on conventional interferon and ribavirin therapies have led to the use of complementary medicine in approximately 60% of patients infected with HCV. Many patients who take alternative therapies either delay or do not seek the use of conventional therapies. Despite the widespread use of these modalities, few, if any, well-designed clinical trials have been published to evaluate the efficacy of complementary medicine in patients infected with the hepatitis C virus.(19-22) Physicians must keep an open mind and familiarize themselves with the purported efficacy and potential toxicities of alternative medications in order to provide effective counsel to their patients. Patients must inform their physicians of all their medications, alternative or conventional.

Physicians need to focus more on the impact of chronic hepatitis C therapy on the quality of life of their patients. This is because poor quality of life due to the therapy or other reasons impacts adherence, especially in the initial 12 to 24 weeks of therapy. As well, the patient's quality of life impacts on his or her family. Failure to remain on treatment will compromise the clinical benefits of therapy, such as virological response. Failure to maintain an adequate quality of life while on therapy can lead to difficulties with intrapersonal relations at home and work, depression and decreased feelings of self-value and utility. Chronic hepatitis C therapies, such as peginterferon plus ribavirin, which have fewer side effects and less impairment in health-related quality of life, also have greater sustained virological response rates as compared with

unmodified interferon with and without ribavirin.(8) In addition, physicians and patients need to consider the impact of treatment on quality of life when making decisions about alternative therapies for hepatitis C treatment.

References

1. National Institutes of Health Consensus Development Panel Statement. Management of hepatitis C. Hepatology 1997;26(3Suppl 1): 2S-10S.
2. Davis GL, Balart MD, Schiff ER, Lindsay K, Bodenheimer HC, Perrillo RP, Carey W, Jacobson IM, Payne J, Dienstag JLet al. Assessing health-related quality of life in chronic hepatitis C using the sickness impact profile. Clin Ther 1994;16:334-343.
3. Ware JE, Bayliss MS, Mannocchia M, Davis GL, the International Hepatitis Interventional Therapy Group. Health-related quality of life in chronic hepatitis C: Impact of disease and treatment response. Hepatology 1999;30:550-555.
4. Bonkovsky HL, Woolley JM, the Consensus Interferon Study Group. Reduction of health-related quality of life in HCV and improvement with interferon therapy. Hepatology 1999;264-270.
5. Davis GL, Balart LA, Schiff ER, et al. Assessing health-related quality of life in chronic hepatitis C using the sickness impact profile. Clin Ther. 1994;16:334-343
6. Ware JE, Kosinski M, Keller S. SF-36 Physical and Mental Health Summary Scores: A User's Manual. Boston: The Health Institute, New England Medical Center, 1994
7. Younossi ZM, Boparai N, McCormick M et al. Assessment of Utilities and health related quality of life in patients with chronic liver disease. Amer J of Gastro 2001; 96:579-583.
8. Krupp LB, LaRocca NG, Muir-Nash J et al. The fatigue severity scale. Arch Neurol 1989; 46:1121-1123.
9. Gralnek IM, Hays RD, Kilbourne A et al. Development and evaluation of the liver disease quality of life instrument in persons with advanced, chronic liver disease-the LDQOL1.0. Amer J Gastro 2000;95:3552-3565.
10. Yacavone RF, Locke GR, Provenzale DT et al. Quality of life measurement in gastroenterology: what is available?. Amer J Gastro 2001; 96:285-297.
11. Bernstein DE, Kleinman L, Barker CM, et al. Relationship of health related quality of life to treatment adherence and sustained response in chronic hepatitis C patients. Hepatology. 2002;35:704-708.
12. Foster GR, Goldin RD, Thomas HC. Chronic hepatitis C infection causes a significant reduction in quality of life in the absence of cirrhosis. Hepatology 1998; 27:209-212.
13. Rodger AJ, Jolley D, Thompson SC et al. the impact of hepatitis C virus on quality of life. Hepatology 1999;30:1299-1301.
14. McHutchison JG, Ware JE, Bayliss MS et al. The effects of interferon alfa-2b in combination with ribavirin on health related quality of life and work productivity. J. of Hepatology 2001; 34:1400-147.
15. Hassanein T et al. Treatment with 40KDAPeginterferon Alfa-2a (Pegasys) in Combination with Ribavirin Significantly Enhances Quality of Life Compared with Interferon Alfa-2b Plus Ribavirin EASL2002. Abstract 622.
16. Afdhal N, Dieterich D, Pockros P et al. Epoetin alfa treatment of anemic hepatitis C infected patients allows for maintenance of ribavirin dose, increases hemoglobin levels and improves quality of life versus placebo: a randomized, double-blind, multicenter trial. Hepatology 2003:124;A714.
17. Perillo RP, Thuluvath PJ, Rothstein K et al. Improved work productivity, safety, and quality of life with pegylated interferon (40kD) alfa-2a therapy in the treatment of chronic hepatitis C. Hepatology 2000
18. Raseneck J, Zeuzum S, Feinman SV et al. Peginterferon alfa 2a improves HR-QOL outcomes compared with unmodified interferon alfa 2a in patients with chronic hepatitis C. Pharmacoeconomics 2003; 21:341-349.
19. Eisenberg DM, Davis RB, Ettner SL, et al. Trends in alternative medicine use in the United States, 1990-1997:results of a follow-up national survey. JAMA. 1998;280:1569-1575.
20. Flora K, Hahn M, Rosen H, et al. Milk thistle for the therapy of liver disease. Am J Gastro.1998;93:139-143.
21. Angulo P, Patel T, Jorgensen RA, et al. Silymarin in the treatment of patients with primary biliary cirrhosis with a suboptimal response to ursodeoxycholic acid. Hepatology. 2000;32:897-900.
22. Ernst E. Harmless herbs? A review of recent literature. Am J Med. 1998;104:170-178

Life with HIV-HCV Coinfection

Heather Timmermans Wilantewicz, RPA-C
Director of Clinical Services
The PATH Center
The Brooklyn Hospital Center

On July 25, 2003 I sat down with Sean*, a peer educator and patient in the PATH Center to discuss life with HIV-HCV Coinfection. Excerpts from the interview are below.

Q: Tell me a little about yourself.
I am 53 years old and a patient and peer educator in the PATH Center. I was diagnosed with AIDS in September 1997 and hepatitis C in September 1999. I came to the PATH Center in 1999 because I had been to places before where I didn't feel important. I wasn't taking care of myself. I wasn't adhering to my regimen. I thought I was healthy because I had never been in the hospital. For a long time I was in denial because I had never gotten sick. I never had thrush or any opportunistic infections or pneumonia.

I could have gotten my HIV through drug use or sex. I experimented with everything. It is a possibility that if I didn't get HIV I would have died (of drugs). This (HIV diagnosis) may have saved my life. It was the HIV that forced me to put the drugs down. My taking charge with the HIV helped me challenge my drug and alcohol issues. It all goes hand in hand. It didn't make sense to take medicine for my HIV and then drink and drug. It didn't make sense to drink alcohol because of my liver. It has been a journey. Once my HIV was under grips, then we had to deal with my hep C-that was the last big obstacle.

Q: How did you select the PATH Center for your medical care?
When I moved to Brooklyn someone said you should try the PATH Center. From when I first stepped into the clinic, it was like a spiritual awakening. The first people I met were you (HTW) and Dr. Berkowitz. And the second time I came here, you both knew who I was. I was no longer a number. It made me have a different perspective about caring and about myself. When I saw how much you cared about me it made me take a look at myself. You both cared more about me than I did. That inspired me. It really did. Everything has gotten much better-I have 100% adherence, undetectable; my T-cells have tripled. I have gained weight. I feel so much better. And all of this is the result of building up a good dialogue with my medical provider.

Q: What services does the PATH center provide?
Excellent service. All kinds of services. An oral hygienist, dentists, support groups, case management, psychiatry, primary care, social work, nutrition, treatment adherence counselors, an HIV-Hepatitis C Coinfection clinic, outreach and it is

going to get larger too where we have a one-stop-shopping family program.

Q: Why did you become a Peer Educator?
I went to a peer education course and liked the idea of helping other people. It helps me stay connected and focused with my treatment. It keeps me on top of new things, new problems that come about and with reading the literature. I don't know all the answers when I speak to patients but I know who to send them to.

Q: What does a Peer Educator do?
I don't give out medical solutions. I help people adhere to what their doctor has given them treatment for. For example, keep your pills where you can see them and will remember to take them like on your nightstand. Carry water with you. Carry an extra dose with you in case you don't come home on time. And the importance, of course, of trying not to use drugs and alcohol. That has been a big thing with me too. Once I was able to let that go I was really able to give all my attention to my adherence.

Sometimes if (patients) find out that you are a consumer they are a little more honest with you than they would be with their doctor. I tell them, 'everything you've done, I've done too. You can be honest with me.' I open up that door. Then I tell them that it is important to be honest with their doctor. Tell them if you are having a problem. Maybe they can give you an easier regimen or maybe they can give you a referral to a drug program. Are you a product of domestic violence? Sometimes they just need someone to talk to. Maybe I don't even have to give them any advice. Maybe I can just give them an ear. Maybe they have the answers in them. But they need to talk about it. Especially newly diagnosed people when there is so much information and maybe they just need someone to help them organize the information. Someone just doesn't arrive the perfect patient-cause I'm not and I'm still working on it. It is an ongoing process of learning how to take care of yourself.

Q: What has been the biggest challenge of being a peer educator?
A big challenge is to share with people the importance of maintaining gratitude for where we are today because a lot of people didn't make it this far. From when I first started there are so many more choices. You can still go to school. You can still have relationships. Women can still have children. You have to LIVE with the virus and not die with the virus.

It is also difficult to let people realize that a doctor is only a human being and your doctor can't work miracles. He can only present the facts or what he knows as the facts. You are responsible just as much as they are. You have to take just as much responsibility for your life as you put in their hands. It is not a one way thing.

Q: How have you changed over the time?
I have grown so much. My taking charge with the HIV helped me challenge my drug and alcohol issues. It all goes hand in hand. It doesn't make sense to take medicine to maintain your HIV and then go out and drink and drug. It doesn't make sense to take alcohol and drink for you liver. It has been a journey and I am so blessed to have come here because my life is so much better today than it was four years ago when I came. So much better. I have a life and I have a purpose. The important thing is to make the most out of each day. We only have today.

Q: How did you make the decision to take the hepatitis C treatment?
Counseling with my medical provider. She gave me information and time to think about taking the treatment. We talked about all of the different stages of liver (disease) and all of the functions of the liver and how important it is. I realized that the liver is a big organ. It's like the brain is the computer and the heart is the engine and the liver is like the factory. It makes all these enzymes and all kinds of processes. It is a large organ and an important organ. Because I have HIV, the acceleration of the hepatitis C and the process of deterioration can be so much quicker for me.

My HIV was stable and I was emotionally ready. So I had the liver biopsy - it wasn't bad - and my PA taught me how (to take the hepatitis C medicine.) And it has been about 6 months. No matter what the outcome I feel good knowing that I did my part of trying to make this work to the best of my ability. Even if (my hepatitis C) isn't cured I can still end up with a healthier liver. Down the line I don't want to say- I wish I had or I should've. That is a good feeling-to challenge something and do your half.

Q: What is a liver biopsy?
In a liver biopsy, a doctor uses a needle to extract a piece of your liver to look at it under a microscope to see what the stage of liver disease. Everyone is different but, for me, it was not as painful as you would think. It felt like a finger had poked me in my side real quick. It is so quick. Just a little ouch. Then there was just a little soreness for a day.

Q: What does hepatitis C treatment entail?
The treatment for me entails additional daily pills of Ribavirin-2 in the morning and 2 at night with my (HIV) regimen and once a week I take my pegylated interferon. Two or three weeks (into treatment) we added erythropoietin, which I take on the same night as my peginterferon. The erythropoetin, (Procrit) has helped me with anemia and my fatigue.

What kind of side effects did you have on hepatitis C therapy? (People can get different side effects.) The side effects I had were muscle cramps and fatigue. But I know there is something that does make a difference and that was water. When I remember to drink my water I can see a difference. I feel better. Something as simple as staying hydrated. There are some rough nights but nothing that I really couldn't handle because all I have to think about is succeeding-the possibilities of the treatment and I think it is worth the sacrifice. Challenging this and addressing this gives me comfort.

I can't say for everyone, but for me it hasn't been as bad. A little fatigue-that is a small price to pay if you are going to save one of the most important organs in the body-your liver. I can deal with that.

Q: Do you have some tips for someone taking Hepatitis C therapy?
It is important to get your rest before you take that shot. You have to eat. Hydration, rest and a stress free environment. And a positive attitude. Because a lot of it is mind over body.

Talk about your feelings. It is all right if you complain. Talk to someone who can give you inspiration. Don't overload your plate. Try to be around other people who can take you outside of yourself. Do some exercise and get out of the house. Do some positive activity. No matter what it is-cooking, reading, going to a museum. Go to a movie. Go to the library. Try to stay busy. Because if you stay idle you start thinking about how bad you feel. But if you are around people who are laughing and having a good time it helps. A support group helps. I go to support groups. I have a few. I go here, the PATH Center, on Tuesdays, I go to my NA, and I have my NATAP groups and educational workshops. I keep busy.

Q: What is the message to give someone with HIV and Hepatitis C?
The message is that we have come a long way. Get educated. Get connected. And take charge of your coinfection. Consider taking the hepatitis C treatment because if you really can't handle it, you can always stop. I think it is best to confront the challenges of every aspect of your health and try to improve on it. Knowledge is power. You need to know what is going on with your body. Talk to your doctor. If you don't tell your doctor everything, he or she cannot treat what you don't tell him or her about.

Q: What is the motto you live by each day?
The important thing is to make the most out of each day. Each day should be better than the day before. Little steps. Do something today a little better than you did yesterday. It can be a little thing. Start with an extra glass of water or one less cigarette or eat extra vegetables. Or be more in tune with your scheduling, adherence or doing something for someone else. Just try to be a little bit better today than you were yesterday and by the end of the week you will be a hell of a lot better.

Q: Where are you getting your support from?
I get it from the PATH Center. I share with friends. A lot I get from NA and AA. But I do think it all began right here. This hospital means life to me. It is a symbol of life. It gave me life. It all happened when I came here. It is a wonderful thing.

*changed name

Prevention and Control of Infections with Hepatitis Viruses in Correctional Settings

By Rachel Maddow D. Phil.

In January 2003, the Centers for Disease Control and Prevention published recommendations for fighting hepatitis in prisons and jails: "Prevention and control of infections with hepatitis viruses in correctional settings" (MMWR 2003; 52[No.RR-1]).

Highlights include recommendations that all prisoners get hepatitis A and B vaccinations, that all prisoners be asked about hepatitis C risk factors, and that all prisoners who report hepatitis C risk factors be tested for hepatitis C antibodies.

The CDC also recommends that prisons and jails "establish criteria based on the latest [hepatitis C] treatment guidelines for the identification of prisoners who might benefit from antiviral treatment".

These federal recommendations do not legally bind prisons and jails, but they can have a great deal of influence on corrections administrators. Experience with HIV/AIDS in prisons and jails shows that courts often cite federal guidelines as minimum standards for correctional institutions.

The new CDC hepatitis/corrections guidelines can be obtained on the internet for free in two formats:

(1) For pdf format (which requires Acrobat Reader software), visit: www.cdc.gov/mmwr/PDF/rr/rr5201.pdf

(2) For html format (recognized by all web browsers), visit: www.cdc.gov/mmwr/preview/mmwrhtml/rr5201a1.htm

NATAP in the Caribbean

By Nadia Cohen

On April 22nd, 2003 NATAP visited San Juan, Puerto Rico to conduct this year's first HIV/HCV Co-infection training in the Caribbean. The trip marks our second year providing educational forums on the island, establishing an annual tradition. The forum – facilitated in Spanish – focused on HIV treatment, and Hepatitis C and HIV/HCV Co-infection treatment. Speakers included Dr. Rafael Ortega, Director of Treatment Education at NATAP; Dr. Maribel Rodriguez-Torres, Fundacion de Investigacion de Diego; and a special presentation on Fuzeon, the first entry inhibitor, by Dr. Lizette Santiago, of Programma SIDA of San Juan. The program was extremely well received by the HIV/AIDS community drawing over 300 consumers and providers to the University of Puerto Rico auditorium.

On the heels of Puerto Rico came a training in St. Croix, U.S. Virgin Islands, held on May 15, 2003. The training drew over 100 HIV service providers, including nurses, social workers and HIV specialists from the island and neighboring St. Thomas. The event was co-sponsored by VICARE (a local HIV/AIDS healthcare organization), The American Red Cross and Project Hope. Delegate Donna M. Christian-Christensen (VI), was represented by her senior legislative aid Michael Thurland. Mr. Thurland opened the training, welcoming the Virgin Islands' community to the training and briefly describing the significance of HIV/HCV co-infection in the territory.

Dr. Danielle Milano of the Boriken Neighborhood Medical Center in East Harlem, New York, captivated the audience with information about HIV and Hepatitis C prevention and treatment, discussing treatment options, side effects, issues specific to women and those specific to the intravenous drug using community. Dr. Milano's experience working with disenfranchised communities and populations coupled with her accessible speaking style prompted an open dialogue on treatment and care throughout the day.

The success of our recent work in the Virgin Islands and Puerto Rico sheds much needed light on the lack of HCV and HIV treatment education available in either location. Continued education and training is necessary to fully address the high infection rates in the Caribbean.

Most recently, NATAP returned to Las Vegas, Nevada on June 19th to conduct a HIV/HCV co-infection forum in conjunction with the Southern Nevada Area Health Education Center. Jules Levin, and Dr. David Margolis, Chief of the Infectious Disease Section of Dallas Veterans Affairs Medical Center spoke on HIV/HCV co-infection and HIV diagnosis, treatment and care. Amidst soaring 100+ temperatures, the event drew participants from around Nevada and neighboring Arizona.

In the months to come NATAP's HIV/HCV co-infection training will take place in Minneapolis, MN; Phoenix, AZ; Denver, Co; and New York, NY. Check the NATAP web site (www.natap.org) to find out dates and specific locations.

Check Out NATAP's Upcoming Events

Our events are always:
Fun
Informative
and Free!

Please feel free to call NATAP
to register or find out more information.

New York

Monthly Hepatitis C/HIV Co-infection Support Group
Next Meeting: Tuesday, September 23rd
5:30pm to 7:30pm
NATAP Office
580 Broadway Suite 1010, New York, NY 10012

Hepatitis C Treatment and Management of Side Effects
Heather Timmermans-Wilantewicz, RPAC
Tuesday, September 25th, 2003
6:00pm to 8:30pm
North General Hospital
1879 Madison Ave.
Located Downstairs in the Cafeteria

Hepatitis C Awareness Day
May 4th, 2004
St. Mary's Park
Bronx, NY

National Events

HIV and Hepatitis C Co-infection
Tuesday, September 23rd, 2003
and again on Thursday, September, 25th 2003
9:00am to 3:30pm (both days)
Community Bridges
Central City Addiction Treatment Center
2770 E. Van Buren, Phoenix, AZ 85008

HIV/Hepatitis C Co-infection: Your Future, Your Choices
Friday, November 21st, 2003
10:00am to 4:00pm
Four Points Sheraton at Denver University
1475 Colorado Boulevard
Skyline Ballroom, Denver, CO 80222

National AIDS Treatment Advocacy Project (NATAP)
580 Broadway, Suite 1010
New York, NY 10012
Tel: (212) 219-0106
Fax: (212) 219-8473
Email: info@natap.org
Treatment Website: www.natap.org