

Hepatitis Education Project

Frequently Asked Questions About

Hepatitis C

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**Originally written by the late David Lang, HEP Board Member
Born March 9, 1950, Died June 26, 2001**



1. What is a Virus?

A virus is a piece of genetic material surrounded by a protein shell. The protein shell attaches itself to cellular membranes and invades the cell by fusion. Viral replication occurs in the cytoplasm of the invaded cell. Virions are then transported to the cellular membrane and released.

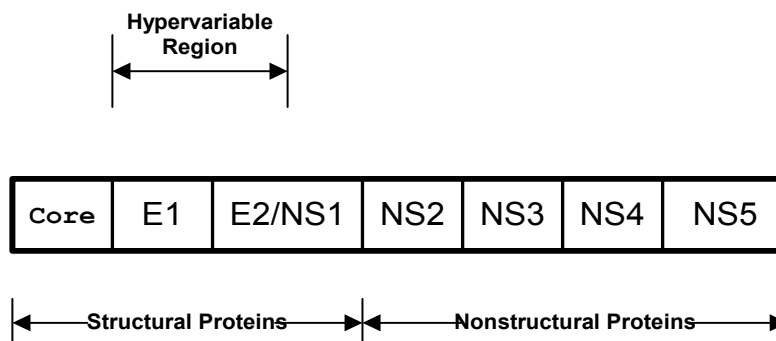
2. What is the Hepatitis C Virus?



Hepatitis literally means inflammation of the liver. Hepatitis C is caused by a virus, sometimes referred to as HCV. The hepatitis C virus is a flavivirus. Other flaviviridae are; St. Louis encephalitis, Powassan encephalitis, Yellow Fever and Dengue Fever. The hepatitis C virus (HCV) is species specific. Humans and chimpanzees can be infected with the virus. HCV is also organ specific. It only replicates in liver cells although it may be found in others.

There are six known genotypes of HCV; 1a, 1b, 2a, 2b, 3a, 3b. In the US over 80% of genotypes found are 1a and 1b. **The hepatitis C virus replicates inside its host every 7 to 9 hours and typically produces about 1 trillion viral copies per day.** The virus is able to evade the host's immune system by mutating the hypervariable regions (E1, E2 envelope glycoprotein) of the viral genome. The resulting mutation is called a quasi-species.

HCV is the leading cause of liver transplantations in the US. At present an estimated 10,000-12,000 Americans die each year from complications of the hepatitis C virus. The CDC estimates that number will triple in the next 10 years.



Hepatitis C Genome Structure

3. What are the risk factors for HCV transmission?

HCV is transmitted primarily through blood-to-blood contact. Risk factors include: receiving blood, blood products or organs before 1992, intravenous drug use, needlestick injuries, long-term kidney dialysis, and hemophilia. HCV can also be transmitted through tattoos, piercing and acupuncture if heat sterilization of tools by autoclave is not used. Other potential modes of transmission are intranasal cocaine use, sharing of toothbrushes, razors, nail files, or nail clippers with an infected person, and unprotected sex with multiple partners. Mother to child transmission occurs in about 5% of mothers who are HCV positive. Monogamous sexual partners with hepatitis C patients show less than 5% contract HCV and that may be due to other risk factors. HEP would urge everyone with any of the above risk factors to be tested for hepatitis C.

HCV is not transmitted through casual contact such as shaking hands, hugging, sneezing, coughing, and sharing a glass, utensils, and combs or by nursing infants.

4. What is the Natural History of Hepatitis C?

After initial contact with the virus, the incubation period until the virus is detectable is from 2 to 6 weeks. The acute period of the disease is the first 6 months after the initial infection. After six months, 85% of patients will fail to clear the hepatitis C virus and become chronic. Chronic HCV may take 10 to 20 years or more to progress to liver damage. In 20% of patients with chronic hepatitis C, liver disease will slowly advance to cirrhosis of the liver during the first 10-20 years. HCV patients with heavy to moderate alcohol consumption may develop cirrhosis, or scarring of the liver, and end stage liver disease in as little as 5 to 7 years. Hepatocellular Carcinoma (HCC) will develop in 1 to 5% of HCV patients with cirrhosis of the liver. HCC develops more commonly in men than women.

Anyone diagnosed with HCV is urged to have a liver biopsy. **A liver biopsy is the only method by which liver damage can be correctly assessed.** An initial biopsy can be used as a baseline for future testing and evaluation. A liver biopsy may show:

Inflammation

Periportal necrosis

Interlobular necrosis

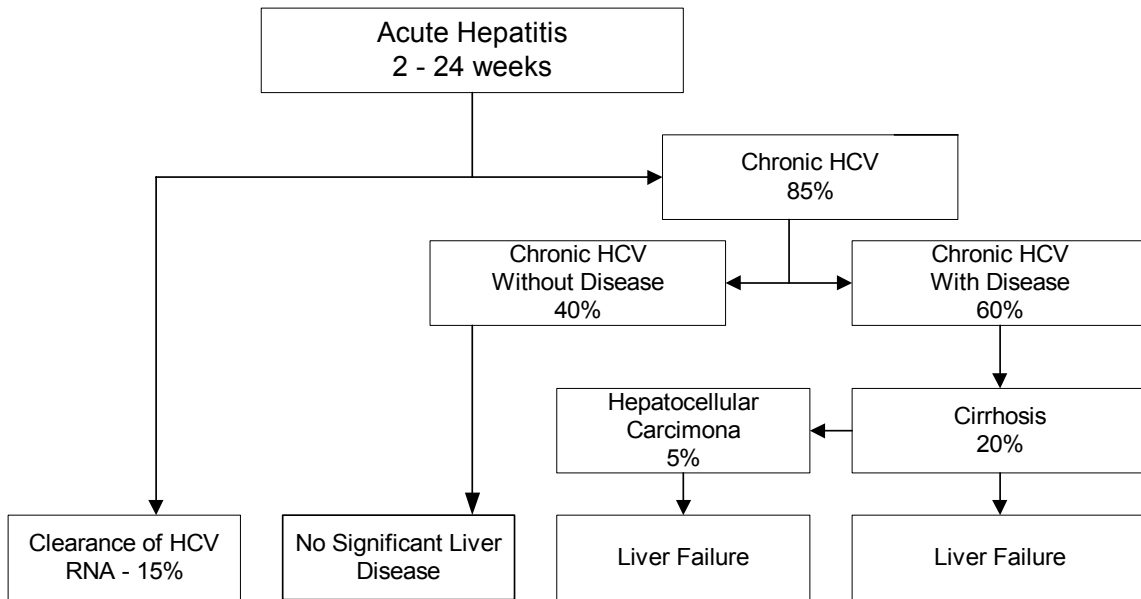
Portal inflammation

Fibrosis

Bridging Fibrosis

Cirrhosis

There is no correlation between ALTs and symptoms, symptoms and pathology or ALTs and pathology. In other words, there is no clear relation between symptoms, liver disease progression, liver enzymes and viral load.



Natural history of HCV infection

5. How is Hepatitis C diagnosed?

Anyone with elevated liver enzymes, ALT and AST, shown in their blood panels should be screened for HCV. An antibody screening test, ELISA (Enzyme-Linked ImmunoSorbent Assay), is effective in screening 90% of patients with HCV. Antibody screening tests are not accurate for acute stages of the disease or immune suppressed or immune deficient patients. A qualitative PCR (polymerase chain reaction) test is used as a confirmatory test. A PCR test detects RNA genetic material of the virus in the blood serum. PCR is extremely sensitive and can detect as few as 10 viral copies per milliliter of blood serum. Qualitative PCR results are measured as positive or negative for the presence of the hepatitis C virus. In 1 to 3 weeks after initial exposure, HCV RNA can be detected in blood.. A quantitative PCR test measures the number of viral copies per milliliter. Quantitative PCR testing and genotyping of HCV RNA can be used as a predictor of response to therapy.

6. What are the Extrahepatic Symptoms of Hepatitis C?

In acute hepatitis C patients 30% have flu-like symptoms while 70% are asymptomatic. Less than 20% of chronic HCV patients have extrahepatic (outside the liver) symptoms. In some cases symptoms can be disabling. Extrahepatic HCV symptoms may include:

- | | |
|--------------|------------------------|
| Fatigue | Pain in Joints |
| Nausea | Short Term Memory Loss |
| Malaise | Dizziness |
| Stomach Pain | Vascular Spiders |

Pain in Upper Right Quadrant

Some extrahepatic diseases that are associated with hepatitis C patients are:

Depression - Sadness, lethargy, despair, anger, insomnia, poor appetite, or weight gain, obsessive thoughts, and terrible guilt without a loss or out of proportion to the loss.

Essential mixed cryoglobulinemia - The presence of cryoglobulins in the blood. These are abnormal forms of protein molecules that precipitate in the extremities at cold temperatures and re-dissolve at normal body temperatures. This can cause skin rashes and joint pain.

Fibromyalgia – Diffuse body-wide pain that is often disabling.

Glomerulonephritis – A kidney disease similar to Lupus.

Keraconjunctivitis sicca - A persistent dryness of the cornea and conjunctiva due to decreased function of the tear glands (Sjogren's syndrome).

Lichen planus – An autoimmune rash of unknown origin.

Neuropathy – Painful nerve damage, usually in the feet.

Non-Hodgkin's type, B-cell lymphomas – Cancer of the lymph gland system

Poor Appetite and/or Nausea

Porphyria cutanea tarda - Cutaneous lesions on exposed portions of the body frequently associated with alcoholism or hepatic disease.

Seronegative Arthritis - Inflammation of a joint or joints, characterized by pain, swelling, stiffness and redness.

Skin Rashes – Purpura, vasculitis or urticaria

7. What are the symptoms of advanced liver disease?

Only about 10 - 15% of those infected with the hepatitis C virus will progress to advanced liver disease. Symptoms of cirrhosis or end-stage liver disease are:

Swelling of the feet and ankles (edema)

Swelling of the abdomen (ascites)

Cryoglobulins

Dark colored urine

Enlarged Liver

Enlarged Spleen

Light colored or fatty stools

Pain in the right shoulder/neck area

Bruising easily

Flapping Tremors

Fainting

Blackouts

Loss of Cognitive Function

Variceal Bleeds

Hallucinations

Coma



8. What are the Treatment Options for Hepatitis C?

Alpha interferons either alone or in combination with the anti-viral ribavirin, are currently the only drugs scientifically shown to result in sustained response. Natural interferons are produced in the body when invaded by a virus. Interferon stimulates the immune system to attack the invading virus and any infected liver cells. Fevers, chills, nausea and general malaise are caused by the interferon your body releases. Interferon treatment has two goals: a) clearing the virus from your system and/or b) causing some remission of liver disease. Spontaneous remission of chronic HCV is something less than

1%. It is recommended that children only be treated with monotherapy since Ribavirin™ has not been adequately evaluated.

Studies of a long acting interferon, called pegylated interferon, are currently ongoing, and one form of pegylated interferon was approved by the FDA in early 2001. This interferon is injected once per week and is more effective than alpha interferons since it supplies a constant level of interferon to the body. Studies of pegylated interferon combined with ribavirin are currently ongoing and are showing better results than the current standard of care. This combination therapy may be approved some time in 2001.

The National Institutes of Health Consensus Development Conference recommends that treatment should be limited to those patients with progressive liver disease as evidenced by fibrosis, moderate to severe inflammation and necrosis by liver biopsy. Individuals with less severe degrees of histology should be managed on an individual basis.

Duration of treatment varies. For interferon monotherapy a 48-week treatment is recommended for any genotype. For combination therapy in patients with HCV genotype 2 or 3, a 24-week treatment is recommended. For combination therapy in HCV genotype 1, a 48-week treatment is recommended. Non-responders can be identified by assessing the ALT level and qualitative PCR at three months of treatment with interferon. Patients with abnormally high ALT levels and detection of HCV by PCR RNA are non-responders and treatment should be discontinued. Response rates vary according to some different factors. Genotypes 1a and 1b have a lower overall response rate than types 2a, 2b, 3a and 3b. Early detection of HCV infection can raise the response rate. A high viral titer (greater than 1mU/mL of blood serum) can negatively affect response rate. The presence of advanced liver disease can lower predicted response. **None of these predictors of response should be used to deny treatment!**

Contraindications for interferon treatment are: Patients with dual infections of HCV and HIV, patients who are active alcohol users, patients with solid-organ transplants, patients with clinically decompensated cirrhosis, patients with autoimmune hepatitis, patients who have been infected for many years without significant liver disease. Patients with clinical depression should be treated for depression before starting interferon treatment and then carefully monitored during interferon treatment.

Uncommon side effects of interferon treatment are: Autoimmune, especially thyroid, disease, severe bacterial infections, seizures, depression, retinopathy, hearing loss and tinnitus.

Side effects of Ribavirin can include anemia, fatigue and irritability, itching, skin rash, nasal stuffiness, sinusitis and cough, angina pectoris and some rare cases of myocardial infarction and stroke.

It is recommended that all HCV patients be inoculated for HAV and HBV. A dual infection with HCV + HBV can be devastating and a dual infection with HAV and HCV can be deadly.

A liver transplant is the treatment of last resort. It does not eliminate the hepatitis C virus and does not eliminate all extrahepatic HCV symptoms. Liver transplant patients with HCV are only given interferon treatment if the virus has become active to the point where the transplanted liver is being affected. Prognosis for a liver transplant patient with HCV is nearly the same as transplant patients without HCV or from 10 to 13 years (i.e., 50% mortality rate at 10 to 13 years post transplant).

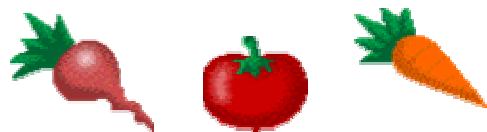
There are also many people who chose to treat their hepatitis through lifestyle changes and complimentary therapies. For information on alternative treatments – what to use and what to avoid - contact the Chairperson of the HEP Holistic-Nutritional Committee via the HEP office at 206-732-0311.



9. What Can I Do to Help Protect My Liver?

DO NOT DRINK ALCOHOLIC BEVERAGES! The destructive combination of alcohol and HCV is synergistic and exponential. Studies have shown that even moderate drinking, 1 to 2 drinks per day, can accelerate disease progression to cirrhosis. Your liver must process any substance that is inhaled, eaten or absorbed. If you use tobacco products, stop. Limit your coffee consumption. Avoid recreational drugs. Avoid toxins like gasoline and hydrocarbon fumes. Avoid oil-based paint or hardwood finish fumes. Avoid solvents or paint thinners that can be absorbed through the skin. If you are going to try herbal or other alternative therapies contact the Alternative Medicine Chair of HEP for information at 206-732-0311 and ask what to avoid and what will help.

10. What About Nutrition?



Unless you have cirrhosis of the liver, a balanced low-fat diet with 5 servings of fruits and vegetables and a minimum of 4 ounces of animal protein or the equivalent (1oz. Of animal protein = 1/2 cup of legumes) is recommended. Protein is very important since the liver converts protein into amino acids, the basic food of every cell in your body. Amino acids help liver cells regenerate. Individuals with hepatitis C should restrict the amounts of iron rich foods in their diet, such as red meats and cereals fortified with iron. If you take a multivitamin, choose one without iron. Iron may play a part in viral replication. Consult a registered nutritionist or dietician for detailed information.

For HCV patients with cirrhosis of the liver – **Consult a registered dietician**, preferably one with experience in treating patients with end stage liver disease. Patients with cirrhosis need diets specifically designed for each individual for their particular stage of disease. Since an impaired liver cannot convert protein as easily, protein intake should be

monitored to prevent ammonia buildup in the blood. Wasting of muscle tissue may warrant a higher fat intake. Amino acid supplements can be prescribed if needed.

11. Glossary

Acute infection – A suddenly occurring infection that may resolve itself or turn into a chronic infection.

ALT – Alanine aminotransferase (ALT) is an enzyme released from liver cells.

Amino acids – The basic food for all cells, amino acids are produced from protein processed in the liver.

Antibody – A molecule produced by the immune system in response to a foreign body.

Ascites – Fluid within the abdomen caused by cirrhosis of the liver.

AST – Aspartate aminotransferase (AST) is an enzyme released from liver cells.

Assay – A test or analysis.

Asymptomatic – Disease without signs of illness.

Biopsy (liver) – A thin sample of liver cells taken with a hollow needle.

Blood serum – Plasma in which blood cells are suspended.

Carcinoma – A cancerous tumor.

Chronic infection – An infection that lasts for a long period of time.

Cirrhosis of the liver – The result of long standing damage to the liver resulting in the formation of scar tissue and the increased resistance to the flow of blood through the liver.

Cognitive function – Recognition of objects and spatial relations.

Cytoplasm - The jelly-like substance that well-defined subcellular structures are suspended in.

DNA – DeoxyriboNucleic Acid is a component in the cells of all living matter that carries genetic information.

Edema – The swelling and fluid buildup in the feet and ankles.

ELISA – Enzyme-Linked ImmunoSorbent Assay (ELISA) is a test for the presence of HCV antibodies. Sometimes referred to as EIA.

Encephalopathy – Brain function abnormalities, which may include confusion, disorientation, insomnia, blackouts and may progress to coma.

Enzymes – Naturally occurring substances in the human body that help a chemical reaction take place.

Extrahepatic – Outside or not relating to the liver.

FDA – The Food and Drug Administration – A US Government agency formed to check the safety of our food supply and the safety and efficaciousness of drugs.

Fibrosis – Scar tissue in the liver.

Flapping tremors – With arms extended in front of the body and palms outward with fingers pointing up, hands will “flap” in unison. Flapping tremors are a symptom of advanced cirrhosis of the liver.

Flavivirus – A group of related RNA viruses including the hepatitis C virus.

Genotype – Genetic information that is unique to an organism.

HAV - Hepatitis A Virus – transmitted by any bodily fluid, especially fecal matter. Commonly contracted through contaminated food.

HBV – Hepatitis B Virus – commonly transmitted through sexual or blood contact.

HCV – Hepatitis C Virus – commonly contracted through blood-to-blood contact.

Hemodialysis – Blood cleansing technique used for renal (kidney) failure.

Hemophilia – A hereditary bleeding disorder.

Hepatic – Related to the liver.

Hepatocellular carcinoma – Liver cancer detected by measuring Alpha Feto Protein in blood serum.

Histology – The study of microscopic tissue and/or cells.

Interlobular Necrosis – Dead liver cells between liver micronodules.

Knodell scale – A method of scoring liver damage from inflammation to cirrhosis. See references.

Malaise - A vague feeling of bodily discomfort.

Non-responder – A HCV patient that has had no response to interferon treatment.

Partial responder – A HCV patient who has responded to interferon treatment but relapsed.

Pathology - The study of the causes of diseases or abnormalities.

PCR – Polymerase Chain Reaction – A method of testing for minute quantities of DNA and RNA.

Pegylated interferon – Interferon bonded with a long chain protein, propylene glycol.

Periportal necrosis – Dead liver cells in the periportal portion of a liver lobule.

Portal inflammation – Inflammation of the portal vein.

Portal vein – The large vein feeding into the liver. The portal vein is formed posterior to the neck of the pancreas by the junction of the superior mesenteric and splenic veins.

Serum – The fluid portion of blood.

Sustained responder -A patient whose virus has remained undetectable 12 months after interferon treatment.

Variceal bleeding – Bleeding from abnormal blood vessels in the esophagus.

12. References and Resources:

Since information regarding hepatitis C changes too fast to be up-to-date in a reference book, I have chosen to only list web sites for references. If you do not have a computer or Internet access, go to your local public library or Internet café or the Patient Information Center at the HEP office to examine these sites.

Non-profit HCV support and education groups:

<http://www.scn.org/health/hepatitis> – Home page of the Hepatitis Education Project – That's us!

<http://www.hepc-connection.org> – The Hep C Connection. An excellent newsletter, support groups and information about hepatitis C (303) 393-9395 or (800) 522-HEPC.

<http://www.hepfi.org> – Hepatitis Foundation International. PATS telephone network (800) 891-0707.

<http://www.liverfoundation.org> - The American Liver Foundation. (888) 4HEPUSA.

<http://pages.prodigy.com/hepc/> - Hepatitis C International. Information and a newsletter worth ordering.

<http://www.hcvglobal.org> - Ken Akinaka, the co-inventor of the hepatitis C conference.

<http://www.geocities.com/HotSprings/5670> – HepCBC Vancouver, B.C., Canada.

<http://hepcesn.net/> - Hepatitis C Education & Support Network

<http://www.hcvadvocate.org> - Hepatitis C Support Project –Bay area advocacy, support and education.

<http://www.hcop.org/>- Hepatitis C Outreach, POB 6677, Aloha OR, (503)591-8927 Support groups and information.

Hepatitis (HCV) Wellness Advocate - Back to Life (949) 654-4250 Los Angeles area support.

Hepatitis C Information:

<http://hepnet.com/nihstate.html> – National Institute of Health, Consensus Statement of HVC mgmt.

<http://www.epidemic.org/theFacts/> - The Facts about hepatitis C by C. Everett Coop.

<http://www.beincharge.com> – Schering’s Be In Charge program.

<http://www.hepnet.com/webs.html> – Useful links to HCV resources.

<http://members.bellatlantic.net/~clotho/> - A comprehensive look at HCV and treatments by a lay expert.

<http://hometown.aol.com/pbcers/ssd.htm> - HCV information and resources.

<http://www.junction.net/hepcure/index.html> - Tons of medical and research information.

<http://www.urmc.rochester.edu/smd/mbi/med/lec3.html> - University of Rochester Medical Center virology information.

<http://www.geocities.com/HotSprings/5670/drugco.html> - A list of pharmaceutical companies doing HCV research.

Hepatitis C Related Conditions:

<http://www.arthritis.org/> - Arthritis Foundation home page.

<http://www.niddk.nih.gov/> - National Institute of Diabetes and Digestive and Kidney Diseases.

<http://www.hemophilia.net/index.htm> – Hemophilia Resource Network.

<http://www.meddean.luc.edu/lumen/MedEd/medicine/dermatology/melton/lichen1.htm> – Photo of Lichen Planus.

General Medical Information:

<http://www.ncbi.nlm.nih.gov/PubMed/> - National Institute of Health scientific studies.

<http://www.cdc.gov/ncidod/diseases/hepatitis/c/index.htm>– Center for Disease Control.

<http://www.ama-assn.org> - American Medical Association.

<http://www.thelancet.com/> – The Lancet.

<http://www.fda.gov> – The Food and Drug Administration home page.

<http://www.howstuffworks.com/cancer.htm> - Excellent information about cancer

<http://www-micro.msb.le.ac.uk/224/VirPath.html> - Basic viral pathogenesis - how does a virus work?

<http://nccam.nih.gov> - National Center for Complimentary and Alternative Medicine.

<http://www.sciencedaily.com:80/> - Latest research news.

<http://www.quackwatch.com> – A non-profit member of the Consumer Federation of America.

<http://www.artigen.com/newswire/scitech.html> – Health care news.

<http://whyfiles.news.wisc.edu/> - Examine the science behind the news.

<http://www.rxmed.com/prescribe.html> and <http://www.rxlist.com> Check out OTC and prescription drugs here.

<http://www.disserv.stu.umn.edu/disability/> - Disability Specific Website

<http://www.hcrc.org/contrib/green/layman.html> – Health Care Reality Check.

<http://www.cfids-me.org/disinissues/> - Disability Benefits Information Website

<http://victoria.tc.ca/Community/HepC/> - The Hepatitis C Society of Canada, Victoria B.C. Chapter

<http://my.webmd.com/> - WebMD, a good place to research studies

Organ Transplant Information:

<http://www.livingbank.org/> - Organ and Tissue donor registry.

<http://www.shareyourlife.org/> - Coalition on Donation - Are you an organ & tissue donor?

<http://www.cspinet.org/> - Center for Science in the Public Interest (CSPI) Home Page.

http://www.unos.org/frame_default.asp - United Network of Organ Sharing.

Other Resources:

<http://hometown.aol.com/pbcers/ssd.htm> - Social Security Disability, how to apply.

The Hawkins Center - Legal and support services for people with disabilities in Richmond, CA call 510-232-6611.

Veterans Aimed Toward Awareness - Terry Baker, Middletown, DE, call 1-800-430-4119.

sci.med.diseases.hepatitis – Hepatitis Newsgroup. Warning! A person posting messages to a newsgroup is not protected against Spam or Flames or False Advertising.

Join the on-line e-mail support group by sending an e-mail to: listserv@maelstrom.stjohns.edu

In the body of the message: Subscribe HEPV-L (last name, first name). Do not include subject or signature. Expect a large volume of e-mail, somewhere between 90 and 200 messages per day. And remember, not everything you hear on the Internet is true. Do your homework and check out information from other listmembers.

Holistic-Nutritional Information

What can you do to keep your liver healthy, reduce HCV symptoms and improve your immune system? Various foods, herbs, stress reduction, emotional support, etc. may play a part in the health of your liver. Certain drugs, herbs, foods, and toxins in your environment should be avoided. Contact the HEP office at 206-732-0311 for info on the holistic support group.

HEPNEWS is the newsletter of the Hepatitis Education Project. It contains articles about HCV news, upcoming events and speakers, an order form for subscription to HEPNEWS (\$10.00/Year), order form for books or video, a list of HEP support groups in the State of Washington and a list of videos from the HEP lending library plus other resources.

For a free copy of the HEPNEWS call the HEP office at 206-732-0311 or write to:

**Hepatitis Education Project
4603 Aurora Ave N.
Seattle, WA 98103-6513.**

Books Available for Purchase from HEP:

**Hepatitis C: A Personal Guide to Good Health
By Beth Ann Petro - \$13.00**

**Living With Hepatitis C: A Survivor's Guide
By Gregory T. Everson, M.D., and Hedy Weinberg - \$15.00**

**The Hepatitis C Handbook second edition
Five star rating from Amazon.com Customers!
By Matthew Dolan - \$20.00**

