HepCSC

The Hepatitis C Society of Canada
Victoria Chapter
Presents

Peppermint Patti's FAQ's

HEPV-L's HEPATITIS C FAQ v3.0

January 7, 1999

This FAQ is dedicated to the memory of David H. Kehrer, LTC John Heintz (Peters) and his wife Patricia, Daniel Bodiford, and Dr. Horst Imler

III.5.0 Ofloxacin
III.6.0 Thymosin
III.7.0 Cyclosporine Therapy
III.8.0 Reticulose
III.9.0 Transplant
III.10.0 Others

PART IV: TREATMENT (Alternative Medicine)

IV.0.1 Acupuncture
IV.0.2 Chiropractic
IV.0.3 Energy Healing
IV.0.4 Reflexology
IV.0.5 Homeopathy
IV.1.0 Herbal Treatments and Vitamins
IV.1.1 Kombucha Tea
IV.1.2 Reishi/Shitake Mushrooms
IV.1.3 Dandelion
IV.1.4 Milk Thistle
IV.1.5 Artichoke
IV.1.6 Licorice Root
IV.1.7 Spiruilna
IV.1.8 Garlic
IV.1.9 Thymic Factors
IV.1.10 Vitamin C
IV.1.11 Vitamin B12
IV.1.12 Vitamin E
IV.1.13 Natural Interferon Boosters
IV.1.14 Other Herbs or Vitamins
IV.2.0 Exercise
IV.3.0 Stress Management
IV.4.0 Positive Attitude
IV.5.0 Tai Chi/Chi Kung/Yoga/Meditation
IV.6.0 Other Ways to Keep Yourself Healthy

PART V: NUTRITION

V.1.0 What Should I Do About Nutrition?
V.1.1 Foods to Avoid
V.2.0 Nutrition and Cirrhosis
V.3.0 Coffee, Tea, Caffeine and Other Stimulants
V.4.0 Salt

PART VI: DRUGS AND ALCOHOL

VI.1.0 Alcohol
VI.2.0 Tobacco
VI.3.0 Marijuana
VI.4.0 What are the Effects of Recreational Drugs?
VI.4.1 Intravenous Drug Use Precautions
VI.4.2 Cleaning Fits
VI.4.3 Methadone

PART VII: HOW CAN HCV AFFECT MY EMOTIONAL LIFE?

VII.1.0 How is Depression Related to Hepatitis?
VII.1.1 Mood Changes

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Subject: Part 0: Administrivia
Subject: 0.00 Copyright

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0.01 INTRODUCTION

This document answers frequently asked questions (FAQ) about the hepatitis C virus (HCV), its treatment, and related complications.

This FAQ is not comprehensive, and there will be further FAQs describing other types of hepatitis (viral - A,B,D,E,G, Autoimmune, toxic) and related liver disorders and complications, as well as treatments, electronic resources and other specialized topics sometime in the near future. These related FAQs will likely be found near where you have found this one.

0.02 DISCLAIMER

The information presented in this document was written and developed by patients and members of the HEPV-L mailing list.

It represents an informal catalog of accumulated knowledge by people who for the most part are not medical professionals. As this file is developed further, we hope to include references and citations which will document more of the statements that are made here. Much of the information contained in this FAQ was compiled from the varied and personal experiences and opinions on the HEPV-L mailing list. As useful as this information may be, it must not be considered medical advice, and must not be used as a substitute for medical advice. And as always, don't forget to use your common sense. It is important that anyone who has, or thinks they may have, hepatitis should consult with a licensed health care practitioner who is familiar with liver disease.

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PART I - THE BASICS

I.0.1 WHAT IS HEPATITIS?

Hepatitis is an inflammation of the liver. "Hepato" is Greek for "liver," and "itis" means "inflammation." The different types of hepatitis are caused by different things, but they all produce inflammation of the liver. Viral hepatitis refers to several common contagious diseases caused by viruses that attack the liver.

The most important types of viral hepatitis are hepatitis A, hepatitis B, and hepatitis C. Newly discovered forms of viral hepatitis also include hepatitis D, E, and G. Non-viral forms of hepatitis can be caused by toxic agents (drugs or chemicals), alcohol, or autoimmune processes. Another form of hepatitis is toxic hepatitis.

Toxic hepatitis can be caused by viruses or by liver damage due to toxic substances. Toxic hepatitis is a deterioration of the liver cells caused by chemicals, alcohol, drugs, and industrial compounds.

Alcohol abuse is a common cause of toxic liver damage.

I.0.2 WHAT HAPPENS IN THE BODY?

The hepatitis A and E viruses first enter the gut and begin reproducing.

They spread to the liver and multiply in liver cells. Hepatitis B, C, D, and G enter the bloodstream; when they pass through the liver, they enter liver cells and begin to reproduce. The body attacks the infected cells, which causes the liver to become inflamed. In hepatitis B infection, the liver usually repairs itself, leaving antibodies to the surface antigen, which shows that the infection occurred, but that the body defeated it.

When someone catches the hepatitis C virus, their body produces antibodies to try to destroy it. More often than not, the antibodies fail to identify the hepatitis C virus properly. The infection then remains long-term. Most infected people don't know they have the virus. This is because for some people there will be no symptoms and for others, symptoms may take an average 13 years to develop. Some people may have hepatitis C for 20 years or more before finding out.

The way that hepatitis affects people is different for different people. Some are not affected by the condition, but others are affected very badly.

It currently seems that if 100 people catch hepatitis C:

- 15-20 people will get rid of it within 2-6 months (much like we get rid of a flu virus)
- 60 people will have a long-term infection that may cause no problems or may cause levels of liver damage ranging from mild to serious.
- 20-25 people will have a long-term infection that leads to serious liver damage after 20 years. Of these people, 10-15 will remain stable and the other 10 will progress to liver failure or liver cancer after another 5-10 years.

Hepatitis C infection doesn't always make people sick. When someone does get sick, symptoms take a long time to develop (approximately 13 years).

Symptoms often stay at a certain level and don't always get worse. They can come and go with no real pattern.

Some people with chronic infection don't have any noticeable liver damage or symptoms. These people remain well, but **THEY ARE INFECTIOUS AND SHOULD TAKE CARE TO REDUCE ANY RISK OF TRANSMITTING THE VIRUS TO OTHERS.**

Data on the clinical course of HCV is limited because the onset of infection often goes unrecognized, and the early course of the disease is indolent and protracted in many individuals.

Prospective cohort studies are few, typically small, include relatively few subjects whose date of infection can be well documented, (e.g.

blood transfusion recipients and victims of accidental needle sticks), and have relatively short followup. The natural history of disease appears to differ according to geography, alcohol use, virus characteristics, (e.g., genotype, viral load), coinfection with other viruses, and other unexplained factors. - National Institutes of Health Statement on Hepatitis C 1997

I.0.3 WHAT IS THE INCUBATION PERIOD?

The incubation period (the amount of time that elapses between infection and the development of symptoms) varies for the different hepatitis viruses. Hepatitis A and E may develop as few as two weeks after exposure, but usually appear after four weeks. For hepatitis B and C it may take up to six months before symptoms develop. (The average incubation period is two to three months for hepatitis B and six to nine weeks for hepatitis C.) In experiments on chimpanzees, hepatitis D developed two to ten weeks after infection.

After initial exposure, HCV RNA can be detected in blood in 1-3 weeks. Within an average of 50 days (range 15-150 days), virtually all patients develop liver cell injury, as evidenced by elevation of serum alanine aminotransferase (ALT). The majority of patients are asymptomatic and anicteric. Only 25-35 percent develop malaise, weakness, or anorexia, and some become icteric. Fulminant liver failure following HCV infection has been reported but is a rare occurrence. Antibodies to HCV (anti-HCV) almost invariably become detectable during the course of illness. Anti-HCV can be detected in 50-70 percent of patients at the onset of symptoms and in approximately 90 percent of patients in 3 months after onset of infection. HCV infection is self-limited in only 15 percent of cases. Recover is characterized by disappearance of HCV RNA from blood and return of liver enzymes to normal. - National Institutes of Health Statement on Hepatitis C 1997

I.0.4 HOW DOES HEPATITIS C USUALLY BEGIN?

For a slight majority of patients, the illness begins suddenly as though one had come down with the flu. Except that this "flu" doesn't seem to completely go away. For many other patients, the onset appears gradually over a long period of time. Infants and young children often have no symptoms at all.

Many other symptoms may also be present, however they will typically be different among different patients. These include: fatigue, low-grade fever, headaches; slight sore throat, loss of appetite, nausea, vomiting, sensitivity to light, and stiff or aching joints.

Many people develop a pain in the right side, over the liver area.

The urine may become dark brown, and the feces may be pale. In severe acute infections, some people may develop jaundice in which the skin and whites of the eyes become yellowish.

The degree of severity can differ widely among patients, and will also vary over time for the same patient. Severity can vary between getting unusually fatigued following stressful events, to being totally bedridden and completely disabled. The symptoms have a tendency to wax and wane over time.

I.0.5. WHAT ARE THE DIFFERENT TYPES OF HEPATITIS?

The different types of VIRAL hepatitis are:
A (formerly called infectious hepatitis), B (serum hepatitis),
C (formerly called non-A, non-B hepatitis), D (delta hepatitis),
E (transmitted through the feces of an infected person) Cryptogenic (or Non-A,B,C,D,E,G)
G (a virus transmitted through infected blood products)
More hepatitis viruses are being discovered, but may be less common.

Other viruses, such as Yellow Fever, Epstein-Barre virus, Cytomegalovirus, as well as parasites and bacteria, can cause hepatitis as a secondary effect.

Other types of non-viral hepatitis are: Autoimmune, Wilson's disease, hemochromatosis, drug or chemical induced, alcoholic hepatitis.

I.0.6 WHAT IS THE FUNCTION OF THE LIVER?

The liver:

- Stores iron reserves, as well as vitamins and minerals
- Makes bile to help digest food
- Detoxifies poisonous chemicals, including alcohol, beer, wine, and drugs - prescribed and over-the-counter as well as illegal substances. Acts as a filter to convert them to substances that can be used or excreted from the body
- Converts food we eat into stored energy, and chemicals necessary for life and growth
- Makes your blood
- Manufactures new proteins
- Makes clotting factors to help blood clot
- Removes poisons from the air, exhaust, smoke and chemicals we breathe.
- Manufactures and exports important body chemicals used by the body. One of these is bile, a greenish-yellow substance essential for the digestion of fats in the small intestine.

I.0.7 HEPATITIS C VIRUS (HCV)

HCV is a form of hepatitis caused by an RNA virus of the Flaviviridae family that targets the liver. HCV accounts for the majority of the hepatitis cases previously referred to as non-A, non-B hepatitis, and is responsible for 150,000 to 250,000 new cases of hepatitis each year.

The virus, which typically has a six to nine-month incubation period, presents symptoms such as: fatigue, nausea, loss of appetite, dark urine, and jaundice; and if left untreated can lead to liver cancer and death. According to a recent report by a committee sponsored by the National Institutes of Health, nearly four million individuals in the U.S. are infected with HCV. The report also noted that treatment of the disease with current drugs is disappointing and estimated that the number of U.S. deaths caused by HCV will triple in the next 10-20 years.

I.0.7a WHEN WAS THE HEPATITIS C VIRUS DISCOVERED?

In 1987, Michael Houghton and colleagues at Chiron Corporation in California discovered part of the genetic material of HCV using molecular recombinant technology. This discovery allowed the development of tests to detect specific antibodies. The first enzyme immunoassay (EIA) test made available in 1989 employed only a single recombinant protein to detect antibodies and produced a significant proportion of both false positive and false negative results. An antibody test that could be used to increase the safety of the blood supply and of transplantable organs and tissues was available by 1990.

In mid-1995 the hepatitis C virus was seen for the first time ever by scientists with the aid of an electron microscope. It is a linear single-strand RNA (ribonucleic acid) virus 40-50 nanometers in size.

It is covered with a lipid envelope and is encased with glycoprotein peplomers or "spikes".

I.0.8 WHO GETS HEPATITIS?

People who have ever had blood transfusions or blood products before screening was introduced (1990), and people who have ever shared injecting equipment for drugs should be tested for the hepatitis C virus. Other people who should consider having the test done are those who have been tattooed, had body piercing or a needlestick injury. People with abnormal liver function tests with no apparent cause would also benefit from having a hepatitis C antibody test.

Healthcare workers who perform "exposure prone procedures" should also be tested.

Hepatitis C currently causes between 150,000 and 250,000 new cases of chronic infection in the United States each year. Hemophiliacs and intravenous drug users are at the greatest risk, but anyone, of any status or age, and in any walk of life, is at risk for acquiring the hepatitis C virus. Researchers have

found that many people infected with hepatitis C don't even know it. From 20 to 40 percent of patients in inner-city hospitals are infected, as are 80 percent of intravenous drug users.

I.1.0 HOW IS IT TRANSMITTED?

"Relax...you have cooties...but they aren't as bad as you are imagining." - Cindy Torchin: cindyt@cocug.org Listowner HEPV-L ---

Most people with hepatitis C contracted it either through a blood transfusion or receiving a blood product (plasma, etc.) that was contaminated with hepatitis C, or by sharing needles with intravenous drug users that were infected with hepatitis C. Prior to 1990 blood could not be screened for HCV. Thanks to HCV testing with modern sensitive methods, the risk of acquiring hepatitis C from blood transfusion is now less than 1%. The other people who acquire hepatitis C include health care and laboratory workers that may get stuck with an infected needle or instrument, people receiving medical/dental procedures, people receiving hemodialysis, body piercing, sharing razors, toothbrushes, nail clippers or people who have had tattoos or manicures that were performed with poorly sterilized equipment. Infected mothers can pass the virus to the fetus in utero but this occurs less than 1% of the time. It may occur more readily if the mother is also infected with the human immunodeficiency virus (HIV) that causes AIDS.

Cases of hepatitis C with no evidence of exposure through blood transfusions, needle sticks or needle sharing are called "sporadic".

How these individuals became infected is unknown.

Forty percent of all cases of hepatitis C were contracted through unknown means by people who have are in no current risk category.

What this means is that we are **all** at risk for contracting hepatitis C.

1.1.0a HOW HCV IS NOT TRANSMITTED

1. The hepatitis C virus is NOT airborne.
2. It is NOT spread by:

   a. sneezing and coughing
   b. holding hands
   c. kissing
   d. using the same toilet
   e. eating food prepared by someone with HCV
   f. holding a child in your arms
   g. swimming in the same pool

3. The virus IS in the blood of an infected person.
4. Hepatitis C can be spread by using something with infected blood on it such as:

   a. razors, nail clippers or scissors
   b. tooth brushes and water pics
   c. tattoo or body piercing needles
   d. illicit IV drug needles and paraphenalia (cottons, spoons, etc.)
   e. tampons or sanitary napkins

5. The virus must enter the body through the skin or mucous membrane.

I.1.1 HCV AND BLOOD TRANSFUSIONS

Anyone who received a blood transfusion or a blood product before 1992 is considered to be in a high risk group. Chance of infection by transfusion today is said to be 0.12%. Blood banks began screening donors for certain markers as early as 1986. In May 1990, screening tests for the hepatitis C virus came into use, and the risk is now thought to be one in 3,300 units of blood, or 0.12% for the typical recipient of a transfusion. - California at Berkeley Wellness Letter, May 1993

HCV acquired through blood transfusion tends to be more severe than through other modes of transmission.

- In a group of patients seen at a referral center, chronic post-transfusion hepatitis C infection was a progressive disease and, in some patients, led to death from either liver failure or hepatocellular carcinoma - N Engl J Med 1995;Vol 332, Iss 22:1463-1466 ---

I.1.2 HCV AND INTRAVENOUS DRUG USE

Investigators at Johns Hopkins report that injection drug users are at high risk for contracting hepatitis B and C, and that many contract hepatitis B or C within the first year of IV drug use.

Dr. David Vlahov and colleagues studied 716 volunteers who had been injecting for six years or less. Seventy-seven percent of them were infected with HCV and 65.7% were infected with HBV. Roughly 20% were HIV-positive. Hepatitis C was more prevalent among those who reported injection drug use for less than four months than among those who reported injecting drugs for 9 to 12 months.

- Am J Pub Health 1996;86:642-646 .

I.1.3 HCV AND IV IMMUNOGLOBULIN (GAMMAGARD/POLYGAM/FACTOR D)

Contaminated batches of Gammagard and Polygam, drugs used in intravenous immunoglobulin therapy, may have caused thousands across the U.S. to contract the hepatitis C virus. Many of those infected by Gammagard were children. Gammagard is primarily used to boost a patient's immune system. Many women in Ireland were infected through the use of contaminated Factor D after childbirth.

Patients who received immunoglobulin therapy with Gammagard should contact their doctor immediately to have liver function tests performed.

I.1.4 NEONATAL TRANSFER OF HCV

Physicians are not very concerned about hepatitis C transmission during birth, and many HCV positive women have given birth to children who were HCV negative. The likelihood of transmission from breast milk is also very small for both HCV and HBV.

Physicians do not advise against breastfeeding.

Neonatal transfer among women infected with the hepatitis C virus has been reported in 5% of pregnancies, but can be as high as 25% if the mother is also HIV positive. Japanese studies, (where a much more severe HCV genotype is prevalent) showed that only 6% of the babies born to HCV positive mothers contracted hepatitis C. Many showed antibodies at birth, but were clear of the virus by 18 months. This is not the case if the transmission is simultaneous with HIV or HBV infection, of if the mother is infected by multiple strains of hepatitis C virus.

Mother-to-baby transmission of HCV may be increased if the mother is also infected with HIV or HBV or has a high titer of HCV in the blood. In the latter circumstance, Japanese researchers have estimated that the risk of transmission can be approximately 10%.

Full recovery from perinatal hepatitis C virus infection is rare, as chronic hepatitis generally develops even in children with prolonged intervals of remission. - "Natural History of Perinatal HCV Infection," Clinical Infectious Diseases, July 1996;23:47-50

According to an abstract by V. Papaevangelou from the 35th Interscience Conference on Antimicrobial Agents and Chemotherapy, "Mother-to-Infant Transmission of Hepatitis C in Children Born to Mothers Coinfected with HIV and HCV," the rate of HCV vertical transmission was not affected by the mode of delivery (vaginally or by C-section).

Recent technological advances have led to the development of several types of invasive procedures in the fetus principally for the diagnosis and management of fetal disorders. There is probably a small but finite risk of transmission of maternal viral infections such as human immunodeficiency virus, hepatitis B and C, cytomegalovirus and herpes simplex during invasive procedures. - "Risk of Fetal Infection from Invasive Procedures," Journal of Hospital Infection 1997 Mar;35(3):169-173

I.1.5 OTHER MEANS OF HCV TRANSMISSION

Like hepatitis B, hepatitis C is spread through exposure to blood from an infected person, such as through a blood transfusion or sharing needles. There is no evidence that the hepatitis C virus can be transmitted by casual contact, through foods or by coughing or sneezing.

I.1.5a SEXUAL TRANSMISSION

The risk of sexual transmission of hepatitis C virus has not been thoroughly investigated but appears to be minimal. Some studies have shown no risk of passing hepatitis C on to a sexual partner, others have shown only a very low risk. The United States Centers for Disease Control and Prevention (CDC) do not recommend a change in sexual practices for those engaged in a long-term relationship with one sexual partner. However, people with acute illness and multiple sexual partners may be at greater risk and should use condoms to reduce the risk of acquiring or transmitting hepatitis C as well as other sexually transmitted infections. The risk is increased if the HCV positive partner is immunocompromised because the virus titer in the blood may be increased under those circumstances. Sex during the menstrual period should be avoided, due to the blood contact at that time. There is also some speculation about the possibility of transmission piggybacked on the genital herpes virus through genital lesions.

The reason that many studies say "multiple sexual partners" when referring to the risk of sexual transmission of HCV, is because people who have multiple sexual partners have a greater risk of contracting other sexually transmitted diseases which can cause open sores and lesions. And with those open sores and lesions you are at greater risk for blood contact. Also, it is thought that the hepatitis C virus tends to "piggyback" on the herpes virus, and if you have herpes you are at much greater risk of contracting or transmitting the virus.

According to a report in the Archives of Internal Medicine, sexual transmission of HCV occurs at a rate of about 1% per year in at-risk partners, and shows that periodic serum immune globulin prophylaxis for sexual partners is protective.

Transmission of the virus "...occurred only in partners of HCV-infected patients with active liver disease," the researchers report. They add an "intriguing" finding that patients who became infected during the study were older and had longer relationships with their partners compared with those who did not become infected. - Arch Intern Med 1997;157:1537-1544

I.1.5b OCCUPATIONAL EXPOSURE (HEALTH CARE WORKERS)

Occupational exposure to HCV is possible in any occupation in which there is exposure to possibly infected blood, (i.e., nurses and phlebotomists through needle sticks, emergency medical technicians through blood at accident scenes, etc.). The risk of HCV infection following a needlestick injury with HCV-

contaminated blood may be as high as 10%. Nonetheless, the risk of occupational transmission of HCV to Health Care Workers is far less than that of HBV.

Needlestick accidents pose a varying rate of transmission, from 0% in 81 Spanish patients followed for 12 months by radioimmunoblot assay II up to as high as 10% in other studies using detection by PCR. This rate is lower than that of HBV (7% to 30%) but is higher than HIV (0.5%). The resultant hepatitis seems to be mild, transient, and less likely to evolve into a chronic hepatitis.

This may reflect a low virus load or different HCV strains. There is no evidence to date to support the use of antiviral therapy for acute exposures. - "Recent Developments in Viral Hepatitis", Current Opinions in Gastroenterology, 1994 ---

I.1.5c TOOTHBRUSHES/RAZORS/NAIL CLIPPERS

It is possible for toothbrushes, razors, nail clippers, tweezers and similar personal care items to come in contact with infected blood. Therefore, sharing of these items is not recommended.

I.1.5d HEMODIALYSIS

Hepatitis C viral infection is a common infection in hemodialysis units, according to a report by Dr. Brian J.G. Pereira of Tufts University in the the January 25, 1996 edition of Family Practice News.

Dr. Pereira points to data from eight studies that indicate a 16% prevalence rate of infection in nearly 2,500 dialysis patients without a history of blood transfusion - a rate "considerably higher" than that seen in the general population.

I.1.6 HIGHLY SPECULATIVE MODES OF TRANSMISSION OF HCV

The following are considered highly speculative because either no studies have been done, conflicting studies have been done, or there is scientific reason to believe this is not a mode of transmission, but there still is no conclusive study to rule it out.

I.1.6a TEARS, SALIVA, URINE, AND OTHER BODY FLUIDS

Body fluids from 14 patients with chronic hepatitis C were analyzed for the presence of hepatitis C viral RNA using the polymerase chain reaction. ...The hepatitis C viral genome was not detected in any saliva or semen sample. These findings suggest that body fluids of patients with chronic hepatitis C are rarely, if ever, contaminated with the hepatitis C virus.

This may help to explain the infrequent transmission of this disease by sexual or close physical contact. - "Absence of hepatitis C viral RNA from saliva and semen of patients with chronic hepatitis C", Fried MW; Shindo M; Fong TL; Fox PC; Hoofnagle JH; Di Bisceglie AM, Gastroenterology 102: 1306-8 (1992) ---

Previous studies have provided conflicting results on the presence of hepatitis C virus-RNA in saliva. In this study, 23 (62%) of 37 patients tested positive for hepatitis C virus-RNA in saliva, using polymerase chain reaction analysis. A slightly greater proportion had a sporadic rather than a parenteral origin of chronic hepatitis C. These results provide a biological basis for saliva as a possible source of hepatitis C virus (HCV) infection, but do not necessarily imply transmission by this route. - "Detection of HCV-RNA in saliva of patients with chronic hepatitis C", P. Couzigou, L. Richard, F. Dumas, L. Schouler & H. Fleury, Gut 34:S59-60 (1993)

We conclude that HCV RNA is present in the saliva of approximately half of patients with acute and chronic hepatitis C, and the presence of HCV RNA correlates with HCV viremia. The efficiency of HCV transmission is low among spouses. - "Hepatitis C virus RNA in saliva of patients with posttransfusion hepatitis and low efficiency of transmission among spouses", J. T. Wang, T.

H. Wang, J. C. Sheu, J. T. Lin & D. S. Chen, Department of Internal Medicine, National Taiwan University Hospital, Taipei, Republic of China.

For up to 20 to 40% of patients chronically infected with hepatitis C virus (HCV), the mode of transmission is still unknown. We demonstrate that tear fluid contains HCV RNA-carrying material with the properties of infectious virus and conclude that smear infection with tear fluid may play a role in HCV transmission. - "Tear fluid of hepatitis C virus carriers could be infectious", H. H.

Feucht, B. Zollner, M. Schroter, H. Altrogge & R. Laufs, J Clin Microbiol 33: 2202-2203 (1995)

I.1.6b CAT SCRATCHES

It is unknown if the hepatitis C virus can be transmitted via cat's claws if the cat scratches one person and immediately scratches another.

I.1.6c MOSQUITOS

Researchers have determined that the hepatitis C virus is not transmitted by mosquitos. There is a lack of epidemiological or physical evidence that it is mosquito-borne and experiments to see any HCV replication in mosquito cells have failed.

There are two ways that mosquitos can transmit illness to humans.

These are "mechanical transmission" in which a small amount of blood may be present on the mosquito's feeding spike.

This type of transmission does not occur with serious human diseases such as HCV, HBV, or HIV. The second way mosquitoes transmit disease is called "biological" transmission. Studies show that mosquitoes can swallow viruses into their middle gut, but once there the virus dies and is digested in the same way we digest food - by breaking it down using acid.

I.1.6d ALTERNATIVE MEDICAL PROCEDURES

Some cases may be related to the use of poorly sterilized needles by medical practitioners in some countries as well as folk medicine and cultural practices that involve skin piercing.

Alternative medical procedures involving invasive medical procedures, particularly those performed in non-medical settings, or involving autologous blood (such as the ozone-enrichment of blood) may transmit the hepatitis C virus. ref: "Transmission of Hepatitis C by Ozone Enrichment of Autologous Blood," Lancet, 1996;347:541).

I.1.6.e HOUSEHOLD TRANSMISSION

Household transmission of hepatitis C is rare. It can occur where blood-to-blood contact happens. This could involve your blood spills coming into contact with someone's open cut, or to a lesser extent, the sharing of razor blades, toothbrushes and sharp personal grooming aids. It is advisable to wipe up blood spills with paper towels and bleach, and to keep razors and toothbrushes separate from those belonging to other family members.

I.1.6f OTHER

A proportion of HCV infected individuals do not fall into any currently recognized risk group. It is thought that some of these cases may have had exposure to injected drugs many years ago which they have forgotten or are unwilling to discuss.

I.1.6g IS HCV ANYTHING LIKE HIV?

Yes and No. HIV and HCV are both RNA viruses. That is both use RNA to carry their genetic code until they find a yummy host! However, these viruses belong to two entirely different families. Sort of like whales and humans are both mammals, but boy what a difference. They have completely different strategies for replication and for survival.

HIV is a retrovirus, and once the virus is in a human cell it copies itself to DNA and migrates into the cell nucleus and integrates into the host genome and is then copied every time the cell copies it's own DNA. Retro meaning it reverts to a DNA virus once it is in the cell. Other retro viruses are HTLV viruses like some types of leukemia.

HCV is a flavivirus. It is related to yellow fever and dengue fever viruses. It replicates by making positive and negative RNA strands and does not make DNA or integrate into the host genome.

There are lots of other structural and envelope differences between these two, but the main point is that HIV and HCV are NOT very similar at all—except they both completely screw up the immune system and there is no known cure.

I.1.7 PREVENTION

Prevention: avoid risk behaviors. Shots of gamma globulin after a person has been stuck with a needle do not seem to work. There are no current HCV vaccines. With screening of the blood supply, the risk of HCV infection from a transfusion has dropped from 10% (1970's) to less than 1%. "Prevention, Diagnosis, and Management of Viral Hepatitis", AMA.

I.1.7a WHEN, AND FOR HOW LONG, IS A PERSON ABLE TO SPREAD THE HEPATITIS C VIRUS?

Some people carry the virus in their bloodstream and may remain contagious for years. The disease may occur in the acute form and be followed by recovery, but the majority of the cases become chronic and cause symptoms for years.

I.1.7b HOW CAN THE SPREAD OF HEPATITIS C BE PREVENTED?

People who have hepatitis C should remain aware that their blood and possibly other body fluids are potentially infective, even when the person carrying the virus is asymptomatic. Care should be taken to avoid blood exposure to others by sharing toothbrushes, razors, needles, etc. Infected people must not donate blood, plasma or semen, and should inform their dental or medical health providers so that proper precautions can be followed.

I.1.7c CLEANING UP BLOOD SPILLS

A 10% bleach (soak for 30 minutes) should be used on all contaminated surfaces. There is no proof that this KILLS everything, but you can't autoclave the world. There are also chemical disinfectants containing phenols and other very expensive ingredients, but for home use bleach is the best we have. Bleach can be VERY VERY corrosive on some surfaces...so be careful what you slop it on.

Pure H2O Bio-Technologies Inc. is currently working on a new germ killing liquid that kills bacteria and some viruses, including hepatitis C .—

I.1.7d WHAT TO DO IN CASE OF AN ACCIDENTAL NEEDLESTICK

Because there is no effective neutralizing antibody or vaccine for preventing hepatitis C virus (HCV) transmission, HCV can be transmitted to health care workers through accidental needlesticks. In a study reported in the journal Clinical Infectious Diseases, after the clinical onset of acute hepatitis, two health care workers who had sustained accidental needlesticks were treated with interferon (total dose, similar to 300 megaunits). Neither individual developed chronic hepatitis. This finding raises the possibility that treatment with low-dose interferon following an accidental needlestick may be beneficial, even when it is started after the clinical onset of hepatitis. - "Early Therapy with Interferon for Acute Hepatitis C Acquired Through a Needlestick." Clinical Infectious Diseases, May 1997;24(5):992-994.

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I.1.8 WHO SHOULD I TELL?

If you have hepatitis C, you are under no legal obligation to tell others. It is up to you to decide whether to tell anyone of your hepatitis C status. Some people, (and unfortunately some health care providers also) may have judgmental attitudes or unnecessarily exaggerated fears of infection. People should carefully consider who they inform, in light of possible discrimination. How people might have caught the virus is not important. Those who have the hepatitis C virus are covered by anti-discrimination laws.

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I.1.9 CAN YOU GET HEPATITIS MORE THAN ONCE?

Once you completely recover from hepatitis A or B you can't get it again, although in some people the condition becomes chronic and can last their whole lives. But since there are at least five different viruses that cause hepatitis, you can get one of the others (though not D if you are immune to B). Becoming infected with B and C at the same time may actually cause a much more severe, dangerous case of hepatitis. A person who has recovered from a case of viral hepatitis could also develop hepatitis again due to other causes, such as alcohol or drugs.

If you have had hepatitis C and clear the virus, you **can** become infected with it again. Because there are so many different genotypes of hepatitis C, and because the virus mutates so rapidly, natural immunity is not developed. Studies with chimpanzees have shown that after resolution of an acute hepatitis C infection, rechallenge with the same strain of HCV causes reinfection. —

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I.1.10 VACCINES

Chiron is preparing to begin clinical trials for a hepatitis C vaccine. Preclinical results have shown promise for this vaccine in preventing HCV disease. If effective, trials will require at least five years to complete.

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Studies of laboratory animals suggest that protective immunity against the hepatitis C virus may not develop: Animals that have recovered from HCV infection have developed hepatitis again after rechallenge with infected material. Another potential obstacle comes from evidence that more than a half-dozen strains of HCV may exist. One strain may predominate in a particular geographic region. Furthermore, different strains are likely to exhibit differing virulence. - Hepatitis C & E: How Much of a Threat? (Special Issue: Emerging Infectious Diseases). Brown, Edwin A. Patient Care. May 15 1994, v28, n9, p105(8)

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PART II - MEDICAL ISSUES

II.0.1 HOW DO I FIND GOOD MEDICAL CARE FOR HEPATITIS?

It is very important to find a health practitioner who is familiar with this illness. The symptoms of hepatitis can be mimicked by other illnesses (autoimmune illnesses, cancer, chronic fatigue syndrome, lupus, arthritis, etc.), and if you in fact have another illness that is not properly diagnosed, you may be losing out on getting treatments that might be effective for you.

It is still an uphill struggle to find a doctor who is experienced in diagnosing and treating hepatitis C. Hepatologists specialize in diseases of the liver, and would be your best choice in physicians, followed by a gastroenterologist (a digestive disease specialist) or an infectious disease specialist. If there is a hepatitis support group nearby, they would be an excellent source of advice in identifying local doctors who may be familiar with hepatitis, or you can contact the American Liver Foundation (ALF) for a list of doctors near you. The best way to identify local support groups is to contact one of the national organizations. If there are no hepatitis knowledgeable doctors in your area and you wish to find an out-of-town specialist, you may read about such specialists from time to time in the newsletter of one of the national organizations.

If your own doctor is sympathetic but not knowledgeable, you might gather together some medical articles on hepatitis and hepatitis treatments and encourage your doctor to study them.

II.0.2 WHAT IS THE DIFFERENCE BETWEEN A GASTROENTEROLOGIST AND A HEPATOLOGIST?

A hepatologist specializes in treating liver disease. A gastroenterologist does guts, essentially. I recommend finding a hepatologist, as they are more likely to be on top of the latest information concerning treatment of hepatitis C.

II.1.0 HOW IS IT DIAGNOSED?

While the newer HCV antibody tests are better; false positive results still occur, and further testing should be used to confirm the antibody test. Abnormal liver function tests (LFTs) suggest chronic disease, but there is no correlation between the level of the liver function tests and how severe the disease is.

A liver biopsy is the best way to identify liver inflammation or early cirrhosis.

Before 1990 doctors could diagnose HCV only by ruling out other possibilities (thus the old name for HCV "non-A, non-B hepatitis).

Hepatitis C antibodies may not develop for two to six months after infection, so only two-thirds of patients who go to the doctor with possible hepatitis C infection can be diagnosed with blood tests. Diagnosis may have to exclude other possible causes such as HAV, HBV, cytomegalovirus, Epstein-Barre virus infection, as well as nonviral liver problems such as fatty liver, or alcohol or drug-related diseases.

Follow-up blood tests are very important in order to determine if the disease has become chronic. The blood tests for antibodies are usually repeated three and six months after the original illness.

Diagnosis is most commonly made after detecting an antibody to a portion of HCV in the blood. This indicates that the person was exposed to the virus and that their immune system made an antibody. The test can show false positive reactions and therefore confirmation is necessary by finding evidence that the Hepatitis C virus is actually in the blood using the polymerase chain reaction (PCR), an extremely sensitive test for viral RNA.

II.1.1 ANTIBODY TESTS

Antibody tests indicate whether the body has been exposed to the virus and has produced antibodies to fight it. They do not determine whether or not someone still has the virus, or how long they've been infected.

II.1.2 WHAT IS A PCR?

Polymerase Chain Reaction (PCR) . HCV PCR tests are a newly developed test that came onto the market in late 1994. HCV PCR tests look for the presence of the virus. Information gained from the HCV PCR can be useful in interpreting unclear antibody test results.

The HCV PCR cannot tell how long someone has been infected.

Basically, your blood sample is broken up and certain parts are "fed" to E.coli bacteria, which grow real fast. When there are enough of them, they are put into the "bacteria-matic".

Then that stuff is separated, and the remains are x-rayed, producing that pretty sheet of stripes that you see in cops and robbers shows and the OJ trial.

There are two sets, one side is the control, which is a known HCV, the other side is you. If they match you have the virus.

There are 3 major tests for HCV.

1) The ELISA test detects antibody to the virus.
2) The RIBA test is the confirmatory test for HCV.
3) The Quantitative HCV PCR test, which measures the amount of virus circulating in a person's blood stream.

II.1.2a WHAT IS A GENOTYPE?

Our genotype does not change. Genotypes are as follows: 1a, 1b, 1c, 2a, 2b, 2c, 3a, 3b, 4, 5 and 3a has the highest response rate to interferon, and people with this genotype are generally younger in age and usually IV drug users.

II.1.3 IS IT POSSIBLE THE TEST COULD BE WRONG?

Antibody tests are usually positive or negative, but sometimes they come back unclear. Tests that come back positive are redone to confirm they are right. Unclear results are repeated and if still unclear, different types of blood tests are done. If you get a positive test result and have no risk background (for example, blood transfusions or injecting drug use) it's a good idea to check with your doctor to make sure that the blood laboratory double checked the result by using confirmatory tests.

II.2.0 BIOPSY

If viral hepatitis infection occurs, it may resolve on its own or become chronic. However, patients with chronic hepatitis often do not experience symptoms. On the other hand, others complain of excessive fatigue, weakness, and a reduced capacity for exercise.

Since liver damage may occur even in asymptomatic cases (no patient complaints), it is important to perform a biopsy and determine whether there is ongoing liver damage. As chronic hepatitis progresses, damage to liver cells may impair liver function. The biopsy of the damaged liver indicates the degree of cellular necrosis (death of liver cells), inflammation (cellular infiltration and swelling), and scarring (scar tissue beginning to replace functioning liver cells). - "Understanding Chronic Hepatitis" - Schering - 10/92 INH-001/17098403

II.2.0a WHAT IS A LIVER BIOPSY?

Liver biopsy is a diagnostic procedure used to obtain a small amount of liver tissue, which can be examined under a microscope to help identify the cause or stage of liver disease.

The most common way a liver sample is obtained is by inserting a needle into the liver for a fraction of a second. This can be done in the hospital with a local anesthetic, and the patient may be sent home within 3-6 hours if there are no complications.

The physician determines the best site, depth, and angle of the needle puncture by physical examination or ultrasound. The skin and area under the skin is anesthetized, and a needle is passed quickly into and out of the liver. Approximately half of individuals have no pain afterwards, while another half will experience brief localized pain that may spread to the right shoulder.

Patients are monitored for several hours after a biopsy to make sure serious bleeding has not occurred. Some patients occasionally have a sudden drop in blood pressure after a biopsy that is caused by a "vagal" reflex and not by blood loss; this is caused by sudden irritation of the peritoneal membrane. The characteristics that distinguish this from a bleeding event are: 1) slow pulse rather than rapid, 2) sweating, and 3) nausea.

II.2.0b WHAT ARE THE DANGERS OF LIVER BIOPSY ?

The risk of a liver biopsy is minimal. The primary risk is bleeding from the site of needle entry into the liver, although this occurs in less than 1% of patients. Other possible complications include the puncture of other organs, such as the kidney, lung or colon.

Biopsy, by mistake, of the gallbladder rather than the liver may be associated with leakage of bile into the abdominal cavity, causing peritonitis. Fortunately, the risk of death from liver biopsy is extremely low, ranging from 0.1% to 0.01%.

A biopsy should not be done if: 1) you have taken aspirin in the last 5-7 days, 2) the hemoglobin is below 9-10 grams/dl, 3) the platelets are below 50,000-60,000, or 4) the prothrombin time INR is above 1.4. Those with bleeding disorders such as hemophilia which can be temporarily corrected with transfused clotting factors can be biopsied safely.

II.2.0c WILL IT HURT?

Most doctors will not do percutaneous needle liver biopsies under anesthesia. This is because the liver is directly under the diaphragm and moves as you breathe. When the needle is inserted through the skin and body wall, the liver must not be moving or else there is danger of a laceration. To keep the liver from moving, the patient has to stop breathing momentarily. Doctors prefer to have you alert and following directions, but if you are very anxious you may want to ask for a sedative to help you relax.

The injections of the local anesthetic and the actual puncture of the liver capsule itself can be a little painful for some people, but it only takes a second and is over very quickly. Other people feel no pain at all, and don't even realize it's over with until the doctor tells them they're finished.

Occasionally there will be a small to moderate amount of pain afterwards. If you find that you are uncomfortable, your doctor will generally prescribe a light painkiller immediately after the biopsy. The pain may be well away from the biopsy site, possibly in the pit of your stomach or typically in the right shoulder.

The liver itself has no pain-sensing nerve fibers, but a small amount of blood in the abdominal cavity or up under the diaphragm can be irritating and painful. Very occasionally, small adhesions (scar tissue) may form at or near the biopsy site, and can cause a chronic pain that persists near the liver area after the biopsy.

II.2.1 CHRONIC PERSISTENT OR CHRONIC ACTIVE - WHAT'S THE DIFFERENCE?

Hepatitis C is considered to be "chronic" if it has persisted for longer than 6 months. The term "Chronic Persistent" used to be used to define hepatitis which persisted for longer than 6 months, but which was not currently causing active damage to the liver. The term "Chronic Active" was used to define hepatitis which persisted for longer than 6 months, and which was actively destroying the liver. The differentiation between "persistent" and "active" is not commonly used any more, with the assumption being that if the virus exists, it is causing damage whether it is moving quickly or not.

About 85 percent of HCV-infected individuals fail to clear the virus by 6 months and develop chronic hepatitis with persistent, although sometimes intermittent viremia. This capacity to produce chronic hepatitis is one of the most striking features of HCV infection. The majority of patients with chronic infection have abnormalities in ALT levels that can fluctuate widely. About one-third of HCV patients with chronic infection have persistently normal serum ALT levels. Antibodies to HCV or circulating viral RNA can be demonstrated in virtually all patients with chronic HCV hepatitis.

Chronic HCV is typically an insidious process, progressing, if at all, at a slow rate without symptoms or physical signs in the majority of patients during the first two decades after infection.

A small proportion of patients with chronic HCV hepatitis - perhaps less than 20 percent - develop nonspecific symptoms, including mild intermittent fatigue and malaise. Symptoms first appear in many patients with chronic HCV hepatitis at the time of development of advanced liver disease.

Although patients with HCV infection and normal ALT levels have been referred to as "healthy" HCV carriers, liver biopsies can show histological evidence of chronic hepatitis in many of these patients. - National Institutes of Health Consensus Statement on Hepatitis C 1997

II.2.2 WHAT ARE THE MAIN SYMPTOMS OF HEPATITIS C?

Acute hepatitis C is almost indistinguishable from acute hepatitis B infection. Patients with acute hepatitis C are frequently asymptomatic (meaning that they have no symptoms), even when liver tests are abnormal. - "Hepatitis C & E: how much of a threat?" Special Issue: Emerging Infectious Diseases, Brown, Edwin A., May 15 1994, v28, n9, p105(8)

Soon after contracting the infection many people have a flu-like illness with fatigue, fever, muscular aches and pain, nausea and vomiting. About 10% of patients become jaundiced (their skin turns yellow). Generally these symptoms resolve and the patient has no symptoms of liver disease for many years. Symptoms may occur from two weeks to six months after exposure but usually within two months.

What are the symptoms of chronic infection and cirrhosis? The symptoms of chronic infection range from no symptoms at all, to gradually progressive fatigue and lack of energy, to complete debility. The effects of the virus vary widely between individuals.

The symptoms of cirrhosis include progressive fatigue, jaundice (yellow skin), icterus (yellow eyes), dark urine (the color of cola), abdominal swelling, muscle wasting, itching, disorientation and confusion, loss of appetite, and easy bruisability.

In an informal survey of hepatitis C symptoms, Scott Warren swarren@idir.net polled 50 people on the HEPV-L list and compiled the following results:

FATIGUE, WEAKNESS, TIREDNESS - 72%

JOINT, MUSCLE PAINS - 52%
MEMORY LOSS, MENTAL CONFUSION - 50%
SKIN PROBLEMS-DRY\ITCHY\RASHES\SPOTS - 44%
DEPRESSION, ANXIETY, IRRITABILITY, ETC - 44%
INDIGESTION, NAUSEA, VOMITING, GAS - 34%
SLEEP DISTURBANCES - 32%
PAIN OR DISCOMFORT IN ABDOMEN - 32%

CHILLS, SWEATING, HOT \ COLD FLASHES - 26%
EYE OR EYESIGHT PROBLEMS - 24%
SENSITIVITY TO HEAT OR COLD - 22%
NO SYMPTOMS - 20%
VERTIGO, DIZZINESS, COORDINATION - 18%
FLU LIKE SYMPTOMS - 18%
HEADACHES - 18%
URINARY PROBLEMS, ODOR, COLORATION - 16%
FEVER - 16%
SLOW HEALING AND RECOVERY - 14%
SUCCEPTIBILITY TO ILLNESS \ FLU - 14%
WEIGHT GAIN, WATER RETENTION - 10%
MENSTRUAL PROBLEMS - 10%
APPETITE \ WEIGHT LOSS - 8%
SWELLING OF STOMACH, LEGS OR FEET - 8%
ORAL, OR MOUTH SORES \ PROBLEMS - 8%
EXCESSIVE BLEEDING - 4%

II.2.2a FATIGUE

The main symptom of most people with hepatitis C is chronic fatigue, ranging from simply getting tired easily to extreme, debilitating fatigue.

II.2.2b UPPER RIGHT QUADRANT (URQ) PAIN (SIDE PAIN)

Even though the liver itself contains no nerve endings, and does not feel pain, many people with HCV experience a pain on the upper right side of their body, just beneath the ribs.

This is thought by some to be "referred pain" from the swelling of the liver capsule due to the disease process. This pain may also be referred to the right shoulder or to the back between the shoulder blades.

II.2.2c LOSS OF LIBIDO

Many hepatitis C patients find that they are no longer interested in sex. This tends to be especially true for those undergoing interferon treatment. This is not necessarily directly related to the hepatitis, but is most likely due to the stress, discomfort and exhaustion caused by the struggle with a chronic illness.

II.2.2d RED PALMS

Red palms can occur in any chronic liver disease and are not specifically caused by the virus. The cause for the redness is unknown, but it's speculated that it may involve upset hormone metabolism or microcirculatory changes.

II.2.2e NAUSEA

A few of the more popular nausea aids are chewing candied ginger, putting a (small) drop of peppermint oil on the end of your tongue, eating small frequent meals, dry crackers and weak tea, and popsicles.

II.2.2f BRAIN FOG

This is the mental fuzziness and forgetfulness that some people experience. It's not the same as encephalopathy, and seems to occur in all stages of the illness. Some people have found taking CoEnzyme Q10, also known as CoQ10, to be helpful (2 30mg capsules per day). Another listmember recommends taking Gingko Biloba.

II.2.2g ITCHING

The build-up of bilirubin in the skin may cause itching.

Itching can be treated with antihistamines, or cholestyramine (which binds bile in the intestines). Actigall and Questran are two drugs reported to help with this problem.

II.2.2h VISION PROBLEMS

Some hepatitis patients complain of blurring vision, and dry eyes. This can be especially true while undergoing interferon treatment.

II.2.2i DIZZINESS

Some people have found that wearing "Sea Bands" helps with their dizziness. Sea Bands are elastic bands that can be bought, usually in sporting goods stores, which press against pressure points in the wrist. They were designed for use in seasickness.

II.2.2j DRY MOUTH

There are two products (mouthwash and toothpaste) by the name of Biotene, which are designed to help with the problem of a dry mouth and gum problems as a result of medication use.

Several listmembers have reported great relief by using these products.

II.3.0 IT'S NOT ALL IN YOUR HEAD!

Some doctors (but thankfully fewer than there used to be) insist on believing that HCV usually has no symptoms, and dismiss the patient's complaints as being "all in their head".

Some HCV+ patients have been treated for depression for many years before their actual diagnosis of HCV was uncovered. Much is still unknown about the hepatitis C virus, and many physicians have not had much experience treating it. Many doctors are not yet familiar with the research which legitimizes the various symptoms which go along with this virus.

Emerging illnesses such as HCV typically go through a period of many years before they are accepted by the medical community, and during that interim time patients who have these new, unproven symptoms are all too often dismissed as being "psychiatric cases". This has been the experience with HCV as well.

II.3.1 WHAT IS THE EVOLUTION OF THE DISEASE?

Three out of four people infected with hepatitis C - not 50%, as once thought - will remain infected for life. Up to half of those people will develop cirrhosis, scarring of the liver, and up to 10,000 will die this year, say doctors and disease trackers meeting in San Diego. The latest findings are sobering because

about 1.4% of the U.S. population is infected with the virus - "Hepatitis C Chronic 75% of the Time", USA Today, 05-15-1995

At least 50-80% of people infected with HCV will develop chronic hepatitis; ultimately, 20-30% of those will progress to cirrhosis.

Another 20-30% may develop chronic HCV infection without abnormal elevations of liver enzymes in the blood. - "Prevention, Diagnosis, and Management of Viral Hepatitis", AMA

II.4.0 WHAT OTHER MEDICAL PROBLEMS CAN BE RELATED TO HCV?

Chronic hepatitis C infection occasionally causes problems for parts of the body beyond the liver. The organs most often affected include the blood vessels, skin, joints, kidneys, and thyroid gland. If chronic hepatitis C infection causes liver cirrhosis (severe scarring of the liver rarely caused by hepatitis C), many problems may arise from the cirrhosis, per se. Potential problems from cirrhosis include fluid accumulation in the abdomen, bleeding into the stomach, jaundice, confusion, poor blood clotting, and susceptibility to infection.

Hepatitis has so many symptoms that it's easy to ascribe all new anomalies to this disease. But HCV patients are not exempt from getting other illnesses also, therefore it is important to regularly monitor your health and to consult with your doctor about the changes as they progress.

II.4.0a CRYOGLOBULINEMIA

One-third to one-half of people with chronic hepatitis C infection have cryoglobulinemia (antibodies in the bloodstream attached to the hepatitis C RNA that happen to solidify when cold).

Hepatitis C is recognized as the most common cause of mixed cryoglobulinemia.

Most of the people with cryoglobulinemia from hepatitis C have had their hepatitis for a long time or have cirrhosis. People with higher concentrations of hepatitis C RNA in their blood do not seem to have a higher risk of having cryoglobulinemia. Usually the cryoglobulins are in low concentration and cause no symptoms.

About twenty-percent of people with hepatitis C and cryoglobulinemia have symptoms. Symptoms most often associated with cryoglobulinemia include mild fatigue, joint pains, or itching.

Occasionally, people with cryoglobulinemia develop vasculitis (inflammation of the blood vessels) which can cause purpura (purple skin lesions), Raynaud's phenomenon (the hands turn white, then blue, and then red from constriction and subsequent dilation of the blood vessels), or numbness in the hands and feet. The presence of cryoglobulinemia does not effect people's response to interferon.

In fact, some people with vasculitis have improvement in the vasculitis as their liver tests improve on interferon.

II.4.0b THYROID AND AUTOIMMUNE PROBLEMS

Chronic hepatitis C infection is also associated with many autoimmune diseases (where the body develops antibodies which attack parts of itself). For example, about one-tenth of people with chronic hepatitis C infection (more often in women and older people) have antibodies to the thyroid gland, one-half of whom may develop hypothyroidism (an underactive thyroid gland).

Additionally, interferon therapy causes hypothyroidism or hyperthyroidism (an overactive thyroid gland) in about one-tenth of those treated.

People with hypothyroidism may suffer from fatigue poor memory, weakness, constipation, weight gain, muscle cramps, intolerance to cold, hoarse voice, coarse skin, and brittle hair. People with hyperthyroidism may suffer from anxiety, insomnia, weakness, diarrhea, weight loss, intolerance to heat, velvet-like skin, and brittle nails. Hypothyroidism can be treated with thyroid hormone pills.

Hyperthyroidism can be treated with pills that block thyroid hormone synthesis. If the thyroid gland dysfunction is from interferon treatment and is caught early, the thyroid gland will return to normal once interferon is stopped.

II.4.0c RHEUMATOID ARTHRITIS-LIKE SYMPTOMS

Hepatitis C infection can present with rheumatic manifestations indistinguishable from rheumatoid arthritis. The predominant clinical findings include palmar tenosynovitis: small joint synovitis, and carpal tunnel syndrome. Risk factors such as transfusions and IV drug abuse or a history of hepatitis or jaundice should be included in the history of present illness of any patient with acute or chronic polyarthritis or unexplained positive RF. In such patients, gammaglutamyl aminotransferase, serologic studies for hepatitis C, and other tests appropriate for chronic liver disease should be performed. - Journal of Rheumatology, June 1996;23(6):979-983.

II.4.0.d FIBROMYALGIA

Fibromyalgia is the name for a condition that typically includes widespread muscle pain, fatigue and abnormal sleep patterns.

Until a few years ago, doctors called the condition fibrositis or muscular rheumatism and believed that for the most part, the condition was "all in the patient's head". Today, fibromyalgia is recognized by medical organizations as a genuine and serious problem.

The symptoms of fibromyalgia typically include pain in many muscles, and around ligaments and tendons, persistent fatigue, waking up feeling tired even after a full night's sleep, headaches, bouts of constipation and diarrhea, abdominal pain, painful menstrual periods, sensitivity to cold, numbness or tingling, and difficulty exercising.

Symptoms vary widely among patients and tend to wax and wane over time. An illness, injury, cold weather or emotional stress may trigger a fibromyalgia episode or make ongoing symptoms worse.

A study at the Oregon Health Sciences University and Portland Adventist Hospital suggests hepatitis C may trigger fibromyalgia ("Fibromyalgia: A prominent feature in patients with musculoskeletal problems in chronic hepatitis C, A report of 12 patients," by A. Barkhuizen, G.S. Schoepflin, and R.M. Bennett, Journal of Clinical Rheumatology, Vol. 2, No. 4, August 1996) . This study is the first to show a link between the two illnesses.

It was determined that the relationship between the hepatitis C virus and fibromyalgia followed three distinct patterns:

In nine patients, fibromyalgia developed as a long-term complication of the hepatitis, arising on average 13.4 years after the virus was acquired.

In two patients, fibromyalgia arose simultaneously with the hepatitis C infection.

In one patient, pre-existing fibromyalgia was significantly worsened by the hepatitis C.

It is unknown why the hepatitis C virus and fibromyalgia may be linked, but the authors suggest that hepatitis C causes chronic activation of the immune system that leads to muscle aching, fatigue, mental changes, sleep abnormalities, and alterations of the neuroendocrine system.

The patients with both hepatitis C and fibromyalgia could be distinguished from most other patients with fibromyalgia alone because they had symptoms unusual to fibromyalgia. These symptoms included synovitis (inflammation of the membrane around a joint, bursa, or tendon) and vasculitis (inflammation of a blood or lymph vessel).

In addition, laboratory findings pointed to a disease process other than fibromyalgia.

II.4.0e DERMATOLOGICAL MANIFESTATIONS

The main dermatological disorders in HCV infection include (1) vasculitis (mainly cryoglobulin-associated vasculitis, the cause of which is HCV in most cases, and, possibly, some cases of polyarteritis nodosa); (2) sporadic porphyria cutanea tarda; (3) cutaneous and/or mucosal lichen planus; and (4) salivary gland lesions, characterized by lymphocytic capillaritis, sometimes associated with lymphocytic sialadenitis resembling that of Sjoegren's syndrome.

Hepatitis C virus is the cause of, or is associated with, various dermatological disorders. In patients with such disorders, HCV infection must be sought routinely because antiviral therapy may be beneficial in some of them. - Arch Dermatol. 1995; 131:1185-1193

II.4.0f PORPHYRIA CUTANEA TARDA (PCT)

Porphyrins are a group of compounds that are mainly synthesized in the bone marrow. They play an important role in many chemical reactions in the body, e.g. with proteins to build hemoglobin. They are later converted to bile pigments mainly in the liver. Porphyrinuria increase of porphyrins in the urine) may be caused by chronic liver diseases. Hepatitis C is a major cause of porphyria throughout the world and may cause many symptoms, including excess blood iron - important in conjunction with an interferon therapy (since elevated blood iron seems to reduce the effect of interferon).

Porphyria cutanea tarda is a rare deficiency of a liver enzyme essential for cellular metabolism. The enzyme deficiency may cause sun exposed skin to blister, ulcerate, turn dark, or bruise. Hair may increase on the forehead, cheeks, or forearms, and the urine may turn pink or brown. It now appears that hepatitis C is the most common trigger of porphyria in people who are predisposed.

Topical sunscreens do not prevent the skin lesions. Avoidance of alcohol and removal of iron by repeated phlebotomy (blood removal) or taking medication that binds to iron sometimes helps. Chloroquine (an anti-malaria drug), which removes a toxic by-product of the enzyme deficiency, may help, as well.

II.4.0g LICHEN PLANUS

Occasionally, people with chronic hepatitis C develop a skin condition called lichen planus. It is a grouping of small, itchy, irregular, flat-topped reddened bumps. The bumps often have a network of very fine gray lines on their tops. The bumps show up most often on the wrists, shins, lower back, or genitals.

Lichen planus also frequently occurs in the mouth, where it looks like a white, net-like plaque. It sometimes shows up as mouth ulcers and can be treated with a steroid mouth rinse called Dexamethasone Elixir or Nystatin tablets.

II.5.0 CYCLES AND FLARE-UPS

Hepatitis flare-ups tend to occur in cycles, where for a while you may feel pretty good, then bad (maybe days to weeks for each period), then good again. It can be frustrating to obtain some relief, but then not know whether you have recovered or if you are merely between cycles.

Some people claim that they begin to feel better in the Spring, then start to feel worse again in August/September, with a low point usually around November/December.

II.6.0 SHOULD I BE VACCINATED AGAINST OTHER TYPES OF HEPATITIS?

Patients with chronic hepatitis C who are at risk for hepatitis B should be offered vaccination during their first contact with healthcare professionals, according to a report from Great Britain's University of Cambridge. ("Prospective Study of Hepatitis B Vaccination in Patients with Chronic Hepatitis C," British Medical Journal, May 25, 1996;312:1336-1337).

Chronic hepatitis C (HCV) infection is estimated to occur in between 70- and 92 percent of intravenous drug users. These IV drug users are also at risk for parenterally or sexually transmitted hepatitis B. Coinfection with hepatitis B virus (HBV) may accelerate underlying liver damage due to hepatitis C.

II.7.0 HCV AND WOMEN'S CONCERNS

Women can be affected by hepatitis C in a different way from men. This is possibly due to hormonal effects and liver damage.

MENSTRUATION : The hormonal effects of HCV can involve menstrual irregularities, particularly if you are experiencing significant hepatitis C symptoms. It is important that your general health is checked as well as your hepatitis C monitored. Tampons and sanitary napkins should be secured in plastic bags before going into the trash.

BIRTH CONTROL : If you are experiencing significant hepatitis symptoms, using the estrogen-based contraceptive pill may be inadvisable.

In these cases, the progesterone-only pill or Depo-Provera may be preferable.

HORMONE REPLACEMENT THERAPY : If you have severe hepatitis symptoms you may need to discuss with your doctor whether hormones should be used for menopausal symptoms. If this is the case, external vaginal creams and skin patches are probably better than pills.

Dysfunctional uterine bleeding and premature menopause, and most any other sort of hormonal aberration is pretty common with chronic liver disease. The liver processes these hormones, and they tend to not get processed properly when the liver is damaged.

While on interferon therapy, many woman find that they come down with one yeast infection after another, due to the immunosuppression.

Waste paper products (napkins and tampons) which have been exposed to blood should be securely wrapped and disposed of in a safe manner. A 10% bleach (soak for 30 minutes) should be used on all contaminated surfaces, and in the laundry for clothing and linens which have been exposed to blood.

Sexual intercourse during your period is not safe.

II.7.1 PREGNANCY AND BREASTFEEDING

A substantial proportion of pregnant women with hepatitis C virus infection have circulating HCV RNA, even when they are asymptomatic, according to a report from Italy. Researcher A.

Floreani and colleagues noted, however, that these women do not have an increased risk of obstetric complications and that pregnancy does not appear to induce symptomatic liver disease. - "Obstetrics (HCV); Circulating HCV RNA Does Not Increase Pregnancy Complications", Hepatitis Weekly, June 24, 1996

If a baby is born to an HCV+ mother and its blood was tested at birth for hepatitis C antibodies, the test would come back positive.

This is because the baby has some of its mother's antibodies.

These antibodies clear naturally over time. A test at 12 months usually confirms a toddler has the virus.

BREASTFEEDING : The hepatitis C virus has not been found in samples of breastmilk taken from HCV+ women. Transmission risk via breastmilk is therefore very unlikely. There are many advantages to breastfeeding. Breastfeeding mothers should check their nipples before each feed and avoid breastfeeding if they are cracked or bleeding.

Circulating HCV RNA does not increase pregnancy complications.

A substantial proportion of pregnant women with hepatitis C virus infection have circulating HCV RNA, even when they are asymptomatic, however, these women do not have an increased risk of obstetric complications and that pregnancy does not appear to induce symptomatic liver disease. "There is no risk to the outcome of pregnancy in an anti-HCV positive pregnant mother. The majority of pregnant women have normal transaminase levels during the course of pregnancy, although a substantial proportion have circulating HCV RNA. Pregnancy does not induce a deterioration of liver disease, and HCV infection does not increase the risk of obstetric complications." - - "HCV Infection in Pregnancy," British Journal of Obstetrics and Gynecology, 1996;103:325- 329

II.8.0 HOW DOES HCV AFFECT CHILDREN?

Children with chronic hepatitis cannot be treated simply like miniature adults. Specific issues and questions need to be addressed when dealing with the pediatric age group.

Pediatric patients are less likely than adults to have symptoms of infection with hepatitis C, leaving the viruses undetected and possibly unknowingly spread. According to information available on the natural history of HCV, the percentage of children who become chronic and the long-term outcomes are similar to the percentage of adults. Children who are chronic carriers of HCV have normal growth patterns.

Liver biopsy appears to be less valuable in children than adults.

Chronic hepatitis rarely progresses to cirrhosis in children.

In 16 HCV children followed for up to 14 years, encephalopathy (mental confusion), ascites (swollen stomach), or bleeding did not develop. The lack of cirrhosis in children with HCV is consistent that a time period of 10 to 20 years or more is required for cirrhosis to occur. Hepatocellular carcinoma occurs very rarely in the pediatric group.

Few studies exist examining interferon use in children with chronic HCV, however a recent study in Hepatology suggests that interferon therapy may be beneficial The rates of initial and long-lasting response were higher in the study than those observed in adults treated with standard schedules. Possible explanations include the shorter time of infection in children, and that most have a mild form of liver disease. The results of this study are encouraging, according to the researchers, but more investigation needs to be conducted.

Many questions still remain about chronic hepatitis C in children.

Further studies need to be done to determine the disease's course and progress as well as the role of interferon treatment.

II.9.0 WHAT ARE THE DIFFERENT CLINICAL INDICATIONS OF HCV?

II.9.1 ELEVATED LIVER ENZYMES

There are two general categories of "liver enzymes." The first group includes the alanine aminotransferase (ALT) and the aspartate aminotransferase (AST), sometimes referred to as the SGPT and SGOT. These are enzymes that are indicators of liver cell damage. The other frequently used liver enzymes are the alkaline phosphatase and gamma-glutamyltranspeptidase (GGT and GGTP) 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 heart disease or muscle disease.

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 a 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 tends not to be elevated in diseases of bone, placenta, or intestine. Mild or moderate elevation of GGT in the presence of a normal alkaline phosphatase

is difficult to interpret and often caused by changes in the liver cell enzymes induced by alcohol or medications, but without causing injury to the liver.

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II.9.1a ELEVATED ALFHA-PHETOPROTEIN LEVELS

It is fairly common for alfa-phetoprotein markers to be elevated in patients with hepatitis C. Alfaphetoprotein is a marker for tumors, but unless your numbers are extremely high (for example, in the hundreds), there is no need for alarm. Your doctor will probably want to perform further studies, such as an ultrasound or CT scan, just to be on the safe side

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II.9.2 JAUNDICE

Jaundice (yellow skin) may appear as a symptom occasionally, but is most common during an acute attack. Jaundice is caused by the buildup of bile pigment that is passed by the liver into the intestines. This same bile buildup can also cause intense itching.

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II.9.3 HEPATOMEGALY, SPLENOMEGALY

Some people experience a swelling of the liver (hepatomegaly) or the spleen (splenomegaly) as a result of hepatitis.

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II.9.4 SPIDER NEVI

Spider nevi are small capillaries that are seen on the surface of your skin. Branches form (grow) from the one capillary and it can either look like a small red spider or a splat (kind of like a squashed spider). They are also referred to as spider angiomas. If you have less than 10 that can be considered normal, more than that and it's an indication of chronic liver disease.

They can be found only above the waist, usually on the chest, upper arms, shoulders, face, neck and upper back.

II.9.5 ASCITES

Occurring in cirrhosis, the accumulation of fluid in the abdominal cavity, or ascites, is related to portal hypertension, significant reduction in serum albumin, and renal retention of sodium. The volume of abdominal ascites in adults with cirrhosis may reach levels as great as 10 to 12 litres (10.6 to 12.7 quarts).

Ascitic fluid may accumulate in the scrotum and in the chest cavity, where its presence, combined with the upward pressure on the diaphragm from the abdominal fluid, may severely affect breathing. Appetite also is often reduced by the abdominal distension.

Ascites are treated by the removal of enough fluid directly from the abdomen by needle puncture to ease discomfort and breathing.

Patients are placed on diets low in salt, and they are given diuretic drugs to increase the output of water by the kidneys. If these measures do not control massive ascites, ascites can be drained internally into the general venous blood system by running a plastic tube from the abdominal cavity, under the skin of the chest, into the right internal jugular vein of the neck (peritoneovenous shunt of LeVeen).

II.9.6 PORTAL HYPERTENSION / VARICES

Sometimes occurring in cirrhosis, portal hypertension is the increased pressure in the portal vein and its tributaries resulting from blockages to the blood flow into the liver. It is usually caused by the scarring processes of cirrhosis. The increased pressure causes varices, or dilations of the veins leading into the portal vein. When varices are located in superficial tissues, they may rupture and bleed profusely. Two such locations are the lower esophagus and the perianal region.

Esophageal varices are likely to bleed most heavily, and this bleeding is frequently associated with the onset of hepatic encephalopathy or coma. Because of their location at the lower end of the esophagus or the upper portion of the stomach, bleeding from varices is often difficult to control. If variceal bleeding persists, surgical formation of a shunt, or artificial passageway, from the portal vein to an abdominal vein may be done.

II.9.7 HEPATIC ENCEPHALOPATHY

Hepatic encephalopathy refers to the changes in the brain that occur in patients with advanced acute or chronic liver disease. If liver cells are damaged, certain substances that are normally cleansed from the blood by the healthy liver are not removed (mainly ammonia, or possibly certain fatty acids). A patient with chronic hepatic encephalopathy may develop progressive loss of memory, disorientation, untidiness, and muscular tremors, leading to a form of chronic dementia. The ingestion of protein invariably aggravates these symptoms.

The treatment of hepatic encephalopathy involves, first, the removal of all drugs that require detoxification in the liver and, second, the reduction of the intake of protein. Restricting the amount of protein in the diet will generally lower the levels of amino acids and ammonia in the bloodstream and brain. Most physicians advise their patients with this condition to eat only about 40 grams of protein a day, and will prescribe lactulose or neomycin to lower amino acid production. Non-meat proteins, such as those found in vegetables and milk, are also recommended. Certainamino acids are used in treatment, since they are considered less likely to cause mental impairment. A dietary supplement rich in these amino acids is used at many liver treatment centers.

II.9.8 CIRRHOSIS

When chronic diseases cause the liver to become permanently injured and scarred, the condition is called cirrhosis. The scar tissue that forms in cirrhosis harms the structure of the liver, blocking the flow of blood through the organ. The loss of normal liver tissue slows the processing of nutrients, hormones, drugs, and toxins by the liver. Also slowed is production of proteins and other substances made by the liver.

People with liver cirrhosis may develop many problems beyond the liver. When the liver is scarred, the blood cannot easily get through the liver, and backs up under higher than normal pressure (portal hypertension). This often causes ascites, which is yellow fluid that leaks out of the bloodstream into the abdominal cavity.

If the ascites becomes tense, it can cause an umbilical hernia (a protruding belly button). The backed-up blood also often creates varices, in which the pressure causes the blood vessels around the esophagus to burst causing significant blood loss. Varices can be treated with beta blockers, or can be obliterated using endoscopically-placed rubber bands or injections of liquid that cause the varices to scar. If endoscopy fails to stop bleeding, a TIPS (transjugular intrahepatic portosystemic shunt) can be created by inserting a short metal mesh tube through a neck vein into the liver and connecting the portal vein in the liver to a regular vein in the liver. Another alternative is to surgically redirect some of the blood flow around the liver.

People with cirrhosis sometimes may develop jaundice (a yellowing of the whites of the eyes or the skin) due to an accumulation of bilirubin in the blood. If the bilirubin is excreted in the urine, the urine may turn dark.

People with cirrhosis are also at risk for hepatic encephalopathy, which is fatigue or confusion caused by ammonia and other products of protein digestion which are inadequately cleared from the bloodstream by the liver.

People with cirrhosis often bruise easily because the liver manufactures reduced amounts of clotting factors. Additionally, platelets may be lower than normal in the circulation if the spleen is enlarged.

A spleen enlarged from portal hypertension may hold onto too many platelets.

Chronic HCV infection leads to cirrhosis in at least 20 percent of patients within 2 decades of the onset of infection. Cirrhosis and end-stage liver disease may occasionally develop rapidly, especially among patients with concomittant alcohol use. - National Institutes of Health Consensus Statement on Hepatitis C 1997

II.9.9 FULMINANT HEPATITIS

In very rare cases hepatitis symptoms develop quickly and become very severe. This less common form of hepatitis is called fulminant hepatitis or fast-progressing hepatitis, and it requires prompt medical attention. It can be fatal in up to 70 to 80 percent of cases. The kidneys may fail, and the liver shrinks as cells are killed. The person may fall into a coma and die. Fulminant liver failure following HCV infection has been reported but is a rare occurrence.

II.9.10 DOES HCV INCREASE THE LIKELIHOOD OF CANCER?

Chronic infection by HCV is associated with an increased risk of liver cancer. The prevailing concept is that hepatocellular carcinoma (HCC) occurs against a background of inflammation and regeneration associated with chronic hepatitis over the course of approximately 3 or more decades. Most cases of HCV-related HCC occur in the presence of cirrhosis. The risk for a person with chronic HCV hepatitis developing HCC appears to be 1-5 percent after 20 years, with striking variations in rates in different geographic areas of the world. Once cirrhosis is established, the rate of development of HCC is 1-4 percent per year. - National Institutes of Health Consensus Statement on Hepatitis C 1997

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Chronic infection with hepatitis C virus (HCV) is regarded as a risk factor for hepatocellular cancer, mostly in patients with liver cirrhosis. We looked for HCV genomes in the livers of patients with hepatocellular cancer who did not have cirrhosis to see whether HCV was directly oncogenic. Cancerous and non-cancerous liver tissue, and serum samples from 19 patients negative for hepatitis B surface antigen were analysed by polymerase chain reaction for the presence of HCV genome, HCV replication, HCV genotyping, and HBV genome. 13 of 19 patients were HCV RNA-positive in cancerous and non-cancerous liver tissue; 8 of 17 tested were anti-HCV positive.

Among the 13 HCV RNA-positive patients, 11 had genotype 1b and 2 had genotype 2a. 7 of 13 serum samples were HCV RNA positive.

7 of 19 patients were HBV DNA positive in cancerous and non-cancerous liver tissue, 5 of them anti-HBc positive. 4 patients were both HCV RNA and HBV DNA positive and 3 were both HCV RNA and HBV DNA negative. The results provide evidence for the association of HCV, mostly genotype 1b, with hepatocellular cancer without the intermediate step of cirrhosis. - "HCV-associated liver cancer without cirrhosis", De Mitri MS; Poussin K; Baccarini P; Pontisso P; D'Errico A; Simon N; Grigioni W; Alberti A; Beaugrand M; Pisi E; et al, Department of Internal Medicine, University of Bologna, Italy, Lancet 345: 413-5 (1995)

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Previously, we reported the high prevalence of hepatitis C virus (HCV) infection in patients with oral cancer or oral lichen planus in Kyushu, Japan. We now report a 61-year-old man with chronic hepatitis C and no oral lesions who developed oral cancer 6 months after interferon therapy (interferon alpha, 6 million units (MU) daily for 2 weeks and then 3 times a week for 14 weeks). This case emphasizes the need for periodic oral cavity examinations of hepatitis C patients and contributed to the investigation of oral cancer and HCV. - "Oral cancer and hepatitis C virus (HCV): can HCV alone cause oral cancer?--a case report." Kurume Medical Journal, 1996 Vol 1, Issue 43, pp 97-100

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It is thought that treatment with interferon reduces the risk of later developing liver cancer. "The low incidence of hepatocellular carcinoma in patients treated with interferon suggests that interferon may prevent the development of hepatocellular carcinoma." - "Risk Factors and the Effect of Interferon Therapy in the Development of Hepatocellular Carcinoma," Journal of Gastroenterology and Hepatology 1997 Feb;12(2):149-155

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An association between chronic hepatitis C infection and non-Hodgkin's lymphoma has been reported. " HCV Infection and Extrahepatic Malignancies," Journal of Clinical Gastroenterology 1997 Mar;24(2):87-89

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II.10.0 HOW MANY OF US ARE THERE?

Hepatitis C accounts for 20% of community-acquired hepatitis in the US. Approximately 200 case of hepatitis C are reported in New York State each year. -- "Prevention, Diagnosis, and Management of Viral Hepatitis", AMA

Each year, 150,000 new cases of hepatitis C infection occur in the United States.—" Hepatitis C & E: how much of a threat?" Special Issue: Emerging Infectious Diseases, Brown, Edwin A., May 15 1994, v28, n9, p105(8)

The (US) Center for Disease Control and Prevention, estimates that at least 17 ½ million people (in the US) are living with chronic hepatitis C infections and as many as 150,000 Americans are newly infected with hepatitis C each year.

PART III - TREATMENT (Conventional Medicine)

A number of new therapies for hepatitis C are emerging in clinical practice. Combination approaches of Interferon and Ribavirin are currently being tested and will likely prove to be beneficial. Within two to three years we expect to see a whole new class of drugs which will be oral, have low toxicities, and improved efficacy. These drugs will likely need to be taken lifelong and may need to be taken in combination with each other as is currently the case in HIV disease. - "Emerging Therapies for HCV," - Scripps Clinic and Research Foundation, Liver Disease Study Group

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III.1.0 INTRON A (INTERFERON ALPHA 2B, RECOMBINANT)

Interferon is a genetically engineered product originally licensed in 1986 to treat hairy cell leukemia. It is a copy of a protein found naturally in low levels in the human body. It was OK'd by (US) FDA Feb. 25, 1991, to treat hepatitis C. The product, alpha interferon, is the first effective treatment against this form of hepatitis, which affects an estimated 150,000 Americans each year.

According to the manufacturer's (Schering-Plough) literature for using Interferon in the treatment of Hepatitis C: 3 million units per dose 3 times a week Interferon has an effective cure rate of about 25% .

Besides hairy cell leukemia and hepatitis C, alpha interferon is licensed for treatment of AIDS-related Kaposi's sarcoma and genital warts. Schering-Plough Corporation of Kenilworth, N.J., which markets a version of the product under the trade name Intron-A, received approval for the product's use for hepatitis.

Treatment: Interferon has been approved for chronic HCV. Patients are selected for therapy on the basis of persistently abnormal liver function (blood) tests, rather than on the presence or absence of symptoms. It's not known what should be done for patients with mild chronic HCV infection; since some patients with mild disease can go on to develop cirrhosis, a trial of therapy with interferon is usually recommended. It's recommended that such patients be referred to specialists with knowledge in liver disease (gastroenterologist/hepatologists). -- "Prevention, Diagnosis, and Management of Viral Hepatitis", AMA

About half of patients treated with interferon respond, with better blood tests and better liver biopsies. Half the patients who respond relapse once the interferon is stopped. -- "Prevention, Diagnosis, and Management of Viral Hepatitis", AMA

Alpha interferon seems to work better the sooner it is used after infection. However, in many cases of hepatitis C the symptoms get worse again when the treatment is stopped. In one study, half of the chronic hepatitis C sufferers who had responded to alpha interferon had a relapse within six months after treatment stopped.

Thus only 25 percent of HCV patients respond favorably without relapsing.

The average six months of injections three times a week are expensive ($75 a week). Many patients also suffer side effects, such as flulike symptoms, a reduction in the number of disease fighting white blood cells, and a decreased number of platelets in the blood. (Platelets are needed for blood clotting.)

Factors most closely associated with response to interferon are: 1) absence of fibrosis or cirrhosis in the pretreatment liver biopsy; 2) HCV genotype other than 1; 3) lower RNA levels in the blood (e.g., less than 2 million/ml); and 4) shorter duration of infection (which often isn't known).

III.1.0a WHEN IS INTERFERON TREATMENT NOT INDICATED?

Patients with chronic hepatitis B or C, with fluid in the abdomen ascites), bleeding from dilated veins in the esophagus (variceal bleeding), or mental confusion (encephalopathy) should be treated only in a clinical trial. Others not suitable for treatment are those with symptomatic heart, lung or kidney disease, with human immunodeficiency virus (HIV) infection or organ transplant recipients on prednisone, cyclosporine and FK-506 and patients on antidepressants or with a history of suicide attempts. Interferon should not be given to women considering pregnancy, nor to the intended father. Patients with active substance abuse (alcohol or illegal drugs) should not be offered this therapy. - "Interferon Treatment for Hepatitis B and C Fact Sheet", American Liver Foundation

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III.1.0b INTERFERON "BREAKTHROUGH" AND "NON-RESPONSE"

Recombinant interferon alfa (r-IFN alpha 2) has been shown to normalize the aminotransferase levels in approximately 50% of patients with chronic hepatitis C virus (HCV). Few patients experience a relapse during the eatment, in spite of a complete initial response (breakthrough). Continued treatment with r-IFN alpha 2, even at higher doses, did not restore the previous response in any patient. All of them were then switched to natural lymphoblastoid IFN, and this rapidly restored a complete response in all of the patients. - "Breakthrough during recombinant interferon alfa therapy in patients with chronic hepatitis C virus infection: prevalence, etiology, and management." - Hepatology Vol. 21 no. 3 pp. 645-9 1995 Mar

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A report in the Archive of Virology 1997 ;142(3):535-544 suggests that an inapparent coinfection of the hepatitis B virus (HBV) along with the hepatitis C virus may be implicated in cases of resistance to interferon treatment. In addition, HBV replication may persist in patients in whom HCV replication was inhibited by interferon treatment.

III.2.0 IRON REDUCTION THERAPY

A new study published in the fall issue of American Journal of Gastroenterology, Vol 89, No. 7, suggests that using "Iron Reduction Therapy" along with interferon can result in an effective cure rate in the area of 75-80% and that adding cytokines and antivirals such as ribavirin can improve effectiveness even further. The theory behind this is that viruses need iron to replicate, and by reducing the hepatic iron in the liver you prevent them from replicating. It should be noted that this new procedure is not yet FDA approved and is still in the early trial stages.

Iron is an element required for replication of virtually all virulent microorganisms. Reducing the amount of iron helps to limit the replication of the hepatitis C virus. The role of iron influencing the natural history of viral hepatitis was reported in a study more than 15 years ago (Blumberg BS, Lustbader ED, Whitford PL. "Changes in serum iron levels due to infection with hepatitis B virus." Proc Natl Acad Sci USA 1981;78:3222-4). In this study it was observed that patients with hepatitis B viral infection with higher serum iron or ferritin levels had greater likelihood of development of chronic infections than those with lower levels, who more often resolved their infections spontaneously.

Increases in levels of serum ferritin, iron, and transferrin saturation also have been noted with high frequencies in patients with chronic hepatitis C,2 and the higher levels have, in general, been associated with lesser likelihood of response to interferon therapy.

Complete responders to interferon have, on average, lower hepatic iron concentrations than do noncomplete responders.

In a report by Hayashi and colleagues ("Improvement of serum aminotransferase levels after phlebotomy in patients with chronic active hepatitis C and excess hepatic iron." Am J Gastroenterol

1994;89:986-8) it was reported that iron reduction alone, by repeated venesection (bloodletting), led to significant improvement in serum alanine aminotransferase (ALT) levels in chronic hepatitis C.

III.3.0 RIBAVIRIN

Many hepatitis C patients show a clear-cut biochemical response to ribavirin, with a lowering of liver enzyme levels.

However, the ribavirin does not clear circulating hepatitis C virus RNA and relapses occur after they discontinue taking the drug.

III.3.1 INTERFERON AND RIBAVIRIN COMBINED (REBETRON)

Recently the U.S. Food and Drug Administration approved the Rebetron combination therapy (interferon-alpha2b plus ribavirin) for the treatment of chronic hepatitis C patients who have relapsed following alpha interferon therapy. At six months post treatment, 45.7% who received the combination therapy had undetectable virus levels, compared to the 25% response rate to interferon alone.

The recommended dosage for this combination therapy is 3MIU of interferon-alpha2b (Schering-Plough brand name Intron A) injected subcutaneously three times per week and 1000 - 1200mg of ribarivin (Schering-Plough brand name Rebetol) capsules administered orally in a divided daily dose for a duration of 24 weeks. This combination therapy is packaged as Rebetron by the drug company Schering-Plough, with the interferon and ribavirin bundled together in one package.

A six-month treatment with Rebetron is estimated to cost between $6,400 and $8,600 depending upon dosage.

The most common side effects associated with the combination therapy are: Flu-like symptoms, such as headache, fatigue, muscle pain, fever, and the destruction of red blood cells which may be severe enough to result in anemia.

Psychiatric disorders have also been reported. Depression is a fairly common side effect, and in some cases it may become severe. Rare cases of suicidal thoughts and suicidal attempts have been reported.

The combination therapy is associated with a significant risk of abnormal fetal development, and women of childbearing potential should not begin combination therapy until a report of a negative pregnancy test has been obtained.

At the present time, the FDA has approved Rebetron combination therapy only for HCV patients who have previously undergone alpha interferon therapy and who have relapsed. It has not yet been approved for "naive" patients (meaning those who have not yet taken interferon alone), but FDA approval for this use is expected shortly. However, physicians can prescribe drugs for individuals for whom they think it will be helpful.

Therefore, physicians can prescribe combination therapy for naive patients prior to FDA approval for that specific use.

III.3.2 LOW DOSE ORAL INTERFERON AND HIGH DOSE INJECTABLE INTERFERON - COMBINED

According to a news release from Amarillo Biosciences, Inc, dated May 12, 1997, a study is commencing to test low dose oral interferon alpha as a combination treatment with high dose injectable interferon

alpha in hepatitis C patients in Canada and Mexico. The company has compiled preliminary data indicating that pretreatment with low dose oral interferon alpha preconditions patients to respond better to injectable interferon alpha. A clinical trial will be conducted with Dr. Elliott Alpert of Montreal as the principal investigator and another hepatitis expert located in Mexico as co-investigator. The study is expected to eventually enroll 180 patients and could take 2-3 years to complete.

III.3.2 CONSENSUS INTERFERON (INFERGEN)

Consensus interferon, or CIFN, is a synthetic form of one type of interferon. Created by Amgen scientists, the drug has undergone extensive clinical testing for treating hepatitis C, cirrhosis and a form of cancer.

According to the NIH Consensus Development Conference on Management of Hepatitis C 1997:

Consensus interferon at a dose of 9 ug administered tiw for 24 weeks is safe and effective for the treatment of chronic HCV infection in interferon-naive patients and results in a sustained HCV RNA response rate of 12 percent.

When compared with MU (15 ug) IFN alfa-2b, 9 ug CIFN may result in higher sustained HCV RNA response rates in patients with genotype 1 and in patients with high pretreatment viral loads.

In patients failing prior CIFN or IFN alfa-2b therapy, retreatment with a higher dose of CIFN (15 ug) for 24 weeks results in sustained HCV RNA response rates in 8 percent of nonresponders and 32 percent of relapsers and is well tolerated.

III.3.3 NATURAL SOURCE INTERFERON ALPHA-N3 - HUMAN LEUKOCYTE-DERIVED (ALFERON)

Alferon, produced by Interferon Sciences Inc., is an injectable, natural-source, multispecies alpha interferon produced from human peripheral blood leukocytes which is currently in clinical trials for the treatment of hepatitis C. The preliminary results of the trials are encouraging and further studies are planned.

It is thought that the chance of "breakthrough" is less when using natural source interferon, than with the standard interferon alpha 2b preparation. If the results at the end of clinical trials are favorable, the company intends to seek FDA approval of Alferon N Injection for the treatment of hepatitis C by the end of the third quarter 1998.

III.3.4 ROFERON (INTERFERON ALPHA 2A, RECOMBINANT)

III.3.4 LYMPHOBLASTOID INTERFERON (WELFERON, OMNIFERON)

III.3.5 PEGYLATED INTERFERON (PEG-INTRON A)

PEG-Intron A is a modified form of Schering-Plough's Intron A (interferon alfa-2b, recombinant), developed by Enzon, Inc. to have longer-acting properties. Currently in Phase III clinical trials, PEG-Intron A is administered once a week, compared to the normal dosage of 3 times a week for Intron A.

III.3.6 INTERFERON AND GM-CSF - COMBINED

Effects of granulocyte/monocyte colony stimulating factor (GM-CSF) have generally been disappointing: it is expensive, poorly tolerated, and without beneficial effect except perhaps in a rare patient who develops severe neutropenia due to interferon, in whom GM-CSF may permit continuation of higher doses of interferon.

An open label trial of GM-CSF plus high-dose interferon (IFN) alpha 2b was performed in 16 patients with chronic hepatitis C, who either failed to clear virus with 6 months of daily high-dose IFN (5 MU daily) therapy (n = 22) or were considered untreatable because of advanced disease and leukopenia (n = 2). The dose of GM-CSF used was 500 mu g subcutaneously twice weekly, The dose of IFN used was 5 MU daily, Both agents were administered for 4 months. Five of the 16 hepatitis C virus patients responded to combined therapy having previously failed IFN therapy alone.

No such differences for responders and non-responders were seen with the hepatitis C virus patients, These data suggest that the combination of GM-CSF and IFN may be more effective at achieving viral clearance than IFN alone. - "A Preliminary Experience with GM-CSF Plus Interferon in Patients with HBV and HCV Resistant to Interferon Therapy," Journal of Viral Hepatitis 1997 ;4:101-106

III.3.7 BETA INTERFERON, RECOMBINANT

According to a report in the Journal of Interferon and Cytokine Research 1997 Jan; 17(1):27-30, the intramuscular administration of interferon-beta (IFN-beta) at a dosage of 6 million units three times per week for 6 months was evaluated in 90 patients included in a multicenter, randomized, controlled trial for the treatment of chronic hepatitis C. At the end of the study, the researchers concluded that intramuscular IFN-beta at the dosage used has little efficacy in the treatment of chronic hepatitis C.

While the efficacy of beta-interferon has been proven to be ineffective when administered intramuscularly, a study reported at the 1996 Annual AASLD conference (" Therapy of Chronic Hepatitis C Non-Responders to Alfa-Interferon: A Preliminary Report of Intravenous Natural Beta-Interferon") reports that beta-interferon has been proven to be efficacious when administered by intravenous infusion, and that intravenous beta-interferon can be a well tolerated effective treatment for patients with chronic hepatitis C non-responders to [alpha]-IFN.

Another study reported at the 1996 Annual AASLD conference ("Analysis of Amino Acid Residues 2209 to 2248 of NS5A of HCV-1b in Relation to the Response to Interferon Beta Therapy"), suggests that some HCV patients with genotype 1b who have a mutant type of the NS5A2209-2248 gene are sensitive to interferon beta therapy regardless of lower doses and shorter treatment periods compared to interferon alpha. HCV-1b patients with the intermediate or the wild type of the NS5A2209-2248 gene are resistant to interferon beta therapy.

III.4.0 URSODEOXYCHOLIC ACID (ACTIGALL)

Ursodeoxycholic acid (UDCA) has been used in chronic liver diseaes and can limit hepatocyte injury. The various mechanisms of action of this hydrophilic bile acid include direct cytoprotection, detergent action on dysfunctional microtubules, immunomodulation and induction of hypercholeresis. It has recently been used in the management of chronic hepatitis, cirrhosis, post liver transplant rejection, graft -versus-host disease and acute viral hepatitis, where it not only relieves symptoms of cholestasis but also arrests ongoing hepatocyte necrosis.

According to a study reported at the American Gastroenterology Association Digestive Disease Week meeting in Washington in May 1997 (Treatment of chronic hepatitis C with interferon with or without

ursodeoxycholic acid: a randomized prospective trial), combination therapy with UDCA plus interferon was no more effective than interferon monotherapy in inducing a biochemical response in previously untreated patients with chronic hepatitis C. UDCA was, however, useful in prolonging the sustained biochemical response of IFN therapy in this small pilot study

III.5.0 HYPERICIN (VIMRx, HIFRITZEN)

A new drug discovered by Israeli scientists Professor David Lavi, formerly the director of Organic Chemistry Department at the Weizmann Institute and his son, Dr. Gad Lavi, a senior lecturer at N.Y.U., is in the second stage of clinical testing in humans with AIDS and hepatitis and the reports are very promising.

The new drug neutralizes viruses like hepatitis C as if it were an antibiotic, according to Dr. Lavi. The drug is produced from a plant that grows primarily in Europe and North American and is called Hifritzin. It is claimed the active substances in the drug neutralizes the virus and causes it to lose its power to attack healthy cells in the body. - The Jewish Free Press, Friday March 7, 1997

III.6.0 THYMOSIN

Thymosin alpha 1 is a protein produced by the human body, the cow and others which is supposed to enhance the immune system. It is associated with the thymus gland, which shrinks as we get older - yet has important role in immunity. There are over the counter products which take raw cow thymus - dry - defatted - and process the gland in tablet form which some claim when taken causes the human body to increase natural production of "thymosin alpha 1". Dr. Burgstiner in Savannha, Georgia, believes he cured himself of hepatitis B by using this formula (telephone 912-355-5755). That preparation is called "Thymic Fractions" and is produced by a company in California called Bio-Naturals at 800-991-7990. The reference to Dr. Burgstiner can be found in Naomi Judd's book " Love Can Build A Bridge" paperback edition - Pages (480-482) Dr. Burgstiner believes that this preparation must be taken with vitamins to act as coenzymes in order to be effective.

There is also a synthetic "thymosin alpha 1" being produced by a company called SciClone Pharmaceuticals - Telephone - 415-358-1446 available only in trials - It is given intravenously and has been - and is currently being studied for use in treating hepatitis B and C - in hepatitis B the results have been promising - and it is now being studied in combination with interferon.

III.6.1 THYMOSIN AND INTERFERON COMBINATION

In November 1996, SciClone Pharmaceuticals, Inc. commented on results from a randomized, placebo-controlled, double-blind phase III study in chronic hepatitis C patients receiving a combination therapy of thymosin alpha 1 and interferon alpha-2B. A life-table analysis showed almost 50% of the 65 patients had complete normalization of ALT in the thymosin combination treated group and in less than 20% of the interferon-only treated group. The study showed a statistically significant reduction in ALT levels in the combination group and significant complete normalization of ALT levels, as compared to the interferon only and placebo groups. Also observed were significant early virologic response in patients treated with combination therapy when compared to the interferon arm."

III.7.0 NAC

In chronic hepatitis C, oxidative stress increases and plasma and liver GSH concentrations decrease. Oral NAC (1800 mg/d), although having little effect alone, tends to enhance the response to interferon.

According to a report in the Journal of Interferon Research (13:279-282 1993), In interferon-unresponsive patients, the addition of 600 mg tid of oral N-acetyl cysteine (NAC), a glutathione

precursor, resulted in a steady decrease of ALT values in all patients, with complete normalization in 41% of cases after 5-6 months of combined therapy. The authors conclude that NAC enhanced the response to interferon in chronic hepatitis C, and suggest that further studies were needed to determine whether antioxidant therapy would be useful in conjunction with interferon treatment of hepatitis C.

III.8.0 PROTEASE INHIBITORS

HCV protease is one of the proteins that catalyze critical steps in the viral life cycle of hepatitis C. Recent efforts have focused on the molecular mechanism of hepatitis C replication as this has proven to be a successful approach in the treatment of HIV. The combination of HIV protease inhibitors and nucleoside analogs have been the first major breakthrough in the treatment of AIDS. There are similarities between the HIV and hepatitis C viruses as they are both RNA viruses which have a tendency to mutate. The HIV protease inhibitors are aspartate proteinases whereas the HCV protease is serine-based. This makes it unlikely that any of the current drugs being used for HIV would be effective in patients with hepatitis C.

Particular attention is being focused on the NS3 protease domain of the hepatitis C virus as this is an enzyme considered essential for replication of the hepatitis C virus. Recently the crystal structure of the hepatitis C virus NS3 protease domain was reported by two separate groups in the journal, Cell. This will no doubt lead to rapid development of protease inhibitor drugs by a number of biotechnology and pharmaceutical companies who are racing to accomplish this. Other logical targets for inhibition are the NS3 helicase and the NS5b polymerase enzymes as these are also essential for viral replication. It is likely that a number of inhibitor drugs will reach clinical testing phase in the next 18 to 36 months. (As of yet there are no protease inhibitors in clinical trials.) - "Emerging Therapies for HCV," - Scripps Clinic and Research Foundation, Liver Disease Study Group

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Shering-Plough has signed an agreement with Corvas International to collaborate on research to seek orally bioavailable inhibitors of a key protease necessary for hepatitis C virus replication.

III.4.1 RIBOZYME GENE THERAPY

Ribozymes are enzymes which have the ability to cause a catalytic cleavage of a targeted RNA. Ribozymes directed against the hepatitis C virus RNA have been developed which have the ability to destroy the virus' replicative material. Although these compounds have been produced using recombinant bench techniques they have not yet been proven safe or effective in vivo. It is anticipated that these compounds may have unpredictable and non-specific effects on other cells and therefore may be potentially toxic. More work is needed on these drugs before they will reach the clinic. - "EMERGING THERAPIES FOR HCV," From the Scripps Clinic and Research Foundation, Liver Disease Study Group

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III.4.2 ANTISENSE BASED THERAPIES

Antisense drugs are large, highly charged molecules which form DNA-RNA or RNA -RNA hybrids with the target RNA receptor.

In the case of hepatitis C this hybrid would form with the hepatitis C RNA which is the viral replicative material. This occurs by simple Watson-Crick base pairing. Once an anti-sense DNA hybrid has been formed it inactivates the viral replication process.

- "Emerging Therapies for HCV," - Scripps Clinic and Research Foundation, Liver Disease Study Group

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III.7.0 AMANTADINE

Amantadine (trade name Symmetrel) is a drug commonly used in the treatment of Parkinson's disease, and for the prophylaxis and treatment of illness caused by the influenza A virus. It is thought to prevent viral uncoating and thus viral multiplication.

Amantadine was recently tested in patients with HCV, and clinical trials will be beginning soon.

(From the 96th annual meeting of the American Gastroenterological Association, Digestive Disease Week , San Francisco, CA, May 21, 1996)

Dr. J.P. Smith presented the results of a recent trial of the antiviral agent, amantadine hydrochloride, in patients with chronic hepatitis C infection who had previously failed to respond to interferon alpha-2b. Twenty-two patients were treated with orally administered amantadine HCl, 100 mg twice a day, for 6 months.

These same patients served as their own controls during two intervals of no treatment (24 months before and 12 months after previous treatment with interferon) and during interferon therapy. Twenty of the 22 patients completed the 6-month study of amantadine.

Thirty percent of those patients completing the study demonstrated a complete response to therapy as demonstrated by the normalization of serum alanine aminotransferase (ALT) levels. Forty percent of the patients achieved a partial response (defined as a reduction in ALT of greater than 50%), and 30% failed to respond to amantadine therapy. Responders and partial responders maintained therapeutic benefits 6 months after treatment was stopped.

Two patients were discontinued from the study as a precaution due to cardiac-related side effects. Two patients reported difficulty concentrating, two patients reported constipation, and one experienced insomnia, but none of these patients discontinued the study. There was no observed decrease in WBC levels, nor was there any detrimental effect on the bone marrow attributable to treatment with amantadine.

Dr. Smith noted that the comparative costs of therapy at the Hershey Medical Center were $120 for 6 months of therapy with amantadine HCl vs $3,000 for interferon.

As shown by this study in 20 patients, amantadine HCl (which has the additional benefit of being taken orally vs by subcutaneous injection for interferon) may prove to be a useful alternative to interferon in treating patients with chronic hepatitis C. - "Treatment of Chronic Hepatitis C with Amantadine", J. P. Smith, The M. S. Hershey Medical Center, Pennsylvania State University Hershey, PA

III.8.0 OFLOXACIN

On the basis of the recent report on the antiviral effects of ofloxacin (OFLX) which is antibacterial drug, a study was designed to test the efficacy of OFLX in combination with interferon by a open clinical trial method. Analysis of HCV-RNA titer revealed that it decreased markedly after the beginning of combination therapy. HCV-RNA titer became negative in 8 cases of 11, and in 1 of 8 patients HCV disappeared by OFLX. However, the effects of OFLX were not monitored by HCV-RNA titers. ALT normalised rate at the end of the study in group I and group III (control) were 87.5% and 69.0% respectively, which differences were not statistically significant. The results of the trial indicate that the combination therapy of interferon and ofloxacin may be a possible strategy for the treatment of type C hepatitis. - "Combination therapy of interferon and ofloxacin in patients with chronic type C hepatitis", Takada N.; Yamazaki Y.; Sato T.; Furukawa T.; Matsuzaki H.; Shimada K.; Iwasaki K.; Furube M.; Tomioka H., Japanese Pharmacology and Therapeutics (Japan), 1995, 23/SUPPL. 3

III.9.0 CYCLOSPORINE THERAPY

Interferon therapy is of proven efficacy in chronic hepatitis C, but it is not universally effective and is often limited by side effects. Cyclosporine A (CsA) is a potent immunosuppressant widely used in organ transplantation. We conducted a pilot study to determine whether CsA therapy could affect aminotransferase activity and hepatitis C virus RNA levels in patients with chronic hepatitis C. The

findings suggest: that CsA, even in a relatively low dose, reduces serum aminotransferase levels without serious side effects in patients with chronic hepatitis C, although an antiviral effect was not noted. - "Cyclosporine Therapy Affects Aminotransferase Activity But Not Hepatitis C Virus RNA Levels in Chronic Hepatitis C," Journal of Gastroenterology and Hepatology 1997 JAN;12(1):62-66

III.11.0 TRANSPLANT

When does a liver transplant need to be done? This is a very complex issue and must be answered on a case by case basis. Anyone with hepatitis C should be followed by a physician regularly. If signs of progressive disease appear, the person needs to be referred to a gastroenterologist (specialist in digestive diseases and liver diseases). Since hepatitis C is known to progress very slowly, it is not necessary to have a liver transplant until the disease has reached "end stage". Factors to be assessed include the rate of progression of the disease, whether or not complications of liver failure have occurred and laboratory value including albumin, bilirubin, and prothrombin time.

What are my chances with a liver transplant? The survival rate after liver transplant overall is approximately 80% at one year, and 70% at five years. The odds for hepatitis C are approximately the same as for the average liver transplant for another reason.

How long will a new liver last? No one knows how long a transplanted liver can last. The longest reported survivor is 25 years. Ten year survival is commonplace. Hopefully improvements in techniques and medications that are continually occurring will allow most patients receiving liver transplants today to have long productive lives.

WILL THE HEPATITIS C BE CURED BY A LIVER TRANSPLANT?

No. Hepatitis C can live in cells other than in the liver. Once the old liver is removed and the new one is connected the hepatitis spreads back into the liver within the first weeks to months after the transplant. This is the bad news: at present we have no way to make the hepatitis C go away completely. The good news is that overall results with hepatitis C after liver transplantation is good. Although the disease comes back it does not seem to greatly damage the liver in the majority of cases. It is possible for the hepatitis to return so severely that the new liver fails, but this is uncommon. Long term results (ten years) are difficult to interpret since we have only been able to diagnose hepatitis C since 1990. Many people that were transplanted in the 1980's may have gotten hepatitis C at the time of transplant, since the blood supply was contaminated then. These people may have different chances compared to those that had transplant because of hepatitis C. Realistically it is likely that hepatitis C will be a long term problem in liver transplant recipients that harbor the virus.

We do not yet know how bad a problem this will be.

What can be done for hepatitis C that comes back in a transplanted liver? No treatment has been shown to change the course of the disease. Interferon alpha is being tried in experimental settings without much success.

I have hepatitis B and hepatitis C. Can a transplant still be done? Yes, some transplant centers are currently doing liver transplants for this indication.

Where do donated livers come from? Livers are donated, with the consent of the next of kin, from individuals who have brain death, usually as the result of a head injury or brain hemorrhage.

How can I donate my organs? If you wish to be an organ donor, carry an organ donor card and place an organ donor sticker on your medical identification card.

Statistics to date:

There are 6,684 on waiting list for livers
There were 3,922 done in 1995

804 died waiting

III.12.0 OTHERS

Some have found relief of symptoms using anti-gas medications such as symethicone for abdominal pain. Some recommend taking metronidazol daily to control ammonia and claim that it is better than neomycin due to nephrotoxic issues when neomycin is used long term. Many people use Lactulose for encephalopathy problems.

Some people have had good luck using Actigall or Questran to control itching.

PART IV TREATMENT (Alternative Medicine)

There have been few research trials to check the effectiveness of natural therapies, but many people report positive benefits. If you decide to use natural therapies, it's vital that you see a practitioner who is properly qualified, knowledgeable and well-experienced. It's also advisable to continue seeing your regular doctor or specialist. If a natural therapist suggests that you stop seeing your medical specialist or doctor, or stop a course of pharmaceutical medicine, **consider changing your natural therapist.** Ask searching questions of whichever practitioner you go to:

- Is the treatment dangerous if you get the prescription wrong?
- how have natural therapies helped people with hepatitis C?
- what are the side effects?
- Is the practitioner a member of a recognised natual therapy organization?
- how much experience have they had of working with people with hepatitis C?
- how have they measured the health outcomes of their therapy?
- how do they aim to help **you**?

Most typical health insurance will not cover alternative medical procedures, but that's beginning to change. Many alternative procedures are now covered under medical insurance in the states of Washington and Oregon, and it looks it's a trend which is beginning to spread.

Alternative Health Insurance Services of Thousand Oaks, California covers both allopathic and complementary/alternative treatments.

Patients may choose any provider, M.D. or N.D., or D.O. or D.C.

Subscribers must meet a deductible of up to $1000, and the plan pays 80% of the first $5,000 eligible medical expenses in a year, then 100 percent thereafter, with a $2 million maximum. The plan includes prescription drug cards, with a $5 copayment, as well as "named partner" coverage for homosexual or non-married couples and their families. Alternative Health Insurance Services: 1-800-966-8467.)

Another plan is offered by American Western Life Insurance Co.

In Foster City California: Prevention Plus. It covers a full range of alternative therapies. Enrollees use a naturopath as their primary care physician, or the gatekeeper who refers to other alternative practitioners. There is a $5 copayment for prescriptions, including herbal medicines. The company also has a 24-hour 800 Wellness Line staffed by naturopathic physicians, saving on doctor visits where possible. (American Western Life: 1-800-925-5323)

IV.0.1 ACUPUNCTURE

Acupuncture is a form of medical therapy that involves inserting thin, solid needles into selective sites on the surface of the body.

IV.0.2 CHIROPRACTIC

Chiropractic is a healing profession in which the spine, joints, and muscle tissue are manipulated in order to restore the proper function of the nerves. The chiropractor does not use drugs and surgery in treating diseases.

IV.0.3 ENERGY HEALING (Reiki, Hands of Light, Touch Therapy etc)

The gentle energy of Reiki (ray-kee), is an ancient spiritual practice which enhances natural healing processes. Reiki is called by various names in different parts of the world: "prana" in India, "qi" or "chi" in China, "spirit" in Western traditions, etc, and simply translates as "life force". Reiki is a means of adding more energy to our "life force" battery to help "jump start" the healing process. A Reiki treatment is essentially the "laying on of hands," an ancient technique common to many spiritual traditions. In a typical Reiki treatment, the client lies down (fully clothed) on a padded treatment table. Energy is transferred to the client through the hands of the practitioner in a sequence of standardized positions where the hands are placed. In each position, the hands are simply rested on the client for 3-5 minutes.

A full treatment usually takes about an hour. A Reiki treatment is a spiritual practice because it works directly with energy, or "spirit." There is no pressure applied and no manipulation of tissues (as in massage, for example).

IV.0.4 REFLEXOLOGY

Reflexology is a specialized type of massage treatment which works on the theory that reflex areas on the feet and hands are linked to other areas and organs of the body. It is felt that blocked energy, congestion, or tension in one part of the body (generally the foot or hand) mirrors congestion or tension in a corresponding part of the body. Thus, when you treat the big toes there is a related effect in the head, and treating the whole foot can have a relaxing and healing effect on the whole body.

IV.0.5 HOMEOPATHY

Homeopathy offers several remedies for the treatment of hepatitis. They are Mercury and Natrum Sulfuricum. Natrum Sulfuricum has clinically been found a valuable remedy for spinal meningitis, and has also found to be quite useful as a liver remedy as well.

IV.0.6 RETICULOSE

(Information provided by Commonwealth Pharmaceuticals, British West Indies, manufacturers of Reticulose)

Patients with Hepatitis A and 18 patients with Hepatitis B were treated with Reticulose. 9 Patients with Hepatitis A and 17 patients with Hepatitis B were controls and treated with placebo. The treated patients received Reticulose for a 15 day period, while the control received saline. Based upon laboratory findings of several parameters: Prothrombin times, Serum bilirubin, white blood cell count, and clinical observations, Reticulose treated patients appeared to show significant improvement. The bilirubin levels of 83% of patients with Hepatitis B, treated with Reticulose for 15 days were in the normal range in 30

days. None of the control patients treated with placebo were within normal range in 30 days. Of Hepatitis A patients treated with Reticulose, 100% showed normal bilirubin after 30 days. Of control patients with Hepatitis A, only 22% were in normal range after 30 days. The findings in this preliminary trial lead to the conclusion that Reticulose appears to significantly reduce the recovery time and return to normal for patients with an acute episode of Hepatitis A or B. Further study is indicated.

Conclusions: In this preliminary Human Clinical Trial in 53 patients with Hepatitis A or Hepatitis B, one half of whom were treated with Reticulose, the results demonstrated positive clinical and laboratory effects. 18 patients with Hepatitis B and 9 with Hepatitis A were treated with Reticulose, compared to 17 control patients with Hepatitis B and 9 control patients with Hepatitis A treated with placebo. Patients were diagnosed for Hepatitis A or B by appropriate laboratory tests of blood, urine, x-ray and physical examination, with special attention to Anti-HAV IGM and Hepatitis B surface Antigen to carefully differentiate those with A from those with B. We realize, however, that liver biopsy is the positive method for hepatitis diagnosis, but physical limitations prevented our using this method in this study. Based upon laboratory findings, serum bilirubin levels of 83% patients with Hepatitis B, treated with Reticulose for 15 days were in normal range in 30 days, 50% in 15 days, and 22% in 10 days. None of the control patients were in normal range after 30 days with placebo treatment. In the Hepatitis A patients treated with Reticulose, 100% showed normal bilirubin levels after 30 days, 89% after 15 days, and 33% after 10 days.

In the control patients with Hepatitis A only 22% were in normal range after 30 days, 11% after 15 days, and 11% after 10 days.

In all of the Reticulose treated patients, the white blood cell count showed significant increase, indicating stimulus to the immune system. In all of the Reticulose treated patients, the prothrombin times returned promptly to normal range while the controls did not. The results appear to demonstrate significant improvement in the patients treated with Reticulose, especially those with Hepatitis B. - "The use of Reticulose in the Treatment of Hepatitis A, B & C," Excerpted from: Journal of the Royal Society of Health Volume 112, No. 6, pages 266-270 December, 1992

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Advanced Viral Research Corporation, Miami, Florida, announced that the U.S. Food and Drug Administration (FDA) has instructed the company to cease all activities directly related to the previously announced pilot AIDS study assessing the effects of the company's drug "Reticulose on the viral load of persons who have been diagnosed with HIV." - Benefield Jr., William, AIDS Weekly, 02-20-1995, pp 18.

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IV.0.6 TRADITIONAL CHINESE MEDICINE (TCM)

In a report in the Chinese Journal of Integrated Traditional and Western medicine (1994), a claimed rate of cure of 56%, with most other patients showing improvements, was obtained when the following formula was administered to treat hepatitis C:

astragalus: 30 grams
salvia: 30 grams
forsythia: 30 grams
red peony: 30 grams
ho-shou-wu: 15 grams
crataegus: 15 grams
moutan: 15 grams
gardenia: 15 grams
dandelion: 15 grams
bupleurum: 10 grams

The herbs are decocted and the amount indicated here is taken in two divided doses each day, for three months. The formula can be modified to address specific symptoms by adding additional herbs (e.g. for pain in the liver area, loss of appetite, or abdominal distention). As with treatments for hepatitis B, the formula contains herbs for treating damp-heat (forsythia, gardenia, dandelion, and bupleurum), blood

stagnation (salvia, red peony, crataegus, moutan), and deficiency of qi and blood (astragalus and ho-shou-wu).

Due to the long course of therapy, one may wish to substitute dried extracts: a dose of three teaspoons (9grams), three times daily of this formulation should produce similar response [about 27 grams per day of dried extracts is roughly equivalent to a decoction of 160 grams of crude herbs, somewhat less than is recommended in the above clinical trial. Some patients may experience loose stool or diarrhea in response to this therapy (e.g. ho shou wu, gardenia, and dandelion can act as laxatives), thus one may need to adjust the formulation somewhat if this reaction occurs and persists.

IV.0.7 OZONE THERAPY

This is an experimental treatment, popular mostly in Europe, in which the blood is removed from the body, has ozone bubbled through it with the intention of killing the virus, and then the blood is returned to the body. I personally do not believe this is a safe practice, and would strongly recommend against it. Ozone bubbled through blood to kill viruses in vitro damages the living cells in it as well a removing the viruses. Ozone injected into your veins or aerated through your colon is a poison and has the very real potential of killing you rapidly. Ozone is very reactive and not stable in the lower atmosphere and does not remain ozone very long in any reactive media.

There have been reported cases of patients acquiring hepatitis C from improperly sterilized equipment used during ozone therapy.

- "Transmission of Hepatitis C by Ozone Enrichment of Autologous Blood," Lancet, 1996;347:541

IV.1.0 HERBAL TREATMENTS AND VITAMINS

IV.1.1 KOMBUCHA TEA

IV.1.2 MEDICINAL MUSHROOMS (REISHI / MAITAKE, SHITAKE)

Medicinal mushrooms may stimulate many aspects of the immune system, including the production of interferon.

In the Orient, Reishi is considered a Fu Zhen herb (immune modulation).

Presently, Reishi has various applications including lowering or raising blood pressure, stimulating liver actions, blood cleansing, and acting as an adaptogen in helping the body fight the effects of stress.

Chinese herbalists prize it for its abilities to regenerate the liver. In high doses, and to some degree normal doses, Ganoderma maybe classified as a liver detoxicant and protectant.

Toxicity studies show no toxic effects on humans. In research, patients are given much higher doses, as high as 10 grams of extract per day, with no ill effects.

The potency of Reishi mushrooms is usually based on its level of triterpenoids. One can determine the level of this by tasting it. The more bitter it is, the higher the level of triterpenoids.

Because Reishi is a polypore, (a group of hard, woody, bracket-like mushrooms) it is not eaten, but cut into pieces and made into a tea. In China, the average dose is 3 to 5 grams a day. Other popular forms of delivery are the water/alcohol extracts and powders.

- "Reishi: Ancient Medicine is Modern Hope", Linda McGlasson, Health Foods Business Consumer Education Series, January 1992.

IV.1.3 DANDELION (Taraxacum officinale)

The name dandelion is sometimes loosely applied to other milky-sapped weeds with fluffy yellow flowers. But true dandelion is that ubiquitous weed growing prolifically in millions of lawns, backyards and pastures throughout America. This perennial herb has deeply cut leaves forming a basal rosette in the spring and flower heads born on long stalks. All leaves and the hollow flower stems grow directly from the rootstock. The creator of the comic strip "Marvin" once had his adorable diapered hero surveying a clump of dandelions and then thinking to himself, "Dandelions are Nature's way of giving dignity to weeds!"

The late naturopathic physician, John Lust, stated in his Herb Book that dandelion root is good for all kinds of liver problems, including hepatitis, cirrhosis, jaundice and toxicity in general, as well as getting rid of gallstones. Bring 1 quart of water to a boil, reduce heat to low and add about 20 tbsp. of fresh dandelion leaves, stems and clean, chopped root. Simmer as long as it takes for the liquid to be reduced to just a pint, then strain. Take 3 tbsp. six times daily, Dr. Lust recommended.

For those desiring something more convenient in capsule form, there is the AKN Formula from Nature's Way, which contains considerable dandelion root and other cleansing herbs. It can be obtained from any local health food store. - "Heinerman Encyclopedia of Fruits, Vegetables and Herbs", John Heinerman, Parker Publishing Company

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IV.1.4 MILK THISTLE

Milk Thistle (Silymarin) is reported to be an anti-inflammatory and mast cell stabilizer that helps protect the liver against toxin, drugs, and the affects of alcohol (Better Nutrition for Today's Living, March 1993).

Use extract of milk thistle (Silybum marianum). "...European research shows that it stimulates regeneration of liver cells and protects them from toxic injury" Usually stocked in health food stores under the names milk thistle, silybum, or silymarin.

Take two capsules two or three times a day until liver function returns to normal.

Contains the active flavonoid Silymarin and is used for all liver disorders such as jaundice and hepatitis. Milk Thistle contains some of the most potent liver producing substances known. Milk thistle prevents free radical damage by acting as an antioxidant, protecting the liver. Stimulates the production of new liver cells and prevents formation of damaging leukotienes.

IV.1.5 ARTICHOKE (cynara scolymus)

The artichoke has a long folk history in treating many liver diseases. Recent evidence supports this longtime use. The active ingredient in artichoke is cynarin. this compound is found in highest concentrations in the leaves.

Cynara extract has demonstrated liver-protecting and regenerating effects, and promotes the outflow of bile from the liver to the gall-bladder. This is very important because if the bile is not being transported adequately to the gallbladder, the liver has an increased risk of being damaged.

IV.1.6 LICORICE ROOT (glycyrrhiza glabra)

Studies have shown a component of licorice to be effective in treating viral hepatitis, particularly chronic active hepatitis.

This is probably due to its well documented antiviral activity.

A glycyrrhizin-containing product is widely used intravenously in Japan for the treatment of hepatitis.

If licorice is used over a long time it is necessary to increase the intake of potassium rich foods.

IV.1.7 SPIRULINA (BLUE-GREEN ALGAE)

Researchers report that spirulina, an extract of blue-green algae, contains a substance that shows antiviral activity against HIV. Studies have not yet been conducted on it's effectiveness against the hepatitis C virus.

IV.1.8 GARLIC

Garlic is a natural antibiotic. It protects the body from infection, detoxifies the body, strengthens blood vessels, and lowers blood vessels. Garlic contains a natural antibiotic, antifungicid, and has many antiviral properties.

IV.1.9 THYMIC FACTORS

Thymic Factors is a combination of drugs including thymus, Enzymatic Poly-Peptide Fractions, Crude Thymus Extract, Thymosin, Thymopoletin, Thymus Humoral Factor, other nutrients, herbs, vitamins, and enzymes, developed by Carson B. Burgstiner,M.D after he contracted hepatitis B. He claims to have 83 cases of Hepatitis B, 23 cases of hepatitis C, 28 cases of Rheumatoid Arthritis, and arrested 12 cases of Systemic Lupus (some of whom were taking 22 different drugs and are now asymptomatic), 10 cases of Multiple-Sclerosis, 12 cases of Psoriasis, 7 cases of people with Squamous Cell Cancer of the skin.

This formulation has not been through official clinical trials, and the claims have not been proven, but many listmembers on the HEPV-L mailing list report that they feel better and have more energy while taking Thymic Factors.

Dr. Burgstiner's Recommendations for Preventative Maintenance: 2 Thymic Factors with 1 Thym-A-Vites vitamin twice daily in AM & PM to be taken with food or meals.

Dr. Burgstiner's Recommendations for Chronic Conditions: 4 Thymic Factors with 2 Thym-A-Vites vitamins twice daily in AM & PM to be taken with food or meals.

Continue at this level until you are satisfied with the results or bloodwork is normal. Then go to the maintenance dose of 2 Thymic Factors with I Thym-A-Vites vitamin twice daily in AM & PM to be taken with food or meals.

Dr. Burgstiner's office may be contacted at the number below.

They will send you an information packet in a few days. The formula is called Thymic Factors, and the vitamins are made by Sundown (super multiple, minus iron).

Carson B. Burgstiner,M.D., 5354 Reynolds St. # 304, Candler Professional Bldg., Savannah, GA 31405 Phone (912)355-5755 fax (912)355-5759

In 1996 a company Preventive Therapeutics, Inc. started manufacturing the original formula of Dr. Carson B. Burgstiner, which is being sold and distributed by them as well as by many health food stores.

The containers consists of 180 tablets, 30 day supply. There is a picture of a bird and flowers on the label.

When Preventative Therapeutics was contacted, they gave the following advice: When first taking the Thymic Formula until stabilized 2-3 months, take 6 tablets twice daily (total 12 tablets) 12 hours apart. When stabilized take 3 tablets, twice daily.

Preventive Therapeutics, Inc. is located in Duluth Georgia, a suburb of Atlanta GA. 1150K Court Drive, Duluth GA 30136. Telephone: Toll free:1-888-372-8259;770-417-2835, fax:-770-409-0110 Contacts: Ed. Callaway, RPH, Jim Williamson or Pat Stephens

IV.1.10 VITAMIN C

Linus Pauling the two time Nobel Prize winner said that vitamin C is very beneficial to hepatitis patients. He recommends a bare minimum of 10,000 milligrams = 10 grams a day. 20,000 - 50,000 milligrams a day is much better = 20 to 50 grams. Take pure vitamin C. Take the pills three to four times a day instead of once a day. Vitamin C is an antiviral agent. The only side effect known is diarrhea which should slow down and stop as you get used to the vitamin C. You can get Linus Paulings books at your local library.

It was recently reported on HEPV-L that taking over 2000 mg of vitamin C per day will block iron uptake from the blood effectively elevating our iron levels. This is detrimental to HCV-Positive individuals, and can block or slow down the effectiveness of interferon.

IV.1.11 VITAMIN B12

Some hepatitis patients report having more energy when they take extra vitamin B12.

IV.1.12 VITAMIN E

Vitamin E is reported to assist the liver in detoxifying the blood.

IV.1.13 NATURAL INTERFERON BOOSTERS

Studies indicate that many natural substances can activate the body's own production of interferon. Some better known natural interferon boosters are:

Astragalus : a Chinese herb that enhances the antibody reaction to foreign invaders of all types, including cancer.

Boneset : a native American Indian herb with antiseptic, anti-viral properties used for the treatment of colds and flus, coughs, fevers, indigestion and pain.

Chlorophyll : a plant pigment which can be found in a long list of green leafy vegetables and algae like spirulina, chlorella and barley green.

Coenzyme Q10 : an antioxidant involved in the electron transport chain needed for all energy dependent processes in the body. CoQ10 increases helper T-cells and reduces infection risk.

Echinacea : the most popular herb in North America used as a treatement for toothaches, bites or stings and all types of infections.

Ginkgo : a potent central nervous system antioxidant for the treatment of circulation disorders, memory problems, high blood pressure, depression, tinnitus and immune system disorders.

Melatonin : a hormone produced by the pineal gland with strong antioxidant and immune system boosting properties. .

IV.1.14 OTHER HERBS OR VITAMINS

Essiac Tea is an Ojibway tea thought to cleanse the body of toxins and boost immunity, which some people have found to be helpful. (Personally, it seemed to make me sicker - Patti).

IV.2.0 EXERCISE

Symptomatic hepatitis patients may need to avoid stressful activities, and each person's tolerance for stress will be different, and can change. It is nonetheless important for people who can exercise to do so, up to their level of tolerance. This should be done with care, since crossing the "invisible line" of exercise intolerance may prompt a flare-up.

IV.3.0 STRESS MANAGEMENT

Typically, one of the most beneficial things a person with hepatitis can do is to avoid stress and get lots of rest.

Stress does not merely mean only unpleasant experiences, but rather any biological stressors, physical or emotional, which prompt a protective reaction in the body. Failure to avoid stress often leads to short-term and long-term set-backs which may be serious.

High-stress events sometimes seem to "trigger" the flare-ups of the virus and they will usually worsen the symptoms if the virus is already active. Medical studies show that stress plays an important role in several immune-mediated illnesses.

IV.4.0 POSITIVE ATTITUDE

Laughter and a positive spirit are good for the body.

They provide interferon, the body's natural infection fighter, and produce endorphins to combat depression and anxiety.

IV.5.0 TAI CHI / CHI KUNG / YOGA / MEDITATION

IV.6.0 OTHER WAYS TO HELP KEEP YOURSELF HEALTHY

- Avoid exposure to chemical fumes, gasoline fumes, etc.
- Use the least toxic products (cleaning products, health and beauty aids, etc) available in your home and on your body

PART V - NUTRITION

V.1.0 WHAT SHOULD I DO ABOUT NUTRITION?

Many dieticians and medical experts working with hepatitis C feel that except for alcohol, diet has little direct effect on the activity of the virus and the outcome of long-term infection.

There is no specific dietary approach that can be recommended which can guarantee to alter the outcome of any particular liver disease. This isn't to say that modifying your diet has no effect.

Nutrition and the liver are interrelated in many ways.

Everything we eat, breathe and absorb through our skin must be refined and detoxified by the liver, special attention to nutrition and diet can help keep the liver healthy.

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.

Bitter foods are useful as they stimulate the digestive process and assist the liver. Eating salads containing bitter leaves such as dandelion or chicory 10-15 minutes before meals is a long-standing European recipe to aid the liver.

In Taiwan, a diet high in vegetables was associated with a lowered risk of liver cancer in people with hepatitis C.

Vegetable juices have a particular nature that helps lessen the bloated and stagnant feelings often associated with liver conditions.

Vegetable juices act to flush out the body and relieve some of the symptoms that people with liver disease experience, such as heaviness and lethargy. The juice of carrots, beets, cucumber, spinach, celery , wheat grass and parsley are all used in liver cleansing fasts, and are generally thought to be good for livers.

Drinking 2-3 litres of water each day is universally recommended for good health, but also protects against lymphatic congestion, which would put further strain on the liver.

As for diets in particular, The Alternative Medicine Guide says:

Jonathan Wright, M.D. recommends a diet low in protein to minimize stress on the liver. Whole foods diet that follows a hypoglycemic regime, of small meals throughout the day, avoiding stressor foods such as refined sugars, alcohol, and caffeine. Consume plenty of filtered water. Drinking fresh lemon juice water every morning and evening followed by vegetable juice is one of the most therapeutic regimes for the liver. Do this consistently for two to four weeks and then several mornings a week for several months and whenever liver symptoms reoccur. Have lots of vegetables each day. Ideal is at least one salad and one meal of steamed or lightly sauteed vegetables per day. Grains that are easily digestible, such as millet, buckwheat, and quinoa are very good.

According to the Encyclopedia of Natural Medicine:

A natural diet, low in natural and synthetically saturated fats, simple carbohydrates (sugar, white flour, fruit juice, honey, etc), oxidised fatty acids (fried oils) and animal fat, and high in fibre is recommended.

... Natural substances to help your liver detoxify are as close as your kitchen cupboard. Eating foods rich in lecithin (soybean), essential fatty acids (salmon, flax oil) and green leafy vegetables rich in fibre and antioxidants like vitamins C and E, are all gourmet cuisine for your liver. Lowering your intake of saturated fats, refined carbohydrates and animal protein and avoiding excessive amounts of alcohol are other recommendations that are good both for your liver and overall body health. Dandelion root and artichoke are both excellent spring time dietary condiments that are very helpful in improving liver bile flow. In addition to these food choices, supplements like L-methionine are an excellent choice for a congested liver. This sulfur-containing amino acid not only improves bile flow but also helps protect liver glutathione. Glutathione peroxidase is one of the body's major detoxification enzymes and is in part defended by methionine during a toxic challenge to the liver...

The article goes on to describe the function of Milk Thistle.

It concludes that the most potent substances for protecting the liver are Milk Thistle, Dandelion and L-methionine. L-methionine is classed as a "supplement," and Milk Thistle and Dandelion as "botanical medicines." - "Protecting and Enhancing Liver Function," by Ronald G. Reichert, ND , *Alive: Canadian Journal of Health and Nutrition* (#161, March 1996): pp. 14-16.

V.1.1 FOODS TO AVOID:

PEANUTS: Some peanuts contain aflatoxins, a mold which increases the chance of liver cancer.

RAW SHELLFISH: Vibro vulnificus, a bacteria, can be contracted by eating raw oysters, etc. Shellfish, if uncooked, can be very dangerous for people with liver disease. Either avoid or be careful that the shellfish you eat is well-cooked.

SATURATED FATS: It's generally best to keep fats at a minimum.

V.4.0 SALT

Those who are prone to episodes of ascites should try to maintain a very low sodium diet (less than 3 gr/day - I shoot for 1-2gr/day).

PART VI - DRUGS AND ALCOHOL

VI.1.0 ALCOHOL

There is no question that alcohol is bad in HCV. Studies have shown that patients that drink 3 drinks per day have a higher incidence of cirrhosis. Our own center has shown that patients with HCV and drink have a worse activity index on the liver biopsy.

Alcohol is thought to magnify the progression of hepatitis C and vice versa. No one knows if there is a safe amount of alcohol to consume if you have hepatitis C. Certainly heavy intake (more than 3 drinks a day) should be avoided. The safest course of action is not to drink alcohol at all if you are known to have hepatitis C.

Whether one or two drinks a day increases the rate of progression of liver disease is not currently known.

EFFECT OF ALCOHOL ON HCV REPLICATION: A critical question is whether or not alcohol and hepatitis C infection are synergistic in a combined liver injury. In some patients, there are both histologic features of alcoholic liver injury and chronic viral hepatitis, but in most studies the predominant pattern is chronic hepatitis.

Alcohol may enhance the replication of hepatitis C and produce a more severe injury independent of the direct alcohol-induced toxic injury. There is a correlation between HCV RNA levels and amount of alcohol consumed. Alcoholic patients with HCV infection have higher hepatic iron concentrations, which may be germane to increased HCV replication. Clinical evidence of hepatic activity and viral levels is significantly greater in those consuming greater than 10g of alcohol per day.

EFFECT OF ALCOHOL ON PROGRESSION OF CHRONIC VIRAL C HEPATITIS TO CIRRHOSIS AND HEPATOCELLULAR CARCINOMA : There is a more rapid development of cirrhosis and hepatocellular carcinoma in the alcoholic with chronic HCV infection. The period from transfusion to the diagnosis of cirrhosis is shorter in the heavy drinker.

The risk for the development of hepatocellular carcinoma in alcoholic cirrhotics is 8.3 times higher in the HCV(+) patients than HCV(-) patients, and the prevalence of anti-HCV among alcoholics with HCC is 50-70 percent. Therefore, alcohol may modify the replication of HCV as well as the oncogenicity of HCV in hepatocellular carcinoma.

INTERFERON THERAPY IN ALCOHOLIC PATIENTS WITH CHRONIC HEPATITIS C : Among alcoholic patients with chronic hepatitis C who remained abstinent during therapy with interferon, there was a significantly lower rate of HCV RNA clearance in those who consumed 70g/day of ethanol as compared to 70g/day up to the time of interferon therapy. - "Hepatitis C and Alcohol," by E.R. Schiff, abstract submitted by the author to the National Institute of Health Conference on Hepatitis C, held March 24-26, 1997, in Bethesda, Maryland

An important cofactor of disease severity appears to be alcohol and alcohol should be avoided in those with chronic HCV infection." - "Natural History and Clinical Aspects of HCV Infection." H.J. Alter. Department of Transfusion Medicine, National Institutes of Health, Bethesda, Maryland. Cancer Biotechnology Weekly, 01-29-1996, pp 20.

Many people complain of increased pain in the liver area after eating high fat meals. With saturated fats, the liver must work harder than normal to neutralize their harmful effects.

V.2.0 NUTRITION AND CIRRHOSIS

Many chronic liver diseases are associated with malnutrition.

One of the most common of these is cirrhosis. Cirrhosis refers to the replacement of damaged liver cells by fibrous scar tissue which disrupts the liver's important functions. Cirrhosis occurs as a result of excessive alcohol intake (most common), common viral hepatitis, obstruction of the bile ducts, and exposure to certain drugs or toxic substances.

People with cirrhosis often experience loss of appetite, nausea, vomiting and weight loss, giving them an emaciated appearance.

Diet alone does not contribute to the development of this liver disease. People who are well nourished, for example, but drink large amounts of alcohol, are also susceptible to alcoholic disease.

Adults with cirrhosis require a balanced diet rich in protein, providing 2,000 to 3,000 calories a day to allow the liver cells to regenerate. However, too much protein will result in an increased amount of ammonia in the blood; too little protein can reduce healing of the liver. Doctors must carefully prescribe the correct amount of protein for a person with cirrhosis. In addition, the physician can use two medications (lactulose and neomycin) to control blood ammonia levels. Persons with cirrhosis often experience an uncomfortable buildup of fluid in the abdomen (ascites) or a swelling of the feet, legs, or back (edema). Both conditions are a result of portal hypertension (increased pressure in the veins entering the liver). Since sodium (salt) encourages the body to retain water, patients with fluid retention can cut their sodium intake by avoiding such foods as canned soups and vegetables, cold cuts, dairy products, and condiments like mayonnaise and ketchup. In fact, most prepared foods contain liberal amounts of sodium, while fresh foods contain almost no sodium at all.

The best-tasting salt substitute is lemon juice. In general, a reduction in meat protein which is the most toxic protein to the brain and substituting vegetable protein is advised when cirrhosis is present.

V.3.0 COFFEE, TEA, CAFFEINE AND OTHER STIMULANTS

In the book "Healthy Healing" by Linda Rector-Paige, N.D., PhD, she says: "...Some of the health problems of caffeine are...well known—headaches and migraines, irritability, stomach and digestive problems, anxiety, and high blood pressure. As an addictive stimulant, it works as a drug, causing jumpiness and nerves, heart disease, heart palpitations. Caffeine in excessive amounts, can produce oxalic acid in the system, causing a host of problems waiting to become diseases. It can lodge in the liver, restricting proper function, and constrict arterial blood flow.

It leaches out B vitamins from the body...It depletes some essential minerals, including calcium and potassium...however the caricinogenic effects often blamed on caffeine are now thought to be caused by the roasting process used in making coffee, tea and chocolate.

Since decaffeinated coffee has been implicated in some forms of organ cancer, conclusions are being drawn that caffeine is not the culprit—the roasted hydro-carbons are..."

— unfiltered coffee raises serum cholesterol, liver enzymes. One study in the British Medical Journal shows that cafetiere (brewed, unfiltered) coffee raises serum LDL cholesterol levels and serum concentrations of alanine aminotransferase (ALT). Cafetiere coffee is made by pouring boiling water over ground coffee in a container with a sieve plunger. Dr. Rob Urgert and others at Wageningen Agricultural University in the Netherlands observed that unfiltered coffee raised alanine aminotransferase 80% above baseline levels relative to filtered coffee. Once the subjects stopped drinking cafetiere coffee, the liver enzyme and LDL cholesterol concentrations returned to baseline levels. The Dutch investigators write that "Daily consumption of five to six cups of strong cafetiere coffee affects the integrity of liver cells..." and they attribute the increases in cholesterol and alanine aminotransferase concentrations to the diterpenes cafestol and kahweol that are abundant in cafetiere. - BMJ 1996;313:00-00.

A Japanese research team reports that heavy drinking reduces the efficacy of interferon therapy in habitual drinkers with chronic hepatitis C and that this effect can be reversed by abstinence.

Dr. Kunihiko Ohnishi and colleagues from the Saitama Medical School in Saitama, Japan, evaluated the effect of alcohol consumption in 95 patients who had a confirmed diagnosis of chronic hepatitis C and were receiving treatment with interferon

Dr. Ohnishi reports that the rate of response to interferon therapy was 36% in infrequent drinkers, 33% in moderate drinkers, 26% in heavy drinkers who had stopped drinking and 6% in heavy drinkers who continued to drink. Dr. Ohnishi and coinvestigators note that these results demonstrate "...for the first time, that the adverse effect of habitual heavy drinking on the efficacy of interferon therapy might be reversed, at least in part, by abstinence for more than 6 months before the start of interferon therapy." - Am J Gastroenterol 1996;91:1374-1379 .

Alcoholism appears to be a predisposing condition for hepatitis C virus infection, but not hepatitis B. ("Alcoholism is Associated with HCV, but not HBV in an Urban Population," The American Journal of Gastroenterology, March 1996;91(3):498-505) The study adds to the accumulating evidence suggesting that hepatitis C virus is related to alcohol consumption.

Rosman et al. concluded that the increased seroprevalence of hepatitis C in actively drinking alcoholic patients without known risk factors suggest that alcoholism, in some way, is a predisposing factor for HCV infection.

We conclude that infection by both HCV and HBV may play a role in the development of HCC, and that alcohol consumption may promote carcinogenesis. Hepatogastroenterology 42: 151-154 (1995) "Relation between markers for viral hepatitis and clinical features of Japanese patients with hepatocellular carcinoma: possible role of alcohol in promoting carcinogenesis." Y. Matsuda, Y. Amuro, K. Higashino, T. Hada, T. Yamamoto, M. Fujikura, K. Yamaguchi, S. Shimomura, H. Iijima, T. Nakano

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According to DSHS; DASA (Division of Alcohol & Substance Abuse) in Washington State - in curriculum for ADIS: The liver is the body's "garbage disposal," removing waste products from the bloodstream. This includes alcohol and mind altering drugs.

The rate of removal varies, depending on the drug. The alcohol in one can of regular beer is removed in one hour, while the active ingredient from 4-5 hits of marijuana takes 3-8 days to be removed.

VI.2.0 TOBACCO

Cigarette smoking combined with the hepatitis C virus is known to be a heavy risk factor in developing primary hepatocellular carcinoma.

VI.3.0 MARIJUANA

Marijuana presents no problems for the liver. - New South Wales Users and AIDS Association "Hepatitis C and Drug Use"

It has been shown that marijuana interferes with the effectiveness of interferon alfa-2a in the treatment of genital warts due to drug-induced impairment of cellular immunity. ("Genital Warts do not respond to systemic recombinant interferon alfa-2a treatment during cannabis consumption", Gross G; Roussaki A; Ikenberg H; Drees N., Dermatologica, 1991, 183(3):203-7) Whether this is also true for marijuana use during interferon alpha-2b treatment for hepatitis is unknown.

VI.3.1 COCAINE

A study of blood donors who showed traces of past infection with the liver-damaging disease hepatitis C has uncovered a possible link between the infection and snorting cocaine. Snorting "could be an unrecognized route" for the hepatitis C virus to get into the body, said a team of medical researchers led by Dr. Cathy Conry-Cantilena of the National Institute of Allergy and Infectious Diseases.

But the researchers noted that cocaine abuse may not be the actual cause of the hepatitis. Cocaine users may simply be more prone to other behaviors that make them vulnerable to the infection.

Hepatitis C is usually passed via contaminated blood. The researchers said it was possible the straws used to snort the drug could be tainted with blood and the virus could get into a user's body through the wall of the nose, which is often damaged in cocaine snorters.

VI.4.0 WHAT ARE THE EFFECTS OF RECREATIONAL DRUGS?

If you are HCV+, alcohol and other drugs are likely to put added strain on your already stressed liver. And even if you already have HCV, you are still open to re-infection if you expose yourself to the virus through unsafe drug use. There are several different types and variations of HCV, and every time you catch a different type, it is like you have been infected for the first time. People with multiple infections of HCV are often the ones who become sicker. It is advisable to avoid alcohol and all street drugs.

If users are opiate dependent methadone may be an alternative in this phase of infection, simply because it is available in pure form.

Hepatitis generally increases the chances of overdosing (especially on alcohol, and benzodiazepine tranquilizers such as Serepax, Rohypnol, Valium, Mogadon and Temazepam) because the liver cannot handle the doses of drugs to which the user was formerly accustomed.

Serepax is better than other benzodiazepines but it still presents problems.

Heroin is relatively harmless during hepatitis infection but all drugs present problems, whether in pure or impure forms. Amphetamines and benzodiazepines are medium destructive and alcohol is the worst.

In as far as drug use is concerned, purer forms of drugs are advisable in all cases (for instance methadone is better than street heroin, pharmaceutical amphetamines are better than street amphetamines) but this is only a minor improvement, for it is the liver's function of removing drugs from the body which is affected by the hepatitis C virus. It is best to be aware of any possible problem in this area and the specific relationship between specific drugs and the liver.

It is best to be entirely drug free during the acute phase of hepatitis infection so that the liver can repair itself. Drug-taking presents less problems if you have a healthy liver. - New South Wales Users and AIDS Association "Hepatitis C and Drug Use"

VI.4.1 INTRAVENOUS DRUG USE PRECAUTIONS

When injecting drugs, the best protection is to never re-use injection equipment. Cleaning injection equipment is not guaranteed to kill the hepatitis C virus.

To avoid hepatitis C when injecting:

- have a fit, spoon, water, filter, swab and tourniquet
- wash your hands with warm soapy water before and after injecting
- clean the spoon with a fresh swab
- keep all your utensils separate from your friend's utensils
- inject yourself - but if someone else does inject you, make sure they've washed their hands
- if you get blood on your hands, go and wash them before you touch anything on the table - if someone asks you to pass them something, tell them to wait.

- If you do touch something before you're able to wash your hands, treat it as contaminated
- dispose of your used fits, filters, swabs, etc, properly by putting them into a sharps container - or use an empty plastic drink bottle or detergent container. (Look for the letters PET on the bottom of the plastic bottles, as these are especially strong.) Be careful not to dispose of your fits in aluminum cans or glass bottles. Kids collect cans for recycling and could get needlesticks, and glass bottles can easily break.
- remember - use new equipment every time. Cleaning equipment doesn't always kill the hepatitis C virus.
- remember - wash your hands with soap and water before and after injecting. You can't always see minute amounts of blood.
- remember - make the bench or table where you're injecting as clean as possible.

VI.4.2 CLEANING FITS

We don't know that disinfection or cleaning really works so be safe and use all new equipment every time you hit up. Reusing fits should be a last option only. If you're cleaning fits, remember the following guidelines:

- Immediately after use, rinse fit in cold water until signs of blood are gone. Squirt water down sink or into an old drink bottle.
- Do this as soon as you've used the fit since dried or clotted blood is hard to wash out and can block the fit. Always use cold water as hot water will clot blood in the fit and block it.
- fill the fit with fresh high-strength bleach. Use the strongest bleach available (which is usually the most expensive). With the fit full of bleach, replace the cap over the needle and shake it for 30 seconds or more. Time this on a watch or count it out slowly. Then squirt the bleach out into the sink or an old drink bottle. Now repeat the bleach process, again shaking for thirty seconds.
- with another container of fresh clean water rinse the fit out at least two times. Again, squirt the water down the sink or into an old drink bottle, not into your containers of bleach or clean water. Empty all your containers down the sink when you are finished.

Remember that this way of cleaning fits can't be guaranteed to kill the hepatitis C virus. - Hepatitis C Council of NSW

VI.4.3 METHADONE AND HEPATITIS C

The effects of methadone can alleviate possible painful symptoms of hepatitis C. Although this may be helpful, it can camouflage early signs of liver damage (if it develops). Flu-like hepatitis C symptoms may give the impression that you are on prescription pills. If this causes problems at the clinic where you receive your methadone, it may be useful to remind them of the complicating effect of hepatitis C symptoms.

If you experience flu-like symptoms of hepatitis C, these symptoms should not be misinterpreted as withdrawal symptoms from opiates.

People should be careful with methadone dosages and aware of their real tolerance for drugs. This is especially important if liver damage is severe. - Hepatitis C Council of NSW

PART VII - HOW CAN HCV AFFECT MY EMOTIONAL LIFE?

VII.1.0 HOW IS DEPRESSION RELATED TO HEPATITIS?

Many emerging illnesses, before they have gained acceptance by the medical community, have initially been discounted as being hysteria, depression, etc. Before the hepatitis C virus was identified in 1989, many of its symptoms were correlated to depression, and many un-read physicians today still believe that HCV is normally asymptomatic.

Another issue is that HCV patients can get "secondary depression" if their lives have been disrupted because their illness has interfered with their job or their social or family life. This indirect consequence of the illness may be taken by some medical professionals as indicating a cause rather than an effect of the observed symptoms.

VII.1.1 MOOD CHANGES

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VII.1.2 DEALING WITH A CHRONIC DISEASE

Many people never fully appreciate their health until they suddenly have to face the fact that they now have an illness that is not going away. This new state of affairs can make you feel angry and depressed, and it's hard to get beyond the question "Why me?"

People commonly work through what Dr. Elisabeth Kubler-Ross has identified as the five stages of adjustment as they learn to accept a chronic illness. There are feelings of denial, anger, depression, bargaining and acceptance. All of these feelings are natural, and there is no fixed time schedule for your passage through the stages, and many times the stages overlap.

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VII.1.2a ACCEPTING

Realize that you have to experience the pain in order to work through it. Don't try to hide the physical and emotional hurt.

Experience the pain and then let it go. Don't be afraid to express the hurt you feel.

Learn to laugh, try to see humor in your situation, and to enjoy the simple pleasures of life.

Keep the lines of communication open. It helps to know that someone understands how you're feeling and can help bear the load.

Don't neglect your personal "self-time." Being alone can provide a personal perspective from which calm, wise judgements, opportunities for personal growth, and a new optimism about life can emerge.

Don't hesitate to seek counselling for your special situation.

Some problems are too big to work through on your own.

Take responsibility for yourself and realize that you DO play a role in your illness.

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VII.1.3 DEALING WITH A LOWER LEVEL OF ENERGY

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VII.1.4 IRRITABILITY

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VII.1.6 HOW CAN HCV AFFECT MY SEX LIFE?

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VII.1.6 HELPING A FRIEND OR FAMILY MEMBER WITH HEPATITIS C

TIPS FOR COPING WITH HAVING A FAMILY MEMBER WITH HEPATITIS C

Remember:

1. You cannot cure your family member.
2. Despite your efforts, symptoms may get worse, or may improve.
3. If you feel much resentment, you are giving too much.
4. It can be as hard for you to accept the illness, as it is for the ill family member.
5. Acceptance of the disease by all concerned may be helpful, but not necessary.
6. You may learn something about yourself as you learn about a family member's journey through illness.
7. Separate the person from the virus. Love the person, even if you hate the virus.
8. Separate medication side effects from the disease/person.
9. It is not OK for you to be neglected. You have needs & wants too.
10. Your chances of catching hepatitis C from casual contact or sexual contact with a family member is extremely low, providing proper precautions are taken to avoid blood contact.
11. The illness of a family member is nothing to be ashamed of.
    Reality is that you may encounter discrimination from an apprehensive public.
12. No one is to blame.
13. Don't forget your sense of humor.
14. It may be necessary to revise your expectations.
15. Acknowledge the remarkable courage your family member may show dealing with the illness.
16. Your family member is entitled to his own life journey, as you are.
17. Survival-oriented response is often to shut down your emotional life. Resist this.
18. Inability to talk about feelings may leave you stuck or frozen.
19. The family relationships may be in disarray in the confusion around the disease. It may be necessary to renegotiate the way things have been done in your relationship, both emotionally and physically.
20. Recognizing that a person has limited capabilities should not mean that you expect nothing of them.
21. You may experience grief issues about what you had and lost, or about what you never had.
22. After denial, sadness, and anger comes acceptance. The addition of understanding yields compassion.
23. Diseases are a part of the varied fabric of life.
24. It is absurd to believe you may correct a physical illness such as hepatitis with talk, although addressing social complications may be helpful.
25. Symptoms may change over time while the underlying disorder remains.
26. The disorder may be periodic, with times of improvement and deterioration, independent of your hopes or actions.
27. Don't shoulder the whole responsibility for your ill family member.
28. Forgive yourself and others for mistakes made.
29. Physicians have varied degrees of competence.
30. If you can't care for yourself, you can't care for another.
31. The needs of the ill person do not necessarily always come first.
32. It is important to have boundaries and set clear limits.
33. Chronic illness affects the entire family, not just the person who actually has the disease.
34. It is natural to experience a cauldron of emotions such as grief, guilt, fear, anger, sadness, hurt, confusion, etc. You, not the ill member, are responsible for your own feelings.
35. You are not alone. Sharing your thoughts and feelings with others in a support group is helpful and enlightening for many.
36. The chronic illness of a family member is a trauma for the entire family. You pay a price if you do not receive support and help.
37. Support the Hepatitis C Foundation and the search for a cure!

VII.1.6a WHAT *SHOULDN'T I SAY?

People with hepatitis C tend to hear a lot of - well...there's no nice way to say it - "Crap" from usually well-meaning people. We understand that most people really do want to help, but sometimes they just don't seem to think before they speak.

Here are a few of the "Worst" things you can say to your HCV-Postive friend:

1. "Will you stop that constant whining?
2. "You just need to get out and exercise more"
3. "It's all in your head."
4. "No one ever said life was fair."
5. "Stop feeling sorry for yourself."
6. "There are a lot of people worse off than you?"
7. "You think you've got problems..."
8. "Maybe you should eat better/take vitamins."
9. "There is always somebody worse off than you are."
10. "Cheer up!"
11. "You're always feeling sorry for yourself."
12. "Have you been praying/reading the Bible?"
13. "You don't look sick!"
14. "Everybody knows HCV doesn't have any symptoms. You're just looking for attention."
15. "That which does not kill us makes us stronger."
16. "Believe me, I know how you feel. I was sick once."
17. "So, you feel sick. Don't you always?"
18. "Oh, cheer up!"
19. "Go out and get some fresh air... that always makes me feel better."
20. It doesn't matter what your experience was with biopsy, interferon, side effects of treatments, you HAVE to get the treatment/procedure done. I don't care about your excuses.
21. Gosh.. I would love to be a couch potato and not work all the time, it's not such a hard life that way...
22. I only want to hear good news

VII.1.6b WHAT SHOULD I SAY?

Do you really want to help? Here are a few of the "Best" things you can say to your HCV-Positive friend:

1. "I love you!"
2. "I Care"
3. "You're not alone in this"
4. "I'm not going to leave/abandon you"
5. "Do you want a hug?"
6. Don't say anything, just hold my hand and listen.
7. "I'm sorry you feel so bad. I am not going to leave you.
   I am going to take care of myself so you don't need to worry that your pain might hurt me."
8. "I listen to you talk about it, and I can't imagine what it's like for you. I just can't imagine how hard it must be."
9. "If you need a friend....." (and mean it)
10. "Is there anything I can do to help?" (and mean it)
11. "I am going food shopping tomorrow. Give me your list and I will pick up everything for you and bring it home to you and put it away."
12. "I don't care if you get tired and cranky. I love you and spending time with you is still fun."
13. "I will be over in half an hour with (you put it in)dinner, a video, and then I will leave so you don't have to entertain me."
14. "It's okay, you don't have to be brave for me. Let me be the strong one for a while."
15. "It is a gift to me that you permit me to help and support you. I know how hard it is for you to ask for help."

PART VIII - LIVING WITH HCV

Know that it's not you. It takes a lot to adjust to your new, lessened capabilities, and the adjustment is made more difficult by the expectations of you and those around you who have been long accustomed to dealing with your "normal, healthy self".

- Patients often find an equilibrium point at which they can function. As in combating any chronic illness, a positive hopeful attitude is essential.

- Be prepared for a possible lack of acceptance from some from whom you might expect support. This may be a shock, but when you cannot regularly "go bowling" with the gang, or you increasingly depend on being accommodated at home or on the job, and when you have a condition that your doctor may not certify or that other people have already heard of as "that disease that junkies get", then your emotional world will become quite different.
- Find new sources of support. It will be important to create a new family-and-friends support structure. This can be done through HCV support groups, electronic networking, pen pals, and other means.
- You will need to take the time to create a new self image for yourself, to know that your new physical limitations do not limit you as a person, as a soul, no matter what other people are thinking. And take some advice from those who have travelled this difficult road before you—consider reading from books like the ones listed in the Appendix below.

VIII.1.0 LIFE PROBLEMS CREATED BY HCV

PART IX - DEALING WITH INTERFERON THERAPY

"Tis better to suffer the slings and arrows of outrageous interferon, than to be sawed in half for a transplant." - Cindy Torchin cindyt@cocug.org

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Taking care of yourself during your interferon therapy is important.

It can lessen some of the physical side effects you may experience.

A few simple tips can make a big difference in how you feel, and knowing some ways to take care of yourself can give your emotions a boost at a time when you may be feeling that much of what's happening to you is out of your control.

This feeling can be easier to deal with when you discover how much you can contribute to your own well-being. Remember though, that self-help is never a substitute for professional medical care. Be sure to ask your doctor and nurse any questions you may have about your medication, and tell them about any side effects you may experience.

IX.1.1 GENERAL TIPS FROM SCHERING

To help relieve some of the side effects of Intron A (interferon alfa-2b, recombinant) for Injection therapy, follow this simple A-B-C approach:

- A nalgesics such as acetaminophen or ibuprofen can be used to prevent or partially alleviate the fever and headache.
- B edtime administration of Intron A therapy will allow you to sleep through the "flu like" symptoms of therapy.
- C onserve your energy; try to get plenty of rest.
- D rink plenty of fluids; keep yourself well hydrated before and during therapy.
- E at balanced meals; make sure your are getting an adequate amount of calories in you diet.
- F ocus on the positive; maintain a healthy mental outlook.

The most common side effects associated with Intron A therapy are mild to moderate flu-like symptoms, which usally diminish after the first few weeks of therapy. These may include fever, headache, fatigue, weakness, chills, and muscle and joint pain.

Other frequently occurring symptoms are nausea, loss of appetite, diarrhea, and hair loss. They are common at the start of therapy and should not alarm you. If you have any questions about your side effects or medication, make sure to call your doctor.

IX.2. HOW DOES INTERFERON WORK?

Alpha interferon works differently in the various diseases it is used to fight. In hepatitis C the virus invades and destroys liver cells; interferon lowers the virus population to a level where it no longer causes injury. Interferon helps by stimulating immune cells that in turn repel the invasion. Some hepatitis patients don't respond to interferon at all; others do, but some of them relapse when they stop taking it.

IX.2.1 WHAT WILL INTERFERON ACHIEVE:

Even when the interferon does not cure the disease, it can help to put the virus into remission for awhile, giving your liver a much needed break, and helping you to live longer and more comfortably.

IX.2.2 CLINICAL TRIALS:

Your doctor may also suggest that you join a clinical trial for new treatments, or you may want to bring up this option with your doctor. Clinical trials are carefully designed research studies that test promising new HCV treatments. Patients who take part in research may be the first to benefit from improved treatment methods. These patients also can make an important contribution to medical care because the results of the studies may help many people. Patients participate in clinical trials only if they choose to and are free to leave at any time.

IX.2.3 WILL I BE ABLE TO CONTINUE WORKING WHILE I'M TAKING INTERFERON:

Most people are able to continue working while they are being treated with interferon. It may be possible to schedule your shots late in the day or right before the weekend, (or whenever you determine your worst side effects - if any - occur) so they interfere with work as little as possible.

If your interferon treatment makes you very tired, you might want to think about adjusting your work schedule for a while. Speak frankly with your employer about your needs and wishes at this time. You may be able to agree on a part-time schedule, or perhaps you can do some of your work at home. Under Federal and state laws, some employers may actually be required to allow you to work a flexible schedule to meet your treatment needs.

IX.2.4 HOW WILL I KNOW IF THE INTERFERON IS WORKING?

Your doctor and nurse will use several methods to measure how well your treatments are working. You will have frequent physical exams and blood tests. Don't hesitate to ask the doctor about the test results and what they show about your progress.

While tests and exams can tell a lot about how the interferon is working, side effects tell very little. Sometimes people think that if they don't have side effects, the drugs aren't working or that if they do have side effects, the drugs are working well.

But side effects vary so much from person to person, that having them or not having them usually isn't a sign of whether the treatment is effective. If you do have side effects, there is much you can do to help relieve them. The next section of the FAQ describes some of the most common side effects the people may experience while taking interferon, and gives you some hints for coping with them.

If you are reading this section before you begin taking interferon, you may feel overwhelmed by the wide range of side effects it describes. But remember: Every person doesn't get every side effect, and some people get few, if any. In addition, the severity of side effects varies greatly from person to person. Whether you have a particular side effect, and how severe it will be, depends on your own particular dosage and injection schedule, and how your body reacts. Be sure to talk to your doctor and nurse about

which side effects are most likely to occur for you, how long they might last, how serious they might be, and when you should seek medical attention for them.

IX.3.1 SIDE EFFECTS

IX.3.1a NAUSEA

Nausea and vomiting can often be controlled or at least lessened. If you experience this side effect, your doctor can choose from a wide and ever-growing range of drugs that help curb nausea and vomiting. Different drugs work for different people, and it may be necessary to use more than one drug to get relief.

Don't give up. Continue to work with your doctor and nurse to find the drug or drugs that work best for you.

You can also try the following ideas:

- Avoid big meals so your stomach won't feel too full. Eat small meals throughout the day.
- Drink liquids at least an hour before or after mealtime, instead of with your meals.
- Eat and drink slowly.
- Stay away from sweet, fried, or fatty foods.
- Eat foods cold or at room temperature so you won't be bothered by strong smells.
- Chew your food well for easier digestion.
- If nausea is a problem in the morning, try eating dry foods like cereal, toast, or crackers before getting up.
- Drink cool, clear, unsweetened fruit juices, such as apple or grape juice, or light-colored sodas, such as ginger ale, that have lost their fizz.
- Suck on ice cubes, mints, or tart candies..
- Try to avoid odors that bother you, such as cooking smells, smoke, or perfume.
- Prepare and freeze meals in advance for days when you don't feel like cooking.
- Rest in a chair after eating, but don't lie flat for at least 2 hours.
- Wear loose-fitting clothes.
- Breathe deeply and slowly when you feel nauseated.
- Distract yourself by chatting with friends or family members, listening to music, or watching a movie or TV show.
- Popsicles
- Sea Bands are elastic bands worn around the wrist, with a small built-in "bump" which presses against an accupressure point on your wrist. Many people find these to be extremely helpful for both nausea and dizziness. Sea Bands can be found in most Sporting Goods departments, or fishing supply stores.
- Peppermint tea works wonders for nausea, as does a **small** (very small) drop of peppermint essential oil on the tip of your tongue.
- Many people find chewing on candied ginger (available in the spice department, or in the Oriental foods section of your grocery store)

IX.3.1b HAIR LOSS

Some people experience hair loss as a side effect of interferon, but it doesn't always happen. It may range from a slight to moderate amount of hair loss, but I have never seen anyone become completely bald from the doseages given for hepatitis.

The hair grows back after the treatments are over. When your hair does begin to grow back in, it may come in thicker, curlier, or straighter than it did before your interferon therapy.

Hair loss can occur on all parts of the body, not just the head.

Facial hair, arm and leg hair, underarm hair, and pubic hair may all be affected.

Hair loss usually doesn't happen right away; more often, it begins after a few weeks. At that point, hair may fall out gradually or breaks at or near the skin, and the scalp may become tender.

Any hair that is still growing may become dull and dry.

To care for your scalp and hair:

- Use mild shampoos.
- Use soft hair brushes.
- Use low heat when drying your hair.
- Don't use brush rollers to set your hair.
- Don't dye your hair or get a permanent.
- Have your hair cut short. A shorter style will make your hair look thicker and fuller. It will also make hair loss easier to manage if it occurs.

There is a special type of shampoo and conditioner designed specifically for people undergoing chemotherapy. Many people have reported good results using it while taking interferon. The brand name is "Nioxin" and it is sold only in salons.

IX.3.1c FATIGUE

Fatigue is a common symptom of hepatitis, and it can become worse while you are taking interferon. Here are some things you can do to help yourself feel better:

1. Get plenty of rest. Sleep more at night and take naps during the day if you can. Try to schedule regular rest periods each day.
2. Limit your activities: Do only the things that are most important to you.
3. Delegate tasks. Don't be afraid to get help when you need it. Ask family and friends to pitch in with things like child care, shopping, housework, or driving.
4. Eat well, and be sure to include plenty of healthy foods.
5. When sitting or lying down, get up slowly. This will help prevent dizziness.
6. Don't stand when you can sit.
7. Plan your activities and assemble everything before you start.
8. Reschedule daily tasks so you do some only 3 or 4 times a week so you have time to rest each day.
9. Use a cart, wagon or basket to carry things from one part of the house to the other to eliminate retracing your steps.
10. Sit on a stool in the bathroom while shaving or applying makeup. Prop elbows up on counter if you can.
11. Use warm, not hot water for baths or showers. Hot water increases muscle fatigue.
12. If your fatigue is severe, think about asking your doctor for a handicap sticker for your car.
13. Shop when you are at your peak energy.
14. When shopping alone, ask a grocery clerk to carry out groceries.
15. If you arrive home from grocery shopping tired, put away only the perishables. A family member of friend can do the rest.
16. Shop by phone whenever possible.
17. Avoid peak shopping/traffic hours.

IX.3.1d MOUTH PROBLEMS

If mouth dryness bothers you or makes it hard for you to eat, try these tips:

- Ask your doctor if you should use an artificial saliva product to moisten your mouth.
- Drink plenty of liquids.
- Suck on ice chips, popsicles, or sugarless hard candy. You can also chew sugarless gum.

- Moisten dry foods with butter, margarine, gravy, sauces, or broth.
- Dunk crisp, dry foods in mild liquids.
- Use lip balm if your lips become dry.

- If possible, see your dentist before you begin taking interferon to have your teeth cleaned and to take care of any problems such as cavities, abscesses, gum disease, or poorly fitting dentures.
- Brush your teeth after every meal. Use a soft toothbrush and a gentle touch; brushing too hard can damage soft mouth tissues.
- If your gums are too sensitive for even a soft toothbrush, use a cotton swab or gauze. Use a nonabrasive toothpaste or a paste of baking soda and water.
- Rinse your toothbrush well after each use and store it in a dry place.

IX.3.1e INFECTIONS

Interferon can decrease your white blood cell count (these are the cells that fight infections). Your doctor will check your blood cell count often while you are taking interferon, and If your white cell count falls too low, your doctor may lower the dosage of interferon for awhile to give your body a chance to rebuild its defenses.

When your white count is lower than normal, it is very important to try to prevent infections by taking the following steps:

- Wash your hands often during the day. Be sure to wash them extra well before you eat and before and after you use the bathroom.
- Clean your rectal area gently but thoroughly after each bowel movement. Ask your doctor or nurse for advice if the area becomes irritated or if you have hemorrhoids.
- Stay away from people who have diseases you can catch, such as a cold, the flu, measles, or chickenpox. Also try to avoid crowds.
- Don't cut or tear the cuticles of your nails. Use cuticle cream and remover instead.
- Be careful not to cut or nick yourself when using scissors, needles, or knives.
- Use an electric shaver instead of a razor to prevent breaks or cuts in your skin.
- Use a soft toothbrush that won't hurt your gums.
- Don't squeeze or scratch pimples.
- Take a warm (not hot) bath, shower, or sponge bath every day.
- Pat your skin dry using a light touch. Don't rub.
- Use lotion or oil to soften and heal your skin if it becomes dry and cracked.
- Clean cuts and scrapes right away with warm water, soap, and an antiseptic.
- Wear protective gloves when gardening or cleaning up after animals.
- Do not get any immunization shots without checking first with your doctor to see if it's all right.

Even if you take extra care, you may still get an infection. Be alert to the signs that you might have an infection and check your body regularly for its signs, paying special attention to your eyes, nose, mouth, and genital and rectal areas. The symptoms of infection include:

- Fever over 100 degrees F.
- Chills.
- Sweating.
- Loose bowels
- A burning feeling when you urinate.
- A severe cough or sore throat.
- Unusual vaginal discharge or itching.
- Redness or swelling, especially around a wound, sore, pimple, or boil.

Report any signs of infection to your doctor right away.

IX.1.4 IMPORTANCE OF WATER

It is extremely important to drink all of the water that you can stand (and then drink some more) when you are taking interferon. It not only dramatically decreases the severity of side-effects, but there is also a danger of serious kidney infections if you do not drink enough. Milk/soda/coffee/tea don't count.

You need genuine water.

IX.1.5 STORAGE

According to a Schering representative: Intron is stable undiluted for 7 days at room temp and 30 months in the reefer.

Reconstituted Intron is stable for 1 month in the reefer and never at room temp.

IX.1.5a TRAVELING WITH INTERFERON

When flying with interferon, it won't be affected by going through the x-ray machine. If you are worried about it, you can always just stick it in your pocket and walk through the metal detector.

In order to keep the interferon cool, you can pack it in a Thermos bottle, or freeze a blue ice pack and put it into a soft thermal lunch bag, and wrap the interferon in newspaper so that it doesn't sit directly on the ice. This should last you for a few days.

When in a hotel you can just fill the ice bucket and then put a glass with the interferon bottles on top so if the ice melts the interferon will not get wet.

IX.1.6 TIMING OF INJECTIONS

Schering (the manufacturers of Intron-a) recommend giving yourself the injections in the evening so that you can sleep through the worst of the side effects.

A better idea is to keep track of when your worst side effects occur, and then time your shots so that they occur when you are asleep. For some people, this may even mean giving yourself the injections in the morning.

IX.1.7 INJECTION HINTS

First, wash your hands before beginning.

Take the box to where you inject, open up the box and take the vial out.

Clean the injection site with an alcohol wipe.

Wipe the vial top with an alcohol wipe also.

Now its time to find out where you are gonna make a hole. The nursing term is "clean to dirty". You put the pad at the spot where you are gonna inject and using a circular motion clean from that point out a few inches.

Fill the syringe. Pull the top off the syringe. Pull the cover off the needle. Holding the vial in one hand, have the syringe in the other and brace both hands together. The reason is to not miss the center of the vial and nick or blunt the needle.

(This part applies only to the powdered form of interferon. You can skip this paragraph if you're using the new pre-mixed, already in the syringe stuff.) Turn the vial upside down and draw in the IF. If its real cold, or the syringe is a 29g or smaller getting the stuff in can be a problem. Let it calm down and push out the air. (vial and syringe still upside down) Then draw to the full dose, occasionally pushing out air bubbles. I draw a little more past the fill level, so if its a 3ml dose instead of the .5cc I go to a couple of

small marks beyond .5. Flick the syringe near the vial with your finger, this makes air bubbles gather and go out the needle.

Take the needle out of the vial.

Holding the syringe upside down, push the plunger to the correct level (ie .5cc) this gets rid of any air in the needle.

With one hand pinch the skin/fat layer at the injection site.

As fast as possible push the needle into the layer with the syringe almost parallel to the skin (hold the syringe similar to the way in which you hold a pencil). The faster the needle goes in the less pain there is.

Very slightly pull back on the plunger to check for blood. If the syringe fills with blood, it means you've hit a vein and need to start the procedure over again.

If there is no blood in the syringe, you can then push the plunger.

Pull the syringe straight back. You get less bleeding if you don't play twister. Drop the syringe in the sharps container.

Syringes: I've found that the .5cc ½ inch 29 (or 28) gauge insulin syringe to be the best. Gauges that are numbers like 24 or 22 are bigger and hurt more.

Things that happen after injection:

Sometimes there will be a tiny bit of blood after an injection.

This just means you've probably popped some capillaries or punctured a small vein. It's nothing to worry about, just cover it up with a bandage and let it clot.

The day after a shot, a red area is quit normal. They can range from dime size to silver dollar size and may feel hot and tender.

A small area is fine, but if it gets much bigger and hotter, or you see something that looks infected, contact your doctor.

Bruising is also very common after shots.

Sites: Most people use their thighs for injections. Some people find the lower abdominal area ("not" around the belly button) to be the least painful spot for injections.

Sharps containers: You should be provided with one, either from where you get your interferon (pharmacy or home delivery) or your doctor's office. If you have a problem getting one, puncture-proof soda bottles can be used to temporarily hold the used syringes until you can take them to your doctor's office and ask them what to do with them. If you do this enough times, eventually, someone might get the idea you need a real sharps container. If you have children and/or cats, keep your sharps container locked up. The hole is inviting to small hands and paws.

Some find it helpful to numb the injection site beforehand. An icepack (or a bag of frozen peas) placed on the injection site a few minutes ahead of time will make the shot relatively painless.

To help prevent bruising, some people recommend using only half of the diluent provided (this applies to the powdered formulation only, and not to the new pre-mixed syringes).

IX.1.7a INJECT-EASE:

If you are having a problem giving yourself a shot, ask your pharmacist for a B-D Automatic Injector, Inject-Ease.

They cost about $25.00, and are well worth every penny. You simply load the syringe into the automatic injector, place it on the injection site, and push a button. It is virtually painless, and also makes it much easier to choose a site to inject, thereby giving you more sites per thigh.

IX.1.7b BRUISING AND DILUENT AMOUNTS

If you are experiencing a lot of bruising after your injections, you may find that it helps to reduce the amount of diluent used when mixing the powdered form of interferon. Schering always overfills their diluent bottles or syringes. When using the powdered form of Intron-A, you only have to use enough diluent to disolve the powder. 0.4 to 0.5cc is a comfortable volume for subcutaneous injection. The only time you need to absolutely use a known volume is when you use a 3mu vial for multiple doses and you have to know how much you put in so you know how many mu per cc and what the volume will be for fewer than 3mu a dose.

IX.1.7c NEEDLE SIZE

Many "Interferon Rangers" recommend not using the syringe that comes with your interferon prescription, for the actual injection. Use that one to mix the interferon powder, and buy a box of ½ cc Microfine IV 29 gauge syringes to use for the injection. The needle that comes with your interferon is a fairly large gauge and inserting it through the rubber stopper of the interferon vial dulls it a little. Using a smaller gauge needle will make the injection more comfortable, and using a separate needle to mix the diluent with the powder will keep your injection needle sharper.

IX.1.8 HELP! I THINK I HIT A VEIN!

When giving yourself an injection, it's recommended that you pull back slightly on the plunger, to check for blood, before actually injecting. But, occasionally people forget, and it's almost a sure thing that at least once you will pull the needle out and find blood and bruises. Unless you are injecting into your neck and hit the jugular you have no problem! And even then, with the size of needles we use, it would be real hard to have a bleeding problem. The skin is "rich" with blood supply, so its just a matter of time before you "nail" something that bleeds or shows up as a bruise (not just the normal interferon reaction).

Normally, if you hit an actual vein, there will be no doubt in your mind, as the blood tends to come up into the needle very quickly. If you see that happen before you actually inject, just start over again with a fresh dose. If you only see bruising or a small drop or two of blood, chances are that you only went through some capillaries and it's nothing to worry about.

The only important thing to do if you are bleeding after an injection is to cover it with a band-aid. Even for long-term interferon users there is enough clotting factor to stop the bleeding in a few minutes. The band-aid is to stop making a mess. Interferon is given intramuscularly and intravenously for other conditions, so even if you are "lucky" enough to find a real vein or vessel the interferon won't hurt you.

Some people say it is not necessary to discard the dose. The caution against injecting the interferon intravenously is because interferon is very irritating and can cause a slight phlebitis (inflammation of the vein). Also it will be painful once the reaction starts, with swelling and redness. If that ever happens to you first apply cold compresses to keep the swelling down and take your favorite painkiller. If after 24 hours the swelling becomes worse, along with increased pain and redness, apply warm compresses and call your doctor or go to the emergency room. —

IX.1.9 WHAT TO DO WHEN YOU CAN'T AFFORD THE INTERFERON

Schering-Plough, the manufacturers of Intron-A recombinant alpha-interferon 2b, have a cost sharing program called "Commitment to Care" designed to help those in need of interferon therapy who are unable to afford it. The program is based on a sliding-scale based on your income, with the cost to you ranging from free in some cases, to whatever their scale says you can afford. They will first try to find programs in your State that may help, and if none are found they will determine what you are able to pay and absorb the rest of the cost.

The number to call for the "Commitment to Care" program is 1-800-521-7157, ext 147.

The interview will take approximately a half hour. Some of the questions you will be asked are:

- name and address of the prescribing doctor -dosage you will be using
- when you were diagnosed
- your income (need to send them tax forms or pay stub to verify)
- number of people in household
- why you are unable to pay
- cost of your rent or mortgage
- any outstanding loans
- amount of credit card debt
- any savings

IV ONE

(800) 892-9622

Call for help with interferon costs. This operation will accept whatever your insurance company will pay as full payment in most cases. For dosages above 3 million units, your physician must write a special request to your insurance company first.

They send your prescription in pre-mixed dosage syringes, alcohol swabs, Band-Aids and a Sharp's biohazard container for the used syringes, each month by FedEx. They deliver nationally, so their office location does not preclude anyone from using their service.

And the staff is available 24 hours a day to answer any questions or give you any assistance you may need.

IX.1.10 INTERFERON TREATMENT OF HCV WITH CIRRHOSIS

In patients with hepatitis C who have cirrhosis, the rate of sustained response following interferon therapy is only half that of patients without cirrhosis. Although it has been suggested that a higher dose regime in patients with cirrhosis may improve response, this remains largely untested. The results of a recent Australian study where cirrhotic patients were given an intense interferon programme of 4.5 MIU daily for 24 weeks suggests that future studies in cirrhosis should be carried out exploring higher doses and longer durations of therapy. - "Interferon Treatment of HCV with Cirrhosis," Journal of Viral Hepatitis 1997 ;4:85-88

PART X - WHERE DO WE GO FROM HERE?

X.1.0 LONG TERM PROGNOSIS (WILL I EVER GET CURED? AM I GOING TO DIE?)

Current studies indicate that most (80%) people infected with hepatitis C will develop a chronic state of infection. About 30% those with chronic infection will go on to develop cirrhosis of the liver. The disease appears to progress slowly, symptoms often do not appear for ten or twenty years.

After an average followup of 18 years, a prospective study of patients who received blood transfusions showed no difference in overall mortality between HCV-infected cases and noninfected controls. Liver-related mortality, though rare, was twice as high in the cases (3.2 percent vs. 1.5 percent). A recent European study showed survival among HCV patients with compensated cirrhosis was 91 percent at 5 years and 79 percent after 10 years. Among patients developing decomensated cirrhosis, however, 5-year survival was only 50 percent. - National Institutes of Health Statement on Hepatitis C 1997

The overall severity of chronic hepatitis C is controversial.

There is no question that HCV can lead to cirrhosis and hepatocellular carcinoma (HCC) and that end-stage chronic hepatitis C is now the leading indication for liver transplantation. At question is how frequently and how soon these serious consequences occur.

A controlled prospective study (Seeff) has shown that after 20 years of follow-up, patients with transfusion associated hepatitis C had no increase in overall mortality and only a slight increase in liver-related mortality compared to controls who did not develop hepatitis. Another prospective study (Koretz) has shown that the probability of developing clinical cirrhosis or liver related mortality was 20% and 5%, respectively after 16 years; comparable values were 24% and 3% in the NIH series. The paradox between the relatively benign mortality figures and the observed fatal outcomes resides in the indolent nature of progressive HCV infection.

Progression is generally measured in decades and most subjects acquiring infection in mid-life or later will succumb to their underlying disease or old age before they develop end-stage chronic hepatitis C. By inference, it appears that the HCV mortality risk is approximately 4% in the first two decades and the risk will increase over time in those that do not succumb to other events.

- "Natural History and Clinical Aspects of HCV Infection." H.J. Alter. Department of Transfusion Medicine, National Institutes of Health, Bethesda, Maryland. Cancer Biotechnology Weekly, 01-29-1996, pp 20.

Despite the increased risk of cirrhosis and liver cancer, some question exists about HCV's overall contribution to premature mortality. In one study with almost 20 years of follow-up, patients with chronic, posttransfusion hepatitis C did not have significantly higher mortality when compared to an uninfected control group.

- "Hepatitis C & E: How Much of a Threat?" (Special Issue: Emerging Infectious Diseases). Brown, Edwin A. Patient Care. May 15 1994, v28, n9, p105(8)

X.2.0 CURRENT RESEARCH, TESTING AND CERTIFICATION OF NEW DRUGS AND TREATMENTS IN THE U.S. AND ABROAD

There is a great deal of research going on, regarding the possible prevention and treatment of hepatitis.

Researchers at Emeryville-based Chiron, which discovered hepatitis C and markets the blood-supply screening test, are working on a vaccine they hope to have in clinical tests by 1996. They are also working on an immunotherapy that might ease the severity and slow progression of the disease for those already infected.

In the July 25, 1997 issue of the journal "Science", scientists report that they have cleared a major hurdle in hepatitis research, for the first time growing and purifying an infectious form of the hepatitis C virus in the laboratory. This will make study of the virus much easier, will enable scientists to better understand the factors and mechanisms that determine whether virus is cleared from the body or produces a chronic infection.

PART XI - EMPLOYMENT AND DISABILITY

XI.1.0 INCOME SECURITY: JOB AND/OR DISABILITY BENEFITS

XI.1.1 HOW DO I HANDLE PROBLEMS ABOUT MY JOB?

- If your work is, or will likely be, affected by your illness, educate your boss about your condition. Do this soon.
- You may need their support later when more problems may arise, and it will be easier to educate them while you are still relatively productive and "credible".
- Understand that you might have to make some severe changes: a change of job, or perhaps an involuntary loss of your job and a shift to disability benefits.
- Beware of the trap of losing important disability benefits if you switch to part time work. Many HCV patients whose health was spiralling downwards had switched to part-time work to preserve their place with their employer. Later, when their health deteriorated even more and they needed to seek disability benefits, they found out too late that those benefits for a part-time employee did not include a liveable income, whereas if they had gone straight from full-time to disability, the disability payments were much more liveable. Be careful.

XI.1.2 WHAT PROBLEMS DO I FACE IN SEEKING DISABILITY BENEFITS?

You can order a Disability Workbook for Social Security Applicants for $20.00 from:

Physicians' Disability Services, Inc., P. O. Box 827, Arnold, Maryland 21012

XI.1.3 APPLYING FOR SSI / SSDI

According the to Social Security Administration's SSA Pub.No. 05-10029 April 1995, the definition of "disability" is as follows:

"Disability under Social Security is based on your inability to work. You will be considered disabled if you are unable to do any kind of work for which you are suited and your disability is expected to last for at least a year or to result in death."

1. Are you working? If you are and your earnings average more than $500 a month, you generally cannot be considered disabled.
2. Is your condition severe? Your impairments must interfere with basic work-related activities for your claim to be considered.
3. Is your condition found in the list of disabling impairments?
   We maintain a list of impairments for each of the major body systems that are so severe they automatically mean you are disabled. If your condition is not on the list, we have to decide if it is of equal severity to an impairment on the list. If it is, your claim is approved. If it is not, we go to the next step.
4. Can you do the work you did previously? If your condition is severe, but not at the same or equal severity as an impairment on the list, then we must determine if it interferes with your ability to do

the work you did in the last 15 years. If it does not, your claim will be denied. If it does, your claim will be considered further.

5. Can you do any other type of work? If you cannot do the work you did in the last 15 years, we then look to see if you can do any other type of work. We consider your age, education, past work experience, and transferable skills, and we review the job demands of occupations as determined by the Depart. of Labor.
   If you cannot do any other kind of work, your claim will be approved.

   If you can, your claim will be denied.

   To get information from the Social Security Administration, call 1-800-772-1213.

PART XII - IMPORTANT INFORMATION

XII.1.0 WHAT ELSE IS IMPORTANT FOR ME TO KNOW ABOUT HCV?

Medical research and acceptance of the illness will develop only if our national support organizations which promote them are strong. Be sure to support your national groups, and when your national group calls for letters and phone calls to be sent to public officials and media, please get your family and friends to assist you in responding to those requests. We may be able to make greater achievements if we act in unison.

In the USA, the largest source of research money comes from government allocations. Therefore, contacting your Congressman about the importance of Hepatitis research is very important.

Did you know ?.....

The World Health Organization estimates that **one in every hundred** humans have the hepatitis C virus, and that this number is increasing!

The World Health Report states that Worldwide: 100,000 Million people are chronically infected with Hep C.

28.5 times MORE people are infected with Hepatitis than with HIV.
150,000 - 180,000 new cases of Hepatitis C are expected this year.
200,000 - 250,000 new cases of Hepatitis B are expected this year.
40,000 new cases of HIV are expected this year.
8,000 - 12,000 Hep C patients are expected to die in 1997

Since close to 4 million people in the U.S. have HCV, it is the most prevalent chronic viral infection in the United States, and possibly the world.

Interferon (alone) successfully treats between only 10%-15% of HCV patients.

The HCV virus has a half-life of approximately six hours - in other words, if you start with two million, six hours later there are three million, etc. Hence the 3mu three times per week interferon dosage is not the most effective.

HCV is the leading indication for liver transplants.

According to the New York Blood Center, as many as 25% of people receiving blood transfusions in the early 1960s were being infected with contagious diseases and the majority were infected with hepatitis.

About one-third of hepatitis B and C cases result from unknown sources. This means someone does not have to be among the high-risk groups to become infected with the virus.

XII.1.1 HCV INFORMATION RESOURCES

XII.1.2 NATIONAL (USA)

- The American Liver Foundation have very nice, down-to-earth pamphlets on Hepatitis and Interferon and stuff, which they will send to you by calling their number: 1-800-223-0179 The American Liver Foundation also provides physician referrals.

- The American Liver Foundation Liver Transplant Fund Program. The American Liver Foundation Transplant Fund Program provides: Liver transplant patients with fundraising guidance Trustee and administration services of patients' funds at no charge. Educational information about liver diseases and transplantation. Information Brochure, Policies and Procedures, Fundraising Suggestions

For more information, including application form, resources list, and patient agreement form, please contact the ALF Liver Transplant Fund Program at : 1-800-GO-LIVER (465-4837) Fax (201)256-3214 Email txfund@liverfoundation.org

American Liver Foundation , 1425 Pompton Avenue, Cedar Grove, NJ 07009

- The Hepatitis C Foundation. Support and information. - Contact: Steve Longello Phone: (215) 672-2606. Support line: 1-800-324-7305 web site: http://www.hepcfoundation.org/ email: hepatitis_c_foundation@msn.com
- The Hepatitis Foundation International, 30 Sunrise Terrace, Cedar Grove, New Jersey 07009, USA. HIF's toll free line for callers in North America is (800) 891-0707.
- National Digestive Diseases Information Clearinghouse: (301) 654-3810.
- National Institute of Diabetes and Digestive Diseases at (301) 496-3583, but they simply refer you to the Digestive Diseases Clearinghouse number listed above.
- The CDC Hepatitis Branch Hotline numbers are (888)4HEPCDC, (888)443-7232 or (404) 332-4555. The voice mail allows you to request Faxed information to be sent to you or you can listen to a recording.
- "Focus: On Hepatitis C" a national newsletter devoted to Hepatitis C. Has articles on everything you could imagine, from the latest scoop on hep, to personal interviews, to good healthy recipes. Address is: Quantum Media Group 130 Prim Road; Suite 510 Colchester, VT 05446-1326 Tel: 802-655-2579 or 802-655-3415.

You can reach the editor, Jason, at Jason385@gnn.com, or visit their web site at: http://pages.prodigy.com/VT/hcv/hcv.html

- Gammagard: Robins, Kaplan, Miller & Ciresi is a national (USA) law firm with offices in eight U.S. cities including Minneapolis and St. Paul. CONTACT: Philip A. Pfaffly, 612-349-0820, or Gary L. Wilson, 612- 349-8413, both of Robins, Kaplan, Miller & Ciresi, or Gail D. Shore, 612-925-6102 of Shore to Shore Communications.
- American Chronic Pain Association, Inc., P.O. Box 850, Rocklin, PA 95677, (916)632-0922. 500 Chapters in the United States, Canada, Australia, New Zealand, and Russia. Provides a support system for those suffering chronic pain.
- U.S. Medic Alert: Medic Alert, P.O. Box 381009, Turlock,CA 95381-9009,1-800-432-5378 Canadian Medic Alert: Medic Alert, P.O. Box 0988 Don Mills, Ontario, Canada M3C2T9 1-800-668-1507 Tax deductable. Chains, bracelets in a variety of styles. $35.00 Includes important info for medics. 1-800 # is engraved, and when called, any info you supplied to Medic Alert is given to medic/nurse/dr. Wallet size card with dr. name, # and emergency contact, etc. included
- Thyroid Foundation of America, Inc., ACC 630, Massachusetts General Hospital, Boston, MA 02114 (617)726-8500 Provides health education and support for thyroid patients and health care professionals.
- The Well Spouse Foundation, P.O. Box 28876, San Diego, CA 92198 (619)673-9043 (914)357-8513 Support groups; gives emotional support to spouses of the chronically ill; raises consciousness of professionals to the plight of the well spouse; advocates for legislative changes in insurance coverage for respite care and long-term care; produces a bi-monthly newsletter, WSF Newsletter.
- Agency for Health Care Administration, HMO/Managed Care Hotline, Toll Free: 1-800-226-1062 The HMO/Managed Care Hotline is a toll free telephone line maintained by the Agency for Health Care Administration to quickly respond to emergency or urgent quality of health care complaints and concerns by members of HMO's and managed care organizations.

The Hotline is available between 8 a.m. and 5 p.m., Monday through Friday and is answered by experienced, registered nurses who work with members to resolve problems.

•• A good source of patient contacts is narcotics anonymous groups or drug-abuse recovery groups. Many people in these groups have hep C and they meet regularly and pass information around a lot.

XII.1.7 LOCAL ASSOCIATIONS AND SUPPORT GROUPS:

XII.1.7a UNITED STATES

ALABAMA (BIRMINGHAM): American Liver Foundation support group. Meets the second Thursday of every month at 6:30, ALF Office Conference Room, 4 Office Park Circle, Suite 304, Birmingham Alabama.

For more information, contact Virginia Greene, (205)879-0354

ALASKA (KENAI PENNINSULA): Hepatitis C support group is now forming. For information, contact Cheri Murphy in Soldotna at: (907)262-9197 or email: kcmurph@ptialaska.net

CALIFORNIA (LONG BEACH): Southern California United Liver Association support group meets at St Mary Medical Center, 1050 Linden Ave, Long Beach CA 90813. For more information, contact (310)914-8252.

CALIFORNIA (LOS ANGELES): Southern California United Liver Association, 11646 West Pico Blvd, Los Angeles, CA 90064 Phone: (310)914-8252

CALIFORNIA (MARIN COUNTY): Marin County Liver Disease and Transplant Support Group for liver disease and transplant patients and their family/support people/caregivers, meets the first Thursday of each month, 7:00 PM to 8:30 PM at the Tamalpais Creek Retirement Center, Activities Room, 853 Tamalpais Avenue, Novato. Take the DeLong exit off 101 and head west. Make a right on Novato Blvd.

and a left at the first light (Tamalpais Avenue). Plenty of free parking, and handicapped-accessible. Refreshments. For more information, call 415-485-8829.

CALIFORNIA (MORENO VALLEY): American Liver Foundation support group, Inland Empire Chapter, 21439 Blossom Hill Lane, Moreno Valley, CA 92557 For more information, contact Russell D. Hamilton, Sr, (909) 778-1807

CALIFORNIA (NORTHRIDGE): Southern California United Liver Association support group meets at Northridge Hospital, 18300 Roscoe Blvd., Northridge CA 91325. For more information, contact (310)914-8252.

CALIFORNIA (ORANGE COUNTY): Southern California United Liver Association support group meets at the UCI Medical Center, Bldg. 53, Room 212, 101 City Drive, South, Orange CA 92668. For more information, contact (310)914-8252.

CALIFORNIA (SAN DIEGO COUNTY): The American Liver Foundation Support Group at Scripps Green meets the first Wednesday of each month at 6:00 P.M. The first hour is a presentation by the Scripps medical team on various hepatitis/liver disease topics and the second hour is a support group. For more information, contact Phyllis at ALF (619) 291-5483.

CALIFORNIA (SAN FRANCISCO): American Liver Foundation support group, San Francisco Bay Area Chapter, P.O. Box 150421, San Rafael, CA 94915-0421. For more information, contact Cres VanKeulen at (415) 258-1682

CALIFORNIA (SANTA CRUZ): Hepatitis support group meets the 3rd Monday of each month. For more information, contact Jerry Kelly at (408)438-7187.

CALIFORNIA (WALNUT CREEK): Meetings are held on the last Thursday of each month at 7pm in Aspen Room #2 (downstairs) at the John Muir Hospital, corner of Ygnacio Valley Road and La Casa Via. (Sorry, no contact name or phone number available.)

COLORADO: HepC Connection. For more information, contact: Ann Jesse at 1-800-522-HEPC or (303) 393-9395, address: 1714 Poplar St., Denver, CO 80220.

COLORADO: American Liver Foundation support group, Rocky Mountain Chapter, P.O. Box 117, Wheat Ridge, CO 80034. For more information, contact Lee Gerstner at (303) 940-3664

CONNECTICUT: American Liver Foundation support group, Connecticut Chapter, 1 Bradley Road, Suite 405, Box 4062, Woodbridge, CT 06525.

For more information, contact Norma Pisetsky at (203) 397-5433

FLORIDA (BROWARD COUNTY): For more information, contact: (561) 434-0092

FLORIDA (FT LAUDERDALE): Meetings are held on the 3rd Wednesday of every month at the Florida Medical Center, 5000 West Oakland Park Blvd, in Fort Lauderdale, FL. For more information, contact: (954) 587-3777

FLORIDA (ORLANDO): Orlando Hepatitis Support System, 5624 Deepdale Drive, Orlando, FL 32821 (407) 238-9422 or (407) 238-2368 or email: peaches@magicnet.net

FLORIDA (ST PETERSBURG): Tampa Bay Hepatitis and Liver Disease Support Group, Inc. St. Petersbug Meetings are held the second Tuesday of each month, 7:00-9:00 p.m. (please be prompt) at the Columbia Edward White Hospital, Auditorium - Suite 1G, 2299 9th Avenue, North St.Petersburg, FL. For more information, contact: Don Vausio - (813)577-0836 or Peggy Tatka - (813)684-4678

FLORIDA (TAMPA): Tampa Bay Hepatitis and Liver Disease Support Group, Inc., Tampa Meetings are held the fourth Thursday of each month, 7:00 - 9:00 p.m. (please be prompt) at the University Community Hospital, Hospitality Room (past the Cafeteria), Bruce B. Downs & Fletcher, Tampa, FL For more information, contact: Don Vausio - (813)577-0836 or Peggy Tatka - (813)684-4678

FLORIDA (TAMPA): The Liver Disease Support Group holds meetings on the first Monday of each month at "The Health Source" at University Square Mall, 2140 Fowler Ave. Tampa FL 33613. For more information contact: M.J. Fitzsimmons (813) 899-9255 or email: mjfitz@IntNet.net

GEORGIA (ATLANTA): American Liver Foundation support group, Atlanta Chapter,4250 Wieuca Overlook, NE Atlanta, GA 30342. For more information, contact Helen Gitlin at (404) 255-1648

HAWAII: There is a Hepatitis Support Group on the last Thursday of every month at Wilcox Hospital, Conference Room A, in Lihue, Kauai, Hawaii. It is from 6:30 p.m. till 8 p.m. Interested may call: Teresa at (808) 826-7825.

IDAHO (BOISE): Southwest Idaho Hepatitis Support Group, meets every 3rd Tuesday, St. Alphonsus Medical Center, Board Room, 7-9 pm. Contact: Steve Bingham, 208-342-3945.

ILLINOIS (CHICAGO): American Liver Foundation support group, Illinois Chapter, 225 W. Washington Street, Suite 2249, Chicago, IL 60606. For more information, contact Paul Ladniak at (312)-419-7086

IOWA: Hepatitis C Foundation sponsored support group. For information contact (800)324-7305.

IOWA (CEDAR RAPIDS): Hepatitis Education Project sponsored support group. Call 1-800-218-6932 for more information.

IOWA (DAVENPORT): American Liver Foundation support group, Quad Cities Chapter, 4328 Ridgewood Court, Davenport, IA 52807.

For more information, contact Patti Erpelding at (319) 359-1994

KANSAS (KANSAS CITY): A meeting is held the second Wednesday of each month at KU Medical Center, Prarie Room, which is nearby Delp cafeteria. Parking is available in the parking garage across the street from the main hospital entrance on Cambridge, 2 blocks west of State Line Road at 39th street. Ask at the info desk for directions to the Delp cafeteria. Phone (913)677-6561.

KANSAS (WICHITA): Hepatitis C Foundation support group meets the 3rd Thursday of each month at 7:00pm. For more information, call (800)324-7305

MASSACHUSETTS (BEVERLY): Beginning on Monday February 17, 1997 and continuing every 3rd Monday of each month, Beverly Hospital will offer support group meetings for all individuals affected by

Hepatitis C. This group welcomes all people with Hepatitis C as well as spouses, older children, friends and anyone with a concern about this disease. For more information, contact: Hepatitis C Seminar & Support Group, 85 Herrick St. Beverly, Massachusetts (508) 922-3000 extension 2240.

MASSACHUSETTS (NEWTON): American Liver Foundation support group, New England Chapter, 246 Walnut Street, Suite 401, Newton, MA 02160. For more information, contact Judi Kaplan Elkin at (617) 527-5600.

MASSACHUSETTS (WORCESTER): Hepatitis support group, meets the first Monday of each month from 6:30- 8:00 @ U-Mass Hospital Worcester, MA in Lecture Hall B. For more information, contact Larry at lotl@ziplink.net

MICHIGAN (WEST MICHIGAN): Hepatitis C Foundation sponsored support group. For information contact Mary Kolanowski (616)336-9351 or (800)324-7305.

MINNESOTA (ROCHESTER): American Liver Foundation support group, Rochester & Southeastern Minnesota Chapter, 615 Eighth Avenue, SW, Rochester, MN 55902. For more information, contact Sylvia Aronson at (507) 289-0914.

MISSOURI (ST. LOUIS): Hepatitis C Support Organization meets the second Monday of each month at the Clayton Library, corner of Central and Maryland, from 7-8:45 p.m.Contact person is Nancy Marsh, 2665 Midland Ridge Drive, St. Louis, MO 63114.

(314) 428-7973.

NEBRASKA (OMAHA): Hepatitis C Foundation sponsored support group. For information contact Kay Helms (402)398-1487 or (800)324-7305.

NEW HAMPSHIRE : Hepatitis C Foundation sponsored support group. For information contact Roberta Glenn (603)652-4326, Ed Nash (603)742-4732 or (800)324-7305.

NEW JERSEY (CENTRAL JERSEY): Hepatitis C Foundation sponsored support group. For information contact, Valerie Mead (908)247-2628, Barb Verb (908)937-8820 or (800)324-7305.

NEW JERSEY (NORTH JERSEY): Hepatitis C Foundation sponsored support group. For information contact John Sorrentino (201)743-2380 or (800)324-7305.

NEW JERSEY (SOUTH JERSEY): Hepatitis C Foundation sponsored support group. For information, contact Libby Leidolf (609)935-0807 or (800)324-7305.

NEW MEXICO (ALBERQUERQUE): Hepatitis C support group meets the 4th Saturday of each month at the Lovelace HR Center at 1258 Ortiz SE, Albuquerque, NM from 9am to 11am. For more information, contact Janet Brown at (505)292-4338.

NEW YORK (LONG ISLAND): The Hep C Courage Group holds meeting in Manhasset. For more information, contact Judy or Gina at (718)595-2805 or email Gina at: Left74@aol.com.

NEW YORK (MELVILLE): American Liver Foundation support group, Greater New York Chapter, 200 Broadhollow Road, Suite 207, Melville, NY 11747. For more information, contact Mary Beth Tully at (516) 393-5076.

NEW YORK (ROCHESTER): Hepatitis C Foundation Support Group, 16 Sanders Farm Dr., Penfield, New York 14526 Contact: John Trowbridge at (716) 377-9330 or (800)324-7305.

NEW YORK (ROCHESTER): American Liver Foundation support group, Western New York Chapter, 75 Buckland Avenue, Rochester, NY 14618. For more information, contact Nancy Koris at (716) 271-2859.

NORTH CAROLINA (CHAPEL HILL): American Liver Foundation support group, Triangle Area Chapter, UNC Department of Medicine, Div. of Digestive Diseases & Nutrition, University of North Carolina at Chapel Hill, CB #7080, 423 Burnett-Womack Bldg., Chapel Hill, NC 27599-7080. For more information, contact Robert S. Brown Jr., MD, MPH at (919) 966-2516.

OHIO (CLEVELAND): American Liver Foundation support group, Northern Ohio Chapter, 9500 Euclid Avenue, Ab2, Cleveland, OH 44195. For more information, contact Sharon Mendelsohn at (216) 444-8409.

OHIO (COLUMBUS): The HEPCAT support group meets every other Thursday at the OSU Medical Center. For more information contact: Emma Birch 614-337-1450 email: EBirch@aol.com.

OHIO (TOLEDO): American Liver Foundation support group, Toledo Chapter, 419 Saint Clair St., N., Apt. 303, Toledo, OH 43604. For more information, contact Richard Gee at (419) 243-5777.

OREGON (COOS BAY): Hepatitis Education Project sponsored support group. Call 1-800-218-6932 for more information.

OREGON (MEDFORD): American Liver Foundation support group, Southern Oregon Chapter, 2578 Table Rock Road, #15, Medford, OR 97501. For more information, contact Barbara Bransford at (541)857-9245.

PENNSYLVANIA (LANCASTER): Hepatitis C Foundation sponsored support group. For information, contact Jean Collin (717) 394-7110 or (800)324-7305.

PENNSYLVANIA (LEIGH VALLEY): Hepatitis C Foundation sponsored support group. For information, contact Dianne Slagle (610)432-2481 or (800)324-7305.

PENNSYLVANIA (PHILADELPHIA): Hepatitis C Support Group - Contact: Steve Longello of the Hepatitis C Foundation. Weekly support group meetings and a 24 hour "hotline" (800)324-7305.

Phone: (215) 672-2606 or email: hepatitis_c_foundation@msn.com.

PENNSYLVANIA (PLYMOUTH MEETING): American Liver Foundation support group, Delaware Valley Chapter, 600 West Germantown Pike, Suite 400, Plymouth Meeting, PA 19462-1046. For more information, contact Deborah Katz at (610)260-1497.

TENNESSEE (MEMPHIS): Hepatitis Support Group meets the third Wednesday of every month at 6:00, Lobby Conference Room, St. Francis Hospital, 5959 Park Avenue. For more information, contact UT: (901)448-05813, Shirley: (901)853:4606, or Ann: (901)755-0403

TENNESSEE (NASHVILLE): The Nashville Hep Support group is currently forming. For more information, contact Jim Nevels at (502)886-2754 or email: vgnevels@hop-uky.campus.mci.net.

TENNESSEE (NASHVILLE): Hepatitis C Foundation sponsored support group. For information contact Mary Harrington (615)385-3718 or (800)324-7305.

TEXAS: Texas Liver Coalition, Phone: 1-800-72-LIVER.

TEXAS (WACO): LifeMatch Group. For more information, call: (254)840-9620.

VIRGINIA (NORFOLK): Hepatitis support group sponsored by Schering-Plough meets at Leigh Memorial Hospital, in the private dining room on the 2nd Thursday of each month. For more information, contact Dianna Pullium (757) 552-8587.

WASHINGTON STATE: Hepatitis Education Project - HEP - sponsors fifteen support groups state-wide. P.O. Box 95162, Seattle, WA 98145-2162, phone (Seattle metro area) 206-447-8136. Outside the Seattle metro area call 1-800-218-6932. Email graham@wolfenet.com or saraa@halcyon.com

WASHINGTON STATE (KENNEWICK): Hepatitis C support group meets on the third Monday of every month at Kadlec Medical Center, the Columbia Room, Richland WA at 6:30 pm. For more information, contact Joyce at (509)627-8053 or Julie at (509)627-0786

WASHINGTON STATE: Parents of Kids with Infectious Diseases (PKIDs), P.O. Box 5666, Vancouver, WA 98668 Provides service to parents and families all over the US, and some other countries.

For more information, contact Trish Parnell at (360)695-0293 voice (360)695-6941 fax or email pkids@pkids.org. A Web site is also available at: http:// www.pkids.org

WASHINGTON STATE (YAKIMA): Hepatitis C Support group meets 4th Monday of each month at 7:00 pm at Wellness House, 210 S.

11th Ave. Suite 40, Yakima, WA 98942. For more information call Ellie at 509-452-5456 or Wellness House at 509-575-6686.

WEST VIRGINIA: Hepatitis C Foundation sponsored support group. For information contact Dana Mack (304)273-2450.

Promoting HCV Canadian Research and a Canadian Clinical Trial Network for HCV

HepCAN

The online support group for Canadians and everyone else.

Check us out on the Web at http://www.egroups.com/list/hepcan or contact: squeeky@pacificcoast.net or hepchc@iforward.com

To subscribe send an email message to hepcan-subscribe@egroups.com

THYROID FOUNDATION OF CANADA

C.P./P.O. Box 1597
Kingston, Ontario
Canada K7L 5C8
(613)542-8330
Provides information to the public, and publishes a quarterly newsletter.

BRITISH COLUMBIA:

Castlegar/Grand Forks/Trail Contact: Robin, 365-6137.

Cowichan Valley Hepatitis C Support Services. Meetings: 1st Thursday 7-9 PM. 464 TCH. Duncan. Contact: Debbie, 748-5450 or Leah 748-3432. vhepc@hotmail.com

Enderby HepCURE Meetings: Last Sunday of each month 2-4 PM, for High Tea, The Raven Gallery, 701 George St. Contact: Marjorie, 558-7488. www.junction.net/hepcure/index.html

Kelowna HeCSC Meetings: Last Saturday of each month, 1-3 PM, Rose Avenue Education Room in Kelowna General Hospital. Contact: Michael, 860-8178 or eriseley@bcinternet.com

Nanaimo HeCSC Meetings: Second Thursday of each month, 7 PM, Health Unit-Central Vancouver Island, 1665 Grant St. Contact: Helen, 245-8759.

New Westminster Support Group: Meetings: Second Monday of each month, 7:00-8:30 PM, First Nation's Urban Community Society, Suite 301-668 Carnarvon Street, New Westminster. Contact Dianne Morrissette, 525-3790.

Parksville/Qualicum 163 Memorial Street, Parksville. Open daily from 9AM to 4 PM, M-F. Contact: (250) 248-5551. dbamford@island.net

Penticton HeCSC Meetings: Third Thursday of each month, 7-9 PM, Penticton Health Unit, Board rooms. Contact: Leslie, 490-9054, bchepc@bc.sympatico.ca

Richmond: Meetings: Fourth Tuesday of each month, 7 to 9 PM, Westminster Health Unit, 7000 Westminster Hwy., main floor, room 3. Contact: Guy, 244-1704. guy@fatherswithoutchildren.com or Carmel at Richmond Health Unit, 279-4069.

Sunshine Coast Meetings: First Thursday of each month, 7:30 PM, Coast Garibaldi Health Unit in Gibsons. Contact: Karen, 885-6413. karen_felske@sunshine.net

Vancouver CLF Meetings: Second Thursday of each month, 7:30 PM, Nurses' Residence of VGH (12th and Heather). Signs will direct you.. Contact: the CLF, 681-4588 or Herb, 241-7766. HMoeller@compuserve.com

Vernon HepCURE Meetings: 1st Tuesday 12-2 PM and 3rd Tuesday of each month, 6-8 PM, the People Place, 3402-27th Ave.. Contact: Marjorie, 558-7488. www.junction.net/hepcure/index.html

Vernon HEPLIFE Meetings: 2nd and 4th Wednesday of each month, 10 AM-1 PM, The People Place, 3402-27th Ave. Contact: Sharon, 542-3092. sgeegee@msn.com

Victoria HeCSC Meetings: Last Wednesday of each month, 1-3 PM, and again at 7-9 PM, St. John the Divine Church Lounge, 1611 Quadra St. (Entrance through the rear, marked Annex). Contact: (250) 388-4311. hepcvic@pacificcoast.net

White Rock Support Group: Meeting Room #2, Peace Arch Hospital. Contact Lisa Peterson at 538-8704

XII.1.3c AUSTRALIA/NEW ZEALAND

NEW SOUTH WALES: Hepatitis C Council of NSW, P.O. Box 432 Darlinghurst 2010, 345 Crown St., Surry Hills NSW Phone: 02 9332 1853 Fax: 02 9332 1730 Support Line: 1-800-803-990 Publishes a quarterly newsletter: The Hep C Review

VICTORIA: The Hepatitis C Foundation (VIC) Inc.: P.O. Box 65, Fairfield 3078,Phone: Melbourne (03) 9280 2316

QUEENSLAND: The Queensland Hepatitis C Council Inc., Coordinator: Mr.. Jeff Ward Info/Support line: (07) 3229 3767 Administration: (07) 3229 9238 Fax: (07) 3229 9305

XII.1.3d ENGLAND / SCOTLAND

THE BRITISH DIGESTIVE FOUNDATION: 3 St Andrews Place London, NW1 4LB Telephone: 0171 486 0341 Fax: 0171 224 2012 email: bdf@bdf.org.uk

FIFE: Hepatitis C - Both Sides of the Border/C For Yourself, P.O. Box 14466, Glenrothes, Fife, Scotland KY7 6WA Contact: Feyona McFarlane email: seyonehcv@mcmail.com

GLASGOW: Hepatitis C - Glasgow, 53 Fulwood Avenue, Knightswood, Glasgow G13 4BD Contact: Norma Cameron, Jimmy McKay

IPSWICH: The British Liver Trust, Central House, Central Avenue, Ransomes Europark, Ipswich IP3 9QG Phone: 01474-276326 Info Line: 01473-276328

OXFORD: Hepatitis C - Oxford, 83 Priory Road, Minchery Farm, Oxford OX4 4ND Contact: Helena Borkowski

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XII.1.3e GERMANY/AUSTRIA

Deutsche Hepatitis Liga e.V.: Postfach 200666, D 80006 Muenchen

Deutsche Leberhilfe e.V.: Postfach 242, D 49303 Melle

Hepatitis League Austria e.V.: c/o chairman Ingo Rezman, Boltzmanng.21/4/17, A-1090 Wien/Austria Phone and Fax: 01/3152727 or Mobile 0663/863875 Email: IRezman@aol.com

Verein der Lebertransplantierten Österreichs : Kontakt: Mag. Edith Freundorfer, AKH Wien, Transplantationszentrum, 1090 Wien, Währinger Gürtel 18-20 Tel. (01) 40400 —

HOLLAND: Landelijk Infocentrum Hepatitis: telefoonnummer is 030-2502372.

XII.1.3f URUGUAY

GRUPO C: c/o C.A.S.A. (Centro Anglicano de Solidaridad y Ayuda), Reconquista 625 Montevideo, Uruguay Telefax: (+598) 2 955 419

XII.1.4 WHAT HCV RESOURCES ARE AVAILABLE ON THE INTERNET AND USENET?

There is a Hepatitis support discussion group (mailing list) called HEPV-L To subscribe, send an e-mail message to: LISTSERV@MAELSTROM.STJOHNS.EDU and in the body of the message type: SUBSCRIBE HEPV-L FIRSTNAME LASTNAME (that's your first and last name)

For more info, contact: Peppermint Patti clotho@bellatlantic.net

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The HCFPAEC Activist mailing list is concerned with letter writing, political action, and reform in regards to hepatitis C research and funding. To subscribe, send an e-mail message to: LISTSERV@MAELSTROM.STJOHNS.EDU and in the body of the message type: SUBSCRIBE HCFPAEC Firstname Lastname (substituting your own first and last names of course)

For more info, contact: Beau beauh@roanoke.infi.net

There is also a support mailing list for spouses of those with hepatitis. For more info, contact: Betsy Donohoe ;donohoe@techline.com

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Parents of Kids with Infectious Diseases (PKIDs) now has their own web site and mailing list. For more information, contact Trish Parnell, email: trish@buyersandsellers.com http://www.pkids.org

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Residents or citizens of Canada dealing with Hepatitis C may join an informal email newsgroup called HEPCan . For more information, contact: Darlene Morrow mailto:hepchc@iforward.com, or squeeky@pacificcoast.net

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There is a Hepatitis Mail List for those in 12 step programs (most notably Narcotics Anonymous and Alcoholics Anonymous)... although it is not a twelve step program... it is to provide a means of sharing experience, strength and hope for those who are involved in a 12 step program of recovery and who are also victims of the disease of hepatitis. To subscribe they need to address the post to: maiser@listserv.ant.net and in the body of the message type:

"subscribe 12StepHe"

or, contact rivadder@ids.net and they can add you to the list manually.

AOL Chatrooms :

"Hepterminal": 12 Noon EST Monday-Friday, 11 PM EST Saturdays

"Hepconnection": 3 PM EST Saturdays

Usenet newsgroup: sci.med.diseases.hepatitis

For a list of recommended World Wide Web sites, see Appendix C.

XII.1.5 BIBLIOGRAPHY: SUGGESTED READING

— The Encyclopedia of Natural Medicine by N.D.s Michael Murray and Joseph Pizzorno. (pub: 1991, Prima Publishing in Rocklin, California). It has a good chapter on "Liver Support" and another on Hepatitis, with a suggested daily regimen of nutritional supplements and botanical medicines.

—"The Hepatitis C Handbook," by Matthew Dolan is available worldwide via mail order using credit card. Customers need to call Central Books, 99 Wallis road, Hackney, London in the UK; the number is 011 (from the USA) 44 (0) 181 986 4854. If you are calling from other countries find the international code for the UK. Alternatively you can fax them on 011 44 181 533 5821 Their email address is Peter@centbks.demon.co.uk It will cost the local currency equivalent of thirteen pounds sterling plus post and package. "The Hepatitis C Handbook" can also be ordered in the U.S. through the Hepatitis C Foundation, 1502 Russett Drive Warminster, PA 18974 (215)672-2606

—"How to Reverse Immune Dysfunction," by Mark Konlee.

He heads a group called Keep Hope Alive. In this book he lays down all the things that are good and bad for people suffering from chronic viral nfections. Topics include : complete diet and complete recipes, lots of holistic anti-virals, specific treatments for a variety of medical problems. He also talks about your bodys temperature and how it relates to viral infections. To order a copy of this book, contact Mark at "Keep Hope Alive," P.O. Box 27041, West Allis, WI 53227 The cost is $19.95 plus 2.00 for priority mail.

— Prescription for Nutritional Healing - Balch and Balch One of our subscribers says: "This is a book that has been very helpful to many folks. It has a clear explanation of what the liver does, of cirhossis, and a lot of info about herbs, vitamins, supplements, fasts,- you name it- this might help some people to answer questions about nutrition issues. Although the book was published before HepC was identified, it is still a very useful item- paperback- large size- available in book and health food stores.

—"Sick and Tired of Feeling Sick and Tired" by Donoghue and Seigel. ISBN 0-393-03408-9. Published in New York by W.W.

Norton. $23. - A WONDERFUL book, for patients and caregivers alike.

If you can only get one, get this one!

Also try reading or listening to any of the material from Bernie Seigal the cancer surgeon cum motivational speaker from Yale.

Good stuff! His organization is ECAP (Exceptional Cancer Patients)
—Stedman's Pocket Medical Dictionary (ISBN0-683-07921-2) - $22.
A good general companion.
—"The Puzzle People" - An autobiography of Dr. Tom Starzl, the pioneer who developed the techniques that made liver transplantation possible. It's available from the American Liver Foundation. It's a great read about one of the most compassionate and human of physicians/surgeons on the face of the earth. Given some of the horror stories we read daily on the HEPV-L list, this one will really give you a positive boost!

—"The Alchemy of Illness" by Kat Duff, 1993, Pantheon Book, New York. $19

—"Diseases and People - Hepatitis" by Alvin, Virginia & Robert Silverstein, 1994. 128 pp., Enslow Publishers Inc., Hillside, NJ, ISBN 0-89490-467-1

—"Milk Thistle, the Liver Herb," by C. Hobb (bkit) 32pp. $10.00 Includes the history, folk uses, and recentscientific testing of this important liver protecting herb. Learn about how to use Milk Thistle to help heal and protect the liver for hepatitis, cirrhosis, environmental toxicity, alcoholism, drug abuse, etc.

- Available through the Hepatitis C Foundation, 1502 Russett Drive Warminster, PA 18974 (215)672-2606

—"Natural Liver Therapy," by C. Hobb $10.00 Up-to-date practical information on how the liver works, dietary guidelines for maintaining a health liver, herbs for the liver and gall bladder.

Includes holistic treatment programs for a variety of liver-related complaints, including poor digestion, acne, emotional imbalances, hepatitis and cirrhosis, PMS, and breaking addictions. - Available through the Hepatitis C Foundation, 1502 Russett Drive Warminster, PA 18974 (215)672-2606

—"Foundations of Health," by C. Hobb $15.00 The complete digestive and liver herbal, including scientific reviews, using bitters to improve digestion, stress-releasing techniques, and diet food therapy. Includes helpful recipes for the liver flush, sauerkraut, yogurt, cleansing and relaxing teas, etc. Over 20 beautiful line drawings. - Available through the Hepatitis C Foundation, 1502 Russett Drive Warminster, PA 18974 (215)672-2606

—"Mainstay: For the Well Spouse of the Chronically Ill" by M. Strong, New York: Penguin Books, 1988
—"In Search of the Sun: How to Cope with Chronic Illness" by H. Aladjem, New York: Macmillian, 1988
—"Could Your Doctor Be Wrong?" by J.A. Goldstein, New York: Pharos Press, 1991
—"Living with Chronic Illness: Days of Patience and Passion" by C. Register, New York: Free Press, 1987
—"We Are Not Alone: Learning to Live with Chronic Illness" by S.K. Pitzele, New York: Workman, 1987
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XII.1.6 WHAT NEWSLETTERS, MAGAZINES AND VIDEOS ARE AVAILABLE?

Available through Dragon Productions (Jim Shepard), 1616 Anchor Way, Azle, TX 76020 4901 E-mail: bacafe@flash.net http://www.flash.net/~twb/BACafe , the following videos are available for a suggested price of $29.95 plus $3.00 shipping (US) for each video. Loaner tapes are available on a limited basis for those in need. Wholesale to support groups and other helpful organizations is $15.00ea + shipping.

Videos available:

"Christopher Hobbs Video Interview; Alternative Treatments for HCV," Whether or not you are trying interferon, you will find excellent and hard to find information from an acknowledged master or alternative medicine. This video is now available direct from Dragon Productions, and covers wholeism, natural pain control, Milk Thistle, Diet, Traditional Chinese Medicine, and more. The video interview runs over an hour.

"HCV Positive," This video features the commentary of HCV Positive individuals and explores how they are dealing with the Hepatitis C Virus in their lives. Program length: one hour-ten minutes. VHS.

"Transplant Video #1," features a one hour conversation with David and Kathy, two transplant recipients from California.

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The following videos are available from the Hepatitis C Foundation , 1502 Russett Drive, Warminster, PA 18974 (215)672-2606 or 1-800-324-7305:

"Living With Hepatitis C" - $29.95 plus $4.95 shipping and handling

"Conversations on Hepatitis C" - $29.95 plus 4.95 shipping and handling

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"Hepatitis C Video," $39 American Liver Foundation , 1-201-256-2550 or

1-800-223-0179

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APPENDIX A:

WHERE TO GET THE CURRENT VERSION OF THIS FAQ

Usenet:

E-Mail : send a message to Peppermint Patti at mailto:clotho@bellatlantic.net , and say "Send me the FAQ please!"

Web:

http://members.bellatlantic.net/~clotho

http://www.flash.net/~BACafe (In the Peppermint Room)</A>
http://www.tiac.net/users/birdlady/hep.html http://www.tiac.net/users/dscherm/Hepatitis

ftp:

APPENDIX B:

COMMON ABBREVIATIONS

Below are shown common medical abbreviations that HCV people often come across.

MEDICAL ABBREVIATIONS AND TERMS

ALT - Alanine aminotransferase - a protein which, when found in the blood in elevated quantities, generally indicates liver damage. Also sometimes called SGOT.

ANTIBODY - A protein secreted by cells of our immune system in response to infection. The antibody binds to an "enemy" molecule, in this case, a specific part of the hepatitis C virus.

This is meant to prevent the virus from infecting other cells or destroy it. As with other viral infections, the presence of antibodies does not necessarily mean a virus will be eliminated from the body.

AST - Aspartate aminotransferase - a protein which, when found in the blood in elevated quantities, generally indicates liver damage (although less specific for liver damage than ALT).

Also sometimes called SGPT.

BLOOD & BLOOD PRODUCTS - Components of blood including red cells, platelets and plasma which are separated out by blood banks. Plasma is processed and purified to produce specific medical purposes, eg. Factor VIII.

CARRIER - Practically all people who are HCV+ "carry" the virus. The term "carrier" is often misused, though, to mean someone who has the hepatitis C virus yet is in good health.

In regard to hepatitis C, the term "carrier" is used less and less. Better definitions of illness status include "antibody positive" or "antibody negative"; "symptomatic" or asymptomatic". Most important to note, is that all people who are hepatitis C antibody positive need to be aware of potentially passing on the virus.

CBC - complete blood count

CDC -- Centers for Disease Control and Prevention (USA agency), responsible for estimating prevalence rates and making epidemiological studies

CIRRHOSIS - A condition where scar tissue develops in the liver - to the extent where such scaring becomes extensive and permanent. Cirrhosis interferes with the normal functioning of the liver.

COQ10 -- co-enzyme Q10, a naturally occuring substance which some patients find helpful; available without prescription

DHHS -- Dept. of Health and Human Services (USA agency)

FATTY LIVER: abnormal lipid increase in the liver, probably related to reduced oxidation of fatty acids or decreased synthesis and release of lipoprotiens, causing inadequate lipid clearance from the liver.

FDA -- Food and Drug Adminstration; a USA agency which regulates drug approvals, nutritional supplements, and food quality and labeling

FIBROSIS - Scar formation resulting from the repair of tissue damage. If it occurs extensively in the liver it is called cirrhosis.

GENOTYPE - Different genotypes of the one virus are similar enough to be regarded as the same type but have some minor differences in their RNA composition. These differences may mean the virus reacts differently to our immune response or to drug treatments and natural therapies.

HCC - Hepatocellular carcinoma, or liver cancer.

HCV -- Hepatitis C Virus

HEMOCHROMATOSIS: excess of iron absorption and presence of iron-containing deposits (hemosiderin) in liver, pancreas, kidneys, adrenals, and heart. It may be associated with hepatic enlargement and insufficiency and esophageal bleeding from varices.

HEPATIC COMA, CHOLEMIA: peculiar syndrome characterized by slow or rapid onset of bizarre behavior, disorientation, flapping tremors of extended arms, and hyperactive reflexes, and later lethargy and coma. It seems to be caused by intoxiation with ammonia, a product of protein digestion that the diseased liver fails to convert into urea.

HEPATIC ENCEPHALOPATHY: serious complication of advanced liver disease probably caused by cerebral toxins, including ammonia, certain amines, and fatty acids. It is clinically manifested by personality changes and impaired intellectual ability, awareness, and neuromuscular functioning.

HEPATIC FAILURE, FULMINANT: clinical syndrome caused by extensive necrosis of the liver, which may be induced by hepatoxic drugs and may lead to progressive encephalopathy and a fatal prognosis.

HEPATIC NECROSIS: destruction of functional liver tissue.

HEPATITIS, VIRAL: acute or chronic inflammation of the liver caused by the hepatitis virus A, B, C, delta, E, G

HEPATOMA: tumor of the liver.

IVDU - Intravenous drug use

IVIG -- intravenous gamma globulin

NIH -- National Institutes of Health (USA agency); largest medical research institution in the world

NON-A NON-B HEPATITIS - The old term for hepatitis shown not to be caused by the A&B viruses. In 1988, this form of hepatitis was shown to be mainly caused by HCV.

NSAID -- non-steroidal anti-inflammatory drugs; examples: naproxen, ibuprofen; used for pain

PCR -- polymerase chain reaction; a DNA technique used for identifying viruses and other life forms

PORTAL HYPERTENSION: a portal venous pressure greater than 20 mm Hg associated with splenomegaly, increased collateral circulation, varicosity, bleeding and ascites. It may result from:

INTRAHEPATIC BLOCK: block within the liver, or - EXTRAHEPATIC BLOCK: block within the portal vein.

SGOT - (See ALT)

SGPT - (See AST)

SSA - Social Security Adminstration (USA agency), responsible for retirement and disability benefits

SSDI - disability benefit program form the SSA (USA)

VIRAL LOAD - The amount of virus present in a person's bloodstream. It is usually measured by the PCR quantitative test and the result is given in number of virus particles per ml of blood.

APPENDIX C - SOME RECOMMENDED WEB SITES (in no particular order) ARE:

Peppermint Patti's Junk Drawer: http://members.bellatlantic.net/~dotho
Ask Emaliss - Hepatitis Info & Support: http://soli.inav.net/~webbsite

The Hepatitis C Foundation: http://www.hepcfoundation.org email: hepatitis_c_foundation@msn.com
The BA Cafe : http://www.flash.net/~twb/BACafe
Hepatitis Haven: http://www2.pcix.com/~jeanne/hep.html
David Hunter's HCV Information Page: http://world.std.com/%7Edfh
Scotty (the Reezer) Warren's Hepatitis Home Page: http://idir.net/~swarren/
The Hepatitis Information Network: http://www.hepnet.com
Brian Arens' Chronic Hepatitis Home Page: http://ourworld.compuserve.com/homepages/BGARENS
Rick Lane's Hepatitis C Info Page: http://www.interthresh.com/~rick/hcvinfo.htm
The Canadian Liver Foundation: http://www.liver.ca
The Hepatitis C Society of Canada (HeCSC): http://web.idirect.com/~hepc; email: HeCSS@idirect.com; email: squeeky@pacificcoast.net
Melissa Palmer, MD, a Hepatologist in New York: http://www.liverdisease.com/
UNOS Website (Transplant): http://www.ew3.att.net/unos
New England Journal of Medicine: http://www.nejm.org
CenterWatch Clinical Trials Listing Service: http://www.centerwatch.com
Pharmaceutical Information Network Home Page: http://pharminfo.com/pin_hp.html
RxList - The Internet Drug Index: http://www.rxlist.com
Schering-Plough (manufacturers of Intron-a): http://www.hep-help.com
Hepatitis Weekly: http://www.holonet.net/homepage/1h.htm
Columbia University Diseases of the Liver: http://cpmcnet.columbia.edu/dept/gi/disliv.html
Current Papers in Liver Disease: http://cpmcnet.columbia.edu/dept/gi/references.html
American Association for the Study of Liver Diseases (AASLD): http://hepar-sfgh.ucsf.edu/
American Liver Foundation (ALF) Homepage: http://sadieo.ucsf.edu/alf/alffinal/homepagealf.html
Doctor Database: http://cos.gdb.org/maps/cos/exp/states/expstates.html Clickable U.S. map that allows users to query a medical practitioner database. Specialties and credentials are presented.
ChronicIllnet: http://www.calypte.com/about.html
Disability Resources: http://disability.com/cool.html
Emotional Support Resources: http://www.lib.umich.edu/chdocs/support/emotion.html

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NOTE Please remember that the above is not medical advice. It is opinions, mostly from different members of this Listserv. Always see your doctor, before trying anything unusual.

http://members.bellatlantic.net/~clotho Go soothingly on the greasy mud, for therein lies the skid demon. - Chinese Road Sign