

**I AM YOUR LIVER.....**  
**.....and these are just some of the things I do for you!**

I store the iron reserves you need, as well as a lot of vitamins and other minerals.

I make bile to help digest your food and help get rid of some of your dietary cholesterol.

I detoxify poisonous chemicals you give me, and that includes alcohol, beer, wine and drugs - prescribed and over-the-counter as well as illegal substances. I act as a filter to remove alcohol and toxic substances from the blood and convert them to substances that can be excreted from the body. I remove poisons from the air, exhaust, smoke and chemicals you breathe.

I also process drugs and medications absorbed from the digestive system, enabling the body to use them effectively and ultimately dispose of them

I store energy, like a battery, by stockpiling sugar (carbohydrates, glucose and fat) until you need it. That stored energy is what keeps you going in the morning until you eat breakfast.

I manufacture new proteins that your body needs to stay healthy and grow.

I make clotting factors that stop the bleeding when you nick yourself shaving or paring an apple.

I help defend you against the "germ warfare" going on in your body all the time. I take those cold germs, flu bugs and other germs you encounter, and knock 'em dead - or at least weaken them.

I manufacture the cholesterol you need to synthesize Vitamin D.

I am the ONLY organ in your body that can completely regenerate, even from a small portion of healthy liver.

You may think your brain or your heart is the most important part of you but, without a healthy liver, nothing works right.....not your brain, not your heart...nothing!

**WARNING:**  
**I can't, and won't, tell you I'm in trouble until I'm almost at the end of my rope... and yours.**

I am a non-complainer. Overloading me with drugs, alcohol and other junk can destroy me!  
*This may be the only warning you will ever get.*

If you ever have a blood test run and it shows elevated liver enzymes ( shown on the blood test results as ALT and AST), NEVER ignore those results - follow up - find out more - be insistent! Learn what those results mean....educate yourself...be your own best health advocate!

**Why is the liver so important in nutrition?**

85-90% of the blood that leaves the stomach and intestines carries important nutrients to the liver where they are converted into substances the body can use. The liver performs many unique and important metabolic tasks as it processes carbohydrates, proteins, fats and minerals to be used in maintaining normal body functions.

**Carbohydrates**, or sugars, are stored as glycogen in the liver and are released as energy between meals or when the body's energy demands are high. In this way, the liver helps to regulate the blood sugar level, and to prevent a condition called hypoglycemia, or low blood sugar. This enables us to keep an even level of energy throughout the day. Without this balance, we would need to eat constantly to keep up our energy.

**Proteins** reach the liver in their simpler form called amino acids. Once in the liver, they are either released to the muscles as energy, stored for later use, or converted to urea for excretion in the urine. Certain proteins are converted into ammonia, a toxic metabolic product, by bacteria in the intestine or during the breakdown of body protein. The ammonia must be broken down by the liver and made into urea which is then excreted by the kidneys. The liver also has the unique ability to convert certain amino acids into sugar for quick energy.

**Fats** cannot be digested without bile, which is made in the liver, stored in the gallbladder, and released as needed into the small intestine. Bile (specific bile "acids"), acts somewhat like a detergent, breaking apart the fat into tiny droplets so that it can be acted upon by intestinal enzymes and absorbed. Bile is also essential for the absorption of vitamins A, D, E, and K, the fat soluble vitamins. After digestion, bile acids are reabsorbed by the intestine, returned to the liver, and recycled as bile once again.

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There are health conditions that can effect the function of your liver. Some of them can be and, in fact, almost always are completely and utterly silent. Then, one day, you just sort of don't feel very well - you're fatigued, your appetite is off and when you do eat, it makes you feel unwell. Perhaps you have some mild discomfort in the upper right quadrant of your abdominal cavity or swelling in the abdominal area. You have diarrhea that doesn't resolve after a day or so. Maybe your legs and ankles are swollen. When you finally decide you'd better see your doctor, time can be lost chasing the vague symptoms you're manifesting before the root problem is discovered. That's when you may find out you're in a lot of trouble and that you may or may not be able to be fixed. Some people don't find out how damaged their liver is until they have developed cirrhosis - that's how quiet and well-behaved your liver can be.

## **WHAT ARE THE HEALTH CONDITIONS THAT CAN CAUSE LIVER PROBLEMS?**

In this discussion, I am only taking on two of the conditions that can affect your liver.

There are many others (see list of references). The two we'll be focusing on are:

**Viral Hepatitis** - all forms of hepatitis (A, B, C, D, E, & G). A more in-depth discussion of the various forms of hepatitis appears later in these papers, including how it is acquired, how it is diagnosed and how it is treated.

**Hemochromatosis** - an inherited metabolic disorder in which large amounts of iron are transported from the intestine and accumulate in the liver. A more in-depth discussion of hemochromatosis appears in a later section of these documents including, once again, how it is acquired, diagnosed and treated.

## **WHAT ARE THE MANIFESTATIONS OF A LIVER IN TROUBLE?**

Jaundice, or yellowing of the skin	Darkened urine
Nausea	Loss of appetite
Unusual weight loss or weight gain	Vomiting
Diarrhea, Chalky-colored, clay-colored or black stools (from bleeding)	
Abdominal pain - upper right	Malaise, vague feeling of illness
Generalized itching	Fatigue
Hypoglycemia (low blood sugar)	Low grade fever
Elevated liver enzymes - ALT and AST (see text and Appendix 1 for specific liver tests)	
Loss of sex drive	Depression
Elevated bilirubin, depressed albumin (blood test results)	
Increased prothrombin times (blood clotting times)	

Remember, though.....you may not exhibit all of these symptoms and ones you *are* experiencing may be low key enough that you'll be tempted to dismiss them as unimportant....something that will pass in a day or two...."I can't take time out to go to the doctor today! It'll have to wait..."

For more information about your liver and the conditions that can affect it, see the reference index at the end of this document. There is further information about liver tests and other cautions for those with hemochromatosis. It lists reading materials and internet resources to assist you in becoming more informed.

**VIRAL HEPATITIS**

Hepatitis is a non-specific injury or inflammation of the liver, which can be caused by many things. The most common cause is alcohol consumption. Viral hepatitis is not a bacterial infection and cannot be cured with antibiotics. It is most often acquired through contact with the blood of an infected person (hepatitis B, C and D), but the ingestion of food prepared in unsanitary surroundings or contaminated water can result in Hepatitis A or E. A mother can pass some forms of the virus to her child during childbirth and some forms are also transmitted through sexual activity. A more detailed description of the various forms of viral hepatitis and how they're transmitted follows.

Screening of donated blood for Hepatitis C (HCV) did not begin until 1990 for the HCV antibody and more specific testing for HCV RNA began in 2003. Screening for the Hepatitis B (HBV) surface antigen (like an antibody) began in the early 1970's with testing for the core antigen (a more definitive test) beginning in 1986. Screening for HIV began in 1985.

There are different forms of viral hepatitis (A, B, C, D, E, & G). Hepatitis can be acute (noticeable symptoms following exposure) or chronic (long term, with or without an acute phase).

**ARE YOU AT RISK FOR EXPOSURE TO VIRAL HEPATITIS?**

Did you ever experiment with drugs, use needles to inject drugs, share needles with other people who were injecting drugs, or share a straw to inhale cocaine?

Have you had unprotected sex with multiple partners or had rough sex that resulted in the tearing or abrasion of tissue and bleeding? Are you a man having sex with other men? Have you ever had sex with a woman while she was menstruating?

Have you had any body piercing or tattoos? Were they done in a clean studio (are you sure?) or at a friend's house? Do you share body piercing jewelry?

Have you ever used anyone else's personal hygiene items? Have you ever shared a toothbrush with anyone, or a razor, a nailfile or cuticle scissors - anything that could possibly have blood cells on it?

Did you receive any blood products of any type prior to 1992 and especially between 1978 and 1982?

Any transfusions, plasma, clotting factor (platelets)? Have you had an organ transplant? Extended periods of kidney dialysis?

Did you ever try to assist anyone who was injured and bleeding when you had open cuts on your own hands?

Are you a health professional and have you ever had a needle stick?

Have you ever had any kind of medical treatment, especially injections or blood products, in an underdeveloped country where needles are often reused and only sometimes sterilized?

Do you eat a lot of restaurant food and/or food in other countries with perhaps less than sanitary preparation conditions?

Are you an armed services veteran?

Currently, viral hepatitis is classified into different types that are identified with a letter.

#### **HEPATITIS A (HAV)**

Usually transmitted because of unsanitary conditions, often food borne or in contaminated water. Quickly becomes acute (symptomatic) but usually resolves by itself. See the list of symptoms above.

In more serious cases, the patient is hospitalized to manage symptoms.

#### **HEPATITIS B (HBV)**

Sharing of drug paraphernalia, contact with contaminated blood, sex, and close household contact. Can be passed to babies during childbirth - vaccination within the first twelve hours after childbirth cuts that risk by 95%.

Can remain viable outside the body for many days - perhaps 30 or more.

Often does not have an acute phase (especially in children) and can remain "dormant" for many years (10-30) while it's damaging your liver. Can progress directly to liver cancer without first causing fibrosis (scarring of liver tissue).

A tiny organism - 42 nanometers - easily able to penetrate and infect cells in your body (a nanometer is one billionth of a meter, a meter is 39"). Atoms, molecules (and HBV) are measured in nanometers with an electron microscope.

This virus has been around for over 10,000 years.

#### **HEPATITIS C (HCV)**

Sharing of drug paraphernalia, contact with contaminated blood, sometimes transmitted through sex (especially men having sex with men). Having multiple sex partners, however, does increase your risk for infection.

Can be passed to babies during childbirth. Can remain viable outside the body for 16 hrs. to four days. Often does not have an acute phase and can remain "dormant" for many years while it's damaging your liver.

#### **HEPATITIS D (HDV)**

Hepatitis D is directly linked to active infection with Hepatitis B and is only found in persons with active HBV infection - not all those infected with HBV have HDV, however. Transmitted through needles and sex, although not as easily through sex as HBV. At the time of infection, people are more likely to have sudden and severe symptoms, called fulminant hepatitis.

#### **HEPATITIS E (HEV)**

Similar to Hepatitis A (HAV) - infection is usually acute but does not become chronic. HEV (like HAV) is spread by eating or drinking contaminated food or water. Not common in the US, but always be careful if you're traveling in underdeveloped countries.

**Hepatitis B and especially C are ticking time bombs in our national and international health profiles !**

Up until 1990 or so, people were still getting paid to donate blood. Many of them were drug users. Until 1989, Hep C was known as NANB Hepatitis (non-A, non-B Hepatitis). Screening of the blood supply for this virus did not begin until approximately 1990. If you received any blood products prior to 1992, you are at risk!

It is estimated that 3% of the world's population (over 170 million people) have chronic Hep C. These numbers are probably low. Since the virus can remain undetected and lay dormant for so long, many who acquired this virus in the sixties, seventies, and eighties are only now getting to the point where something will start to manifest in the form of liver problems. Health officials are expecting an a sharp increase over the next 10-15 years in people diagnosed with this condition.

**WHAT CAN YOU DO?  
GET TESTED !!!**

**Get tested for hepatitis A, B & C and also for hemochromatosis. These are the silent liver killers. Be thorough....test for HIV, too.**

The tests to determine if you have ever been exposed to hepatitis are simple and easy. Blood is drawn and checked for antibodies. If you have antibodies, you have had at least some exposure and may or may not be chronic. You may have been exposed and been lucky enough to clear the virus without becoming chronically infected.

If you test positive for Hepatitis A (HAV) antibodies, you may remember having something like the flu, perhaps with some yellowing of the eyes or skin. You may not have experienced those symptoms, however, and your body may have cleared the virus without you even knowing you had been exposed. Most people exposed to HAV clear the virus without assistance.

If you test positive for Hepatitis B or C (HBV, HCV), you will have to have further tests run to see if you are chronically infected or if you cleared those viruses without becoming chronic. More about those tests in a moment.

**If you test negative for HAV and HBV it means you have never been exposed and you can be vaccinated!**

(Note that the vaccine for HBV is NOT effective approx. 10% of the time - it does not "take")

The vaccination is a series of three shots at different intervals. You should have your entire family tested. Since HBV especially is so easily sexually transmitted, the CDC recommends vaccination for anyone who is sexually active. These shots are a routine part of childhood vaccinations.

**If you test negative for Hepatitis C (HCV), count your blessings - there is NO VACCINE for HCV.**

**Most County Health Departments offer free or low-cost testing for anyone with a history of injection drug use. There is also an over-the-counter test kit available called Hep C Check. Your best choice for testing is your family doctor.**

**\*\*IF YOU TEST POSITIVE FOR HEPATITIS\*\***

It is very important that your doctor test for IgG antibodies for HBV. This is a complete antibody that appears if you have been infected and have cleared the virus on your own. People who have been vaccinated also have this complete antibody. If you do not have this complete antibody, you do not have viral clearance or immunity. If you test positive for the antibodies discussed below but negative for the IgG, you have further testing ahead of you and you will need to make a decision about the physician you will be seeing. If you were initially diagnosed by a General Practitioner (GP) who is knowledgeable about hepatitis, you can stay with that doctor. You can ask to be referred to a gastroenterologist - a physician who is responsible for everything in your digestive tract, beginning to end. A better choice would be a hepatologist - a liver specialist.

**FURTHER TESTING FOR HEPATITIS B (HBV)**

1. To picture the HBV cell, imagine a core (which contains core antigens) surrounded by a ring of DNA, enclosed within an envelope and then enclosed within a ring of protein cells called a surface antigens. As you will see, the structure and behavior of HBV is different from HCV. Testing is also done differently and looks for components specific to HBV - surface antigens and core antigens. First, let's back up one step. An antibody is a protein in your blood that recognizes certain components of infecting organisms (like viruses and bacteria). An antigen is a protein or other chemical component of a virus or bacteria that is recognized by antibodies. The HBV surface antigen (HBsAg) is readily detectable in the blood and is the main test for infection. The HBV core antigen (HBcAg), however, is detectable in liver cells - if the infection is aggressive, a smaller version of the core antigen can be found in the blood. This smaller core antigen is known as BeAntigen (HbeAg). High levels of HbeAg core antigens are usually associated with more rapid disease progression and a higher risk of infecting others.

HBV can be acute or chronic. Disease progression seems to be tied to one's age at the time of infection. Those infected in childbirth, infancy or at a young age seem to become chronically infected, but do not necessarily have severe disease early on. A child given a vaccination within twelve hours of birth has a reduced infection risk of about 95%! This also allows the mother to safely breast feed her infant. Those infected later in life seem to be more at risk for severe liver damage in the short term, but are also more likely to get rid of the virus without medical treatment. Most people infected as adults go through an acute stage. HBV tends to be generally more aggressive than HCV in the acute phase, but only about 5 percent of those infected going on to become chronic at a low-key level. Many people infected with HBV will end up having to seek treatment. HBV can go straight to liver cancer without first causing fibrosis.

HBV has eight different varieties (also known as genotypes, A-H), and there are subtypes (Aa, Ab, sometimes seen also as Aa(A1), Ab(A2), etc.).

\_\_\_\_\_ Tests should be run to determine your viral load and, as is the case with Hepatitis C, you may need to have a liver biopsy to determine the level of damage to your liver (if any). At this time, a biopsy is the only sure way to determine or rule out damage to the liver. Certainly you should have a complete blood count test (CBC) including a liver panel to check your liver enzymes (AST and ALT), bilirubin, albumin, cholesterol, iron levels, diabetes factors, and AFP (alpha-fetoprotein, a tumor marker). Your doctor may also want you to have a sonogram to check for tumors - some of the sneaky liver cancers do not produce enough AFP to show up on a blood test. \_\_

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### **FURTHER TESTING FOR HEPATITIS C (HCV)**

1. A CBC (complete blood count) and comprehensive metabolic panel should be run with emphasis on liver enzymes (ALT and AST), bilirubin, albumin, triglycerides, thyroid functions, serum iron levels and rheumatoid arthritis markers. Alpha-fetoprotein (AFP) should be checked and, again, your doctor may want you to have a sonogram to check for tumor activity. See Appendix 1 for more information on specific liver panel test results.
  
2. You should have a quantitative analysis of how many copies of the virus you have in your blood. Blood is drawn and the number of viral RNA copies in a certain measure of blood is assayed. This is called your viral load. A high count, however, is not necessarily an indication of disease severity or a tool to predict disease progression. This test is most critical while you are in treatment. It will allow your doctor to determine if the treatment is working and if treatment should be discontinued due to a lack of reduction in viral load. Literally millions of RNA copies can be contained in a very small amount of blood.
  
3. Your doctor should run a genotyping test. There are six different genetic variations of HCV (called genotypes = genetic types). Each of those genotypes has what are called subtypes. Blood will be drawn and sent off to a special lab where they will determine if you are a 1a, 2b, 1d, 5c, 3a or whatever the test might happen to yield. Overall, including subtypes, there are roughly 60 variations. Genotyping is important because it determines how long you have to undergo treatment to clear this virus from your system. Genotype 1 is the most common genotype in the U.S., comprising about 85 % of the cases. Approximately 10 - 12 % of the remaining cases are genotype 2 or 3. Genotypes 4, 5 and 6 are found mostly outside the U.S., but some are found here. If you are a genotype 1 or 4 and if it is determined that you need to undergo treatment, you will have to treat for 48 weeks using a combination of pegylated interferon and an antiviral called ribavirin. Genotypes 1 and 4 are the most difficult to treat. If you have not cleared the virus (see #2 regarding viral load testing) by week 12, treatment will almost certainly be discontinued. This is because of the unpleasant side effects associated with treatment - no point in making you that miserable if the drugs are not working. Unfortunately for those with genotype 1, failure at week 12 is relatively common with only about a 50 - 60 % success rate at that 12-week juncture. Even more unfortunately for those with genotype 1, relapse after 48 weeks of treatment happens in about 30 - 40 % of cases. Re-treatment is sometimes an option for those people. If you clear the virus and remain clear in followup tests at six months and one year, you have probably achieved what is called a sustained viral response (SVR) and relapse and retreatment should be out of the picture. If you have been diagnosed with genotype 2 or 3, you should be able to treat (if necessary) for only 24 weeks. Once again, you will be assessed at week twelve. These two genotypes, however, have a good rate of success with 75-90 % of patients achieving an SVR and a very low relapse rate. You will still receive followup tests at six months and one year. To be safe, testing is advised for all genotypes for several years following treatment.
  
4. Last, but certainly not least, you will have a liver biopsy. This is an outpatient procedure done at the hospital. A small sample of liver tissue will be extracted (approximately 1" long by 1/16th" or less in diameter). Tiny slices taken from this tissue will be examined under a microscope to determine what damage, if any, the virus has done to your liver. This is called staging. You will receive a 2-number diagnosis. The first number is the "grade" of inflammation and the second is the "stage" of scarring (fibrosis).



There are four basic stages of fibrosis. In the most commonly used staging system, the Knodell system, the damage to the liver is scored as follows:

- 0 = no scarring
- 1 = minimal scarring
- 2 = scarring has occurred and extends outside the areas in the liver that contains blood vessels
- 3= (bridging fibrosis) scarring that is spreading and connecting to other areas that contain fibrosis
- 4=cirrhosis or advanced scarring of the liver

If you have mostly inflammation and little scarring, you and your doctor are in charge of your prognosis. Once you have reached the point of cirrhosis, you are in trouble. The liver is very forgiving, but scarring is usually irreversible. Early diagnosis is critical and can literally be a life or death matter.

### **TREATMENT OF HEPATITIS B (HBV)**

There are currently six drugs available to treat chronic HBV: Baraclude (entecavir), Epivir (lamivudine; 3TC), Intron A (interferon alfa-2b), Hespera (adefovir dipivoxil), Pegasys (interferon alfa-2a) Tyzeka (telbivudine). For more information on these drugs, please go to [www.hivandhepatitis.com](http://www.hivandhepatitis.com) and click on the "Hepatitis B" button at the top of the page. You can also go to Google and type in each drug name for more information. Both forms of interferon mentioned above are also used to treat HCV.

### **TREATMENT OF HEPATITIS C (HCV)**

You may treat HCV at any stage of fibrosis. This is a decision you need to discuss with your doctor. If you are at or beyond than Stage 2, you should seriously consider treatment.

Different genotypes have to treat for different lengths of time. Genotype 1, the most common type in America, treats for 48 weeks but with a caveat - remember we discussed measuring your viral load. If you are a genotype 1 and you begin treatment and you do not reach a point at week twelve of no detectable virus in your system, your treatment will most likely be discontinued. You will be classified as a non-responder. This is not necessarily the end of the world. If you started with the drug manufactured by Roche, you may respond better to the interferon produced by Schering-Plough. Also, many new drugs are currently being tested for this virus and will hopefully be available in the next few years. Genotype 4 also treats for 48 weeks. Genotypes 2 and 3 treat for 24 weeks. They are much more responsive to treatment (especially type 2) and the relapse rate is low. Unfortunately, the relapse rate for type 1 and 4 is fairly high. Sadly, this means that you can be "clear" at week twelve, go through the whole 48-week treatment and then find out at your 6-month or 1-year followup that the virus has come back. I say sadly because the side effects of the two drugs range from mildly uncomfortable to downright miserable. As is the case with any drug, everyone responds differently. For example, if you and I both have a headache and we both take two aspirin, we might both get rid of the headache, but you might have an upset stomach from the aspirin and I might not. There's just no way to know until you start treatment - there are no predictors for side effects. These side effects will be itemized shortly.

The drugs used to treat HCV are pegylated interferon and an antiretroviral, ribavirin. These drugs are manufactured primarily by Roche and Schering-Plough. There are other drugs (protease and polymerase inhibitors) and other forms of interferon being developed by these two companies and other companies. We'll get to those other options in a bit.

Interferons are a naturally-occurring part of your immune system. They are proteins produced by the cells of the immune system in response to challenges by foreign agents such as viruses, bacteria, parasites and tumor cells. Interferons assist the immune response by inhibiting viral replication within other cells of the body.

Pegylated interferon is a man-made replica of natural interferon and the pegylation process gives the drug a longer life in your system. Shots of pegylated interferon are administered once a week subcutaneously in the abdomen. Before pegylation, shots had to be taken three times a week to maintain a sufficient level of the drug in your system.

The other drug used in treatment is called ribavirin and it is an anti-retroviral. Its function is also to inhibit viral reproduction. Ribavirin is a pro-drug, meaning that it is a chemical precursor for the actual pharmacologically active molecule. When the pro-drug is administered, the body converts it into the desired chemical. Both drugs are intended to boost your own immune system in the fight against the virus. These drugs have different names depending on the pharmaceutical company of origin. Roche's drugs are PegIntron/Rebetol, Schering-Plough's drugs are Pegasys/Copegus.

The side effects of both interferon and ribavirin are well documented. Interferon produces flu-like symptoms (chills, fever, nausea, headache, aching joints), depression in some people, fatigue, insomnia, hair thinning or loss, sores in the mouth and throat. Less frequent side effects can include hearing loss and retinopathy (damage to the retina). Ribavirin's most pronounced side effect is hemolytic anemia. This must be carefully monitored as it may worsen pre-existing heart conditions. If you are a woman, you should avoid becoming pregnant during treatment and for at least six months after treatment is over. Don't allow a man in treatment to impregnate you. Ribavirin can cause birth defects.

The side effects with this drug combination can be severe enough to cause people to discontinue treatment. One of the main functions of your treating physician as you go into treatment (besides monitoring your progress in combating the virus) is to manage side effects. As was stated before, however, you won't know until you get into treatment and start using the drugs. I did have someone tell me of two different people who started treatment on the same day. One left the clinic to walk home (a distance of three blocks), got about two blocks, called and said, "I don't think I'm going to make it!". (He did.) The other person lived out of town, headed out after doing the shot, got about 45 minutes out, called and said. "You promised me that everyone in this trial would get drugs, that there were no placebos - I don't feel anything!". Both were on the same drugs. Your doctor will do a complete workup on you - both physical and psychological - prior to treatment and will very carefully monitor you the entire time you're in treatment. As with any medical situation, it is imperative that you be totally honest with your doctor. If you are taking or using any other substances, legal or not, you **MUST** discuss this with your doctor. I do mean anything - herbs, pot, alcohol, vitamins, aspirin - anything!

Side effects for most people resolve fairly quickly after treatment is over. By six months, you could very well be feeling 80-95%. By the end of a year, all side effects should have resolved. Once again, however, remember that everyone is different.

## **THE OTHER SILENT KILLER - HEMOCHROMATOSIS**

Hemochromatosis (sometimes seen as "hemachromatosis") is an inherited metabolic disorder - it is not a disease. It can be acquired, but not from any kind of contact with another person (more about that in a bit). It is most often seen in people of Northern European, Baltic, Celtic and Scandinavian descent, and also those with Jewish heritage. Approximately 10-13 % of the population are carriers for this condition and it is one of the most under-tested health disorders. Additionally, persons affected by this disorder have unusually high levels of the protein that binds with iron to keep it in the body - a protein called ferritin. Both the mother and father of a child have to be carriers of the altered gene for the disorder to be passed along to their child. As that child matures, iron begins building up in their body. That iron is mostly stored in the liver and over time will completely destroy the liver. Not all children born to "carrier" parents will be equally affected.

The excess iron can also damage the heart, the pancreas, the joints and the brain. It builds up slowly and may not be apparent in blood tests until someone is in their fifties or sixties. In women, the diagnosis can occur even later because of menstruation. Iron is carried in the bloodstream and women lose some blood every month, causing the buildup of excess iron in the body to move at a slower pace. Some women are not diagnosed until they become menopausal. Once again, because this is a condition that affects the liver, symptoms can be slow to appear, low-key, and subtle. This condition does not necessarily cause cirrhosis, but can cause organ failure - liver, kidney and heart failure are most common.

Two simple blood tests and one more in-depth blood test are needed to check for this condition. One tests the level of ferritin protein in your system, one checks your serum iron saturation percentage and the third checks for the chromosomal genetic variation that confirms the presence of this condition. If found at an early stage or age, this is a condition that is simple to treat. The treatment is phlebotomy - blood draws. If you have been diagnosed with this condition, your doctor will start you on a schedule of blood draws (usually done at a blood bank) and you may have a blood draw as often as once a week until all of the excess iron has been depleted from your body tissues and blood stream. Depending on how much iron is in your system when this process begins, this can take up to or even over a year. Once your iron levels are under control, you will be on a lifetime regimen of blood draws, usually at regular intervals like once every two or three months. If you do not faithfully adhere to this regimen, iron will once again build up in your body and damage your organs. If anyone in your family tests positive for this condition, everyone should be tested (especially if you're a parent - have your children tested - early diagnosis could save their life!)

### **WHAT ARE THE SYMPTOMS?**

The symptoms are in many ways the same as they are for hepatitis. Certainly you should look at the list for symptoms of liver disease that appeared here earlier. Additionally, however, because the iron can also affect other organs in the body, you may experience:

- Chest pains/heart attacks
- Kidney distress or failure
- Mental disorientation, confusion, inability to concentrate
- Enlarged liver and elevated liver enzymes (ALT and AST)
- Skin that has a grayish or bronze coloration
- Arthritis
- Diabetes
- Peripheral neuropathy (numbness in the extremities)
- Hair loss

This is another condition where the symptoms whisper - you have to be aware and you have to "listen" to your body! Your body will almost always tell you when something is wrong, but you have to be listening.

### **SECONDARY HEMOCHROMATOSIS**

Remember that I mentioned that hemochromatosis could be acquired instead of inherited. Repeated blood transfusions for thalassemias ( a condition that affects the production of hemoglobin) and iron supplementation for anemia are the two most common causes.

Oddly enough, blood that is drawn from a person with iron overload can be used for someone else in, say, a surgery setting. A person with a normal system will simply excrete the excess iron. You wouldn't want iron-rich blood if you needed blood on a regular basis, but one unit or a one-time transfusion won't damage you.

Please see the Appendix at the end of this paperwork for information on a bacterial infection that is particularly voracious in people with hemochromatosis - it's found in raw or undercooked shellfish and can also be found in the sand at the beach.

## **REFERENCES**

### **READING MATERIALS - HEPATITIS**

Living With Hepatitis C: A Survivor's Guide, Gregory T. Everson, M.D.

- All the basics

The Hepatitis Help Book, Misha Ruth Cohen, O.M.D, L.A.C and Robert Gish, M.D.

- Offers the basics plus an Asian perspective for alternative therapies

### **INTERNET RESOURCES - HEPATITIS**

The American Liver Foundation - <http://www.liverfoundation.org>

Information about all liver conditions, acquired and inherited

\_\_\_\_\_PH: 212/668-1000

<http://hivandhepatitis.com>

\_\_\_\_\_A comprehensive and easy-to-navigate web site. Covers the basics about all forms of hepatitis, HIV/AIDS, and HIV/Hepatitis co-infection. Staffed by medical personnel with information geared more toward medical professionals than laypersons. Presents detailed information from all HIV and liver disease related medical conferences worldwide.

HCV Advocate website - <http://www.hcvadvocate.org>

A comprehensive and easy-to-navigate site with lots of information and news

Information in 20+ languages. Started by a HCV survivor, Alan Franciscus.

American Association for the Study of Liver Diseases (AASLD) - <http://www.aasld.org>

European Association for the Study of Liver Diseases (EASL) - <http://www.easl.org>

Hepatitis B Foundation - <http://www.hepb.org>

UNOS - United Network of Organ sharing. Donor and transplant information, transplant facilities listings. <http://www.unos.org/>

### **READING MATERIALS - HEMOCHROMATOSIS**

Living With Hemochromatosis, Gregory T. Everson, M.D.

The Iron Disorders Institute Guide to Hemochromatosis, multiple authors

Exposing the Hidden Dangers of Iron, E. D. Weinberg, Ph.D.

### **INTERNET RESOURCES - HEMOCHROMATOSIS**

American Liver Foundation - <http://www.liverfoundation.org>

PH: 212/668-1000

American Hemochromatosis Society - <http://www.americanhs.org>

(If you have trouble accessing this site, their phone # is 888/655-IRON)

### **OTHER RESOURCES**

Centers For Disease Control (CDC) - <http://www.cdc.gov>

Metabolic Liver Diseases - Mendelian Inheritance in Man - <http://www.ncbi.nlm.nih.gov>

Also look here for medical literature - free searches for primary literature, often with associated abstracts

Clinical Trials - <http://clinicaltrials.gov>

Lab tests - <Http://www.labtestsonline.org>

Anything you could ever want to know about your lab test results or about tests the doctor has ordered for you. Go here to look up tests that are going to be run or have already been run to see why they were run (what the doctor is looking for) and what those tests tell you and your doctor

## **Appendix 1 - Liver Function Tests**

The term "liver function tests" and its abbreviated form, "LFTs," is a commonly used term that is applied to a variety of blood tests that assess the general state of the liver and biliary system. Routine blood tests can be divided into those tests that are true LFTs, such as serum albumin or prothrombin (a plasma protein, coagulating factor) time, and those tests that are simply markers of livers or biliary tract disease, such as the various liver enzymes. In addition to the usual liver tests obtained on routine automated chemistry panels, physicians may order more specific liver tests, such as viral serologic tests or autoimmune tests that, if positive, can determine the specific cause of a liver disease.

There are two general categories of "liver enzymes." The first group includes the alanine aminotransferase (ALT) and the aspartate aminotransferase (AST), formerly referred to as the SGPT and the SGOT. These are enzymes that indicate liver cell damage. The other frequently used liver enzymes are the alkaline phosphatase (alk. phos.) and the gammaglutamyltranspeptidase (GGT) that indicate obstruction to the biliary system, either within the liver or in the larger bile channels outside the liver.

The ALT and AST are enzymes that are located in liver cells and leak out and make their way into the general circulation when liver cells are injured. The ALT is thought to be a more specific indicator of liver inflammation, since the AST may be elevated in diseases of other organs such as the heart or muscle. In acute liver injury, such as acute viral hepatitis, the ALT and AST may be elevated to the high 100s or over 1,000 U/L. In chronic hepatitis or cirrhosis, the elevation of these enzymes may be minimal (less than 2-3 times normal) or moderate (100-300 U/L). Mild or moderate elevations of ALT or AST are nonspecific and may be caused by a wide range of liver diseases. ALT and AST are often used to monitor the course of chronic hepatitis and the response to treatments, such as prednisone and interferon.

The alkaline phosphatase and the GGT are elevated in a large number of disorders that affect the drainage of bile, such as gallstone or tumor blocking the common bile duct, or alcoholic liver disease or drug-induced hepatitis, blocking the flow of bile in smaller bile channels within the liver. The alkaline phosphatase is also found in other organs, such as bone, placenta and intestine. For this reason, the GGT is utilized as a supplementary test to be sure that the elevation of alkaline phosphatase is indeed coming from the liver or the biliary tract. In contrast to the alkaline phosphatase, the GGT is not elevated in diseases of the bone, placenta or intestine. Mild or moderate elevation of GGT in the presence of a normal alkaline phosphatase is difficult to interpret and is often caused by changes in the liver cell enzymes induced by alcohol or medications, but without causing injury to the liver.

Bilirubin is the main bile pigment in humans that, when elevated, causes the yellow discoloration of the skin and eyes called jaundice. Bilirubin is formed primarily from the breakdown of substance in red blood cells called "heme." It is taken up from blood processed through the liver, and then secreted into the bile by the liver. Normal individuals have only a small amount of bilirubin circulating in blood (less than 1.2 mg/dL). Some conditions, including liver disease or the destruction of red blood cells, cause increased levels of bilirubin in the blood stream. Levels greater than 3 mg/dL are usually noticeable as jaundice. The bilirubin may be elevated in many forms of liver or biliary tract disease, and thus it is also relatively nonspecific. However, serum bilirubin is generally considered a true

test of liver function (LFT), since it reflects the liver's ability to take up, process and secrete bilirubin into the bile.

Two other commonly used indicators of liver function are the serum albumin and prothrombin time. Albumin is a major protein formed by the liver, and chronic liver disease causes a decrease in the amount of albumin produced. Therefore, in more advanced liver disease, the level of the serum albumin is reduced (less than 3.5 mg/dL). The prothrombin time, which is also called protime or PT, is a test that is used to assess blood clotting. Blood clotting factors are proteins made by the liver. When the liver is significantly injured, these proteins are not normally produced. The prothrombin time is also a useful test of liver function, since there is a good correlation between abnormalities in coagulation measured by the prothrombin time and the degree of liver dysfunction. Prothrombin time is usually expressed in seconds and compared to a normal control patient's blood.

Finally, specific and specialized tests may be used to make a precise diagnosis of the cause of liver disease. Elevations in serum iron, the percent of iron saturated in blood, or the iron storage protein ferritin may indicate the presence of hemochromatosis, a liver disease associated with excess iron storage. In another disease involving abnormal metabolism of metals, Wilson's disease, there is an accumulation of copper in the liver, a deficiency of serum ceruloplasmin and excessive secretion of copper into the urine. Low levels of serum alpha1-antitrypsin may indicate the presence of lung and/or liver disease in children or adults with alpha1-antitrypsin deficiency. A positive antimitochondrial antibody indicates the underlying condition of primary biliary cirrhosis. Striking elevations of serum globulin, another protein in blood, and the presence of antinuclear antibodies or antismooth muscle antibodies are clues to the diagnosis of autoimmune hepatitis. Finally, there are specific blood tests that allow the precise diagnosis of hepatitis A, hepatitis B, hepatitis C and hepatitis D.

### **For those with hemochromatosis -**

#### RISKS OF EATING RAW OR UNDERCOOKED SHELLFISH

*Advice for persons with liver disease, diabetes, or weakened immune systems...*

#### **Did you know?...**

Each year, millions of Americans enjoy eating raw molluscan shellfish -- especially oysters and clams. But if you have a **liver disease, diabetes, or a weak immune system**, raw oysters or clams containing the bacteria *Vibrio vulnificus* can make you seriously ill.

You can avoid illness simply by:

Eating only oysters or clams that have been thoroughly cooked.

Eating raw oysters or clams only if they are treated and labeled "Processed to reduce *Vibrio vulnificus* to non-detectable levels."



## **What is *Vibrio vulnificus*?**

*Vibrio vulnificus* is a bacteria that can cause severe illness or death to at-risk people who eat raw oysters or clams. From 1989 to 2000, the U.S. Food and Drug Administration (FDA) recorded 282 serious illnesses associated with consumption of raw oysters and clams containing the *Vibrio vulnificus* bacteria. While illnesses are infrequent, about half (149) have resulted in death.

## **Where is it found?**

*Vibrio vulnificus* is found naturally in warm coastal waters, such as the Gulf of Mexico, where levels of the bacteria are elevated during the summer months. *Vibrio vulnificus* is NOT a result of pollution, and can be found in waters approved for oyster and clam harvesting. *Vibrio vulnificus* does NOT change the appearance, taste, or odor of oysters or clams.

## **Are you at risk?**

You are at risk of serious illness if you eat raw oysters or clams and have any of these health conditions:

- Liver disease (from hepatitis, cirrhosis, alcoholism, or cancer)

- Iron overload disease (hemochromatosis)

- Diabetes

- Cancer (including lymphoma, leukemia, Hodgkin's disease)

- Stomach disorders

- Or any illness or medical treatment that weakens the body's immune system

Unsure of your risk? Ask your doctor.

*Healthy people are not at risk of serious infection.*

## **How can you avoid infection?**

If you are at risk, raw or undercooked oysters or clams containing *Vibrio vulnificus* can make you sick.

You can also become infected if these bacteria enter your body through an open wound while swimming in ocean water.

To safeguard your health, take these precautions:

- EAT oysters or clams that have been THOROUGHLY COOKED -- heat destroys the bacteria.

- EAT raw oysters or clams ONLY if they are treated and labeled "Processed to reduce *Vibrio vulnificus* to non-detectable levels."

### **What are the symptoms?**

Symptoms usually occur within 24-48 hours, and may include:

Fever/chills

Skin lesions

Stomach pain/nausea

Vomiting

Diarrhea

Shock

If you have any of these symptoms after eating raw oysters or clams, **seek medical attention immediately.**

For those at risk, infection can lead to death within two days. Early, aggressive antibiotic treatment is the most effective therapy.

*Vibrio vulnificus* rarely affects healthy individuals. When it does, symptoms are mild and temporary.