

## **Provider/Patient Education Guide (P/PEG) #1: What should I do about my hepatitis C?**

### **Do I need vaccines? (Protection against Hepatitis A and Hepatitis B)**

◇ All patients who are not already immune to hepatitis A and hepatitis B should receive vaccines. Immunization is not treatment for hepatitis C but may prevent new hepatitis A and B infections. Acute infection with hepatitis A or B can be life-threatening if you have hepatitis C.

### **Can I Drink alcohol?**

◇ **THERE IS NO KNOWN SAFE LEVEL OF ALCOHOL IN HEPATITIS C.**

Alcohol is an important factor in progression of hepatitis C and development of cirrhosis and liver cancer.

Alcohol consumption has been shown to make hepatitis C progress faster. Even small amounts of alcohol may increase the risk of liver damage associated with hepatitis.

### **How can I protect my loved ones and others from getting hepatitis C from me?**

◇ Hepatitis C is transmitted blood to blood: Don't share needles, cookers, cotton, injection water, toothbrush, razor, nail clippers, or anything with your blood on it.

◇ Hepatitis C can be transmitted sexually and condoms may prevent transmission. If you are in a long-term, monogamous sexual relationship, the Center for Disease Control (CDC) does not require condom use (as long as one or both partners are not HIV positive). However your sexual partner should be informed, and testing is usually recommended.

◇ Children of female patients should be tested: there is a 5% chance of transmitting the virus from mother to fetus, but if co-infected with HIV and HCV there is 17 % chance of passing the virus from mother to fetus.

### **How bad is my liver disease, and will it get worse over time?**

◇ Most patients were infected within the first year of using drugs intravenously. Subtract how old you were when you first used IV drugs from how old you are now to estimate how long you have had the virus. If you have never used drugs intravenously, it is more difficult to estimate the amount of time you have had the virus.

◇ Liver diseases progresses with time. The STAGE of your liver disease will tell you how much scarring you have in your liver, with the final stage being cirrhosis.

◇ 20% of patients with hepatitis C will progress to cirrhosis in 20-30 years. Patients in general progress a stage every 3-5 years, but progression may be more rapid at later stages (i.e. Ishak Stage 4 to Ishak Stage 6 cirrhosis may take only 1.5 years).

◇ Factors contributing to faster progression and more severe liver disease are alcohol, hepatitis B or HIV co-infection

### **What do routine blood tests tell me about my liver disease?**

◇ Liver Enzymes: AST and ALT are enzymes produced by the liver in response to infection. These enzymes do not correspond to disease stage or severity. Up to 1 in 5 patients with chronic hepatitis C and normal liver enzymes may have cirrhosis. **EVEN IF YOUR LIVER ENZYMES ARE NORMAL, THERE IS STILL A CHANCE THAT YOU HAVE ADVANCED DISEASE.** Increased AST and ALT with AST/ALT>2/1 may indicate alcohol use. AST>ALT may indicate cirrhosis

◇ Albumin: is a protein in your blood that is produced by the liver. An albumin < 3.5 may indicate advanced liver disease or cirrhosis. (Other conditions that may cause low albumin include malnutrition related to alcohol, HIV, other medical diseases, or acute infection)

- ◇ **Platelets:** blood elements which help your blood to clot. If your platelets are <150 or have decreased  $\geq 25\%$  from your baseline platelet count, this may indicate advanced fibrosis or cirrhosis. However, alcohol and HIV may also cause low platelets.
- ◇ **Hemoglobin/Hematocrit:** blood cells which carry oxygen. Low hemoglobin and hematocrit may be related to advanced liver disease. Other common causes for anemia are menstruation, medications (i.e. AZT or Bactrim), HIV, hereditary causes, chronic diseases and blood loss
- ◇ **White blood cells:** blood cells which help fight infection. Low white blood count may be related to advanced liver disease. Other common causes include alcohol, HIV, and medications such as Bactrim.
- ◇ **Bilirubin:** a breakdown product of red blood cells, removed by the liver. In advanced liver disease, bilirubin can build up in the blood. High levels can cause yellow skin (jaundice) and yellow eyes (icterus)

### **Do I need a liver biopsy?**

- ◇ Liver biopsy is the best and usually the only way to determine the amount of damage to the liver, but is not always necessary to be treated. Sometimes blood test abnormalities can indicate cirrhosis before confirmation by liver biopsy, however you may still require a liver biopsy to rule out other liver diseases, and to see what degree of ongoing inflammation GRADE as well to confirm the STAGE of the disease.

### **How can I have this disease if I don't feel sick?**

**DON'T WAIT FOR SYMPTOMS BEFORE YOU GET EVALUATION OR TREATMENT**

- ◇ Most patients will not have symptoms from hepatitis C until late stage disease, at which time it may be too late to treat.

Most of the time, symptoms may occur only after cirrhosis develops. Decompensated cirrhosis occurs when the cirrhotic liver stops working well. Decompensated cirrhosis is defined by fluid in the abdominal cavity (ascites), confusion (encephalopathy), or gastrointestinal bleeding (bleeding from esophageal varices or portal gastropathy)

### **Why should I get treatment, and what are the goals?**

(Treatment is once weekly pegylated interferon injections and twice daily ribavirin pills)

**Primary Goal** is getting rid of the virus. Many experts believe that this represents a cure

There is an approximately 50% overall cure rate.

In general, HIV/HCV co-infected patients have a lower overall cure rate.

**Secondary Goals** are to slow down or even reverse progression of hepatitis C liver damage (which may occur even when you don't get rid of the virus), and to prevent end stage liver disease (ESLD), decompensated cirrhosis, liver cancer and death.

For HIV/HCV co-infected patients, treatment may reduce the risk of medication related liver damage

### **How long does treatment last?**

Treatment is a 6-12 month commitment.

### **What about my drug and alcohol addiction?**

Although you may still be able to receive treatment if you actively using drugs, you may want detox/rehab and enrollment in aftercare program before beginning hepatitis C treatment.

Alcohol use directly compromise treatment. It's best to wait at least 1 month and preferably 6 months after you stop drinking. However in some cases you may receive treatment with more recent alcohol use.

## (P/PEG #2) Provider/Patient Education Guide to hepatitis C viral load and genotype

### What is the hepatitis C viral load, and what does it tell me about my liver disease?

The viral load test is a blood test that measures the amount of hepatitis C virus in your blood. It is measured in IUs (international units), and sometimes measured in copies per milliliter of blood

- One reason to do the viral load test is to establish that you definitely have hepatitis C virus in your blood. This is important for people who have tested positive for hepatitis C antibody and have normal liver enzymes
- Another reason to take the viral load is to see how much virus you have before you start hepatitis C therapy  
Less than 800,000 IUs (less than 2 million viral copies/ml of blood) is considered a low viral load.  
Everyone can respond to treatment, but people with low viral loads may respond better to treatment than people with high viral loads.
- Everyone should have a viral load taken periodically during hepatitis C therapy to see how well the therapy is working and to make decisions about whether or not to continue treatment. You will probably have a viral load test after 12 weeks, 24 weeks and 48 weeks of therapy. Ideally, your viral load should decrease by at least 100 fold after 12 weeks.  
(i.e. from 400,000 IU to 4,000 IU). If you are coinfectd with the HIV virus, your HCV viral load may decrease more slowly.
- Hepatitis C viral does not predict severity of your liver disease. Only liver biopsy can assess the extent of damage to your liver.

## What is genotype, and what does it tell me about my liver disease?

A genotype is a blood test that tells what type of hepatitis C virus you have. There are at least 6 genotypes throughout the world but most people in the United States have type 1, 2 or 3. The majority of people in the U.S have type 1. Very few will have genotype 4.

The genotype test can help predict your response to treatment and determine the length of treatment.

All Genotypes respond to therapy, however Genotypes 2 or 3 respond better.

Genotype 1: 42%-46% achieve sustained viral response (SVR = likely cure) after treatment

Genotype 1 requires 48 weeks of treatment

Genotype 2/3: > 80% achieve SVR after treatment

Genotype 2 and 3, in general only require 24 weeks of treatment.

HIV/HCV coinfection may be associated with lower sustained viral response rates and require longer duration of treatment.

The 12 week early viral response rule may not apply.

HIV/HCV genotype 1: 14-29% SVR with 48 weeks of treatment

HIV/HCV genotypes 2/3: 62-73% SVR with 48 weeks of treatment

**P/PEG Guide #3:**

## **AECOM DoSA LIVER BIOPSY INFORMATION SHEET**

### **What is a liver biopsy?**

The liver biopsy is a procedure in which a tiny sliver of liver tissue is taken for analysis. It is done through the skin by a needle. It is the best and often the only way to assess the extent of damage to the liver.

### **Unique Information Provided by Liver Biopsy:**

- Degree of inflammation (activity of the hepatitis C virus)  
Grade 0-18 (Ishak system)
- Degree of disease severity as measured by fibrosis (scarring) of the liver  
Stage 0-6 (Ishak system): Stage 6 is cirrhosis which represents complete scarring of the liver.
- Degree of disease progression: How long have you had the virus? How much damage was done to the liver in that amount of time? How does that predict your risk of cirrhosis, liver failure and liver cancer?  
The median time to progress from Stage 1 to Stage 6 (cirrhosis) is 20 years. The median time to progress from stage 4 or 5 to Stage 6 (cirrhosis) is 1.5 years. The progression of disease is accelerated by 1.5 -4X in HCV/HIV co-infection.
- Do you have cirrhosis? This information is important to determine the need to monitor for varices (dilated veins in the esophagus) and liver tumors. Compensated cirrhotics (people with cirrhosis who still have good liver function) can and should be treated if there are no contraindications.  
Decompensated cirrhotics should be referred for liver transplant evaluation.
- Do you have coexisting liver injury (e.g. alcoholic liver disease, fatty liver disease, medication toxicity) that also needs to be addressed?

Even if your liver enzymes are normal, your liver may have significant scarring and could benefit from treatment: the best way to know for sure is through getting a liver biopsy.

### **Safety of the procedure:**

Liver biopsy can be safely performed as an outpatient procedure by an interventional radiologist or a hepatologist using ultrasound guidance. Complications rates are very low. Less than 1 in 1000 people have significant bleeding. Mortality occurs in less than one in 10,000 people. Some people feel a little right shoulder pain for an hour or so after the biopsy, which can be easily managed with Tylenol.

### **What to do before your liver biopsy?**

- Do not take aspirin, Motrin, NSAID class drugs, or other "anticoagulant" drugs for 10 days before your liver biopsy and for 7 days after your liver biopsy
- No eating after midnight on the day before your biopsy
- Set your alarm or get a friend to give you a wake up call
- Arrange to bring a friend or family member with you to the biopsy

### **What to do day after your liver biopsy?**

- Plan to take it easy the day of your biopsy

**It is very important to keep your appointment so as not to delay your treatment. If you can't make it to your biopsy because of an emergency, call the Ultrasound Department at Montefiore (718-920-4070) to cancel as soon as possible. In addition, please contact your physician or PA, who may be able to move someone else up on the waiting list. Advance notice of a cancellation will avoid problems scheduling biopsies for others. If you have a problem with transportation to the biopsy or don't have anyone to go with you, ask your PA or physician if alternative arrangements can be made.**

**Where to go for your biopsy?: Montefiore Hospital Main Entrance on 210<sup>th</sup> Street. You will go to the Admitting Office to be registered before your biopsy in the Ultrasound Department (Yellow Zone)**

**When?: You should be there by 7 AM**

**Phone Number of Ultrasound Department 718-920-4070**

**DON'T LET YOUR FEARS DELAY YOUR TREATMENT. TALK TO YOUR DOCTOR, PA, AND OTHER PATIENTS WHO HAVE HAD LIVER BIOPSIES. GET THE INFORMATION AND SUPPORT YOU NEED TO MOVE FORWARD.**

## **Patient/Provider Education Guide P/PEG #4:**

### **What are the side effects of hepatitis C treatment and how can I to manage them?**

#### **Basic Principles**

- There are many side effects to combination therapy with interferon and ribavirin. Almost all patients will experience some side effects (but not all side effects!). Remember, the virus has been living happily in your bloodstream and liver for many years and won't go out without a fight!
- Be prepared for common side effects (flu-like symptoms, fatigue, depression, mood changes and weight loss)
- Report all side effects to your provider
- Let your family, friends and clinic staff know that you are going through treatment so they can understand your side effects and give you support
- Most side effects are manageable, but severe side effects may result in lowering your dose or stopping treatment
- 80% adherence to your medications (taking more than 80% of your interferon total dose and ribavirin total dose for more than 80% of the prescribed amount of time) will increase your chances of sustained viral response (SVR =getting rid of the virus for good)
- Attend support groups to learn from other patients who are going through treatment (and to help encourage patients who need treatment!)

#### **General measures for managing most side effects:**

- Timing of injection (may be best scheduled before a weekend, day off or prior to bedtime)
- Use of acetaminophen (Tylenol) to avoid anticipated body aches, headaches, fevers
- Increased daily fluid intake: at least 10 glasses of liquids daily
- Daily light exercise (like walking)
- Adequate rest
- Keeping up calorie intake: may require smaller but more frequent meals/snacks
- Consider pre-treatment with medication for depression to help prevent depression that may be caused or worsened by treatment

## APPROACHES TO THE MANAGEMENT OF SIDE EFFECTS TO INTERFERON

Side effect	Intervention
Flu-like symptoms	Acetaminophen (Tylenol), increase fluid intake, conserve your energy, take your medicine at bedtime to sleep through symptoms. If you are working, consider taking your interferon injection on the last night of your work week. Focus on the positive effects of the medication!
Fatigue	Moderate exercise, routine sleep patterns, avoid caffeine (ask your doctor if you are anemic). If you are anemic, procrit may help.
Insomnia	Avoid caffeine and tobacco before bedtime, may need medication for sleeping. Take Peg in the morning and 2 <sup>nd</sup> dose of ribavirin just before dinner, or at least 3 hours before bedtime
Anorexia/weight loss/taste changes	Small frequent meals, suck on candy (lemon drops are good for taste changes and dry mouth) , may need anti-nausea medication or appetite stimulant
Depression/mood changes	Your provider will check you for depression. You may need to see the psychiatrist. You may need antidepressant medication to get through the therapy. If you or your loved ones notice extreme mood changes, let your provider know right away!
Muscle aches (myalgia)	Mild exercise, massage, warm baths, Tylenol and anti-inflammatories; assess for methadone withdrawal symptoms; consider methadone dose increase
hair loss (alopecia)	Avoid harsh hair products, hair dryers, constricting headwear, daily hair washing Try: using scarves or hat, shorter haircut
Injection site reactions	Apply ice to injection site until numb before injection, rotate injection sites, steroid cream
Low white blood cell count	Your provider may give you an injection (Neupogen) to boost your white blood cell count
Low platelets	You may need a lower dose of interferon if your platelets are too low

\* Note: pegylated interferon can lower the absolute number of CD4 cells (T-Cells) in HIV patients (decreased an average of 140 cells in APRICOT study), but does not affect CD4 percent and is not a cause for concern. In fact, interferon may actually decrease the HIV viral load (decreased 0.9 log or nearly 10 fold in APRICOT study)

## APPROACHES TO THE MANAGEMENT OF SIDE EFFECTS TO RIBAVIRIN

Side effect	Intervention
Nausea	Take ribavirin with food, use anti-nausea medications (compazine)
Pruritis (itching)	Antihistamines, consider steroid cream
Shortness of breath or chest pain	Report immediately to your provider!
Anemia (low red cell count)/fatigue	Your provider may give you an injection (Procrit) that will boost your red cell count.

Remember Ribavirin can cause birth defects! Avoid pregnancy by using two forms of birth control during therapy and for 6 months after therapy stops. (Depo-Provera intramuscular injections may be one form)